THE EFFECTIVENESS OF A PHYSIOTHERAPY DOMICILIARY PROGRAMME FOR HOUSEBOUND PHYSICALLY DISABLED AND THEIR CAREGIVERS IN MANENBERG

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ABSTRACT

Following a request from the Manenberg community a domiciliary physiotherapy programme was established in order to identify the needs of the housebound disabled and their caregivers.

The study was conducted over a 2 year period by means of action research using a combination of qualitative and quantitative research. In the first part of the programme 50 disabled and their caregivers were assessed on scales of functional ability, caregiver burden and socialisation within the community. They were provided with relevant rehabilitation and training programmes until maximum benefit had been achieved and were then reassessed on the same measuring scales. There was a significant improvement in the level of functional ability, decrease in caregiver burden and increase in the number of times that the disabled left their homes per week to socialise within the community.

The second part of the programme was established to investigate the effectiveness of utilising volunteers to reduce caregiver burden in families with housebound disabled.

The third part of the programme assessed the ability of final year physiotherapy students at the University of Cape Town to be able to extend treatment through home visits and the active engagement of relatives and friends in the rehabilitation of the clients.

GLOSSARY

ACTIVITIES OF DAILY LIVING (ADL) refers to functional activities like walking, dressing, bathing, climbing stairs.

ASTHMA is a condition marked by recurrent attacks of wheezing, coughing and a feeling of "tightness" of the chest, due to the constriction of the bronchioles.

BURDEN is defined as "the extent to which caregivers perceive their emotional or physical health, social life and financial status suffering as a result of caring for their relative" (Zarit et al, 1986:261).

CAREGIVER is an individual who assumes the primary responsibility of caring for and supporting the disabled (Brown, 1990:456). This results in the caregiver losing personal freedom (Ayling, 1993:780).

CEREBRAL PALSY is a condition affecting the muscle tone of the body. It may or may not be associated with intellectual, hearing and visual impairment.

CHRONIC ILLNESS refers to any long-term or permanent disability that interferes with the person's ordinary physical, psychological or social functioning (National commission on Chronic Illness, 1956:19).

COMMUNITY-BASED REHABILITATION (CBR) is "a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services" (WHO, 1981a:11).

COMMUNITY-ORIENTED EDUCATION is education provided in an environment which closely resembles that in which students will work after graduation and uses a process in which education and productive work are integrated. A significant proportion of the educational experiences are located outside a tertiary care hospital (WHO, 1987a:412).

CONTRACTURES are the deformities that occur at joints when muscles and soft tissues around them become permanently shortened.

DISABILITY reflects the consequences of the impairment of the person's functional performance and activities. " A disabled person is a human being who through disease, illness, congenital condition or traumatic experience, is impaired in the functioning in one or more areas of daily living. This functional impairment causes unusual and undue dependence on one or more other human beings and/or mechanical devices" (Laurie, 1977:iii). Disabilities represent disturbances as they directly affect the person involved.

DYSPHASIA is an impairment of speech.

EMPHYSEMA results in a loss of elastic tissue in the lungs which causes hyperinflation of the chest.

EMPOWERMENT "implies conscientisation, or raising awareness of reality; and enabling communities to transform that reality, to be in control of their own destiny, to be self-reliant" (Philpott, 1992:28).

FUNCTIONAL ABILITY refers to the individual's capacity to perform daily activities of living. Examples include dressing, feeding, walking and climbing stairs.

FUNCTIONAL PERFORMANCE is the "measurable change in the physical, mental, and/or psychosocial well-being of a resident that results from care and services provided by the interdisciplinary team" (Kaufman, 1994:315).

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" (WHO, 1981a:10).

HEMIPLEGIA is the paralysis of an arm and leg on the same side of the body.

HYPERTENSION indicates high blood pressure. If uncontrolled it can result in the person suffering a stroke.

IMPAIRMENT is "any loss or abnormality of psychological, or anatomical structure or function" (WHO, 1981a:10). It includes abnormalities of body structure and appearance, or the functioning of organs, such as an absent limb, cough, shortness of breath, pain or swelling, which can be caused by a variety of diseases.

INSTITUTIONALLY-BASED REHABILITATION (IBR) is concentrated in the cities, highly specialised and expensive. The institutions are run by teams of highly trained professionals working according to Western standards using sophisticated technology (WHO, 1981a:11).

MICROCEPHALIA is an abnormal smallness of the head.

PARAPLEGIA. Paralysis of the legs and lower part of the body.

POSTURAL DRAINAGE is a means of mechanically tipping the body in different positions to aid the removal of chest secretions.

QUADRIPLEGIA. Paralysis of both arms and legs.

REHABILITATION "is the process of recognition and evaluation of the needs of the disabled person and provision of the necessary skilled, integrated services to enable him to achieve his maximum potentialities medically, socially, and vocationally" (Sharman, 1972:2).

SELF-HELP may be defined as a process, group or organisation comprising people coming together or sharing an experience or problem, with a view to individual and/or mutual benefit. As empowerment commonly means `becoming powerful', self-help may thus be viewed as one form of empowerment (Adams, 1990:1).

SENSORY LOSS is the loss of feeling experienced in the skin, muscles or joints that affect movement.

SOCIALISATION LEVEL in this study refers to the number of times per week the disabled left their homes.

STROKE. Paralysis of an arm and leg on the same side of the body.

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

For ease of reading the word `participants' will be used interchangeably with `disabled', `caregivers' and `volunteers' where appropriate. `Researcher' will refer either to the researcher herself or to the students. `Disabled' will imply `physically disabled' although in some cases clients may also be suffering from additional mental or cognitive disabilities.

"Tell me, I'll forget. Show me, I may remember,

But involve me and I'll understand"

(Rotary Africa, 1994:5)

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

Manenberg is a housing estate situated on the Cape Flats approximately 25 kilometres from Cape Town. It was developed to house people "relocated" under the Group Areas Act (Act 36 of 1966) and, as is the case in most of the housing estates in the area, it experiences immense social problems of poverty, unemployment, overcrowding and crime. As will be seen in Chapter 6 on the Community Profile, many of the people of the community have become apathetic and fatalistic about their situation and the overwhelming problems they experience in their day-to-day living.

Cape Town abounds in high-technology physiotherapy services which deal with degenerative diseases of the wealthy group of society in state and private facilities. In 1992 over 80% of the Cape Provincial health budget was devoted to hospital services (McIntyre and Strachan, 1993). However, the international trend is mirrored in Cape Town in that most of the disabled live in poor communities where appropriate health care consists of providing primary health care services within the communities themselves (WHO, 1980).

Only 5% of the total health budget was allocated to primary health care (McIntyre and Chetty, 1993) demonstrating very little concern for preventative medicine or rehabilitation and care of the chronically ill. Lack of rehabilitative services leads to the perpetuation of the condition of clients with chronic illnesses and the state of their general health frequently deteriorates to such an extent that they become dependent on acute hospital services to meet their needs.

1.2 MOTIVATION FOR STUDY

The Manenberg community, despite its tremendous poverty and unemployment, managed to have the Manenberg People's Centre (MPC) built in 1991 at a cost of R1.2m. In response to the nature and range of problems with which the Advice Office and Civics Association had been dealing, a Health Project Committee (HPC) was formed to look into the health needs of the severely disabled in the community. First year occupational therapy students from the University of Western Cape had recently conducted a survey and had identified 128 severely disabled people living in the suburb. As a result of this the committee felt that there was a great need for the housebound disabled to receive rehabilitation and their caregivers to be given advice and training in the management of their disabled relatives. Most of the caregivers had never received any form of training and were overburdened by their responsibilities and many were not coping with these additional obligations. The devastating effects that severe disability has on both the individual and the caregiver are well documented (Brown et al, 1990; Meiring, 1990).

The Health Project committee envisaged using the MPC building as a facility for vocational training of the disabled and a venue where social events could be arranged for severely disabled people to be able to meet and socialise.

As a result of this the HPC requested that the researcher be co-opted as a member of the committee to assist them developing a strategy for meeting the needs of the housebound disabled. Biddle (1965) states that the likelihood of such an invitation being issued by people who are apathetic and conditioned to being at the receiving end of charity is very small and Batten (1975) and Biddle (1965) maintain that where projects have been decided upon by autonomous groups within a community their success generally seems to require professional input to assist the action group.

The HPC made it very clear that they were not requesting a `free' service, but needed a grassroots development programme whereby the disabled and their caregivers could be empowered to become self-sufficient in managing their daily rehabilitation and maintenance requirements and whereby the disabled would become sufficiently mobile to attend the activities planned for them in the MPC. It was decided that final year physiotherapy students would become involved in the planning, implementation and evaluation of the programme. It was agreed that once it became operational, ways and means of sustaining it would have to be found. This would involve providing certain community members with the knowledge, skills and resources to run the programme themselves with consultative input only from the researcher.

The needs of societies vary according to their current norms and the availability of their resources. Before these needs can be dealt with as social problems they have to be recognised as needs by the citizens themselves, the professionals who provide the services and the authorities which fund them (York, 1982). This concept of social need is an essential element of development planning as it assesses the extent to which problems exist in society (York, 1982). Health requirements are classified by Nghatsane (1987) as a basic human need and include the treatment of illness, access to food and water and the control of harmful environmental factors.

It is very interesting that concern for the disabled had been given such a high priority by the HPC as only a very small proportion of the population was affected and Elliot (1975:5) maintains that education, a reliable supply of clean water and better marketing opportunities are usually accorded a far higher priority as a `felt need' than even acute health care needs. However, Werner (1987) maintains that for a community programme to be successful one has to start with what the people feel is important and work from there. By attempting to address this need indicates that the suburb of Manenberg was obviously a community that had reached a transitional stage with a balanced approach to its needs.

1.3 AIM OF THE STUDY

The aim of the study was to explore and identify the needs of the housebound disabled and their caregivers in Manenberg and to provide them with relevant rehabilitation and training programmes in order to empower them.

1.4 OBJECTIVES OF THE STUDY

1.4.1 To describe the housebound disabled and their caregivers.

1.4.2 To evaluate the functional level of the disabled before and after the programme.

1.4.3 To evaluate the level of caregiver burden before and after the programme.

1.4.4 To measure the number of times the disabled left their homes before and after the programme.

1.4.5 To observe the changes, outcomes and impacts that the programme had on the lives of the disabled and their caregivers that would reflect community development and community participation.

1.4.6 To evaluate the effectiveness of the volunteer involvement in the treatment programme.

1.4.7 To propose a model for extending the final year physiotherapy students' training/curriculum to include active community involvement to empower the housebound disabled, their caregivers and families to sustain the treatment programme.

1.5 ASSUMPTIONS

In order to undertake this study it was necessary to make the assumptions that:

1.5.1 With the rapid changes occurring in the country at the time, a new, more cost-effective and appropriate health policy would come into effect where provision would be made for community rehabilitation posts comprising different levels of health workers who could be trained to sustain the objectives of this project.

1.5.2 Since the researcher and students were invited into Manenberg by a grassroots-based, legitimate local community organisation and that with the application of professional skills the disabled and their caregivers would answer questions both accurately and honestly.

1.6 LIMITATIONS OF THE STUDY

1.6.1 The amount of qualitative data that was generated from the interviews, participant observation and meetings was too large to analyse exhaustively. The results are presented in the form of in-depth case studies rather than by simple statistical tests of the quantitative data collected.

1.6.2 The scarcity of information, literature and research data concerning domiciliary visits for physiotherapy in disadvantaged communities. Where relevant, information gathered in other countries was used. However, the researcher was fully aware of the caution that needed to be exercised in generalising from the communities of one country to another and from one geographical area to another.

1.6.3 The social and emotional aspects of the client's environment could not be comprehensively assessed due to the time-consuming nature of the treatment and training programmes of the participants and the prioritising of the disabled person, caregiver, volunteers and students as research projects.

1.6.4 Researcher bias with the structured interview had to be recognised. The independent findings of the students and the researcher, however, were found to correlate closely.

1.6.5 The subjective responses of the participants were often what the participants thought were appropriate, rather than their true circumstances. Initially this was counteracted by having a member of the Advice Office present during the interviews. Once the researcher and students became familiar with the situation this was overcome by further in-depth questioning.

1.6.6 Due to the students' inexperience the researcher felt that they were not always able to observe and record all the information that could have been obtained by a more experienced interviewer. This was particularly so when open-ended questions were asked. Subtle signs and intimations were not always followed up by further in-depth questioning. This was counteracted by ensuring that the students were always supervised during the interview sessions once the Advice Office staff disengaged from the visits.

1.6.7 As 86% of the sample had been disabled for more than 2 years they could not remember details necessary to respond to all the open-ended questions. This did not, however, have any affect on the outcome of the study.

1.6.8 Problems of a varied nature which extend far beyond physiotherapy intervention were identified by the researchers and expressed by the participants. In the researcher's opinion, the assessment of the disabled by a multidisciplinary rehabilitation team would have produced a much more holistic profile and multi-pronged, integrated intervention.

1.6.9 Students had, by nature of their clinical rotations, only four weeks in Manenberg. This was disruptive when individual programmes extended over a considerable period of time as each month the participants took time to establish trust and relationships with the next set of students.

1.6.10 Respondents who had been disabled for a considerable period found difficulty in recalling facts concerning their disability and earlier treatment received because the research design was ex-post facto. For this reason the responses of 86% of the participants could not be identified from the time of injury or onset of the disease.

1.6.11 Basic health and social welfare reforms had not taken place by the time this programme was completed. This restricted the benefits of development to only a small number of the community. Although substantial benefit had been gained by the participants this could have been even more dynamic had there, for instance, been posts created for community rehabilitation workers who could have ensured that people disabled after the study had been completed could have had domiciliary rehabilitation programmes available to them.

1.7 STRENGTHS OF THE STUDY

1.7.1 The researcher was an outsider to the community and therefore had no vested interest or private agenda for personal gains on the HPC.

1.7.2 Being from an outside resource meant that the researcher and students could assist with problem-solving from a different perspective to which the HPC was accustomed and their presence encouraged matters to be dealt with more quickly, effectively and competently.

1.7.3 Eighty percent of the disabled and their caregivers were frequently visited by more than one group of students which allowed them to be exposed to a greater variety of opinions and techniques for dealing with their problems.

1.7.4 The development of the structured contractual arrangement between the HPC and the outside resource agency, namely, the Department of Physiotherapy of the University of Cape Town.

1.7.5 The benefits that were exchanged between the disabled persons, their caregivers and the researcher and students.

1.8 ETHICAL CONSIDERATIONS

In order to ensure accountability both to the community and to the profession, the following was taken into account:

1.8.1 A guarantee to the HPC that the project would be sustained by the researcher and the students until the committee agreed that it was appropriate to disengage.

1.8.2 Participants were assured that their participation was voluntary and that all information would be kept strictly confidential.

1.8.3 Consent from each participant was obtained for entering into the treatment programme, conducting the interviews and, where necessary, for any photographs that were taken. None of the participants refused any of these requirements.

1.8.4 Permission was obtained from the community leaders to gather data from Manenberg (see Appendix i). The two members approached were members of the MPC which is a legitimate community organisation and they were the leaders who initially requested the assistance of the researcher.

1.8.5 The community leaders were provided with the findings of the study conducted by the researcher in the form of half-yearly reports (see Appendix ii as an example).

1.9 ORGANISATION OF THE STUDY

For ease of reading the part of the study dealing with the rehabilitation of the disabled and the training of their caregivers is presented in Chapters 1 to 10, the part dealing with the training of volunteers in Chapter 11 and the student education component in Chapter 12.

Chapter 2 deals with community physiotherapy in other countries as well as its present state in South Africa and how this impacts on rehabilitation of severely disabled persons.

CHAPTER TWO

COMMUNITY PHYSIOTHERAPY FOR THE REHABILITATION OF THE PHYSICALLY DISABLED

2.1 INTRODUCTION

As a result of improved medical technology and the current growth in the population the demand for physiotherapy rehabilitation is on the increase all the time. At the same time there are insufficient numbers of physiotherapists to provide the necessary therapeutic intervention services needed. This means that many disabled people are not able to achieve their potential functional capacity and quality of life within the family, community or society at large.

Prevalence of disability increases with age (Condie, 1991:73; Disler et al, 1986:354) and is highly correlated with poverty (Disler et al, 1986:354; McLaren, 1986:53, Wilson, 1983:193). This is borne out by the following statements:

> "Disabled persons form the most severely underpriveleged group in the societies of developing countries" (WHO, 1982:53).
>
> "It is among the poorest communities in the developing countries that poverty breeds disablement and disablement breeds poverty, a vicious circle that the poorer communities can least afford" (Wilson, 1983:196).
>
> ".... the massive disability is, clearly, in developing countries" (WHO, 1980:53).

In South Africa there are approximately 3 000 registered practicing physiotherapists, of whom 80% are employed in the private sector. Yet Smith (1991) in her paper on the future of rehabilitation in South Africa claims that 80% of the population is dependent on state health services where there is, in fact, a shortage of physiotherapists. The ratio of physiotherapists per population is 1:2 000 for private practice and 1:18 000 for state services (Proposal of Physiotherapy Services, 1994). However, since there are no statistical data available on the health status of this country and what this ratio ought to be, there is no way of knowing what numbers of physiotherapists are required to meet the needs of the country (Hoffman, 1987; Jette 1980; McLaren, 1986; Mostert, 1987; Templeton, 1985). In the Proposal of Physiotherapy Services (1994) presented to the Minister of Health it was recommended that a ratio of 1:15 000 be achieved as it is known that developed countries demand a ratio of 1:10 000 physiotherapists to population.

Of the physiotherapists in the state sector 1 058 are employed in institution-based posts and only 26 in community-based posts (Community-based rehabilitation draft document, 1992). Kay, Kilonzo and Harris (1994) confirm the severe shortage of physiotherapists working in rehabilitation in virtually all developing countries.

With the present rapid turnover and consequent demand for hospital beds, priority is given to the acutely ill client and to the client who requires only short-term rehabilitation. Thus clients are frequently discharged prematurely before completing their rehabilitation programmes and often without referral for outpatient physiotherapy.

The numbers of disabled people presently receiving treatment as outpatients in the larger hospitals have dropped significantly since the increase of hospital fees and the reduction of hospital transport (Letter to department from medical superintendent 14.08.90) For example, in July 1990, the Groote Schuur Hospital Physiotherapy Outpatient Department arranged transport each day for approximately 20 clients with amputations and 15 to 20 clients suffering from strokes. In March 1993 these numbers were decreased to a total of 4 clients per day. This meant that many disabled people in the community were not receiving any form of rehabilitation whatsoever as they were unable to afford either private practice or hospital fees and were unable to meet the transport costs that either of these involved. Smith (1991) found that 50% of clients discontinue outpatient treatment prematurely after an average of 1.9 attendances.

At the time of this study, the Health Act (No. 63 of 1977) vested the responsibility for rehabilitation in the local authorities, but the planning in terms of this legislation had never been implemented. The hospitals and day hospitals were, therefore, the only facilities available for rehabilitation of the disabled and their resources were totally inadequate to deal with the numbers of disabled requiring rehabilitative services.

Furthermore, until very recently, it had been policy of both provincial and day hospitals not to provide home visits. Thus domiciliary visits were available only in the private sector and nothing was available for people who were not able to pay for this service.

2.2 PHYSIOTHERAPY

> "Physiotherapy is the skilled use of physiologically based movement techniques supplemented where necessary by massage, electrotherapy and other physical means for the prevention and treatment of injury and disease. It is used to assist the processes of rehabilitation and restoration of function including the achievement of personal independence" (Runnalls, 1975: 13).

Cape Town abounds in private and state physiotherapy services that emphasise high-technology curative techniques which are equipped to deal with degenerative diseases of the affluent group of society in hospitals and private practices. Such a development was made possible by the pattern of health expenditure in the past. In 1992 over 80% of the Cape Provincial health budget was devoted to hospital services (McIntyre and Strachan, 1993). The majority of disabled, however, live in poor communities where appropriate health care consists of providing primary health care services within the communities themselves (WHO, 1980).

Over the last two decades there has been a change in emphasis in physiotherapy practice in many First World as well as developing countries. A course of treatment in a hospital department is no longer considered to be the only appropriate form of physiotherapy and a number of physiotherapists have emphasised the necessity for developing physiotherapy services outside the hospital to achieve comprehensive and integrated services in the right place (Bauer, 1975; Burnard, 1988; Gloag, 1985; Menon, 1984; Partridge, 1978; Runnalls, 1975; Scott, 1958; Werner, 1987).

2.3 REHABILITATION

> "Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and the handicapped to achieve social integration. Rehabilitation aims not only at training disabled and handicapped persons to adapt to their environment, but also at intervening in their immediate environment and society as a whole in order to facilitate their social integration. The disabled and handicapped themselves, their families, and the communities they live in should be involved in the planning and implementation of services related to rehabilitation" (WHO, 1981:51).

It is concerned with disabled individuals achieving their maximum potential capacity as persons within a family and the communities in which they live and work and, therefore, involves all health and welfare sectors (Ben-Sira, 1981; Gloag, 1985; MacMillan, 1974; Sharman, 1972).

Rehabilitation of chronic conditions is not a short-term intervention. It may well start during a period of hospitalisation as the result of an acute condition, but continues and takes place in the home, place of work and community until the person has readjusted to a new lifestyle and has reached his/her maximum capacity. For successful rehabilitation to occur, multisectoral liaison is essential to avoid duplication and fragmentation of the necessary therapies and services (Frazer, 1982; Gloag, 1985; MacMillan, 1974; Putterhill, 1984; Schmidt, 1986; Scott, 1985). It also incorporates the education, training and emotional support of caregivers (Frazer, 1982).

Thus rehabilitation can be viewed as being that of a community problem as its reaction towards and action on behalf of the disabled is based on understanding and knowledge of disability. By taking on this responsibility the services are ensured of being appropriate to the needs of the disabled (Scott, 1958).

There is a great deal of variation in the various claims of statistical evidence on disabilities. The World Health Organisation (WHO) estimates that 10% of the world's population suffer from some form of disability (Miles, 1983:5), but no mention is made of the classification, extent of disability or the percentage of disabled requiring physical rehabilitation services. Kay, Kilonzo, and Harris (1994) found that 50% of people with disabilities have limb impairments, but again, no mention is made of rehabilitation requirements. However, these findings were confirmed by a survey of developing nations carried out by Mitchell et al (1989). Mostert (1987) claims that 1.5% of the total population of developing countries could benefit from rehabilitation. These findings were confirmed by Finkenfugel (1991) whose study showed that approximately 1.6% of the people he contacted were in need of rehabilitation. Neither of these two references mention whether the disabled concerned felt they were in need of rehabilitation programmes.

Many authors estimate that only 10% of people with disabilities in developing nations receive trained help (Finkelfugel, 1991; Helander et al, 1983). However, in all the above studies, the type of disability investigated is not classified and not much clarity is provided on what the perception of `disability' was by the communities studied.

Apart from the fact that it is the right of every vulnerable individual to receive rehabilitation (ANC RDP, 1994) Leavitt (1992) points out that it is a means of decreasing the costs of disability to both the individual and society in general.

Frazer (1982) claims that the most crucial period in rehabilitation is during the early weeks of incapacity, before the individual has had time to adjust to the role of an invalid and not reach full functional potential.

An important aspect during all stages of rehabilitation is coping with affective problems satisfactorily as it impinges on motivation to regain motors skills and is an inherent part of overall adjustment (Ben-Sira, 1981; Mia, 1981; Shepherd, 1979; Short, 1981). Unless appropriate rehabilitation is received the disabled can become an unnecessary burden to their families and the community (Sharman, 1972).

Mia (1981:29) cites `education' of the community about disability, its causes and how to help disabled to be integrated in the community as a crucial aspect of rehabilitation.

No rehabilitation policy for the country existed in the Health Act (No. 63 of 1977) and physiotherapists had never been involved in policy making for physical rehabilitation (Smith, 1991:1650).

2.4 COMMUNITY-BASED REHABILITATION (CBR)

> "CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services" (WHO, 1981a:11).

The philosophies of community-based rehabilitation and primary health care are very similar. They both involve measures taken at the community level to use and build on the resources of the community. Thus the impaired, disabled and handicapped persons, their families and their community as a whole are included (WHO, 1981). Intervention includes the immediate environment of the disabled as well as society as a whole in order to promote the social integration of the disabled and their families (Mostert, 1987). The disabled and their families are encouraged to participate in the needs analysis, planning, implementation and evaluation of the entire rehabilitation programme and its processes (Mostert, 1987).

Traditionally physiotherapists have worked in hospital settings (Burnard, 1988; Warren, 1977). However, they no longer are able to provide adequate rehabilitation services now that the average hospital stay for clients has decreased to such an extent, life expectancy has increased and there remains a general shortage of physiotherapists in most countries (Condie, 1993; Menon, 1984).

By expanding services into the community they become more comprehensive and sustainable as rehabilitation can continue after discharge from hospital and they are more relevant to the clients' needs in the community (Frazer, 1982; Partridge, 1977). It is also a means of reaching disabled who have never reached hospital outpatient departments. Several studies have found that CBR is not only an appropriate, effective and feasible approach in developing countries, but that it is also economically viable and cost-effective (Dunleavey, 1974; Frazer, 1980; Mia, 1981; Murray, 1988; WHO, 1982).

When the disabled receive rehabilitation within their community it allows them to reach their potential quality of life amongst people with whom they easily relate. It also assists the family, neighbours and community as a whole to accept the disabled, make allowances where necessary and to support them when and where they need assistance so that they can function at their optimal level (Warren, 1977; Werner, 1987).

CBR is not a new approach to rehabilitation. From as early as 1972 Sharman (1972:5) described how some physiotherapists in the United Kingdom `followed' the discharged client from hospital into the community to continue with their therapy. Graves (1993) and Ogilvie (1989) argue that the reason for the present community physiotherapy services in the United Kingdom being under such pressure is because of the past underfunding and neglect of these services that have now become a growth area in the profession. Australia's interest in community-based health services is based on similar concepts of the services in the United Kingdom (Webster, 1980). From 1961 Ronald Huckstep was developing methods of polio treatment and rehabilitation appropriate to the resources of rural Uganda. Gersten (1966) reported on home programmes in the United States for chronically disabled who required further rehabilitation, but not hospitalisation. In the New Zealand Board of Health Bulletin (1980) the committee encouraged all hospital boards to adopt a wider concept for the role of the hospital by reaching out into the community to provide services that would assist the family in the prevention of disease and the maintenance of health by organising, amongst other, physiotherapy services in the districts. The goal in

India was to provide comprehensive care to the people as a whole with promotive, preventive and rehabilitative services (Ghosh, 1974; Morley, 1986; Patil, 1976).

The World Health Organisation has for some time provided physiotherapists to developing countries like Zambia, Nigeria, Tanzania and Ethiopia to help disabled people in their own communities, particularly with conditions like tuberculosis and leprosy (Determeyer, 1989; Gelling, 1989; Henderson, 1991; Ogilvie, 1989; Profitt, 1989). Various CBR programmes have also been in operation in Canada, Holland and Nicaragua for at least twenty-five years (Burnard, 1988; Byten et al, 1977; Croucher, 1970; Kavanagh, 1971; Kock-Weser, 1987; Partridge, 1978; Rankin et al, 1977; Warren, 1977; Webster, 1980; Wilson, 1976). Mahfoud Boucebci (1981:3) reports that

> "... faced with the lack of available places in the few local specialised institutions, and dissatisfied with sending their children abroad, from 1970 parents of handicapped children in Algiers formed an Association and opened a small multi-purpose centre".

Community physiotherapy means that physiotherapists have to adapt their training received. Instead of spending most of their time in direct client contact on an individual basis, their roles largely involve multisectoral group contact, empowerment, counselling, administration, planning, supervision and evaluation. These roles all contribute to the general comprehensive support of client care (Burnard, 1988; Philpott, 1992).

A community physiotherapy programme is concerned with preventative, curative, rehabilitative and supportive care (Warren, 1977:350).

Thus community physiotherapy, in different forms, has been operational in both developed and developing countries for a substantial period of time, but is still lacking in South Africa. Of the different forms cited, it would appear that, as the urban and rural needs of this country are so diverse, a variety of models would require to be adopted in order to satisfy the needs effectively and comprehensively.

2.5 DOMICILIARY PHYSIOTHERAPY

Domiciliary physiotherapy is a part of community-based rehabilitation, but instead of taking place at a community centre it takes place in the homes of the disabled and does not only involve the disabled, but incorporates the caregivers and other members of the family. Home care programmes are most appropriate for chronically disabled who do not require hospitalisation, but still require rehabilitation services.

A home visit may be done the first time that the disabled requires rehabilitation, but it usually occurs after a period of treatment in hospital. Sharman (1972:1) states that if they do not receive rehabilitation "at the appropriate time, their future is bleak and in addition to being a burden to themselves, they will become an increasing burden on a community from which decreasing percentage is contributing to the economy".

Home visits may also provide maintenance programmes to prevent deterioration once the maximum level of functional potential has been achieved (Gleeson, 1989).

At the time of this study no long-term community physical rehabilitation facilities existed for the discharged disabled in South Africa (Smith, 1991).

Because this study included only housebound disabled persons the obvious site for it to be conducted was in the homes of the disabled. The domiciliary programme was, therefore, an applicable one as it allowed disabled who would previously have been denied physiotherapy treatment access to a rehabilitation programme.

2.5.1 ADVANTAGES OF A DOMICILIARY PROGRAMME

(a) As the aim of any rehabilitation programme is to ensure that the disabled achieve their maximum functional potential the most appropriate and meaningful place for this to occur is in the home as the problems experienced by the severely disabled mostly relate to those in the home. Realistic goals can be set and the rehabilitation programmes can be related specifically to the home environment to ensure maximum functional independence for activities of daily living (Brown, 1990; Burnard, 1988; Frazer, 1982; Partridge, 1978; Putterhill et al, 1984). It is difficult for disabled persons to understand and learn to live with their disability at home when the treatment they have received has been in a hospital. It is extremely difficult for them to adapt these skills without professional assistance in their home environment.

(b) After discharge from hospital certain physical adaptations to the house may be required which can make the difference between dependence and independence for the disabled. Conversing with them and their families and observing the disabled function in their familiar environment gives a greater understanding of the nature and extent of the functional problems and adaptations that need to be made (Condie, 1991; Gleeson, 1989; Partridge, 1977). The caregivers and disabled themselves are frequently able to contribute to providing solutions to alleviate their individual problems (Burnard, 1988; Smyth, 1985; Warren, 1977).

(c) By educating and training the caregivers within their own homes is also a means of providing support to the disabled and their families (Frazer, 1982; Gleeson, Kearney, Lawless, Morris, 1989; Stone, 1987). They have to make many adjustments in various aspects of their lives and such support is helpful in working through them.

(d) A minimal amount of rehabilitation equipment is required since household furniture and gadgets are often more relevant substitutes for expensive equipment used in hospital departments where the environment is totally different from that in which the disabled lives (Frazer, 1982; Partridge, 1978).

(e) The social background and physical environment can be examined more accurately through such a domiciliary programme. By rehabilitating the disabled in their homes it enables them to continue in their normal daily routines. Instead of being expected to fit into the daily hospital ward routine it allows them to choose in which activities they wish to take part and when, allowing them to retain their social contacts and some degree of control of their own lives (Warren, 1977:350). For the disabled that are left home alone while family members are out at work a domiciliary programme provides some form of social contact during the day (Burnard, 1988).

(f) According to Gleeson (1989) and Dunleavey (1974) there are several unpublished studies which show that a domiciliary service is the most economic use of physiotherapists and resources.

Domiciliary visits allow for early, but appropriately timed discharge from hospital thus reducing the costs of providing rehabilitation in expensive high technology hospitals (Dunleavey, 1974; Gleeson, 1989).

Sometimes a working member of the family has to take time off from work in order to escort or transport a relative to a rehabilitation department (Gersten, 1966).

Home visits eliminate transport costs to the client and do away with the need for expensive ambulance services. The reduction in the demand on the ambulance service is a major saving (Burnard, 1988; Frazer, 1980).

Family involvement in the daily rehabilitation programme can reduce the number of visits that the physiotherapist has to make and is a means of providing a service that might otherwise not be provided (Burnard, 1988; Frazer, 1982; Water et al, 1975). The home environment is the best place for the physiotherapist to train the caregiver in the physiotherapy skills and exercise regimens required for successful implementation of the rehabilitation programme and it ensures continuity of treatment (Frazer, 1982; Forster, 1990).

(g) It has been shown that some elderly and confused clients respond better to rehabilitation in their own environment compared to outpatient treatment in hospital as they become less fatigued and disoriented by the travelling, the alien environment and time involved (Kavanagh, 1971; Burnard, 1988).

(h) In homes where there are chronically disabled persons and the maintenance programmes have no effect on the symptoms there is a high rate of non-compliance. Mayo (1981) claims that home visits by an observer increases the level of compliance.

2.5.2 DISADVANTAGES OF A DOMICILIARY PROGRAMME

(a) The disabled might not receive the stimulation and motivation that exposure to other disabled in outpatient departments provide (Gersten, 1966).

(b) Home visits might be more time-consuming than hospital treatments in circumstances where the caregiver may need a great deal of preventative education and supportive care in addition to the needs of the disabled (Warren, 1977).

(c) Clients and caregivers may feel isolated and prefer to be treated in hospital where they have social contact with hospital staff and other disabled. They also receive support from other caregivers attending treatment sessions with their relatives (Versluys, 1986; Warren, 1977).

(d) Warren (1977) warns against the assumption of the lower cost of domiciliary care because community services are not always fully developed and the costs to relatives are not always considered.

2.6 CAREGIVERS

> "A caregiver is any person looking after another, resulting in the caregiver losing personal freedom (Ayling 1993:780)".

The spouse, mother or immediate family members living in the same household usually take on this role. The tasks include basic nursing and rehabilitation skills as well as assistance with activities of daily living. Once maximal function has been achieved a maintenance programme must be continued to prevent physical deterioration (Werner, 1989).

Caregivers are very important persons in the rehabilitation of chronically disabled relatives as, once the disabled are discharged from hospital, their responsibility falls on the caregivers who spend a large portion of the day with the care of the disabled person (Gloag, 1985; Putterhill et al, 1984).

For many years authors (Dean, 1981; Fitzgerald, 1980; Miles and Frizell, 1990; Runnalls, 1975) have advocated that the disabled and their families have to be educated to take responsibility for their rehabilitation and management as no health care system is capable of providing this service on its own, particularly in developing countries where there is a shortage of physiotherapists.

The additional obligations the caregivers have to fulfill place a major burden on them in terms of psychological, physical and financial resources (Anderson, 1988; Forster, 1990; Frazer, 1980; Jones and Vetter, 1985; Lowenthal, 1967; Zarit, 1980). Brocklehurst (1981) found that deterioration in health was common and that 14% of those in employment gave up their jobs in order to care for their disabled relative. Other authors (Carnwath and Johnson, 1987; Wade et al, 1987; Warren, 1977) report on the frequency of depression and isolation experienced by many caregivers.

Sometimes the caregiver's obligations entail being available all day and all night throughout the week (Warren, 1977). They become isolated from their extended families, friends and community and have no time for themselves (Forster, 1990). The burden of the caregivers continue and eventually results in a deterioration of their health and breakdown of family functioning (Stone, 1987; Versluys, 1986). These problems are compounded in developing countries where there are poverty and social tensions (Bauer, 1977).

Miller (1983) maintains that family members need support in coping with the burden of caring for their disabled relatives. Even where some form of community support has been provided the family still carries the main burden (Anderson, 1988; Forster, 1990; Jones and Vetter, 1985).

2.7 AUXILIARY WORKERS

It is not possible to train sufficient physiotherapists to cope with the increasing demands resulting from improved medical technology and increased life expectancy. There are many tasks that persons trained at other levels could perform effectively and efficiently.

Physiotherapy assistants have been successfully employed in hospitals in Canada, the United Kingdom and the United States of America (the researcher's personal experience) for the past forty years. This form of training is now being done in various parts of South Africa and the physiotherapy assistants are registerable with the South African Medical and Dental Council. They are obligated to work under supervision of a physiotherapist.

2.8 SUMMARY

International trends are for physiotherapy services to be extended to include rehabilitation in community-based programmes. The literature shows that physiotherapy assistants and other forms of health workers have been utilised successfully to provide these services.

Rehabilitation services for disabled persons in Cape Town are inaccessible and unaffordable to the majority of the population.

They are situated in large high-technology hospitals situated far from the poorer communities. There are no posts for physiotherapists in the community and the domiciliary services that are offered in the private sector are not affordable to them.

There is a general shortage of physiotherapists coupled with an increasing need for more services. The numbers of disabled are increasing with an increase in the general and particularly of the aging population together with improvements in medical technology.

In order to meet the needs of the increasing number of disabled the caregivers should be equipped with the skills to sustain the rehabilitation programmes at home once they have been discharged from hospital or clinic. A "subsidiary" level of rehabilitation worker should be trained and community posts should be created for them to ensure that the necessary rehabilitation services reach more disabled in need. This would not mean an inferior service as fully qualified professional physiotherapists would be available for education and consultation of the auxiliary staff.

When more posts are created in the community and rehabilitation takes place either in community-based centres or in the homes of the disabled the physiotherapy curriculum will need to be extended to incorporate community-based integrated teaching and clinical experience for the students.

In the next chapter the shortcomings of the health system and the negative effect of this on rehabilitation of the severely disabled are discussed. Two different models of health care are compared and the influence of the coping mechanisms used by the disabled are discussed in terms of their influence on rehabilitation.

CHAPTER THREE

FACTORS INFLUENCING THE REHABILITATION OF CHRONICALLY DISABLED PERSONS

3.1 INTRODUCTION

In this chapter some of the more significant factors influencing the rehabilitation of the disabled in Manenberg will be discussed.

External factors will include medical models, health system approaches, philosophies and the community's response to disability. Aspects internal to the disabled will incorporate the individuals' response to disability, their coping mechanisms and feelings of powerlessness.

3.2 PHILOSOPHIES UNDERPINNING THE PRESENT HEALTH SYSTEM

This study was conducted during the `apartheid' era. `Apartheid' was linked to capitalism where the affluent minority of whites formed the core society controlling the political, economic and other sectors and dominated the majority of people in the country. This created dependency and underdevelopment of the peripheral black society. In capitalistic societies social, economic and environmental factors are ignored as being causes of ill-health. Illness is seen to be located within the body of the individual and this philosophy holds that in order for the worker to achieve the maximum level of productivity only a minimum level of physical and mental well-being is necessary and has to be provided by the state in order to achieve this (Olver, 1984:2). In this free-enterprise philosophy the individual pays for medical services and commodities provided by the health personnel (Klopper, 1986a).

The health system was that of the residual type in that it only provided some form of emergency assistance temporarily to those in need when the individual, family, community or economic systems could no longer cope. It was regarded as a safety net. This assistance was not seen as a right of the individual, but was regarded as a privilege and the service was provided selectively according to the colour of the individual (McKendrick, 1987; Wilensky and Lebeaux, 1965). It was the residual model of service delivery.

3.3 THE PRESENT HEALTH SYSTEM

The tricameral parliament resulted in the health services being provided by three authorities that were responsible to 14 ministers of health (Klopper, 1986a). Under this political system the three houses, namely, the House of Representatives, House of Assembly and House of Delegates represented the `coloureds', `whites' and Asians. `Blacks' had no representation in the political system. Thus there was a minister of health for each of the three racial groups representing each of the four provinces.

Based on racial discrimination the health services were fragmented into `general' and `own' affairs which meant that all hospitals in the Cape were under the authority of the Cape Provincial Administration and the Day Hospitals were under the control of the House of Representatives. This fragmentation increased the costs of the health administration. It allowed job opportunities to proliferate for administrators and health professionals and frequently led to unnecessary duplication of some services and gaps in others (van Rensburg, 1991). In Manenberg this was particularly evident as there were no rehabilitation or maintenance care services available for the disabled suffering from profound residual disabilities which caused them to be housebound.

The maldistribution of services also emphasised the inequality of the health services. There was a far greater concentration of health facilities and services in the urban areas as compared with the rural areas (Rossi-Espagnet, 1983; Savage and Benatar, 1990; Van Rensburg, 1991). This allowed the white population to receive more and better services and facilities while the blacks received less, inferior and even no essential services (Van Rensburg, 1991).

More than 80% of the provincial budget was devoted to curative hospital services centering on illness (McIntyre and Chetty, 1993) and only 5% to preventive services concentrating on health (McIntyre et al, 1991; Savage and Benatar, 1990; Van Rensburg, 1991). Rifkin (1981:377) claims that the greatest potential for health is through what people do themselves to improve their own health rather than emphasising individual treatments. This is confirmed by Savage and Benatar (1990) who claim that modern individual-oriented medicine does not improve the general status of a population as a whole.

Because primary health care received such a small portion of the budget many services were provided in the tertiary hospitals that could have been provided more effectively and less expensively at primary and secondary health care levels (Savage and Benatar, 1990). But it is difficult to know how to do this as there are insufficient basic health and census data for the health services in South Africa to be developed successfully (Klopper, 1986b; Fellingham et al, 1987).

The government encouraged privatisation in an attempt to reduce its own responsibility for medical care, but privatisation was part of the very reason for the very high cost of health services in this country.

Diseases and illnesses were, within this health system, accorded status and considered to be more deserving or undeserving of treatment according to the medical diagnosis (Fuchs, 1974:69).

The elderly or persons suffering from diseases that ultimately lead to chronic disability were not considered to be valued patients in the health care system and consequently major hospitals did not attach great importance to admitting these clients (Webster, 1980). Frequently they did not go further than the Emergency Units and then were discharged directly home or were admitted only until they were regarded as being medically stable. They were then prematurely discharged without having received adequate rehabilitation.

Younger clients suffering from coronary heart disease or severe trauma, however, were regarded as "worthy patients" and were admitted for the necessary length of time, receiving high-technology treatment and rehabilitation as required. Once the acute phase had passed the doctors frequently lost interest in them and that was just the time that the clients become aware of their physical problems (Sharman, 1972:3).

With this system of differentiation of status attached to medical conditions, the responsibility of caring for the elderly and chronically disabled lay with the family and outpatient services while that of the acutely ill fell on intensive high-technology hospital treatment (Webster, 1980).

Olver (1984) claims that this unfair allocation of resources should be better shared by means of developing community health services based on community determined needs and priorities. In great Britain community health services are redefining "worthiness" to include persons and diseases previously unacceptable on the health system's terms (Heggenheugen, 1984:220).

3.4 PRIMARY HEALTH CARE (PHC)

"Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination" (WHO, 1978:8)

The PHC approach emerged as a result of disenchantment with traditional medical care as it did not play a significant part in improving the general health of a nation in spite of all the knowledge and technology available (McIntyre and Chetty, 1993; Savage and Benatar, 1990). Simultaneously, during the 1970's it was recognised that the causes of poor health were not necessarily due to diseases, but rather to poor socioeconomic conditions, political philosophies, nutrition and the environment (Savage and Benatar, 1990). It was at this stage that health came to be associated with development.

National health system studies were done in China, Cuba, Tanzania, India and Nigeria which assisted in formulating a new approach that could be implemented to address the basic health needs of people in developing countries (Djukanovic and Mach, 1975). This led to the Conference on PHC in Alma-Ata in 1978 and became known as the PHC Approach due to its political philosophy. In 1979, the World Health Assembly launched the Global Strategy for Health for All by the Year 2000 (WHO, 1981).

The PHC Approach is based on the following five underlying principles (WHO, 1978:1-6; Bryant, 1988:10-15):

3.4.1 EQUITABLE DISTRIBUTION

Health services must be equally accessible to those in need which includes not only people of different races and income levels, but also those that live in rural and peri-urban areas. It means first contact care and delivery of health services to where people live.

3.4.2 COMMUNITY PARTICIPATION

The community should take an active part in decision-making regarding their health services. This includes individual and community capacity building and empowerment by education in order for people to have sufficient knowledge to address the issues that affect their health status (Heggenheugen, 1984).

Health is a process which is dependent on individual knowledge and choice and medical intervention is only one, and often not the most important, input.

3.4.3 PREVENTION

Preventative and promotive services should be emphasised rather than curative and rehabilitative services. The integration of these services assist in encouraging the promotion of healthy practices and lifestyles by balancing promotive, preventative, rehabilitative and curative services between primary, secondary and tertiary care.

3.4.4 APPROPRIATE TECHNOLOGY

The type of medical investigation and intervention used should be culturally acceptable and appropriate. There should be active channels of referral between first level services and hospitals so that the people can receive services at the most appropriate level. The hospitals should provide services to support PHC research and should provide both basic and continuing education.

3.4.5 INTERSECTORAL APPROACH

The health team approach accepts all health workers, at different levels, as forming an indispensable part of the health system. Community health workers and community rehabilitation workers should not be viewed as a cheap health care option for poor communities.

Health is seen to involve all aspects of living that affect the individual's and community's well-being. These include nutrition, education, water supplies and shelter.

The PHC Approach is much broader than conventional health services. It involves political action and the collaboration of sectors other than health. This means that there has to be an integrated approach to achieve comprehensive health care which can only be achieved if decision-making and planning is decentralised and there is participation of the people in health matters. The emphasis of resources is on allocation to preventative and promotive health activities and to the underserved and disadvantaged population groups. Primary, secondary and tertiary care occurs in an integrated health system. This means that there is a good referral system between first line practitioners, secondary and specialist hospitals and that referral takes place in both directions, namely, from primary to secondary or specialist hospital and vice versa. All levels of health care are involved with other developed sectors of the community as a whole in a process of healthy development.

Rossi-Espagnet (1983) claims that in order to achieve the goal of health for all by the year 2000, special attention should be given to the urban poor living in both city and peripheral areas. However, in a critique of the WHO scheme for CBR Elliot (1975) maintains that education, clean water and better job opportunities are usually given a higher priority than health care and that the disabled are, therefore, given an even lower priority as they form such a small proportion of any community.

PHC should be sustainable for future generations and should employ concerned, caring, and respectful health workers.

3.5 THE RECONSTRUCTION AND DEVELOPMENT PROGRAMME (RDP)

Although this study was completed before the document on the RDP policy framework was released by the African National Congress in 1994, it is essential to include it as it has important repercussions on health care structures and services for the country in the immediate future.

One of the key programmes of the RDP is to start to meet the basic needs of employment, housing, water, electricity, transport, nutrition, health care and social welfare so that family and community life can be reconstructed. These aspects are considered as the individual's rights with "special provision made for those who cannot look after themselves because of specific problems" (ANC, 1994:52).

There is to be a National Health System (NHS) with a single Minister of Health. The NHS will be based on the PHC approach and communities will be encouraged to participate in the planning, managing, delivery, monitoring and evaluation of the health services in their areas.

One of the health care programmes referred to in the document is that of a programme to provide appropriate care for chronic diseases and the promotion of healthy lifestyles. Within the Social Welfare aspect it recognises the role of community-based rehabilitation centres and organisations.

Human resources for the NHS will be achieved through the redistribution of personnel by incentives to work in underserviced areas and by limiting openings for private practice. The document makes it clear that new and shortened training programmes will be developed to train new categories and auxiliary workers.

Although rehabilitation for the disabled has not been dealt with in any detail the document states that "community-based and community-planned rehabilitation programmes must be encouraged to meet the needs of the disabled, and the democratic government must make adequate resources available for rehabilitation" (ANC, 1994:56). This allows an unprecedented opportunity for professional bodies to consult with local communities to work out details of developing their particular priorities and then to report back to the RDP office on the findings.

3.6 BIOMEDICAL MODEL

At the time of this study the health system was based on the biomedical model. It was constructed by medical scientists for the purpose of studying disease and is the prevailing model used in the Western world (Fabrega, 1972:1501). Doyal (1991) maintains that definitions of health systems that focus on physical malfunctioning are referred to as negative definitions.

Illness is seen only in terms of failure of one of the bodily systems. Its basic scientific discipline is that of molecular biology where disease is seen as a deviation from the normal and these norms are measurable biological values occurring at the molecular level and are independent of the social, psychological and behavioural factors that may be affecting the sick person. Thus the label, statistic or numerical value assigned to the biological measure assumes much more importance than the individuals themselves (Mason, 1985).

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

Engel (1977) maintains that the biomedical approach to studying disease has been most successful, but that the exclusion of related psychosocial and cultural aspects interferes with effective patient care. It places more emphasis on technical and laboratory tests than it does on the patient's subjective account. Therefore, psychological and behavioural manifestations and descriptions are not related to biochemical defects.

Clinical skills of interviewing the patient and analysing these reports in terms of psychological, social and cultural terms as well as in physiological and biochemical terms are underutilised. Important aspects of when patients perceive themselves as being ill, when others perceive them as being ill or how much the relationship between the doctor and patient influences therapeutic outcome are not considered. The approach explains the discrepancy that exists between patients experiencing the same type of illness and the doctors' conceptualisation of the illness (Rasmussen, 1975:53).

Duff and Hollingshead (1968) cite its incompleteness as the reason that even affluent people having access to health care complain that the doctors are interested only in their symptoms and not their personal and family problems (Mason, 1985). This is why medical institutions are perceived to be cold, uncaring and impersonal centres for medical research only. It has caused many doctors to question whether their qualifications are sufficiently adequate to offer quality care to their patients (Engel, 1973; Holman, 1976; Rasmussen, 1975).

Diseases and treatments are a mystery to most patients and this frequently results in psychological trauma. This in turn can cause `iatrogenic disease' where the pathology is directly or indirectly caused by medical intervention (Mason, 1985).

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

3.7 THE BIOPSYCHOSOCIAL MODEL

The PHC Approach to health is based on the biopsychosocial model which is a holistic model where the individual is seen in terms of physical, mental, spiritual, cultural and environmental aspects and where the treatment is directed towards all of these aspects, either directly or indirectly (Engel, 1977:132). The role of the health personnel and the health care system and their effects on health are also factors that are taken into consideration.

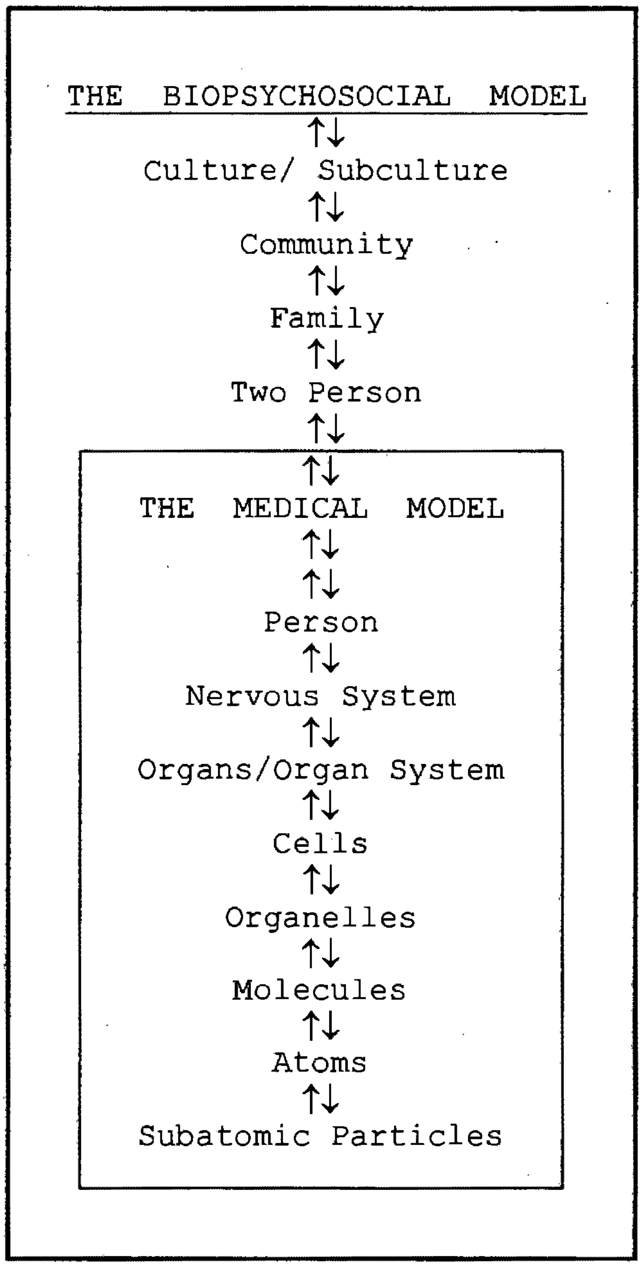


Figure 1: The Biopsychosocial model (Engel, 1960: 459)

A biospychosocial model is thus able to deal with broad issues of health and disease. It allows explanations to be given of why some individuals consider themselves ill and in need of help while others exhibiting the same symptoms consider these to be normal "problems of living" (Engel, 1977:133).

Medical education is far broader in this model. It incorporates social, psychological and biological knowledge and skills so that nonbiological circumstances that affect biological factors are not neglected (Holman, 1976). The doctor is also familiar with the functions of all other health personnel within the health team so that the individual can be referred appropriately for the best intervention to be provided.

In Figure (1) Engel (1960:459) provides a systems approach to the two models of health which clearly shows the comprehensive approach of the biopsychosocial model and the limitations of the biomedical model.

3.8 THE COMMUNITY'S RESPONSE TO PHYSICALLY DISABLED PEOPLE

There is a feeling amongst the general public that people with disabilities are inferior (Botha, 1993). Many physical conditions have been demonstrated to have a stigmatising effect on the disabled and this frequently also spreads to other family members as a "courtesy stigma" (Hardy and Cull, 1973; Sim, 1990:232).

Although the public express sympathetic feelings some people are repelled by the sight of or proximity to physically or mentally disabled people. It causes them discomfort and so they avoid situations where they may come into contact with disabled people. Botha (1993) explains this phenomenon from the point of view of fear. He maintains that people get anxious when they realise that they, too, may one day be in that situation and realise what a devastating impact it would have on their lives. This anxiety and compassion felt simultaneously arises from the fact that the fragility of life becomes more obvious to the nondisabled and they feel guilty about why such a devastating fate should have befallen the disabled when they appear to be responsible citizens and capable in so many other ways.

Botha (1993), a disabled person himself, expresses the feeling that the public's negative perception that people with disabilities are different from nondisabled persons is as a result of their being uninformed and that there is no difference between the ambitions and needs of disabled and nondisabled people.

As a result of the negative feelings and attitudes of the public there is a limited response to the needs of disabled persons by individual members of the public. While most forms of monetary support originate from religious and voluntary service organisations, proportionately little comes from governmental agencies (Hardy and Cull, 1973). Evidence from the International Year of Disabled Persons (1981) shows that governments are aware of the plight of the disabled, but they do not consider it a priority (Miles, 1983).

These attitudes and lack of awareness of the needs of the disabled could be addressed by physiotherapists destigmatising disability by means of educating the general public about the different medical conditions from which the disabled suffer and the ways in which the difficult living circumstances of the disabled could be alleviated by the necessary resources..

3.9 PARSONS' APPROACH TO THE SICK ROLE

Parsons (1951) views the sick role as a deviant state in that the sick person is involuntarily unable to conform to the norms of society. Sickness is seen to be deviant because health is assumed to be the state of normality and sick persons are unable to fulfill their social roles and functions.

This form of deviance is seen to be a situation that occurs within the social system rather than within the individual, but by affecting the individual it ultimately threatens the stability of the entire social system. The medical profession is regarded as a means of controlling and preventing the individuals from being dysfunctional.

Parsons maintains that the sick person is not responsible for his/her condition and therefore it is the person's right to receive medical treatment. Seen from this point of view he/she has a right to be excused from carrying out normal social functions while he/she is temporarily incapable, provided the condition has been legitimised by a health professional and is not merely a personal perception.

The sick person is expected to want to get well and to comply with the medical regimen recommended. These two aspects ensure that the sick person will not enjoy a nonproductive state and seek to prolong or capitalise on the "sick" situation.

3.10 POWERLESSNESS

"Powerlessness is a perception that one's own actions will not affect an outcome" (Miller, 1983:3).

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

The sense of lack of control can also arise from experiences in the health-care system. The disabled may not be given explanations regarding diagnostic tests or the choice of treatment alternatives and may never be involved in the health team's decision-making of choice of treatment.

Once the disabled have been discharged from hospital they become part of their community and society. It is at this stage that their disabilities become obvious as they face restrictions to the opportunities that allow them to participate in society. This is when they become frustrated and passive and no longer participate within the family and community (Checkoway and Norseman, 1986). It ultimately leads to regressive behaviour, depression and anxiety and they become isolated from their families and communities (Miller, 1983).

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

Knowledge and insight about their disabilities are enabling factors for patient control. It allows them to participate in decision-making as they understand alternative courses of action. The disabled can have modifications made to their environment to allow them increased control over their daily activities of living by achieving their maximum functional level.

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

Self-esteem is a power resource and enables the disabled to take an active part in controlling their personal care (Falvo, 1981). For example, a person having suffered a stroke will ensure that family members allow him/her to do as much as possible for himself/herself and will encourage them to assist with activities which will foster further physical improvement and function (Falvo, 1981).

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

Physiotherapy management can assist in preventing the negative aspects from which the chronically disabled suffer by empowering them to function independently as much as possible so that they can fulfill modified roles within their family and gain a sense of control. It is crucial for the physiotherapist to encourage the disabled to participate in decision-making concerning the alternatives of his/her management. In this way compliance and success with the regimen is much more likely to take place.

3.11 COPING

"Coping involves all cognitive and motor activities a sick person uses to preserve bodily and psychic integrity, to recover reversible impaired function and to compensate to the limit for any irreversible loss" (Lipowski, 1970:1).

Chronic disability affects the psychological, family, social and vocational aspects of the disabled persons' lives. Individuals cope with their problems in different ways according to their perceptions of their medical conditions and quality of life as well as their personality type and the amount of family and community support provided (Falvo, 1981; Miller, 1983).

Physical disability can negatively affect an individual's body image and self-concept. Furthermore, stigmatising conditions can result in social isolation and discrimination (Sim, 1990).

Unexpected chronic disability at any time leads to individuals reacting in the following ways:

a) GRIEF

When individuals first realise that they are not going to be able to regain full physical or intellectual functioning or that they will need to alter their roles or vocations they may suffer a period of grieving. The length of time of grieving varies between individuals and ends when they accept the loss emotionally (Falvo, 1981; Sim, 1990).

b) ANGER

They may experience anger at themselves or others as a reaction to their loss. This is frequently exhibited by being uncooperative with physiotherapists, being very demanding or refusing to comply.

c) FEAR AND ANXIETY

Uncertainty about future prognosis, loss of interpersonal relationships, loss of function and financial security can all cause the chronically disabled to either panic or withdraw and become uncommunicative (Gillis, 1980).

d) DEPRESSION

As they realise that their residual disabilities are permanent they may experience sleep disturbances, have difficulty in concentrating and become apathetic and passive. Falvo (1991) warns that if this depression is not resolved it can result in substance abuse or attempts at suicide.

3.11.1 COPING MECHANISMS

There are a variety of coping mechanisms that disabled individuals use to deal with their problems. These are developed over a period of time and vary between individuals and from time to time within the same individual.

a) DENIAL

When individuals cannot accept the outcome of their trauma or disease they do not accept its permanence and frequently insist that they are determined to achieve some unrealistic goal.

b) AVOIDANCE

The disabled minimise their condition and symptoms by not complying with suggested medical regimens. They try to continue with their original lifestyles as though they have been unaffected by their disability (Parsons, 1951).

c) REGRESSION

This is the tendency for the disabled to think and behave in a manner appropriate to an earlier stage of life. Generally, severely disabled have to be dependent on nurses, doctors and physiotherapists for their physical requirements, but when they regress they leave all decision-making and control of their lives to be taken over by others as well. They frequently refuse to help themselves with tasks that are within their capabilities and become over-demanding and attention-seeking (Gillis, 1980).

d) WITHDRAWAL

Extreme regression ultimately leads to withdrawal. The disabled become obsessed with their physical needs and fears to the extent that they isolate themselves from everything that is happening around them and everybody in their environment (Falvo, 1981). This can easily occur in large, acute hospitals where there are strict ward routines and the disabled become cut off from the world outside. The hospital ward routine frequently limits contact with visitors and family and places restrictions on viewing times for television.

e) RATIONALISATION

The disabled use their physical disabilities as an excuse for not achieving goals or completing tasks. Frequently they discuss previous unrealistic life goals and how they have not been able to meet them because of their disability (Falvo, 1981).

f) DIVERSION OF FEELINGS

Negative feelings and behaviours regarding their condition or disability can be diverted into positive actions. For example, a wheelchair bound person who feels extremely angry that he will not be able to walk again may use this energy positively to ensure that buildings are constructed for easy access for wheelchairs or he may participate in sports for the disabled and excel in competitions.

g) APPROACH BEHAVIOURS

These behaviours include talking and vigilant focusing. People using these forms of coping show obsessional sensitivity and compulsive attention to details. They need to have their condition and management explained to them in detail. They suffer from anxiety and express their feelings of hate, fear and repulsion regarding their disabilities and confront these emotions directly.

The way in which people cope with their disability affects their rehabilitation and their final level of functioning. Those who do not accept their disability passively frequently do not adjust to the hospital environment and become labeled as "difficult" clients. They are much more likely to achieve their maximum level of functioning by perseverance than the clients who accept the sick role.

Miller (1983) describes people who cope well as being enterprising and flexible. They do not use negative forms of coping, but set themselves realistic goals and are able to solve problems by dealing with those aspects that they can manage. They communicate well and seek help and accept support when it is offered to them. In this way they are able to maintain high morale and hope.

Physiotherapists can make a strong contribution towards the disabled developing positive coping mechanisms which will help them to deal effectively with their lives.

3.12 CONCLUSION

The health system did not provide adequately for the rehabilitation of chronically disabled persons in Manenberg. Facilities that were available were inaccessible to them because of the distance from the community and they could not afford the transport. They simply could not afford the services that were offered in the private sector or the transport to get them.

Many of the disabled never received physiotherapy rehabilitation as they were discharged prematurely or were never referred to the Day Hospitals.

The health system was based on the medical model which concentrated on the disease only and excluded psychological, social and cultural aspects of the person. This model had proved to be ineffective in improving the level of health of the country.

The biopsychosocial model which incorporates nonbiological circumstances offers holistic management of illness and fits into the primary health care approach. Management of disabled persons with this approach would help to alleviate the feeling of powerlessness from which the chronically disabled suffer and would assist them in using positive coping mechanisms. This would reduce the stress and anxiety placed on the family caring for the disabled.

The family bears the major responsibility for caring for the disabled and is severely affected by having to care for a disabled relative. As family members are the major social support system and play an important role in the rehabilitation of the chronically disabled the next chapter will deal with the dimensions and variations of the family in detail.

CHAPTER FOUR

THE FAMILY AS A SOCIAL SUPPORT SYSTEM FOR THE CHRONICALLY DISABLED

4.1 INTRODUCTION

In this chapter the family as a social institution and some of its structures and major functions are discussed in relation to the role it plays as a support system to the severely disabled. The family coping with chronic illness is analysed from a systems theory perspective.

The ability to live at home depends on the social and environmental situation and not on the disabled person's level of physical function. Thus the family plays an essential role in the maintenance of the disabled relative.

> "The family is a system of interdependent interacting individuals who are related to one another by marriage, birth, adoption, or mutual consent, who may or may not reside in the same household" (Hymovich and Hagopian,1992:57)

The systems approach incorporates different family forms comprising single persons living together, communal families, nuclear, extended and multigenerational families. The whole of the family system is greater than the sum of its individual members (Beavers, 1977:57).

4.2 THE FAMILY AS A SOCIAL INSTITUTION

The family is the basic unit of society which is made up of individuals, but at the same time it is part of the larger social structure (Goode, 1964). The unit comprises people who are usually related by birth, marriage or adoption and who reside in a shared household for some part of their lives.

The members cooperate and collaborate with each other to meet the physical, mental, spiritual, emotional and social needs and wants of all the unit's members (Burgess and Locke, 1953; Duvall and Miller, 1985).

It is the most stable social institution in society and because it is regarded as a major institution in all societies it is most important for the very existence of community life (Duvall, 1977; Goode, 1964; Nzimande, 1987; Stack, 1974). It is the only social institution, apart from religion, which is formally developed in all societies (Goode, 1964:4).

The family often facilitates social change by modifying its structures and activities so that it can conform to the altering needs of society and, therefore, plays an important mediating role by linking the individual to society. In this way it reflects the changes that society in general undergoes as it has an elastic and resilient ability to manage problems and to modify itself appropriately in order to survive. The family can accommodate changes in society and yet still maintain sufficient continuity to rear children in their culture so that they can grow and adapt to their environment (Minuchin, 1974). Because it is capable of achieving this it is the prime source of support to any family members in need, which would include the severely disabled.

The social aspects of the family as an institution centres on aspects of structure and relationships which come into being. The individual survives because of these relationships and interactions within and between families.

The whole family is affected to a large extent by events in the life cycle which produce occasions for family reunions, for example, at births, marriages, deaths and times of major illness or physical trauma (Friedman, 1980:429). According to Aldous (1978) traditional family celebrations or reunions bring families together and contribute to the bonds between members. In geographical environments or communities where resources are limited, family members rely essentially on each other for obtaining the basic necessities of life. This frequently means supporting one other throughout the entire life cycle.

4.3 STRUCTURAL-FUNCTIONAL THEORY

According to Leonard (1970:25) the structural-functional approach is a research strategy whereby the family is regarded as a substructure of society fulfilling specific functions in order for the orderly survival of society. This approach studies the way in which the individual's functions support the family system and the family system's functions support the general social system (Parsons, 1951).

Goode (1964), Billingsley (1968), Nobles (1978) and Walker (1985) have studied the differences between the structure and marital organisation of the various societies. Most marriages are homogamous in that "like marries like" with regard to traits of wealth, prestige and power (Goode, 1964:33). Homogamy is supported by various rules of endogamy which means the requirement of marrying within the religious group or caste or nation. Other rules require exogamy which embraces rules of incest taboos.

The family structure influences the manner in which family members interact with each other. It is an open system which has relationships and interactions with religious, educational and health institutions (Hymovich and Hagopian, 1992:59). The family can be understood from a structural point of view as an universal institution comprising:

(a) rules preventing incest;

(b) the man and woman of a family who cooperate through division of labour based on gender; and

(c) "a socially acceptable, permanent intimate liaison between individual men and women" (Gouch, 1971:760).

Families are adaptable to internal and external influences and they can alter when either circumstances within the family require changes to be made or when circumstances within society at large require alterations to be made (Hymovich and Hagopian, 1992:58).

When changes are brought about within families the individual members adapt their patterns of interaction with each other. The extent to which the family is able to utilise different patterns of interaction when conditions demand its restructuring depends on the strength of the family system (Aldous, 1978).

The family structure has changed over time in order to meet the basic needs of industrial and economic times and because of this family assets and resources can be an indication of the level of interdependence among family members (Goode, 1964:116).

In a period of crisis as is caused by disability, the family's structure is altered as the disabled member's capacity to perform his/her usual role within the family is decreased. The impact on the family functioning will affect the disabled person's role allocation within the family and the way in which he/she is rehabilitated within the family. Parsons (1951) maintains that if role reversal is strongly established and the disabled person takes on no household responsibilities he/she is less likely to rehabilitate.

4.4 THE NUCLEAR FAMILY

The traditional nuclear family comprises a breadwinner father, homemaker mother and numerous children. Steyn, (1994:11) found that in Johannesburg the most common form of family was that of the nuclear type. However, the researcher found that, in Manenberg, this form of household no longer predominates, but that a multitude of family and household types exist and coexist. These comprise large numbers of dual career couples, single parents, childless adults and households headed by women.

4.5 THE EXTENDED FAMILY

The term ***extended*** family is loosely applied to a system in which the society has several generations living under one roof (Farber, 1966; Goode, 1964.) In the Manenberg context ***extended*** family will refer to a household that is enlarged intergenerationally with parents and married children with their children and/or laterally with married siblings.

In the researcher's experience of this particular community the majority of extended families did not consider this the ideal form of living. It was a form that has been forced upon them by the high unemployment rate, poverty, shortage of housing and the long housing waiting lists of the City Council. Many of the families in the study had been on the housing waiting list for ten years and had from nine to fifteen people living in the main dwelling as well as in backyard constructions and shacks. These families were considered to be a form of extended family as they comprise siblings and their families sharing a dwelling as well as intergenerational communal living. This will become a greater problem as the numbers in the sixty-five and above age group of Manenberg are increasing.

Many of the extended families have chosen to live together to support each other as their particular nuclear families were unable to function effectively with a severely disabled family member. Usually some adult had to remain at home to care for the disabled and because of this their family incomes had been severely reduced.

Thus the structure of the extended family involves a broad clan of people related by blood or marriage with a network of relatives, who identify and bond together. In many communities the extended family structure acts as an effective social welfare system by providing care and support to its members for a variety of needs (Odetola and Ademola, 1985:106-109; Williams and Stockton, 1973:39-40). This is found in Manenberg where the families provide caregiver services to their severely disabled family members which, in other parts of the world, are provided by the state.

Beard (1994:11) maintains that it is important for the extended family to be recognised so that benefits of adequate housing, services and facilities can be created for the well-being of the community.

4.6 KINSHIP

"Kinship is a structured system of relationships in which the individuals are bound to one another by complex interlocking and expanded ties" (Murdock, 1949:22).

The manner in which these relationships and interactions are arranged depends on the philosophy of that community. Brooks and Nyirenda (1978) believe that kinship demands that the individuals in a particular family not only share accommodation, but continually live in a manner that it is to the benefit of all those sharing the accommodation.

The importance of the kinship system is in the execution of functions which support the family. Farber (1966:33) has identified the major functions to include (a) supporting the cohesion of its members; (b) maintaining the group's institutional way of life; and (c) supporting and assisting with any problems confronting the members.

Brooks and Nyirenda (1978:147) define kinship as "a web of social relationships within which individual members live and it is this solidarity which is the main influence". As a consequence there is a reciprocal system of sharing resources.

Although Goode (1964:58) maintains that kinship may extend beyond the boundaries of the nuclear and composite families to include everyone who is related by blood, in Manenberg there appears to be another form of accepted kinship. This is a form of reciprocal obligation in that families are found to be caring for a disabled person because, during some stage of the wife or husband' life, the disabled had shown him or her some compassion and had provided accommodation for him or her. These families now accept full responsibility for the care of the disabled, often without any financial reimbursement, and consider the disabled as part of their family. This form of kinship plays a significant role in the support system of the families in Manenberg.

4.7 FUNCTIONS OF THE FAMILY

According to Duvall (1971:5-7), Duvall and Miller (1985:8-9), Goode (1964), Hymovich and Hagopian (1992:61-63), Murdock (1949:10) and Sorokin et al (1965:4) the family fulfills the following functions to ensure the well-being of its members:

4.7.1 Provision of basic amenities. These include food, water, shelter and security.

4.7.2 Ensures survival of the human race by providing the conditions to facilitate procreation.

4.7.3 Social control. The family teaches its members to behave in a manner that conforms to the wishes of the particular society. It also provides feedback to its members about the way in which others perceive their behaviour.

4.7.4 Provision of environmental conditions which foster social, psychological and biological development and maintenance of family members.

4.7.5 Socialisation. Parents and children are the major participants in the process, but grandparents also take over this responsibility in extended families. Information imparted to children is crucial for the achievement of the various developmental stages and the successful management of crises that take place within the family. Socialisation also involves the provision of companionship between members of the family as well as between the family and social groups outside the family.

4.7.6 An environment where cultural and ethical issues are disseminated from one generation to the next. The family is the major source of the value systems and codes of behaviour that provides the individual with a sense of purpose to life.

4.7.7 An environment which fosters affection and mutual respect between husband and wife, parents and children and members of the extended family.

4.7.8 The opportunity to allow mutual respect to be expressed, and where human dignity is nurtured, freedom of speech is approved and the individual's place in the family is affirmed so that self-realisation is achieved.

4.7.9 A stable environment where appropriate responses to intense human experiences like birth, marriage, death and disability can be learned.

4.7.10 Families provide substantial physical, emotional, social and economic support during crises that occur in a family member's life (Biegel and Naparstek, 1982; Caplan and Killilea, 1976; Friedman, 1980; Will and Wrate, 1985). Even in the United Kingdom where community support services are reasonably well developed it is still the family which bears the main burden of care for disabled people (Anderson, 1988; Jones and Vetter, 1985).

4.8 SYSTEMS THEORY IN RELATION TO LONG-TERM CARE

> "The family is a system that operates through transactional patterns. Recurrent transactions determine patterns of how, when and to whom to relate and these patterns underpin the system. It is a self-maintaining system in that it supports selected patterns for as long as possible and allows only a certain amount of change to occur, but beyond a certain point it offers resistance to change" (Minuchin, 1974:52).

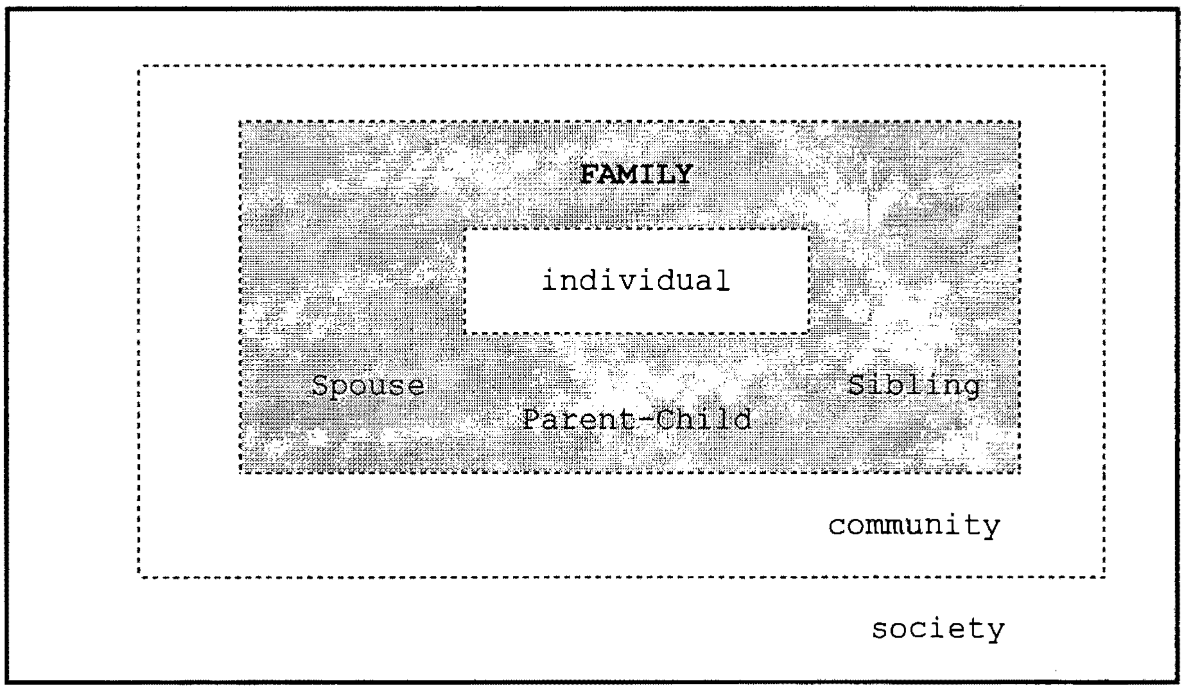


Figure 2: The family system in long-term care (Hymovich, 1992:58)

Figure (2) represents the family system in relation to other systems in this model of long term care (Hymovich and Hagopian, 1992:58). The broken lines indicate how the family system communicates with and relates to its individual members and to the community and society at large.

Disability in one family member has an impact on all family members (Hymovich and Hagopian, 1992; Kerr and Bowen, 1988; Minuchin, 1974). It is capable of causing significant anxiety within a family system which affects the patterns of communication, roles and relationships among family members (Benoleil and McCorkle, 1978; Cassileth and Hamilton, 1979; Kerr and Bowen, 1988). According to family systems theory, families are in a dynamic state of change, perpetually reacting to situations external to the family (Minuchin, 1974). Because of this families having a disabled family member alter in structure and roles performed as they attempt to cope with changes in the disabled relative over the course of the disability.

The first feature of the above model of LONG-TERM care is that of interdependence. Families comprise individual family members who occupy different positions in the system. Each position (husband-father, wife-mother, son-brother, daughter-sister) is behaviourally, physically and emotionally interdependent with the others in varying degrees, depending upon the stage in the life cycle (Aldous, 1978). This interdependence involves both cooperation and conflict. Family subsystems are formed by paired positions (for example, spousal, parental, sibling) in which the behaviours associated with one position assume someone is occupying the other position. These subsystems may be formed by sex, generation, function or interest (Goldenberg and Goldenberg, 1980). In view of the fact that the family is a system, an alteration or deviation in one family member affects all other members. Therefore, a chronic disability in any member will have an effect on all other members. If one spouse is disabled the other spouse may have to take on additional responsibilities or leave a job to remain home with the resulting economic implications. The children may have to relinquish some extramural projects in order to take on additional household tasks or responsibilities by caring for the disabled member. When one parent is disabled the other may spend so much time with the spouse that the children may be deprived of both parents.

The second feature is boundary maintenance. Because family systems interact with other social systems such as educational, religious, economic and health care these community systems have an influence on family functioning. For example, the health system influences services available for the care of the disabled. At the same time, however, the family system tends to maintain its boundaries by individual family members acting within the constraints of the family structure (Parsons, 1951).

Open-system families have many social relationships and interact with social institutions such as religious, school and health institutions. Because these families have greater access to social networks and outside resources they have more energy for problem-solving and life pursuits than families not very open to the outside world (Hymovich and Hagopian, 1992).

Families with restricted networks and little social interaction have little energy coming into the system from the outside to strengthen the family. Such families are vulnerable during periods of crisis and long-term stressful situations because they lack social support and expend all their energy on maintaining their boundaries. In these families where there is little differentiation between the individuals the family members tend to speak for each other. When confronted with chronic conditions this type of enmeshed family becomes overwhelmed and immobilised and it may be difficult to identify who is in charge in the family because all members seem "overtly involved with the patient" (Gray-Price and Szczerny, 1985:59).

Members in a disengaged family function separately and autonomously rather than interdependently. They have little sense of belonging to the family and rarely communicate about their feelings (Hymovich and Hagopian, 1992). Subsystem boundaries within these families are rigid, so only high levels of individual stress lead to support (Minuchin, 1974). Mobilising disengaged families is often difficult for health care providers (Gray-Price and Szczerny, 1985).

Thirdly, the family is capable of adapting to internal and external changes.

Fourthly, family roles may be defined by sex, age or function (Hymovich and Hagopian, 1992). Some of the family roles that need to be identified are related to child care, socialisation, kinship, recreational, provider and housekeeper. However, in each society, these roles are sanctioned and norms are set as to guide the performance of specific societal functions. Children are also expected to participate in certain roles within and between the families. These roles are distinguished by means of privileges and they have particular duties designated to them. Thus each family member and the family as a whole have distinct tasks to fulfill or roles to perform (Aldous, 1978). Each role should be viewed with an understanding that some of the roles are shared between the members of the family and are not mutually exclusive (Nye, 1976). For instance, the provider role, which was traditionally limited to the male domain, and the housekeeper role which was usually designated to the female, are presently undergoing changes and delineation is less clear as these roles become shared.

The way in which a family responds to a chronic illness may be affected by the allocation of roles within the family (Parsons, 1951). When there is a disabled person in a family, role tasks may change among the family members. These changes are sometimes for a period of time only or sometimes they are permanent, depending on the features of the disability. These role changes often create a situation of stress and crisis in the family because these alterations involve restructuring of family interactions (Gray-Price and Szczerny, 1985; Livsey, 1972). As roles are altered, there are changes in the division of labour. Children may be bound to perform household chores previously performed by a disabled parent (Korer and Fitzsimmons, 1985). These additional duties and obligations cut down on free time for these children. Even if the disabled person is able to maintain or accomplish part of his or her role expectations, disability diminishes role accomplishment, making role compliance erratic and unreliable (Hymovich and Hagopian, 1992:60).

4.9 COPING THEORY

Burish and Bradley (1983:3-12) contend that with coping, the family system reduces or prevents the responses that normally occur under stress. According to Pearlin and Schooler (1978:2-21) coping refers to the activation and employment of the supports, skills and aid that is available in a person's social network for dealing with and solving problems. Their theory is based on sociological reasoning and centres on areas related to family life and occupation rather than the psychological theories which are concerned with maladaptive processes and intrapsychic interpretation. Thus they deal with the typical person's or family's style of handling problems related to daily living. This theory and the definitions of Lazarus and Launier (1978: 287-327) and Murphy (1974) are based on the perspective of **efforts** to manage the stressful event, regardless of the outcome. This means that no single coping strategy is better than any other one. The strategy's effectiveness depends on its effects in the immediate situation and in the long term.

The family system is considered to incorporate a resource exchange network within its internal arrangements. This system comprises flexible role relationships and a sharing of power.

Pearlin (1981:337-356) in his discussion on the structure of the coping and stress process maintains that there are many difficult social problems, for example, poverty and crime, with which people contend in life. This hinders them in most situations and causes constant adversity and burden. The majority of these problems require resolution by major social institutions.

Their attention is, therefore, concerned with the array of experiences that occur in the lives of people within their various roles of parents, husbands, wives and providers because it is during these experiences that people react to the hardships that interfere with or obstruct their lives.

There is a vast span of stresses and strains associated with everybody's daily roles in life and there are many different ways in which people deal with these situations that cause stress. When people are unable to cope with certain major social problems it affects their well-being. There are many critical social problems that the individual is not able to control by means of coping processes. Many of these problems arise from social and economic institutions and have an intense effect on the individual's life, but they are unable to be controlled or influenced by the individual personally.

A point is reached when adults realise that they are unable to cope with their difficulties and, in order to avoid being affected negatively, they utilise external resources to deal with the problems. They may approach their relatives or the social services for assistance.

Many social problems are experienced in the family environment and thus affect the functioning of the family as a unit, particularly that of adaptability and cohesiveness. These stresses test the family's fundamental resources and problem-solving framework.

The family can respond to the problems before crises arise or it can select alternative responses which are specific to roles and the situations It can also involve the family's initial level of organisation and the ability to find its unique stylised solutions to specific problems.

Social networks and the potential support they offer are major considerations when studying the effects of stress on the family. Dohrenwend and Dohrenwend (1974:1) maintain that stress is a complex stimulus and may be an implied inner state or a covert response to a situation. Stressful life experiences play a considerable role in the help-seeking process. In order to understand how situations in life interact with other variables one needs to know what conditions influence which behaviours, the circumstances that influence these and the processes involved.

According to Nghatsane (1992:91) help-seeking as a network comprises three groups:

(a) The informal service system. This includes friendship and kinship networks where any individual can be approached for help in identifying the problem, offering direct service or referring the person to a place where assistance can be obtained.

(b) The self-help and quasi-formal system. This group does a great deal of work and includes voluntary organisations comprised largely of non-professionals.

(c) Professional service organisations. These consist of multidisciplinary professionals.

4.10 CONCLUSION

The family is the major social institution for the survival of society. It is resilient and able to modify itself to cope with internal and external problems. It achieves this by altering its structure and roles performed by the various members. A disabled member has an effect on all other members of the family and it is by means of the altered roles that the disabled person is able to survive and the family is able to cope with the stress.

As the intention of this study was to increase the capacity of the disabled to become self-reliant and to assist the families with coping with their disabled relatives by means of community development and community participation these two concepts will be dealt with in the next chapter.

CHAPTER FIVE

COMMUNITY DEVELOPMENT AND COMMUNITY PARTICIPATION

5.1 INTRODUCTION

Community development provides the framework to physiotherapists for extending rehabilitation programmes beyond the hospital and into the community. The concept Community Development will first be examined and its applicability reviewed as a means for improving the quality of life of the housebound disabled and their caregivers in Manenberg.

5.2 COMMUNITY

> "A community is the specific system of action which arises when a human population, settled in a given territory, establishes structural arrangements for adaptiveness to it in order to live and survive as a group, developing interactive relationships amongst its components, which not only define an order kept off equilibrium by some kind of stress, but also originate shared ways of thinking, feeling and acting which are internalised by all the population and with which each individual identifies himself in a particular degree according to his personal living experience and inherited characteristics" (Ferrinho, 1980:1).

Every community is unique and its characteristics have to be assessed when designing appropriate action programmes since resources are unevenly distributed among communities and the people have their own aspirations when choosing intervention programmes. These reflect the values of the particular community (Cox, 1977).

The sociocultural, demographic, economic and ecological factors of a community are interrelated and changes in one of these will automatically bring about changes in the others (Ferrinho, 1980).

5.3 COMMUNITY DEVELOPMENT

> "Community development is the process by which the efforts of the people themselves are united with those of governmental authorities to improve the economic, social and cultural conditions of communities, to integrate these communities into the life of the nation, and to enable them to contribute fully to national progress. This complex process is, therefore, made up of two essential elements: the participation of the people themselves in efforts to improve their level of living ...... and the provision of technical and other services in ways which encourage initiative, self-help and mutual help" (United Nations, 1963:4).

Coetzee (1989:164) maintains that "Development has to be firmly based in human well-being, the quality of human life and a great deal of esteem. It has to focus on the aspirations and needs of people as they are defined by people themselves. All development action should therefore take note of the prerequisite, namely, that the people should participate in shaping their own existence and future".

Community development can be defined as a movement, a method, a programme, a system or a process, depending on the view of the author.

5.3.1 COMMUNITY DEVELOPMENT AS A MOVEMENT.

> "Community development is a movement designed to promote better living for the whole community with the active participation and, if possible, on the initiative of the community. If the initiative is not spontaneous then the community developer should use techniques for arousing and stimulating it in order to secure its active and enthusiastic response to the movement. It embraces all forms of betterment" (Brokensha and Hodge, 1969:35).

It involves conscientising and capacity building of the people. This leads to actions that bring about concrete improvements to the peoples' lives.

This approach aims at sharing power and ultimately to changes in the power structure (Rifkin, 1981).

Mukerji (1961), however, warns that a movement of this nature can stimulate mass action and raise false expectations of the people as frequently the expectations cannot be met.

5.3.2 COMMUNITY DEVELOPMENT AS A METHOD.

It is the method whereby the goals and objectives of a group - government, welfare agency or local - are achieved by carrying out a concrete type of project (Cary, 1975). When used in health care this approach allows professional health workers to influence participants from the community to use new techniques in order to achieve the goals of the health profession. Used in this way self-help and community participation are advanced to some extent, but the emphasis is on the results of the project and not on the development of the people concerned.

5.3.3 COMMUNITY DEVELOPMENT AS A PROGRAMME

Community development as a programme occurs when people participate in self-help programmes which depend largely on their own resourcefulness with some technical and resource input from government authorities to motivate this self-help. In this way the economic, social and cultural conditions of communities become improved in the direction of the general interests of the nation (Mukerji, 1961).

The programme approach to community development emphasises the activities of the project and not the people carrying out the project (Fitzgerald, 1980:30).

Dunham (1960:29) who views community development as "organised efforts to improve the conditions of community life and the capacity for community integration and self-direction" identifies four basic elements in community development as a programme. The progamme has to be planned; self-help needs encouragement; there needs to be resource and technical assistance in the form of personnel, equipment and supplies; and their needs to be integration of various sectors for the support of the community.

5.3.4 COMMUNITY DEVELOPMENT AS A PROCESS.

Biddle (1965) maintains that there are several orderly and progressive steps that a group of participants need to plan in order to achieve the goals they have set before community development can be achieved. By undertaking these steps the participants are involved in the processes of social interaction. They define their needs, plan how to solve their problems and then execute their plans themselves with or without the assistance of outside resources.

This process is problem-oriented and leads to growth and social awareness in the group as well as in the individuals concerned. In this approach the importance is not on what is done, but on how it is carried out and that if the means of getting there are successful the end will be achieved. However, the reverse does not hold. If the end is successful, but the means getting there have not been achieved, it will not lead to community development (Mukerji, 1961).

5.3.5 SYSTEMS APPROACH TO COMMUNITY DEVELOPMENT

Community development occurs when a local community or neighbourhood tries to improve its social and/or economic conditions by means of its own endeavours with or without some outside professional and financial assistance, but with maximum involvement of all sectors of the community (Blakely, 1979:15-23).

The community system consists of a number of communities. Communities are interdependent for survival (Nghatsane, 1987), therefore, any change in one component affects the other components. When pre-planning programmes in community development it is important to consider the entire community system so that any changes brought about in any one section will have positive results and not lead to advancement of that particular system at the expense of another.

5.4 CHARACTERISTICS OF COMMUNITY DEVELOPMENT

5.4.1 It improves the lives of individuals of a community by improving social conditions (Jacobs, 1992). The community itself defines what a better life comprises and then determines the direction and processes that will lead to the improved quality of life (Coetzee, 1989; Ferrinho, 1980; Roberts, 1979). The motivation for the initiation of social improvement programmes sometimes comes from the people themselves, provided they are sufficiently convinced that improvement is possible. Mostly, however, it is stimulated by professionals working in the community (Biddle, 1965; Ferrinho, 1980; Coetzee, 1989; Midgely, 1986; Roberts, 1979). In developing countries people frequently do not take the initiative themselves because they are used to everything being provided and carried out by the authorities and they merely take a passive role (Swanepoel, 1989).

5.4.2 Community development means planned and managed change of social conditions based on needs as defined by the community (Jacobs, 1992; Fitzgerald, 1980, Rifkin, 1981). Thus community participation plays a major role in the planning, management and evaluation of social programmes. The changes that occur in the community affect the physical and economic state of the people as well as their attitudes, self concept, personality and relationships (Ferrinho, 1980; Rifkin, 1981; Roberts, 1979). Because the community is a holistic and integrated system, changes in one component result in changes in other components as each component is part of the social system (Jacobs, 1992; Roberts, 1979).

5.4.3 It involves group action at grass-roots level and, therefore, is concerned with group processes, interpersonal relationships and personal growth. Group action means community participation in its broadest sense involving physical undertakings, decision-making and problem-solving activities. Group action can be effective provided sufficient numbers of people participate in defining the needs and dealing with the problems (Coetzee, 1989; Ferrinho, 1980 ; Fitzgerald, 1980; Jacobs, 1992; Roberts, 1979; Swanepoel, 1989; Twumasi, 1981).

5.4.4 Local action can be sustainable only if there is sufficient community grass-roots participation to assess the community problems and to set strategies to attack the problems so that the action meets the people's needs (Clinard, 1970; Ferrinho, 1980; Fitzgerald, 1980; Jacobs, 1992; Khinduka, 1969; Roberts, 1979; Twumasi, 1981).

5.4.5 It provides learning and managerial opportunities rather than creating structures (Rifkin, 1981; Roberts, 1979). The learning process incorporates individual learning as well as group learning and involves learning of attitudes, skills and knowledge (Roberts, 1979; Khinduka, 1969). The new skills and knowledge gained empower the individual by increasing his/her ability to control outcomes (Blakely, 1979; Midgely, 1986; Rifkin, 1981).

5.4.6 It is objective-oriented as it addresses both concrete and abstract human needs. When people participate in a community project their objective is always concrete. As they address these physical needs, abstract development objectives are achieved simultaneously (Fitzgerald, 1980).

5.4.7 It encompasses internal and external physical and human resources in the form of materials, technology, personnel, equipment and finances. Internal resources emanate from maximum reliance on the community itself. External resource are provided by outside assistance in the initial stages of a community project (Ferrinho, 1991; Fitzgerald, 1980; Rifkin, 1981).

5.4.8 On the whole it addresses small simple projects. These projects are not only relevant to the poor, but are essential to any community that is undergoing rapid social change as it ensures that the people determine the direction of the change. As development occurs it leads to further development efforts by the same group of people or by other groups (Fitzgerald, 1980; Ferrinho, 1991; Graham, 1992; Khinduka, 1969).

5.4.9 It focuses on self-help by making the people aware of their social situation and inducing self-confidence that the people have the ability to control the situation themselves. Self-help projects are considered to be authentic only when they are initiated and established by the community itself (Coetzee, 1989; Ferrinho, 1980; Rifkin, 1981).

5.4.10 Community building and growth occur by the development of community leaders, institutions and the organisational ability of the people (Fitzgerald, 1980; Khinduka, 1969).

5.5 STEPS IN THE PROCESS OF COMMUNITY DEVELOPMENT

5.5.1 AWARENESS OF TENSION

The process of community development begins when individuals of a community realise that they are under stress, although they are unaware of its origin (Roberts, 1979).

5.5.2 IDENTIFICATION OF SPECIFIC PROBLEM OR NEED

A group of people experiencing the same stress recognise that their perceived tension is as a result of a specific problem or need common to the majority of individuals (Jacobs, 1992; Fitzgerald, 1980; Rifkin, 1981). In disadvantaged communities the needs usually present as a lack of food, water, shelter, clothing, treatment of illness or control of harmful environmental factors (Nghatsane, 1987). In communities where the socioeconomic conditions are good their needs may be concerned with the provision of cultural or self-fulfillment activities (Maslow, 1968). Whatever the problem or need identified by the community the stress it causes results in creative energy. Awareness of the need serves as motivation for the group to locate the cause of the deficiency and to find a satisfactory solution (Roberts, 1979). Thus group problem-solving starts with the awareness of the problem and leads to its definition by the group with the motivation to seek solutions.

5.5.3 STAGE OF LEARNING

Group members engage in a period of learning. This involves learning about themselves as individuals, about the other members of the group, about the group as a whole and about their environment. Learning includes communication skills, meeting procedures, group dynamics and interpersonal relationships (Roberts, 1979).

Community workers play an important role during the process of learning and have to take great care not to impose their assumptions and wishes on the group (Swanepoel, 1989).

5.5.4 SETTING OF GOALS AND OBJECTIVES

Once the group has become consolidated and has passed through the stage of learning the goals and objectives are formulated. Decision-making begins from this point and usually involves brainstorming by the individuals of the group in order to formulate strategies for intervention.

Rifkin (1981) maintains that the objectives of the project should never be vague. When the quality of life needs to be improved, it should be achieved through concrete objectives which direct the people's perceptions and actions.

In societies where the government does not allow local decision-making and action, community development is not possible (Roberts, 1979).

5.5.5 STAGE OF ACTION

This is the time when education leads to community development. Implementation of various strategies devised to resolve the problem or need takes place.

The community people play the leading part with experts and professionals playing a facilitating role.

Roberts (1979) maintains that unless the group has passed through the stages of learning and setting of goals and objectives, the action taken often leads to unsatisfactory results.

5.5.6 EVALUATION

Evaluation needs to be done throughout and at the end of the programme. Monitoring should be carried out continuously so that progress can be assessed and incremental changes carried out where appropriate to improve the implementation. At the end of the programme the evaluation assesses whether the goals and objectives have been achieved by the intervention strategies (York, 1982).

In community development various social indicators are used to assess the extent of development that has resulted from the programme put into action. It is a type of `action-research' on social conditions and effects of various forms of social action. The ongoing research leads to further social action (Roberts, 1979).

The evaluation of programmes involving the community stimulates the educational process and the community and the professionals learn from each other in this process. From the results of the evaluation the action group can make decisions about their implementation methods and how to effectively distribute the findings to the community. It is again a time where the outside experts and community people can learn from each other (Rifkin, 1981).

Fitzgerald (1980) maintains that there are no decisive factors which allow certain community development programmes to be successful while others fail.

5.6 ASPECTS OF COMMUNITY DEVELOPMENT PERTAINING TO THE RESEARCH PROGRAMME

5.6.1 DEVELOPMENT APPROACH

As can be seen from the descriptions of the different community development approaches the movement, method and programme approaches have no relevancy to this particular research programme as they emphasise programme propaganda, results and activities respectively. The interest of this research study, however, lies with the development of the people and, therefore, the process approach is most applicable. The systems approach applies to the extent that any changes that occur in one part of the community will have an effect on other parts of the community.

Fitzgerald (1980) states that it is difficult for a community development worker to initiate a community development process in an area where the living conditions are characteristic of that of a slum. This is because, in these areas, the people are often apathetic, feel inadequate and are unaware of resources that could be used. There is also a certain amount of mistrust and insecurity regarding the community worker (Lovell and Riches, 1967).

However, in the Manenberg programme the community itself identified the felt-want of a physiotherapy programme and then enlisted the assistance of the researcher with the problem-solving and execution components, conforming to the community development process approach. Brady (1967) confirms that although underprivileged people may be determined to become self-sufficient, progress cannot be self-generated. In order to be eventually self-sustained there has to be strong outside support as the disadvantaged are unable to do this by their own endeavours.

The community of Manenberg can be defined as a community in transition as it had developed to the extent of organising, erecting and managing the MPC. It had also recognised the disabled and their caregivers as a vulnerable group, identified their needs and invited the expertise of the University of Cape Town Physiotherapy Department for assistance in spite of a multitude of other basic social needs which affected a far larger proportion of the community. This balanced approach to what it considered as desirable development made sustainability of the programme far more viable.

Community involvement in health care is a very good way of motivating grass-roots people to participate in decision-making and action which affect their lives (Adams; 1990; Rifkin, 1981). However, provision of a physiotherapy service by the University Physiotherapy Department to an uninvolved community would not have lead to any form of community development as it would not have lead to capacity building which would empower the people. Unless the community itself had become involved in the research programme community development would not have taken place.

The extent of their involvement was to participate in identifying the needs of the severely disabled and their caregivers, to assist with the management of the rehabilitation programme after training and to assist in the monitoring and evaluation of the programme. Education was encouraged and relevant learning opportunities provided throughout the programme.

5.6.2 THE ROLE OF THE COMMUNITY WORKER

The professional community development worker should simplify technical concepts and language terms so that the grass-roots people can understand what they can do to improve their circumstances or environment (Rifkin, 1981).

The community development worker should have an affinity for working with groups and should appreciate the local people's values and norms. There should be no attempt at persuading the group to conform to the community development worker's personal aims and standards of behaviour (Fitzgerald, 1980; Rifkin, 1981), but should encourage active participation and provide assistance and support to enable them to react positively to difficulties (Batten, 1975; Coetzee, 1989). The community should understand that the community development worker works in partnership with them and only provides knowledge and expertise, but that they will have to take on leadership responsibilities and contribute to finding the solutions to their problems themselves (Fitzgerald, 1980; Swanepoel, 1989).

5.6.3 RESOURCES

Swanepoel (1989) maintains that there is a vast amount of expertise available in all communities, no matter what their socioeconomic level. The researcher made maximum use of the people and the organisational facilities in Manenberg in order to set up and sustain the programme as, at the time the programme was set up, no financial resources were available.

As the community had already defined their needs of a physiotherapy training programme the researcher involved them in planning the different stages of the programme to encourage community control and to ensure that the community considered that it was appropriate. In this way it ensured that the programme served the needs of the Manenberg community rather than the researcher's needs (Rifkin, 1981). It was also a means of increasing their personal and institutional capacities which was more likely to result in a sustainable programme which would improve the quality of life of the disabled and their caregivers (Louw, 1993).

5.7 COMMUNITY PARTICIPATION

"Community participation is an active process whereby the beneficiaries influence the direction and execution of development projects rather than merely receiving a share of project benefits" (Bamberger, 1986:1).

The basic aim of community participation is to foster power to disadvantaged individuals by increasing their capacity to control their resources and decisions so that they can share the benefits produced by their society (Bamberger, 1986; Jacobs, 1992;).

Community development workers or organisations encourage participation by providing opportunities and formal or nonformal training programmes or enabling learning by implementation of projects whereby individuals are helped to identify their own needs and to find solutions to these problems (Bamberger, 1986; Midgely, 1986). Moser (1987) stresses the importance of encouraging women to be involved as much as possible in the decision-making and implementation of projects that affect their lives. Jacobs (1992) warns that community participation does not constitute liaison with community leaders only as they may have their personal agendas which do not fit those of the community and if the leaders lose interest or leave the community the programmes frequently fail.

The level of participation varies from information sharing, consultation, decision-making and initiative taking. The extent of participation can be measured by the number of people involved and the duration or commitment of their involvement (Bamberger, 1986).

Most authors maintain that community participation usually takes place in small disadvantaged communities (Bamberger, 1986; Midgely, 1986; Rifkin, 1981), but others believe that the whole community should be included (Bamberger, 1986; Midgely, 1986).

Midgely (1986) maintains that communities have different capacities for and commitments to community participation and that individuals vary in their wishes to become involved. They also have different personal constraints limiting them from participating. Some have preferences for being involved with different issues more than with others, but the majority of people are happy to be passive and not take any part in decision-making provided that there are others serving their interests (Midgely, 1986).

Checkoway (1982) and Checkoway and Van Til (1978) found that communities with higher levels of income, education and occupation are more willing and able to participate and communities with higher socioeconomic status are more active, organised and influential than communities with lower socioeconomic status. In another study Checkoway (1986) found that nondisabled persons participate more than disabled people, even in programmes designed for the disabled.

Midgely (1986) found that communities comprising different cultures, religions or political affiliations do not participate as much as cohesive and integrated communities.

Although effective community participation is very difficult to achieve, the success of community projects depends on the extent of the community participation. This should be achieved at grass-roots level as early as possible and should be sustained throughout the duration of the project. The researcher should work with the people and not for the people (Jacobs, 1992; McLaren, 1986).

Community participation in the planning and implementation of projects ensures sustainability as the local knowledge and skills used make the project more acceptable and help to mobilise additional local resources (Bamberger, 1986).

Community participation is regarded as being a success only when the project is effectively sustained by the community once all external support has been disengaged (Midgely, 1986:27).

5.8 ASPECTS OF COMMUNITY PARTICIPATION RELATED TO THE MANENBERG STUDY

The foundation of the study was to encourage participation in the programme by the caregivers and disabled. This was fostered by incorporating them in the identification of their own problems in relation to the physical disabilities that were having such a negative impact on their lives. They were assisted by the researcher and students in finding solutions to the problems and then implementing them.

The part of the programme that incorporated volunteers demonstrated that individuals have their personal commitments which limit the extent to which they can become involved and that people also vary in their willingness to become involved.

5.9 CONCLUSION

Great care has to be taken when initiating community projects with the intention of them becoming self-sustaining. They will not become self-sustaining if there has not been adequate community development and sufficient community participation in the identification of the problem, planning, implementation and evaluation stages.

Regardless of how limited the educational level of the individuals in the community they have the ability to learn how to improve their circumstances. Unless they are involved in finding the solutions to their problems so that they can implement the best alternatives themselves the project will not be sustained.

If a community project is to be successful it is extremely important for the community worker to be very familiar with the community itself as well as its environment. Thus a community profile of Manenberg is presented in Chapter Six.

CHAPTER SIX

COMMUNITY PROFILE

6.1 IDENTIFICATION

Manenberg is a Cape Town City Council (CTCC) housing letting scheme encompassing approximately 4 square kilometres.

It is bordered by Klipfontein, Lansdowne, Duinefontein and Vygeskraal roads and lies between the townships of Heideveld, Guguletu, Sand Industria, Primrose Park and Surrey Estate.

The distance from the centre of Manenberg to the Cape Town Central railway station via the N2 and Eastern Boulevard is 25 kilometres.

Manenberg is not well situated with respect to shopping, business facilities or access to other suburbs, but it is reasonably accessible to Epping industrial area where a considerable number of residents appear to work.

Swanepoel (1989:11) defines a community as a "...unique living entity and, like its people, it continuously changes physically and psychologically. It is also in a continuous relationship with its own individuals, its environment and other communities."

However, Gott (1991) and Midgely (1986) maintain that there is no such thing as a community as communities comprise a rich diversity of groups and interests and that the only aspect that is common to the groups is geographical borders.

This would appear to apply to Manenberg in very many aspects. Social interaction among the community members is fragmented and mistrusting due to the level of crime and violence in the area. The community is also differentiated in terms of status and income in that the higher income groups live in the houses bordering on the neighbouring homeownership suburbs. In many ways very little compassion is demonstrated by members of the community. Flat leaseholders exploit poorer people by renting backyard shacks at relatively high sums to homeless families and money lenders demand excessively high interest rates from those in debt.

6.2 HISTORICAL BACKGROUND

Because the vast majority of the Manenberg community comprises `coloured' persons a brief history of this group of the community will be given.

They are an indigenous product of the mixed unions between the early `white' settlers, local Hottentots, slaves and the African inhabitants of the sixteenth and seventeenth centuries in South Africa. During the seventeenth century marriages between `white' men and baptised `non-white' women were permitted and had full social approval and religious sanction. Legitimate children of these marriages were "simply absorbed into the predominantly `white' community" (MacCrone, 1951:3).

Thus today's `coloured' people have their origins in the Cape from these marriages, miscegenation between slaves and Hottentot women as well as from the illicit relationships which occurred as a result of the shortage of `white' women experienced at that time (Lever, 1978:5).

During the eighteenth century it was extremely difficult for slaves to become emancipated and, according to MacCrone (1951:4), the concept started to develop that "slavery was the proper condition of the `black' races". This was the beginning of racial discrimination where a pigmented skin came to be associated with an inferior status in the community and was the basis of the `apartheid' system. It has resulted in the `coloured' people feeling unwanted, divided amongst themselves, disillusioned and bitter (Lever 1978). Brindley (1976) considers these negative attitudes to be the prime cause of the `coloureds' personal despair; even more than that caused by their demographic and socioeconomic problems.

The Commission of Enquiry into Matters Relating to the `Coloured' Population Group (Commission of Enquiry, 1976) cites the lack of an identity and positive self-image in a large proportion of the `coloured' population to the following factors (Fitzgerald, 1980:39-41)

(a) In terms of the Population Registration Act (Act 30 of 1950) the word `coloured' had a negative connotation as this Act defined a `coloured' as a person who was not classifiable as `white' or `black' and who did not form part of the Chinese, Indian or other Asiatic groups. The name `coloured' was defined by the `white' population group and was not based on the `coloured' peoples' perception of themselves sharing their own language, religious beliefs, values, habits and traditions.

(b) Even though they were `culturally white' the `apartheid' system excluded the `coloureds' from the `white' social order. This social segregation was more detrimental to the `coloureds' than the `blacks' and Asians because the `blacks' and Asians had their own cultures to which only some aspects of `white' culture had been added (Mostert, 1987).

(c) The `coloureds' identity became confused because they were often not accepted by either `whites' or `blacks' and yet they were descendants of both groups.

(d) Cohesive and orderly communities were forcibly moved to new areas without consideration of the factors that had been the essence of their cohesion.

(e) The classification into `white' and `coloured' of many areas changed several times during the `apartheid' years leading to anxiety and apprehension as sometimes they lived in areas to which they conformed as far as colour was concerned as it was classified as `coloured' and other times they felt as though they did not belong as the same area had changed to a `white' area and they knew that sooner or later they would have to leave their homes.

(f) The Group Areas Act (Act 36 of 1966) resulted in disparate standards whereby the `coloureds' received inferior housing, education, health care, transport, social services, public safety and security. These factors had a negative effect on family life as well as life in general.

(g) People were removed from residences in areas of their choice and placed in other areas with inferior housing, higher rentals and transport. This lead to them becoming isolated from their extended families, friends and social networks.

(h) When families were forced to leave properties they owned in `white' areas they suffered financial loss as they were not paid out the true market value of the properties. Many `whites' made significant financial profits in these transactions.

(i) `Coloured' persons frequently were removed to unpleasant geographic environments which were isolated from their working and social environments and which made access to shopping and health care facilities very difficult.

(j) The lack of essential community facilities, such as schools, community centres, post offices, libraries, public telephones and police often for several years after their establishment.

(k) The above factors caused a vicious circle of poverty from which most `coloureds' were unable to escape.

It is a population from this historical background who now live in Manenberg.

6.3 DEVELOPMENT

Manenberg, originally known as Heideveld Extension 1, is one of the poorest working class suburbs on the Cape Flats (Carollisen et al, 1988).

It was developed to house people relocated under the Group Areas Act and was proclaimed a Group Area on the 25th June 1965. This act provided for separate demarcated residential areas for the use of the four major racial groups in South Africa, namely, for `blacks', `whites', `coloureds' and Asiatics. Thus involuntary resettlement of disqualified people living in `white' areas was enforced. Although racial segregation has been practised in South Africa since the country was first settled, it was only in 1948 that the National Party government legislated for ethnic and racial separation of the people (Sinclair, 1986).

As a CTCC letting scheme it was planned and constructed by the CTCC itself. Planning was done in 1963 and the first allocation of people to houses was made in June 1967. Completion of houses took place in 1970 and the "infil" houses in 1984. The "infil" scheme is known as such as these houses are all double or triple storeyed flats built in between and behind existing single storeyed houses.

The National Housing Commission, stated that 50% of accommodation was to be made available to families removed as a result of enforcing the Group Areas Act. The majority of people came from District Six and Diep River, but they were also removed from other affected areas such as Salt River, Woodstock, Claremont, Constantia, Lansdowne, Observatory and Maitland (Manenberg Housing Estate Office).

District Six was a community in the heart of Cape Town and home to 30 000 people classified as `coloureds'. It was one of the oldest residential areas in Cape Town and had achieved a high degree of community awareness and cohesiveness. Even though it was a diverse society it had a well developed network of economic and social relationships. The destruction of the neighbourhood broke the network which held this community together. Brindley (1976) observed that this destruction was perhaps the worst aspect that resulted from the policy of forced removals.

The people objected strongly to this forced removal and division of their community. The newly formed communities on the Cape Flats have found it difficult to develop a sense of bonding and common interest that had been present in the past. This is evident today in Manenberg where almost any resident approached will deny any sense of community cohesion.

The words of a victim of this removal sum up their predicament. "We were picked up from District Six and were scattered like sand around the Cape Flats. We had nothing. There was no community left. We could not rebuild". (Badsha, 1986:132).

6.4 DEMOGRAPHIC PROFILE

Unless otherwise stated the data for section 6.4 has been obtained from the 1970, 1980, 1985 and 1991 population censuses.

Mostert (1987) and Klopper (1986b) believe that South Africa lacks a comprehensive system of census data collection and with regard to `non-white' communities information is particularly unreliable. This is confirmed by the Manenberg Advice Office and Civic Organisation as they believe that their population figure for Manenberg at 60 000 is a conservative estimate against the figure of 39 798 given by the 1991 census. Reasons for this are that parents often did not include illegitimate children and that the residents were loathe to admit that they were sub-letting rooms in their dwellings or shacks in their backyards for fear of reprisals from the CTCC.

According to Petre (1985) between 1970 and 1980 the number of people who were resident in Manenberg grew from 17 136 to 38 121. This was probably due to the fact that Manenberg's housing was completed in the late 1970's and the total housing capacity had almost been reached. From 1980 to 1985 the population expanded only to 40 388. This small growth is most likely because Mitchell's Plain had been built early in the 1980's and many of the higher income residents from Manenberg moved there. The 1991 census gives the population figures as 39 798 which is less than that of 1985 and clearly cannot be accurate as most tenants had built shacks in their backyards for rental to accommodate additional residents after 1985.

6.4.1 POPULATION DENSITY

Manenberg has a density of approximately 117 persons per hectare (based on the conservative census population figure of 39 799) which is much higher than most neighbouring CTCC letting schemes (Figure 3).

HOUSING ESTATE	PERSONS PER HECTARE
Bonteheuwel	133
Heideveld	57
Manenberg	117
Primrose Park	21
Surrey Estate	61

Figure 3: Population density of some CTCC letting schemes

6.4.2 RACE GROUP CLASSIFICATION

RACIAL GROUP	PERCENTAGE
Whites	0.08%
Coloureds	99.23%
Blacks	0.25%
Asians	0.44%
TOTAL	100.00%

Figure 4: Race group classification

Figure (4) represents the population of Manenberg classified by race.

6.4.3 POPULATION COMPOSITION

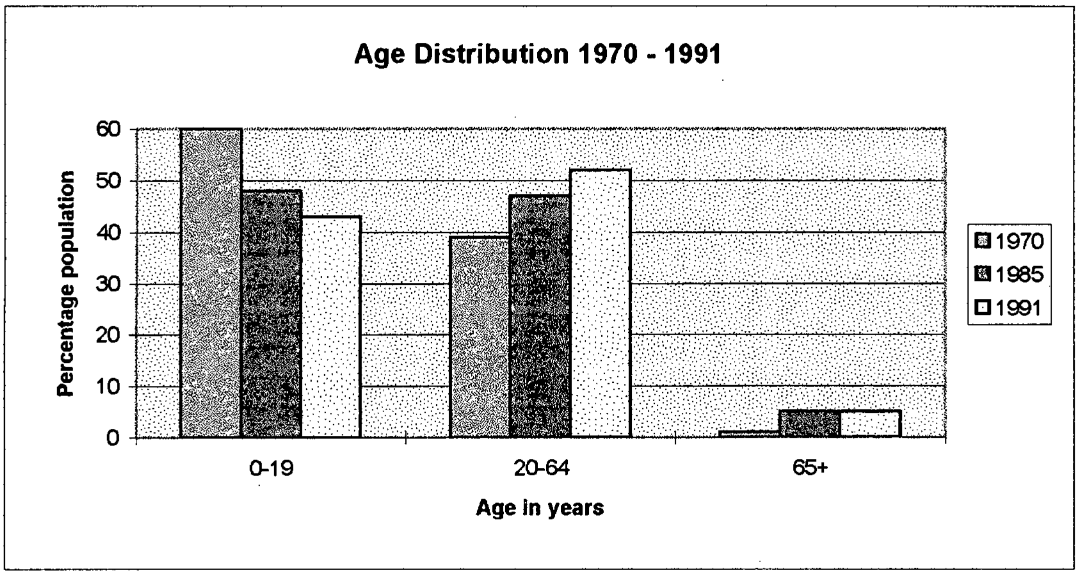


Figure 5: Comparison of age distribution over twenty years

Census figures from 1970, 1985 and 1991 indicate how Manenberg has undergone significant changes in age distribution over this period. Figure (5) indicates how the population has generally become older and the percentage in the above 65 years age group has increased from 1% to 5% resulting in an age group which has a greater degree of dependency as it is the most affected by disabling illnesses.

As the `coloured' population is by far the majority (99.24%) of the population living in Manenberg and it comprises the population from which the research sample

The home language of approximately 87% of the population is Afrikaans, 10% English and the remaining 3% another language.

6.4.4 LEVEL OF EDUCATION

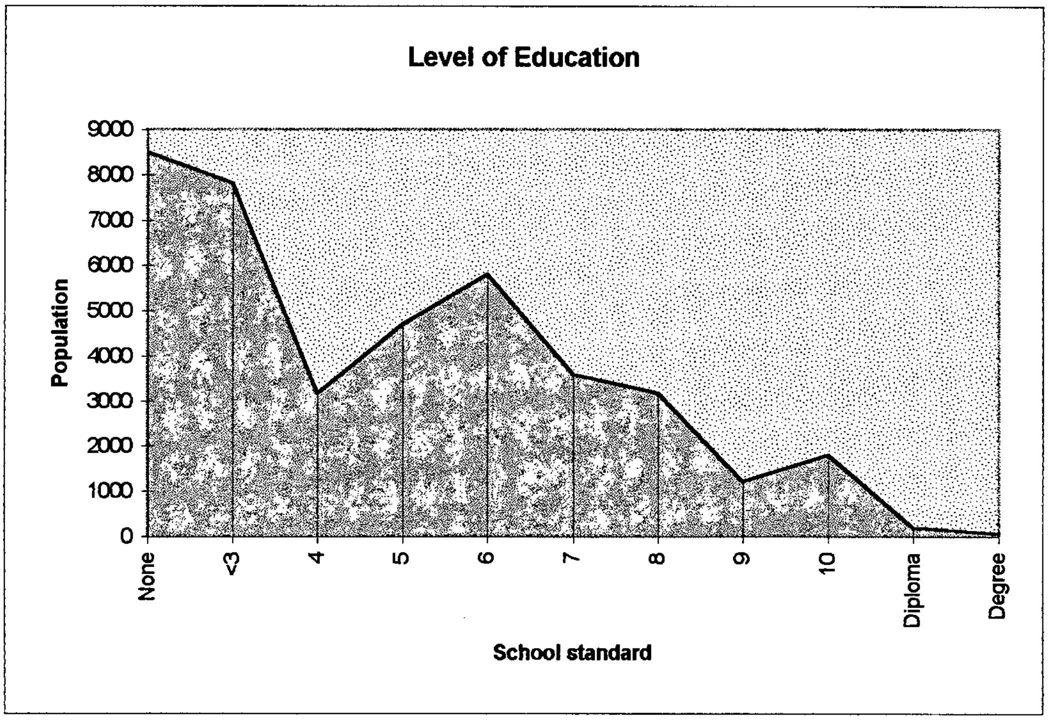


Figure 7: Education profile of Manenberg 1991

From Figure (7) it can be noted that 21% of the population (excluding that percentage under 5 years old) have no formal education. The majority of the population have a standard 4 or less. Furthermore, only 0.3% of the population have professional qualifications, namely standard 10 and above. However, when comparing them with the 6.86% recorded in 1980, one becomes aware of the massive movement of professional people out of Manenberg. Not only does this "brain drain" affect the local economy, but it also means that their are fewer people available to work in an organisational capacity in the community.

Since skill and education are essential to rise above the level of poverty that exists in Manenberg, there is little hope of escape from their deprived lives for the majority of the residents here.

6.4.5 RELIGION

Religion plays a large role in the lives of the Manenberg community. The Manenberg Profile (1991) stressed the importance of religion in helping the people trying to make sense of their lives. There are 19 churches, 3 mosques and 1 Bible Institute ministering to the spiritual needs of the community (Manenberg Profile, 1991). The number of members belonging to each denomination is presented in Figure (8).

DENOMINATION	NUMBER	PERCENTAGE
NGK	1 425	3.6%
Anglican	2 990	7.56%
Methodist	641	1.63
Roman Catholic	1 981	5.01
Christians	8 862	22.43%
Congregational	208	.54%
Lutheran	274	.69%
Apostolic Faith	334	.85%
Islam	8 941	22.63%
Non-Christians	28	.08%
Other	13 816	34.98%
TOTAL	39 500	100.00%

Figure 8: Religious affiliation of population

6.4.6 OCCUPATION

The occupational profile suggests that 41.7% of the total population is economically active and that the most common occupations are in production, transport and manufacturing with the clothing industry and domestic work dominating.

Although very small, there does seem to be a degree of upward mobility as the percentage of the Manenberg population involved in the top three occupation categories increased slightly from 4.43% (1980 census) to 5.41% (1985 census) to 5.8% (1991 census). However, this percentage of the population is minimal and the majority of the people work in insecure jobs that are easily affected by retrenchments during periods of economic recession.

It is difficult to calculate the true unemployment rate as the census was constructed in such a way that individuals who were unemployed, but looking for work, were required to state their previous occupation and were listed under the stated occupation while unemployed persons who did not state a previous occupation were included in the non-classified category (Petre, 1987). It cites the unemployment rate as 62.5% but the guesstimate of the Advice Office is that, presently, it is closer to 70%.

Over two-thirds of the housing units in Manenberg have sub-tenants and it is estimated that in these situations the average number of people per dwelling ranges between 8 and 15, while there have been reports of up to 30 people living in a two bedroomed house.

6.5 HOUSING

The characteristic feature of Manenberg as a township is the indiscriminately mixed sub-economic and economic matchbox-like houses and flats which lack any form of variety.

The outer walls of the buildings are unplastered and the blocks of flats are unattractive with their unkempt appearance and graffiti. Maintenance of housing and the surrounding environment by the CTCC is very poor and the wet winter conditions on the Cape Flats make the houses damp and cold.

Many of the flats have cracks in the walls and leaking ventilation holes to the extent that the rain pours through and causes flooding of the homes. This is especially so in the flats upstairs where the roofs leak. Many of the staircases leading to the second and third floors are rickety (Athlone News 17.07.1991).

Facilities provided are very limited as can be seen below:

- 37% of dwellings have outside toilets which are shared among three or four dwelling units
- 37% of dwellings have no bath or shower provided by

the council
- 40% of dwellings have 2 rooms, 49% have 3 rooms and 11% have 4 rooms
- 3% of dwellings have hot water.

Some tenants have made an effort to improve the appearance of their homes, but most of the houses are in a state of deterioration. The residents are apathetic and fatalistic and tend to wait for the CTCC to provide for all their environmental needs. In 1991 R1 million was allocated by the Regional Services Council in an effort to upgrade Manenberg. This sum was designated to upgrading some of the "poorly built flats" and roads (Athlone News 17.07.1991).

Many landlords allow families to erect shacks in the yards of the houses. They are self-constructed from scrap metal or corrugated iron and as a result of poor workmanship and inadequate and inferior materials the roofs and walls leak in wet weather. Frequently they are built on low-lying ground which periodically gets flooded during the wet winters.

6.5.1 ADMINISTRATION

Housing is presently controlled by the CTCC which operates from two Housing Estate Offices situated in Swakopweg and Duinefontein Street. They are responsible for the collection of rents and the hiring out of the four Council Community Centres located in Manenberg.

Letting and evictions are the responsibility of the Central Housing Office in Cape Town.

6.5.2 HOUSING DENSITY

The housing density per hectare of Manenberg is very high compared to its neighbouring housing estates (Figure 9).

SUBURB	HOUSES PER HECTARE
Bonteheuwel	21
Heideveld	12
Maitland	3
Manenberg	21
Primrose Park	4
Surrey Estate	12

Figure 9: Housing density of some CTCC letting schemes

6.5.3 OWNERSHIP

From April, 1991 the tenants in Manenberg have been able to purchase their own homes from the CTCC and have also been able to upgrade their houses according to their individual family needs and comfort (Athlone News 22.05.1991).

Profits of houses being sold have been used for fencing of the maisonettes, repairing pathways between flats and providing downpipes and gutters (The Argus, 21.9.91.).

At present only 927 of the 7 866 houses are privately owned.

6.5.4 HOUSING STOCK

There are 7 866 housing units and 1 598 families on the waiting list for houses. 50% of all dwellings are sub-economic which is the highest percentage of sub-economic housing in all the CTCC housing schemes and as such caters for the poorer sectors of the `coloured' community.

The `coloured' community in the Cape Peninsula is facing a chronic housing shortage because the state has not kept pace with the housing needs and the serious accommodation shortage has resulted in extensive problems of overcrowding and the tendency to have three generations sharing a home (Cape Town City Council, 1993).

6.5.5 RENTALS

Rent per month is directly related to the income of the official tenant and indirectly to the size of the dwelling. This ranges from R55.00 to R171.00 per month.

Poverty is endemic and with unemployment at 70% people are unable to pay rents, electricity and water bills. 52% per cent of residents' rents are in arrears, 21% have electricity and 24% have water arrears. This is double the amount of total arrears for the municipal area of Cape Town (Cape Town City Council, 1993).

Because of the high levels of gangster activity and lack of security 50% of the residents have their names on waiting lists for transfer to other housing estates.

6.6 EMPLOYMENT

As Manenberg is situated fairly close to major industrial areas there is no industrial activity inside the suburb and there are no sites zoned for this. The major single employer is the CTCC Housing Office which provides work for about 23 people (Housing Estate Office). The schools also provide substantial employment, but most of the people employed by these two departments reside outside the area.

The local shops are generally small, family-run businesses with limited employment opportunities.

No details are available about the informal sector, consisting of trade stalls, shebeens, repair shops and small home industries.

6.7 INCOME AND EXPENDITURE

The widespread poverty of the `coloured' people can be partially attributed to the inequalities in economic and social opportunities open to them. A major cause of such poverty is low wages and other contributing causes are lack of education, lack of specific training and skills and lack of adequate knowledge of budgeting (Lever, 1978).

All data on overall and individual income and expenditure that can be obtained from surveys and the 1991 census reveal substantial margins of error, either because households are likely to disclose distortioned information for fear of rent increases or eviction from low-cost homes or because the figures are derived from overall averages.

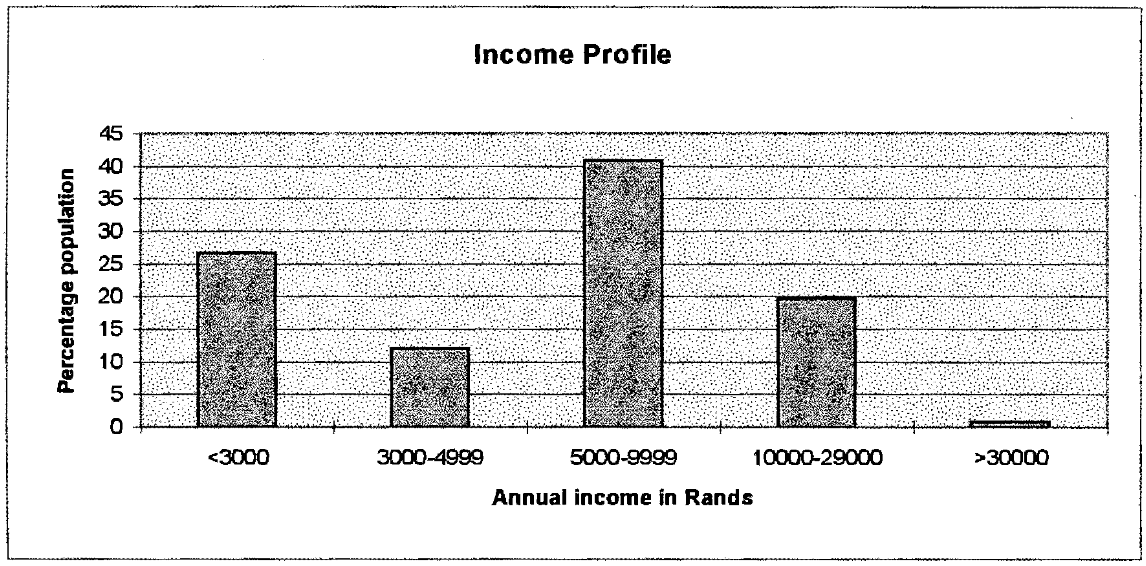


Figure 10: Annual income profile for Manenberg 1991

With regard to the Income Profile (figure 10), as provided by the 1991 census, only 37.45% of the population earned an income during 1991. Of those who did earn an income, 79.53% received an annual gross income below R10 000. Income is calculated according to gross annual wages and salaries and includes pension, grants, subsidies and any other fringe benefits.

These low levels of income are reflected in the increasing dependence on soup kitchens and food parcel handouts which are provided by various organisations in Manenberg.

6.8 COMMERCIAL ACTIVITIES

Manenberg's formal trading sector consists of 16 shops including a barber, butcher, shoe repair store, bakery, as well as two liquor outlets. Most of the shops are of the small "corner-shop" variety, which offer only a narrow range of goods, There are no supermarkets, though one would seem to be feasible in terms of the population size.

The informal sector is dominated by mobile shops which, in conjunction with street vendors and door-to-door dealers, are mainly responsible for the distribution of fruit and vegetables, fish and small retail outlets. An informal market is also established once a week at Nyanga station, where a wide range of non-durable consumer goods are sold. There is also a large `black' market which specialises in the provision of alcohol (shebeens) and drugs (marijuana and mandrax), controlled by the numerous druglords and gangs.

Manenberg does not have formal banking services, although many shops perform certain banking functions such as the cashing of cheques. There is also a noticeable absence of a petrol/service station in the township.

6.9 SERVICES AND FACILITIES

6.9.1 BATHHOUSE

Manenberg township's first bathhouse was opened to the public in Manenberg Avenue in November 1985 (Cape Times 8.11.1985).

6.9.2 ROADS AND PAVEMENTS

Road access to Manenberg is very good as it is served by Duinefontein Road which is a well maintained duel carriage way.

All the road surfaces are either tarred or of cast concrete. Although the CTCC resurfaced one or two of the major roads in 1992 they are generally in bad condition with gravel bedding appearing through the potholes. During the winter pools of water form along the roads as not all of them have stormwater drainage. The CTCC laid further drains in 1991 in order to alleviate this problem (The Argus, 21.09.1991).

The pavements are of sand or gravel and when the wind blows in summer the sand is blown into the houses and street gutters. During the winter the pavements become flooded and large pools of mud form on them.

The stormwater drains that do exist are frequently blocked by household litter and sand from the pavements. Car owners also place bricks and concrete slabs in the gutters as ramps for their cars to be parked on the pavements outside their dwellings.

Most streets have lights, but these are inadequate in many areas because they are too weak and too far apart and the lamps are frequently smashed by vandals.

6.9.3 WATER AND SANITATION

All houses are supplied with water and have waterborne sewerage. Water accounts are paid separately from rents.

6.9.4 ELECTRICITY

All houses are provided with electricity. They are metered separately and their accounts are paid separately from their house rents.

6.9.5 POSTAL SERVICE

The post office provides the usual facilities, including the payment of pensions. It is located in Duinefontein Road. All houses receive the normal daily postal service delivery, 5 days per week.

6.9.6 TELEPHONES

There are no public telephones. Residents use those of the shop owners for a considerable sum of money.

6.9.7 REFUSE COLLECTION

Refuse collections are made from all houses twice per week and the streets are also cleaned twice per week by the CTCC.

This is not very evident as there is a great deal of litter along the pavements and streets as a result of the garbage dumped by residents. Newspaper reports frequently refer to mass meetings called to discuss this problem (Athlone News, 29.04.1992).

6.9.8 FIRE PROTECTION

Manenberg is served by the Wynberg Fire Station. No figures are available to show the incidence of fire in the area, but it is considered to be a "high risk" zone due to the overcrowding in the dwelling units.

6.10 TRANSPORT

Due to the lack of local employment opportunities and the inadequate commercial facilities the residents are very dependent on public transport.

There is a train service direct to Cape Town provided from the Nyanga Railway Station. It serves the townships of Nyanga, Manenberg and Guguletu and at peak hours is extremely overcrowded with people even travelling by hanging outside the doors of the coaches.

Buses run between Manenberg and Mowbray Station Bus Terminus, but there is no direct bus route between Manenberg and the major areas of employment of Epping Industria, Maitland, Paarden Eiland and Ndabeni. Overcrowding is also a problem on the buses as they serve residents from Hanover Park and other townships bordering on Manenberg.

Taxis provide the best form of transport as they travel directly to the industrial areas. This appears to be the most sought after form of transport as the rates are cheaper than that of the buses and trains and they are much faster. However, as they are privately owned and the drivers are paid on a commission basis there is gross overcrowding and the drivers travel at dangerous speeds, frequently being involved in accidents.

Resettlement housing estates have resulted in the situation where the monthly expenditure on travelling to and from work absorbs a large part of the residents' income (Commission of Enquiry, 1976). In Manenberg this has been found to be the highest single cost item for many of the workers. This not only decreases their effective purchasing power, but also prevents the unemployed from travelling to the industrial areas in search of employment (Petre, 1987).

No figures quoting car ownership are available, although it would seem to be in the region of 1 car per 3 to 4 families, in line with the average for most housing schemes in Cape Town (Hitner and Jenkin, 1976).

6.11 EDUCATION

The education system falls under the control of the Department of Education and Culture within the House of Representatives. This education system is generally regarded as being inferior to that of the `whites' under the jurisdiction of the House of Assembly. This perception is experienced by the community in Manenberg too. Reasons for these perceptions include the inadequate teaching facilities, unqualified teachers, lack of sporting facilities, overcrowded classrooms and the syllabus as laid down by the "apartheid" system.

As a result of these problems, scholars have been consistently involved in demonstrating sympathy with various causes and have had direct confrontation with the police on many occasions. In 1985 this led to the death of several students and a large number of detentions took place (Petre, 1987).

High school pupils dumped garbage at the two rent offices in support of dustmen involved in a labour dispute with the CTCC (Cape Times, 30.07.1987). In 1992 the parents occupied Manenberg Primary School and the scholars boycotted school in protest against the removal of its principal (Cape Times, 25.07.1992).

Because of the general standard of education, the degree of poverty and the fact that in most families both parents work it is difficult for them to take an active interest in their children's education. Because of the overcrowding, the inability of the parents to assist them and the frequent lack of electricity that many homes experience it is almost impossible for children to do their homework and progress academically. Many of the mothers are also alcohol abusers due to their social isolation and the lack of constructive leisure time activities that are available to them. This leads to poor parenting and interest in their childrens' educational needs.

There has been an 8.5% decrease in the numbers achieving an high school level of education over the past 15 years (Department of Education and Culture, 1993). This can be partially attributed to the fact that compulsory schooling for `coloured' children was introduced only in 1974. Another reason is that there are too few high schools and so many pupils are turned away. If they are unable to attend schools in neighbouring townships, they end up by joining one of the many gangs and being involved in substance abuse and crime.

Those people wanting or who have acquired a higher level of education generally leave Manenberg leading to a "brain" and "skills drain" from this area.

6.11.1 SCHOOLS

The school buildings are all similar in design. The exteriors are drab and poorly maintained and the surrounding grounds are stark with no attempt at gardens or constructed sports fields.

There are 10 Primary Schools, 3 Senior Secondary Schools, 12 Pre-Schools and 3 Nursery Schools in Manenberg itself. This does not incorporate all the school facilities that serve the Manenberg community as some parents, for various reasons, have chosen to send their children to schools outside the area and there are some children attending these schools who live outside the area (Department of Education and Culture, 1993).

6.12 LIBRARIES

There is one library situated close to the shopping area. It has been closed down for a long period of time due to the gangster activity. The gangsters terrorised the library staff to such extent they felt they could no longer risk their lives by maintaining the service (The Argus, 21.9.91).

6.13 WELFARE

When people were removed from the slums of District Six, in terms of the Group Areas Act, and resettled in the new housing estates on the Cape Flats they were not provided with any welfare services to help them accommodate to a new style of living. This resulted in them continuing a similar life-style to that of the slum from where they originated. The welfare services in the `coloured' urban areas were very limited and were generally remedial in nature for individuals and small groups only and not at all community-oriented. Thus the available social welfare services were not able to meet the communities' needs.

Because the welfare services lack coordination and there is no community participation for overall planning there is a deficit in the provision of preventative services (Commission of Enquiry, 1976).

6.14 HEALTH

The health services in Manenberg are under the control of the Cape Provincial Administration and Cape Town City Council.

6.14.1 CLINICS

There is only one day clinic in Manenberg which is controlled by the Cape Town City Council. There are four community health nurses who operate in and outside (home visits) the clinic (Manenberg Clinic).

They offer the following preventative, promotive and educative services:

child health care
pre-natal care
health education
family planning
family counselling
sexually transmitted diseases
TB treatment
referral to agencies
substance abuse counselling
limited psychiatric care for the mentally disabled
geriatric care.

6.14.2 HOSPITALS

GF Jooste Hospital with 176 beds admits post-acute patients from other hospitals, for example, Groote Schuur Hospital and Victoria Hospital. It does not offer any casualty or outpatient services. It is presently undergoing alteration to an acute hospital with casualty and outpatient services to be put into operation in July 1995.

6.14.3 DAY HOSPITALS

Outpatient medical and antenatal care are provided by the Hanover Park and Heideveld Day Hospitals which are situated in adjoining townships. Medical facilities are obtainable at a sliding scale fee (Manenberg Profile, 1991).

6.14.4 DOCTORS AND DENTISTS

Four private general practitioners and one dentist practice in the community (Manenberg Profile, 1991).

6.14.5 SOCIAL WORKERS

The housing offices do not employ social workers. State employed social workers who do deal with people in the area are employed by the Heideveld and Hanover Park Day Hospitals. They consult within the hospital premises and, only occasionally, do home visits. There are, however, social workers employed by NGO's working in the area (See SHAWCO and Cape Mental Health).

Thus the bulk of this service is carried out by the church leaders, Community Counselling and Training Centre (CCATC), Advice Office in the MPC and the Cape Mental Health Society.

6.14.6 OLD AGE CARE

There are no old aged homes in the community (Manenberg Profile, 1991).

6.15 SPORT, RECREATION AND ENTERTAINMENT

The recreational facilities in Manenberg include:

8 sports fields
6 netball courts
10 play grounds
2 Lounges (night clubs)
1 swimming pool
Silvertree Club providing tennis, rugby and soccer fields and indoor sports.

Most of the recreational facilities lack equipment and are in a poor state of repair.

The CTCC has provided children's playgrounds at various points about the township. These are tarred areas sited at the end of the blocks of flats and are equipped with swings, slides, merry-go-rounds, jungle-gyms and see-saws, but most of the equipment is broken or missing and very seldom does one see any children using the facilities.

The swimming pool and play grounds are underutilised as they are generally regarded as unsafe due to the large presence of gangs that meet in these areas.

There are open spaces throughout the township that could be utilised as playgrounds, but due to lack of funds they are undeveloped and considered to be dangerous as the gangs frequent them.

6.15.1 COMMUNITY CENTRES

There are four community centres available which are controlled by the CTCC. They are conveniently placed so that access to them is easy from all areas of Manenberg.

The centres can be hired out for social functions and each Wednesday afternoon they run a social group for the elderly and disabled who are able to get to the centres independently. They provide crèche facilities during the mornings and after school care in the afternoons, but they do not provide any services or facilities for teenagers.

6.15.2 CINEMA

There are no cinemas.

- Foster Mother support groups.

It employs social workers who deal with counselling and training programmes.

6.16.2 MANENBERG PEOPLE'S CENTRE

The MPC was established in February 1991 in response to the increasing crime rate and other social problems facing the Manenberg community. The centre has developed various programmes to meet the needs of the community as identified by the community itself. These include programmes for:

- cultural development by providing tuition in music, art, dance, drama classes, photography, pottery, karate
- development of training skills
- computer literacy classes given by Community Educational Computer Services
- counselling
- social gatherings for children

The MPC provides office facilities from which the following organisations function:

ANC Local Branch, Advice Office, Manenberg Civic Association, Manenberg Youth Organisation, Ministers Fraternal, NICRO, Call of Islam and CCATC.

6.16.3 ANC LOCAL BRANCH

This organisation is engaged in programmes to stimulate political and crime awareness, provide political education, organise campaigns against gangsterism and assist other structures, for example, the Civic Association.

6.16.4 ADVICE OFFICE

The Advice Office is a service organisation based in the MPC forming a structure to provide information and advice on grassroots issues and socioeconomic problems experienced by the residents.

These issues comprise grants, social pensions, maintenance, arrears with any account, hire-purchase, unemployment funds, unfair dismissals, retrenchment, wife battering, family problems, child abuse, alcohol and drug abuse and legal advice.

It is also engaged in sub-projects such as literacy, crime awareness, women's support groups, child support groups, AIDS awareness, food aid and unemployment, truancy, funeral arrangements and crime awareness groups. (Advice Office).

6.16.5 CIVIC ASSOCIATION

The main function of the Civic Association is to focus on the basic problems of tenants such as housing rentals, electricity and water arrears, maintenance of houses and to campaign for better and more housing, rentals people can afford and scrapping of rental arrears. The association cannot give financial assistance, but is able to advise residents on how to avoid eviction and suspension of water and electricity services (Faldiela de Vries, MPC).

6.16.6 CAPE MENTAL HEALTH SOCIETY

The Cape Mental Health Society provides services to mentally handicapped and mentally ill residents in Manenberg. Field social workers from the society work closely with the psychiatric clinic. Those involved in the area do mainly home visits for family and individual counselling and assessments.

They deal largely with residents affected by sexual abuse, battered women, gangsterism, alcohol and drug abuse.

6.16.7 Association for the physically disabled.

The Association has a social group on Thursday afternoons for the physically disabled at one of the community centres. This caters for the disabled that are sufficiently mobile to get to the centre independently.

This organisation also operates an Attendant Care Scheme whereby trained workers give nursing assistance (bathing, toileting, pressure care) twice per week to the severely disabled in the homes. The service is available to a limited number of disabled people only and involves payment for the service according to income received from their disability grants.

6.16.8 MEALS ON WHEELS

Senior Citizens and Disabled People are supplied with meals on Mondays, Wednesdays and Fridays for a fee of 50 cents.

6.16.9 NATIONAL INSTITUTION FOR CRIME PREVENTION AND REHABILITATION OF OFFENDERS (NICRO)

The organisation is state funded and aims to prevent crime and to rehabilitate offenders. It tries to minimise the time that people spend on the streets with nothing to do by finding work for them. They hope that by providing work their clients' self-esteem and social responsibility will improve. A social worker and a teacher staff this organisation.

6.16.10 COMMUNITY COUNSELLING AND TRAINING CENTRE (CCATC)

This is a non-political task-funded centre which is run by two clinical psychologists and an occupational therapist. It is concerned with the mental health of the people in Manenberg and the clientele is comprised largely of battered women, alcoholics and gangsters. The staff of CCATC perceive the majority of the people as suffering from low self-esteem which ultimately can lead to them joining gangs and becoming involved in violence. Their emphasis is on self-help and they encourage their clients to develop as much as possible so that they in turn can become counsellors themselves.

6.17 SAFETY AND SECURITY

Manenberg has its own police station in Klipfontein Road with 15 policemen and 5 vans operating in the area (Manenberg Police Station). During periods of "unrest" it has also been used as an army base. As it serves the whole of Manenberg and Welcome Estate, Heideveld and Surrey Estate it is overutilised and the community complains of calls going unheeded (Cape Times, 25.07.1992, The Argus, 15.06.1993). At the beginning of 1993 a mobile police caravan was placed outside the library, but this was fired at by the gangs and had to be surrounded by sandbags for protection of the police manning it.

It appears there has been a problem with feedback to the police and problems have been handled by members of the community taking matters into their own hands. This, together with the perception that the police deliberately do not heed their calls, has resulted in a poor relationship between the community and police which has even been hostile at times (Urwin Skinners, NICRO).

In August 1992 NICRO and the Advice Office organised a community/police liaison forum to improve communication and relationships between the community and police. They worked out joint methods of policing which were acceptable and which would build up friendliness in an attempt to combat crime (Athlone News, 11.11.1992).

When the gangster activity escalated to an intolerable level at the beginning of 1993 the police offered to use the Internal Stability Unit (ISU) to stabilise the area, but the African National Congress did not accept this because of their view of the ISU. They requested that the defense force be deployed, but this was turned down by the police as they stated that the defense force could do no more than the police force was doing.

6.17.1 CRIME STATISTICS

According to the Manenberg Profile (1991) the Cape Peninsula has the highest crime rate in South Africa and Manenberg is amongst the top 5 (out of 42) areas in the Cape Peninsula for malicious damage to property, common assault and robbery. It is among the top 10 areas for drug possession, housebreaking, rape and culpable homicide.

Manenberg has long been notorious for gang warfare. There are approximately 45 active gangs, some of them comprising 500 to 600 members (Reportback, 1992). Most of the difficulties seem to stem from a territorial battle between the "Hard Livings" and the "Clever Kids".

Gang fights take place frequently, often involving innocent members of the community in the crossfire as firearms and zip-guns are used. The fights appear to be over the lucrative drug trade. (The Argus, 09.12.1993). Twelve people were killed in crossfire in one week at the beginning of February 1994 (The Argus, 28.02.1994).

Manenberg manifests the negative consequences of oppression which include high levels of interpersonal violence and crime, gangsterism, substance abuse and child neglect (Bloch, (1975); Central Statistical Services, 1991; Clinard (1970).

The overcrowding and fragmentation of the community by the "infil scheme" are also cited as being causes for the high crime rate. This is magnified by the poor street lighting and lack of public telephones making it increasingly dangerous for people to go out after dark (Athlone News, 21.11.89).
According to the Housing Estate Office more than half the residents are on waiting lists for other townships as they would like to leave the violent environment of Manenberg

6.17.2 CRIME AREAS AND EFFORTS TO COMBAT CRIME

The police maintain that the chief areas of crime are the localities where identification of individuals is difficult. These are around the shopping centre and library and the open field near the GF Jooste Hospital. These areas serve as bases for the gangs and it is here that women and children on their way to and from the shops or crossing open fields are attacked, robbed and raped.

Over the years the community itself has made numerous attempts at reducing the crime rate and gangster activity.

In August 1991 the Manenberg Crime Awareness Group was formed comprising the Advice Office, NICRO, SHAWCO, Ministers Fraternal, ANC, Manenberg Library Civic and

Youth organisations. This group organised programmes around creating awareness of the causes of crime in the area (Athlone News 14.8.91).

One year later two hundred Manenberg residents marched to Manenberg police station to protest against the crime and violence in the community (Cape Times 25.07.1992). This was perceived as partly caused by the delayed response by the police to urgent calls when there were gang fights and residents telephoned for assistance. The police maintained that if they did try and intervene in the gang fights many innocent residents would be shot and injured in the ensuing battles as many of the gangs comprised thirty to forty members each.

Since 1992 more than 30 organisations including the police, Neighbourhood Watches, clinics, Welfare organisations, Civic Association, business, mosques, churches, schools, sport and political organisations have met in a community/police forum, called the Community Liaison Forum to strive for peace and safety. The objectives were to develop a network of police and community services which would adequately deal with family violence, battering, child abuse and rape. The second subcommittee dealt with problems such as gang fights and taxi conflicts (Athlone News, 11.11.1992). Following on this forum The Manenberg Women's Group, consisting of 30 mothers concerned about the growing drug problem in Manenberg, ran a workshop to find the root causes of their problem and to work out practical ways in which to tackle these problems.

In 1992 a truce between the "Hard Living" and "Jesters" gangs was brought about by a community meeting held at the MPC (Cape Times 10.1.92). A year later the Peace Committee was formed to curb gang violence between the "Americans", "Hard Living" and "Playboys" gangs. A committee was set up to form structures that would incorporate the gangs concerned in the process for peace (The Argus, 15.06.1993, Athlone News 23.06.1993, The Argus, 09.12.1993). The truce did not last for long as gang warfare in 1993 reached unprecedented heights when fights occurred for the first time during the daytime and a child was killed in the crossfire (The Argus, 20.11.1993).

When the Manenberg Women's Group ran an anti-drug workshop in order to tackle the drug problem it became apparent as to how difficult it was to fight the problem as somehow they were all involved in the drug circle. Drug merchants lived in the blocks of flats and would buy groceries for neighbours, provide loans, and pay rentals of those in their block of flats who were in arrears. Drug merchants were, therefore, very much part of the community life. Members of the community were hesitant in becoming involved in anti-drug marches or giving evidence in court cases involving murder for fear of victimisation as they were scared of the ruthless drug merchants (The Argus, 11.12.1993). The police were also under suspect as some of their family members were among the largest drug merchants in the community and many people felt that this was part of the reason for the police reacting so slowly when they were called out for gang fights.

6.18 LOCAL POLITICAL LIFE

The Department of Coloured Affairs controls many aspects of life in Manenberg, including welfare grants, pensions and schooling.

In spite of the proclaimed government policy the housing estates declared under the Group Areas Act have not been able to develop `coloured' municipalities because they are so fragmented and isolated from each other (Commission of Enquiry, 1976).

Organisations concerned with the upliftment of the people in Manenberg have had an endless struggle to overcome their apathy and to motivate them to take an activate part in fighting the system that has caused their intolerable lifestyle. According to Larrain (1979) this apathy has arisen from the powerlessness they experience from not belonging and has resulted in their acceptance of their oppressed lifestyle. It has reduced their efforts in participating in the mass democratic movement.

Support of the Unity Movement and Cape Action gradually increased until 1983 when they had an effective influence in the area. From then the former United Democratic Front (UDF) aligned bodies gained strength and took over the leadership. Other organisations merged and formed the UDF Manenberg Area Committee. The youth and student organisations became very influential and militant during the resistance of 1985 in spite of frequent harassment by the security forces. This was a tribute to their resilience and commitment (Cape Times, 8.3.1991). Their influence on the broader community has declined quite considerably since the period of intense resistance in 1985. The reason for this appears to be that the general community perceive that every time there has been some mass action their personal standard of living has been affected to their detriment. They also perceive their personal safety to be at risk due to the high crime rate and gangster activity. They do not associate these social problems as resulting from the oppression and repression brought about by the "apartheid" system.

In 1984 the government added separate chambers for `coloured' representatives to the previously all `white' parliament. This was known as the `tri-cameral' government and was not supported by the Manenberg community which expressed its opposition to the system by means of a large stay-away vote.

Since the unbanning of the African National Congress in 1991 it and the National Party have had a fairly equal following. However, their activities have been restricted by the gangsters who have alleged it is a political `no-go' area restraining all pre-election canvassing activities (the Argus, 22.02.1994).

6.19 COMMUNITY PROBLEMS

In a survey of 3 233 residents conducted by the Civic Association (Manenberg Profile, 1991) the following social problems were given in order of the percentage of people listing them as perceived problems:

gangsterism, crime and violence	88%
unemployment and poverty	59%
substance abuse	56%
high rental/rent arrears and electricity costs and arrears	34%
crime	16%
grossly inadequate environment (roads in bad condition, insufficient street lights, inadequate road signs, no decent shops, lack of recreational, medical and child-care facilities, inadequate transport, lack of police protection	27%
dangerous and corrupt environment which results in fear for personal safety	20%
illegal sale of drinks and drugs - shebeens and button houses	12%
housing shortage - overcrowding, lack of privacy	12%
child abuse and neglect	7%

6.20 SUMMARY

The profile provides an overview of the living conditions in Manenberg which is typical of that of a low-income township dominated by a local authority housing scheme. The community shows little internal cohesion or satisfaction with their residential area.

The housing scheme lacks variety and comprises inadequate small dwellings housing large families.

Particular dissatisfaction is caused by the present standard of basic amenities like housing, roads, pavements, recreation facilities, open areas, playgrounds, parks, lack of public telephones and supermarket shopping facilities.

The housing shortage, low levels of education and income, and high unemployment rate are a result and cause of increasing poverty within the township. This poverty is, in turn, reflected in extreme overcrowding, evictions, rental arrears, high crime rates, drug and alcohol abuse, incest and wife and child battering.

In summary, Manenberg is not a highly desirable area in which to live. This is confirmed by the following quotes written by pupils from the area in a literary competition:

> "One cannot help but wonder how life would have been without apartheid - I know for a fact my own life would have been different" (Petersen, 1994:4).

> "Manenberg - sibling of Athlone, smells like gunpowder, looks like Vietnam. Tastes like innocent blood, feels like anger, sounds like Hell" (Isaacs, 1994:4).

However, in spite of all the social problems that exist the community has shown considerable social awareness by the attempts at combating crime by its drug awareness programmes and efforts at negotiations with the police in order to create a safer environment in which to live and raise children.

This is the environment in which the disabled of this study were living. One in which they felt they were even more vulnerable to the criminal elements operating in the area than the general residents as they were seen to be "sitting ducks" by the gangsters.

In Chapter Seven the manner in which the research was actually planned and carried out is presented.

PART TWO

CHAPTER SEVEN

METHODOLOGY

7.1 INTRODUCTION

In this chapter the research design, methods and procedures utilised in the data collection process of this study are presented.

7.2 RESEARCH DESIGN

This was a qualitative study which used the action research approach to explore and describe the environment, circumstances and needs of the housebound disabled and their caregivers.

The action research approach differs from other approaches to inquiry as it is conducted in the natural community setting and engages in capacity building by means of incorporating members of the community in gathering and interpreting data which results in bringing about changes in the community (Argyris, 1985). It is committed to collaboration between researchers and participants of the study (Oja and Smulyan, 1989), in this case the housebound disabled, their caregivers and volunteers who shared in the planning, implementation, analysis and evaluation of the project. When clients are participants in research rather than "subjects", they are more likely to be familiar with and able to contribute to the practical problems involved with the implementation of projects (Van Vlaenderen and Nkwinti, 1990).

The programme was set up at the initiative of the community who recognised the need to enter into a partnership with an external resource agency to effect an improvement in the care for severely disabled of Manenberg. For this reason it was established in Manenberg itself in collaboration with the HPC. The principal tool used was non-formal education, based on the HPC's felt need for the participants to acquire the necessary knowledge and skills to deal with their problems. The researcher and students were able to learn from the participants and the feedback and partnership between the participants, HPC and researcher/students allowed continuous adjustments to take place so that the project was meaningful to the disabled and their caregivers.

The HPC became a structure whereby the disabled and the caregivers were empowered. The activities of the researcher/students were accountable to the committee throughout the study as it was recognised that the power associated with the education, skills and resources of the researcher/students could be used to manipulate and control the programme for personal academic advancement instead of empowering and developing the community.

The researcher/students were under no pressure to achieve quick, visible results and were free to use the process of community development by involving the participants in their own development to stimulate their potential capacities in order to enhance the quality of their families' lives.

> "Qualitative research evolved from the philosophical base of phenomenology, where an interpretive approach to research is encouraged. The setting is the natural setting. Whatever happens in this natural setting or context, is critical to the research and may lead to expansion of a flexible, dynamic research process and more than one interpretation of events" (Stone, 1991:449).

The essential components of this type of research are those of meaning, understanding and subjective reality. The major goal of this study was to gain as much insight as possible into the lives, problems and needs of the disabled and their caregivers in the context of their subjective interpretations and explanations. At no time did the researcher/students attempt to control or manipulate the people or circumstances.

Quantitative research is often very frustrating for physiotherapists who are trying to gain a better understanding of their clients' problems and needs. Frequently the findings repudiate what are known to be complex and diversified treatments and practices. Many of the results are significant statistically, but are not necessarily important to improving quality of life as effectiveness in physiotherapy terms is so frequently measured only in clinical terms and not in terms of functional improvement. It does not matter how much joint range of movement has improved or the amount that muscle power may have increased if the individual is still unable to function more independently.

A combination of qualitative and quantitative methods was used based on 2 year's work by the researcher and 40 final year physiotherapy students.

The qualitative methods employed included structured interviews, physiotherapy records, participant observation, researcher's and students' diaries and case studies. They allowed the complex problems of the participants to be explored and the outcome of the intervention to be studied in terms of behavioural changes. Quality of life for the severely disabled is more important than measurable change. A measurable change may be statistically significant in physiotherapy terms, but may not be important in contributing to an increased level of independence as far as daily functioning in the life of the disabled (Stone, 1991).

Quantitative data, obtained from the structured interviews, were used to measure and compare certain standardised responses statistically which would allow the findings to be generalised. The open-ended qualitative findings gave a great deal more meaning to these findings.

12 case studies will be presented in Chapter Eight in order to describe the real-life context in which the intervention took place and how an attempt was made to initiate change from an holistic view of the process of development.

7.3 STRUCTURED INTERVIEWS

The interviews comprised both subjective and objective components and included aspects pertinent to comprehensive rehabilitation. These were the individual assessment of the disabled in terms of social, physical, mental and functional status as well as an assessment of professional input, social support and physical resources received by the disabled. The caregiver's responsibilities and lifestyle were also examined. In this way, it was intended that the specific needs within the different areas for both the disabled and the caregivers would be identified.

Scores were obtained from the functional, caregiver burden and social interaction scales as these measures were the only accurate objective means of testing changes in the behaviour of the disabled before and after the programme. Subjective open-ended questions pertaining to these aspects were also included. As the ability of the disabled to respond effectively to rehabilitation is affected by his/her cognitive ability, this was rudimentarily assessed with the use of a modified mini mental test (Meiring, 1990).

Interviews A and B (Appendices iii and iv) were essentially the same as far as the measuring scales were concerned. This was deliberately done in order to ascertain the effectiveness of the programme and to increase the credibility of the evaluation design. According to Fitz-Gibbon (1987:58) this is a recognised means of increasing the credibility of a before-and-after design that does not include a control group.

A time series design was used to monitor the functional progress of each of the disabled. The same functional scale was completed at intervals during the individual programmes to provide a clear picture of progress or otherwise over, what frequently amounted to, an extended period of time. It also reduced the problem associated with the single group before-and-after design where there is a probability of some other factor contributing to the changes found (Fitz-Gibbon, 1987:60).

A further attempt was made to increase the credibility of the single group design by including more than one measuring scale, namely, the functional level, number of social contacts as well as the level of caregiver burden. In addition the open-ended questions and detailed descriptions of the case studies supplement the data on the effect of the programme on the participants.

The relationship that often develops between physiotherapists and their clients may be therapeutic in itself. This is a complex situation which comprises both social and treatment components. It is not easy to isolate either of these aspects in order to investigate its effects (Stone, 1991:450).

The researcher recognises that in spite of all the efforts to control the effects of other variables, there is no way of controlling the Hawthorne effect in this study. The relationships that developed between the researcher and students and participants may have been therapeutic in itself and brought about the changes in the level of caregiver burden and the number of social contacts. However, it would not be possible to explain the level of physical and functional improvement purely on this basis.

7.4 THE INTERVIEW ENVIRONMENT

The researcher/students attempted to create an informal and friendly atmosphere so that the participants could feel at ease. At the first meeting they were informed about the purpose of the questions, how they related to the envisaged programme that was to be planned to help them and what was to be done with the data gathered. They were assured of the confidentiality that would be maintained at all times regarding the information obtained.

The participants were asked whether they preferred to be interviewed in English or Afrikaans. As the researcher/students all had a working knowledge of Afrikaans and the participants a working knowledge of English the interviews were usually conducted by the researcher/students in English while the participants responded in Afrikaans. Misunderstanding of questions were able to be rephrased in Afrikaans.

The interviews provided an easy means of establishing a rapport with the participants. During this time nonverbal messages could be interpreted and information regarding the environment, living conditions and the problems which they experienced could be observed and recorded. It also allowed the questions to be rephrased when there was doubt about the participants' understanding of what was being asked.

As it was necessary to obtain the same information from each participant and because of the limited time it was essential to include only standardised open-ended questions to reduce the potential bias as there were 40 different interviewers involved in the programme.

7.5 PARTICIPANT OBSERVATION

> "Participant observation is a field strategy that simultaneously combines document analysis, interviewing of respondents and informants, direct participation and observation, and introspection" (Patton, 1987:75).

The researcher/students were able to become intimately involved in the lives and activities of the families and in this way obtained an inside view of what was happening to them during the time the programme was conducted. The impressions and feelings gained in this way allowed a far greater understanding of their lives and environment than would have been obtained using only the data obtained by means of the interviews.

A great deal of insight was gained into the extent that gangster violence, substance abuse, wife abuse and child abuse occurred and affected the families. This was gained once trust had been established during the programme. Most participants were unwilling to talk about these aspects during the initial interview and yet they had a profound effect on their lives.

Relationships and interaction between family members and participants could be observed as well as between the disabled and their caregivers.

The interactions of the participants and the people within the neighbourhood could be assessed and the spirit of altruism that existed between neighbours could be gauged with the view to establishing volunteer assistance.

Without this strategy available to qualitative study a great deal of essential data would not have been able to have been evaluated or utilised for the benefit of the programme.

7.6 PERSONAL DIARY

In addition to the detailed problem oriented physiotherapy records kept of the participants the researcher and students kept diaries in which each visit to Manenberg was recorded.

Notes were taken of significant events that occurred or discussions that took place during the visits or meetings. Direct quotes of what was said by the different participants were noted and the circumstances were described.

7.7 CASE STUDY

"The case study is the descriptive, analytic, interpretive, and evaluative treatment of the more comprehensive descriptive data that are in the case record" (Patton, 1987:148).

This method of describing the findings was particularly applicable to this study as the circumstances of the participants needed to be dealt with in depth in order to demonstrate and understand the problems, needs and the way in which they were managed.

7.8 POPULATION STUDIED

The population sample comprised 100 subjects, 50 housebound disabled and their respective caregivers. Criteria for inclusion were that the disabled had to be confined to their homes because of the extent of their physical disability.

If there was no response to 3 visits and the neighbours were unaware of any disabled living at that particular address, it was assumed that the disabled did not live there or was no longer housebound and he/she was excluded from the study.

10 of the disabled had been identified by a survey previously carried out by occupational therapy students and the remaining 40 by means of "snowballing". It was assumed, at the end of the study, that the total population had been reached as there were no additional referrals from any source for the last 2 months of the programme.

7.9 SAMPLING METHOD

12 disabled were randomly selected and presented in the form of case studies in order to present the findings in depth and

detail. Patton (1987:59) maintains that "purposeful sampling should not be used purely because a sample used is small and that random sampling substantially increases the credibility of the data".

7.10 DATA COLLECTION

2 final year students and/or the researcher visited the housebound disabled at their homes.

Interview A (Appendix iii) was conducted by the researcher/students and the relevant sections were completed by the disabled, caregiver and researcher/students. They were interviewed simultaneously to avoid causing any feeling of mistrust between them of what had been said. When possible, a member of the Advice Office accompanied the interviewers to encourage community involvement as the success of the programme was totally dependent on the community's participation and support. They also assisted the researcher/students with the interpretation of some of the responses as they were sensitive to the cultural customs and norms of the residents and were aware when the participants responded in a manner they thought was expected of them rather than factually. They were able to interpret what the replies really signified. Their presence was sometimes also found to be a problem as the participants were hesitant about discussing confidential personal issues in front of them and, for this reason, as soon as the researcher/students felt familiar with the environment the home visits were carried out without the Advice Office members.

Comprehensive and problem-oriented physiotherapy records were kept. These incorporated specific goals and objectives for each disabled person and caregiver.

It was explained to the participants that treatments would not be carried out on a daily basis as a service, but that the intention was to teach the caregivers how to assist the disabled achieve their maximum potential of independence. In other words the function of the researcher/students would be to act as enablers and to assist with problem-solving. Visits took place more frequently initially (2 or 3 times per week), whilst the caregivers management needed to be checked and the programmes of the disabled needed to be progressed. Thereafter, they took place as frequently as was necessary. This varied between once per week and once per month. The plan of treatment and treatment programme were appropriate to the particular situation, but always included additional "homework" that was to be done daily between visits. Exact demonstrations of the amount of actual assistance the disabled required was given and the disabled person's condition and handicaps were explained to them in detail. After each home visit the training, treatment, progress and advice given were documented.

Further visits followed to reassess and change the rehabilitation and training programmes and to listen to the families' problems and to assist them with problem solving.

This continued until the researcher/students considered the disabled and caregiver had gained maximal benefit from the assistance provided. Interview B (Appendix iv) was then completed by the caregiver, disabled and researchers/students.

Periodic visits continued to the end of the programme to provide the caregivers with emotional support and to follow up the progress that the disabled had achieved to observe whether this was being maintained.

Whenever possible, the researcher and students walked from home to home instead of travelling by car. This allowed the residents to become aware of the fact that the programme was in operation and provided a great deal of information about the living conditions.

7.11 PILOT STUDY

A pilot study was conducted on 4 disabled and their caregivers to test whether the questions were understandable and appropriate. The 2 students and researcher were present at each interview and recorded observations independently to increase the reliability.

Potential areas of weakness in the questions were identified and corrected. For example, religious affiliation, how the disabled occupied himself/herself all day and whether they possessed a television were important aspects which had been omitted. Some of the closed-ended questions were changed to open-ended to investigate aspects that had not been anticipated when the questions were written.

At this stage observations made suggested that because of the enormity of their burden, some of the caregivers were not always coping with their disabled relatives and that they required some form of additional assistance. This was based on the physical and apparent emotional neglect from which the disabled persons were suffering.

For this reason the researcher initiated a volunteer project whereby volunteers were identified and trained to provide this assistance. This part of the study is presented in Chapter Eleven.

At this stage it was also found unnecessary to translate the questions into Afrikaans as the students and researcher were all capable of translating the questions when the participants had difficulty in understanding them.

The questions were easily understood and it took approximately 45 minutes to complete the initial interview.

7.12 MEETINGS

The Health Project Committee became the action group. Initially it comprised the coordinator of the MPC, chairperson of the Advice Office, a physiotherapist and assistant physiotherapist from Lentegeur Psychiatric Hospital, an occupational therapist from the University of the Western Cape, 2 disabled persons in wheelchairs, 2 to 4 volunteers, 2 physiotherapy students and the researcher. During the programme additional members were coopted onto the committee and those that did not have anything further to offer disengaged.

Meetings were held regularly on the first Tuesday of the month at 14h00 and lasted for approximately 2 hours. The MPC coordinator usually chaired the meetings and the task of taking minutes was rotated amongst the different members (examples provided in Appendix v and vi).

The researcher's role was very much that of enabler, consultant and catalyst.

At the beginning of the programme the problems of the housebound disabled and their caregivers were discussed and the researcher/students suggested various ways in which they could be managed. The decision was taken by the group that the researcher and students would start off by assessing their needs.

At subsequent meetings the group planned to have discussions with other health personnel working in the area and to incorporate them in the programme. Planning decisions were made and short-term objectives were set at each meeting to be achieved by the next meeting. The minutes reflected only the decisions made and who was responsible for performing the tasks.

The number of new disabled that had been visited and the findings of the previous month were reported on at each meeting and discussions took place as to how the volunteers and other committee members could contribute to the progress of the programme. This form of evaluation was essential so that incremental changes could be made to make the programme more effective and to ensure that the objectives were being met.

Judging by the discussions and feedback at the meetings it provided the researcher with the information as to whether the abstract aspects of community development were being addressed simultaneously as the concrete objectives were being achieved.

7.13 EVALUATION

Evaluation involves all the people taking part in a community development project and is an essential aspect of community development if it is to be a learning process (Fitz-Gibbon, 1987; Rifkin, 1981; Swanepoel, 1989). In this study it involved the caregivers, disabled, volunteers, HCP committee members and the researcher/students.

Evaluation gives meaning to statistics as it makes research genuinely human oriented by addressing the question of how the participants lives have changed as a result of the programme (Franklin, 1976; Swanepoel,1989).

According to Franklin and Thrasher (1976) and Patton (1987) participant satisfaction is a valid form of programme assessment if it is used in combination with other measures. In this study this was achieved by measuring the extent of functional improvement and level of caregiver burden in conjunction with open-ended questions on how the programme had affected the participants as well as how they thought the programme could be improved. The researcher was also able to gather data on the programme impacts by means of direct observation of the programme activities and in-depth interviews with the participants during the rehabilitation and training sessions.

The evaluation carried out in this way allowed continual monitoring and incremental changes to improve the programme effectiveness when weaknesses were identified.

Regular half yearly written reports (Appendix ii) were sent to the coordinator of the MPC as a record for the final evaluation at the end of the programme.

7.14 VALIDITY

"A valid measure is one which measures what it is intended to measure (Grinnell, 1985:161)".

Validity in qualitative methods hinges to a great extent on the skill, competence, and rigor of the evaluator because the observer ***is*** the instrument (Patton, 1987:103).

In this study subjective open-ended questions were included in conjuntion with objective scores obtained for the functional level, caregiver burden and social interaction scales in order to verify the validity of the measuring instruments. In the case of the caregiver burden a modified version of Zarit's 20-item scale was used which had been proven to be both adequately reliable and valid (Zarit, 1982).

Since the students and researcher completed individual interview forms during the first and final interviews and these were found to provide the same information and scores on the measuring scales it was a small indication that external validity had been promoted and that the findings could be generalised to similar suburbs.

In order to promote external validity a random selection of case studies are presented.

7.15 RELIABILITY

"A reliable measurement obtains the same result on repeated occasions and by independent individuals administering the instrument (Grinnell, 1985:171)".

Reliability was increased by training the students to ask uniform questions in order to probe the open-ended questions. The same information was recorded by the students and researcher individually and then the findings were compared during the pilot test. Spot checks were made during the programme in order to verify that the findings from the interview forms were consistent.

7.16 CONCLUSION

This phase of the study has broadened the researcher's insight into the scope and importance of domiciliary physiotherapy in terms of care for the disabled, support for their caregivers and the fundamental and essential experience which it provides for students in their clinical practice. The information gained by the researcher was synthesised with the data obtained and used for the recommendations which are presented in Chapter Ten.

Details of the findings pertaining to the disabled and their caregivers are presented in the next chapter. Those relating to student education are provided in Chapter 12.

CHAPTER EIGHT

FINDINGS AND DISCUSSION OF THE DISABLED PERSONS AND THEIR CAREGIVERS

8.1 INTRODUCTION

For ease of reading the findings of the part of the programme dealing with the disabled persons and their caregivers will be presented in this chapter, that of the volunteers in Chapter Eleven and the part dealing with student education will be dealt with in Chapter Twelve.

In view of the vast amount of data that was collected by means of the structured interviews, meetings and observations the findings have been presented in two parts in this chapter.

- The quantitative data obtained from Interview A (Appendix iii) is presented in 8.2 Section A , that from Interview B (Appendix iv) in 8.3 Section B and a discussion on the meetings that took place in 8.4 Section C.

- The qualitative data are presented in 8.5 Section D in the form of 12 case studies in order to document and interpret, as much as possible, the lives of the disabled and their caregivers from their personal frames of reference.

8.2 SECTION A

A total of 296 disabled persons were investigated during the two year period. Figure (11) shows a breakdown of the initial assessments of which only 50 (12.6%) met the criteria of being bedridden or housebound disabled. The unnecessary visits arising from incorrect records caused a great deal of time to be wasted trying to locate the participants, but at the same time provided the researcher with much data on the living conditions of the community. It also made the community aware of the programme through the contacts that were made and by seeing the researcher and students walking around the neighbourhood in their distinct uniforms.

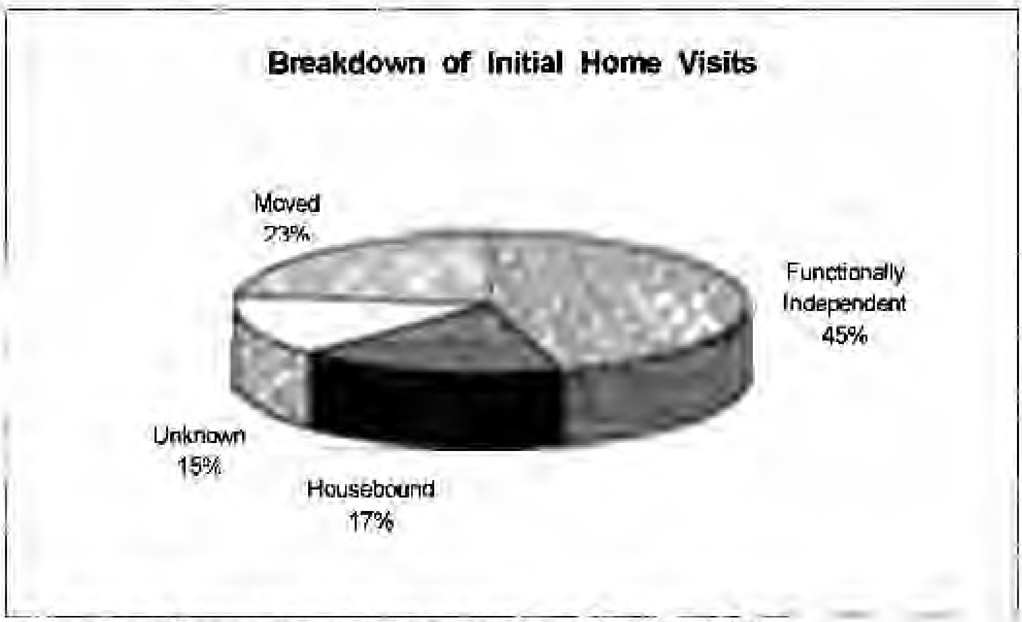


Figure 11: Percentage of disabled meeting inclusion criteria

Only 10 of the participants were obtained from the original list of disabled collated by the occupational therapy student project. The remaining 40 were obtained by snowballing, either by referral from family members of the sample already participating or else by neighbours when knocking on doors whilst searching for disabled to be contacted or addresses that needed to be located. As the programme progressed and the local hospitals became aware of the project, referrals were received of recently disabled persons, some of whom met the criteria for inclusion in the programme.

The sample of 50 housebound disabled and their caregivers took part in the study from April 1992 to March 1994. The disabled consisted of 25 males and 25 females. As the referral system was mainly by snowballing the fact that there were equal numbers of males and females was purely coincidental.

Not one of the disabled or their caregivers meeting the inclusion criteria declined the opportunity of taking part in the project.

8.2.1 PERSONAL DETAILS OF THE DISABLED

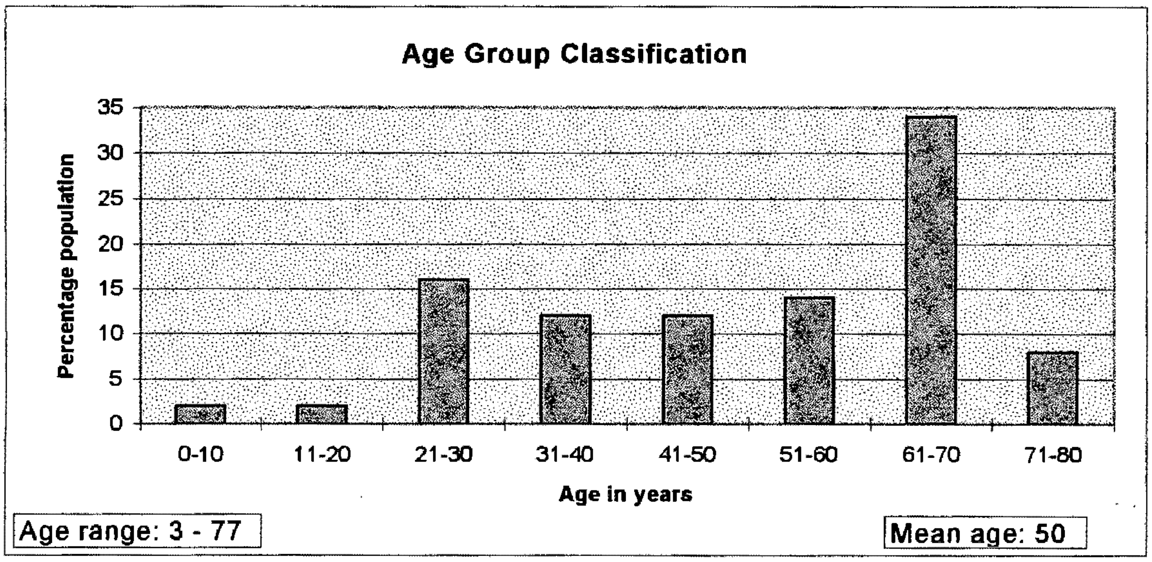


Figure 12: Age group classification of disabled

Information regarding the ages of the participants is provided in Figure (12). The predominant group (34%) fell into the 61 - 70 age group which is to be expected as the predominant group of participants suffered from strokes (see Figure 13), the majority of which occur in older people (Frithz, 1975).

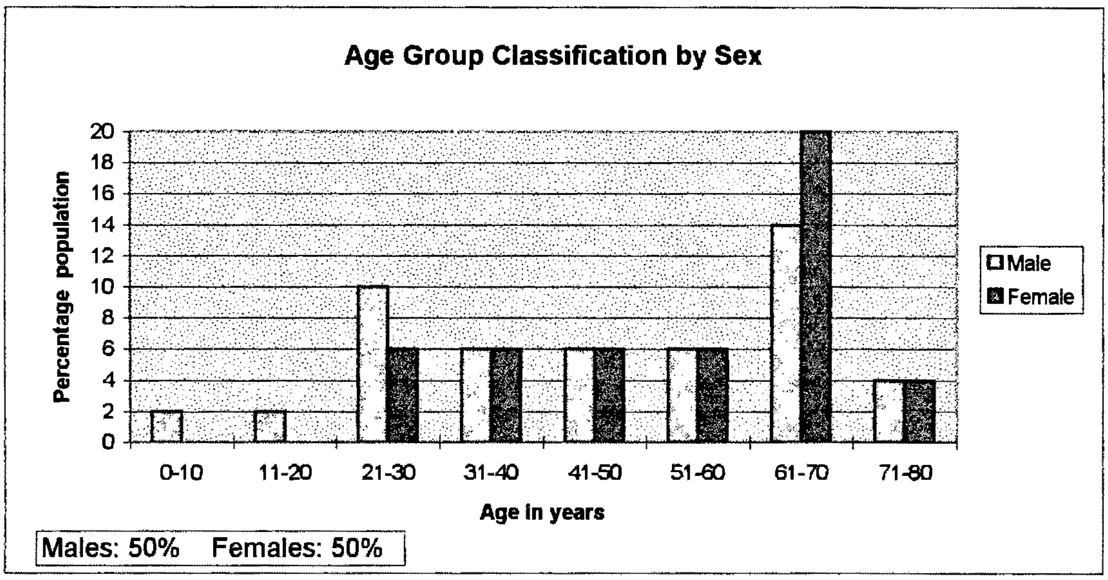
CONDITION	%	RELATED TO VIOLENCE
Respiratory	4	
Cerebral Palsy	4	
Quadriplegia	14	8
Paraplegia	4	2
Hemiplegia (Stroke)	48	
Head Injury	20	
Hemiplegia/Amputation	6	8
	100%	18%

Figure 13: Classification of medical conditions of sample

78% of the disabled fell into the economically active age group, namely, between 15 and 65 years of age. Many of them expressed the wish to return to work, but no longer were capable of doing so. As an example, a 57 year old male stated "I am not the same person any more, can't even look after myself as far as dressing and washing let alone go and work to support my family" (sic).

As Figure (13) indicates, only 9 (18%) of the conditions were violence related. This does not substantiate the perceptions of the HPC that there was a particularly large number of disabled as a result of the high incidence of violence in the area. However, many of the residents disabled as a result of violence did not fall into the category of being housebound. Furthermore, when discussing the findings with medical personnel from Groote Schuur Hospital the doctors mentioned that since the enormous increase in gun-related violence many of the victims did not survive the attacks due to the extent of the trauma suffered, whereas previously, when stabbings were the order of the day, many more victims survived their injuries.

When comparing sex with age distribution (Figure 14) there was very little difference within all the groups excepting for the 61 - 70 age group where there were considerably more females. These findings are of no significance as the length of time from the onset of disability to the first visit on the programme ranged from 2 weeks to 11 years (mean 4.25 years) so that many of the disabled actually fell into younger age groups at the onset of injury or disease.


Age Group Classification by Sex

Males: 50% Females: 50%

Figure 14: Disabled classified by age and sex

Only 10 (20%) of the households had telephones. This meant that frequently unnecessary visits had to be made as individual needs of visits could not be monitored telephonically, but had to be followed up by means of personal contact.

The occupations of the disabled are presented in Figure (15) as at the time of injury/onset of disease and exclude the 2 disabled who were under 15 years of age.

OCCUPATION	PERCENTAGE
Pensioned/Retired	24
Unemployed	36
Domestic Workers	8
Labourers	12
Drivers	6
Manufacturing	10
	96%

Figure 15: Previous occupation of disabled

It was not possible to establish the true income of all the disabled or their families. Once trust had been established they were prepared to acknowledge that they were receiving additional income from room and backyard shack rentals and the sale of sweets or fruit, but they were hesitant about divulging the actual amounts earned from these activities.

The caregivers' relationship to the disabled persons is presented in Figure (16).

CAREGIVER	PERCENTAGE
Self	0
Immediate family	80
Relations	10
Friends	10
Institution	0
Other	0
	100%

Figure 16: Relationship of caregiver to disabled

The 5 people in the category of `friends' were caring for extremely disabled people. Three of them had been good friends for many years and considered it a privilege to be able to offer their disabled friends a home and to look after them.

The other 2 caregivers were obliged to look after the disabled as they had originally been tenants in the dwellings at the time that the disabled became incapacitated. The dwellings were leased in the disabled persons' names and if they had not cared for the disabled they would have had to leave the dwellings and find other accommodation. They did, however, have a great deal of empathy for their disabled friends and looked after them to the best of their ability in spite of them both needing day and night care.

8.2.2 PROFESSIONAL INPUT

PROFESSIONAL INPUT	PERCENTAGE
Community Nurse	18
Day Hospital	36
Doctor	24
Occupational therapist	0
Speech therapist	0
Social Worker	0
Not required	36
Other	0

Figure 17: Type of professional input

Professional input that the disabled were receiving is presented in Figure (17). These were disabled who were receiving regular visits by the community nurses or who attended the Day Hospitals regularly for medication for other illnesses from which they were suffering and for routine `check ups' by the doctor. The researcher/students considered that 18 persons did not require any additional professional input apart from that of physiotherapy. This means that the remaining 32 (64%) would have benefited by input from at least one of the above mentioned categories of health workers.

8.2.3 PREVIOUS PHYSIOTHERAPY RECEIVED

	YES	NO
Treatment of disabled	48%	52%
Caregiver education	38%	62%

Figure 18: Previous in- and outpatient physiotherapy input

These findings are not considered to be accurate as the disabled and the caregivers were frequently unsure of the type of therapy they had received both as in- and outpatients.

Due to the increasingly short duration of client stay in hospitals presently experienced all over the world it is essential that the emphasis of management be placed on education of the disabled and caregivers before discharge, as stressed by Werner (1989). This education should not be given once only on the day of discharge, but should be consolidated by several sessions to ensure the understanding and technical ability of both the disabled and their caregivers. In this study there was a slight trend, although not statistically significant, that fewer disabled who had received education prior to discharge suffered from avoidable contractures and bedsores than those who had not received any education ($p=0.15$). However, there was no difference found between caregivers who had received education and the number of contractures and bedsores as opposed to those who had not received any education and the number of contractures and bedsores ($p>0.05$). What was very evident was that techniques that were required to be performed were taught only once and that the education took place on the day of discharge and the relatives could not remember what had been told to them. They were, therefore, unable to carry out the home programmes taught to them effectively.

Where it could be conclusively shown that subjects did receive outpatient physiotherapy it was found to be a mean of 2.5 months duration with a mean frequency of 3 visits per month. The duration of each visit would have been approximately 1 hour. Smith (1981) found that outpatient physiotherapy was effective in improving and maintaining function and that decreased intensity of treatment was associated with a significant increase in the number of disabled whose level of physical functioning had deteriorated. According to his criteria of treatment 3 times per week for sessions of half a day for a period of 6 months, the treatment received by the participants of this study had been of a very low intensity. While no conclusions could be drawn from the outcome of the outpatient treatments of these participants, the effectiveness must be questioned due to the fact that 54% of them suffered from avoidable associated complications of contractures and/or bedsores.

As Figure (19) indicates 57% of the disabled considered that they had deteriorated in their ability to perform activities of daily living since the time of their last physiotherapy treatment. Many of these disabled formed part of the group of disabled who had developed contractures (Figure 25).

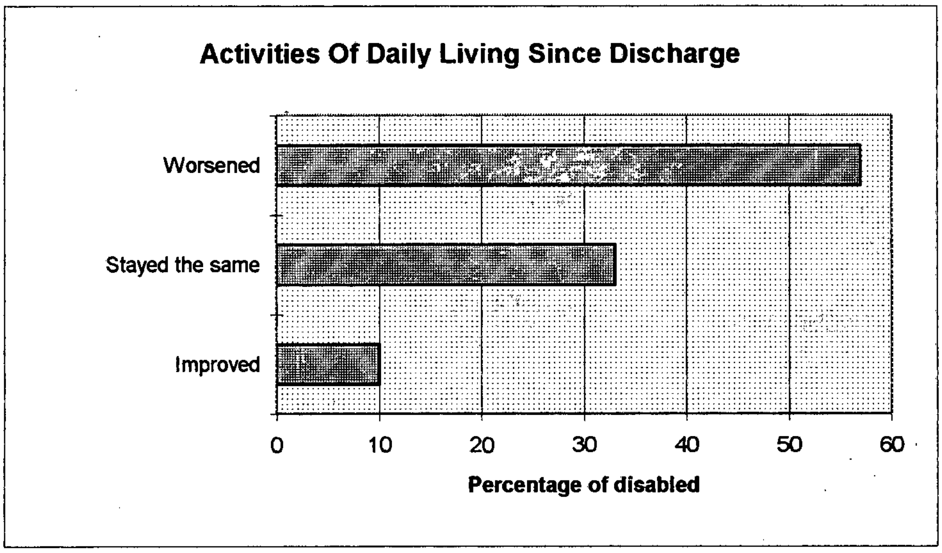


Figure 19: Activities of daily living since last physiotherapy treatment

All of the disabled stated that their disability had affected their lives to the extent that they were unable to be employed or to live independently as far as activities of daily living (ADL) were concerned.

Although 10% of the disabled stated that they were happy with their present level of functional independence all of them expressed the desire to be taught how to become as independent as possible and to have their caregivers taught how to help them to achieve this goal.

8.2.4 SOCIAL CONTACTS

Figure (20) indicates how the disabled rated the amount of their social contact. Eighty percent of them stated that they were dissatisfied with the amount of social contact they had with the community.

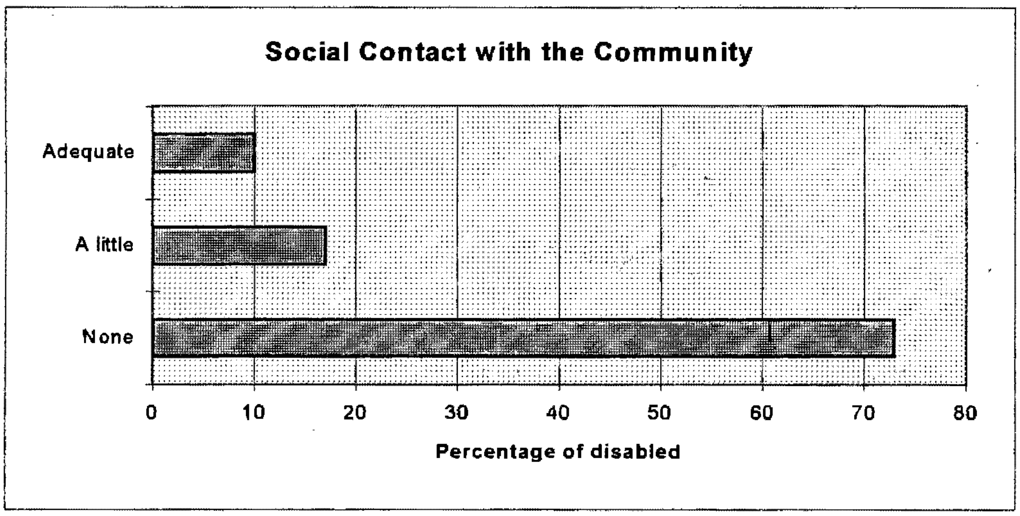


Figure 20: Social contact of disabled with the community

Figure (21) displays the number of times per week that the disabled left their homes. In order to be comprehensive the scale in Interview A (Appendix iii) should divide this into `social' and `living requirements', but because of the nature of the severity of their disabilities they were unable to leave for any `living requirements'.

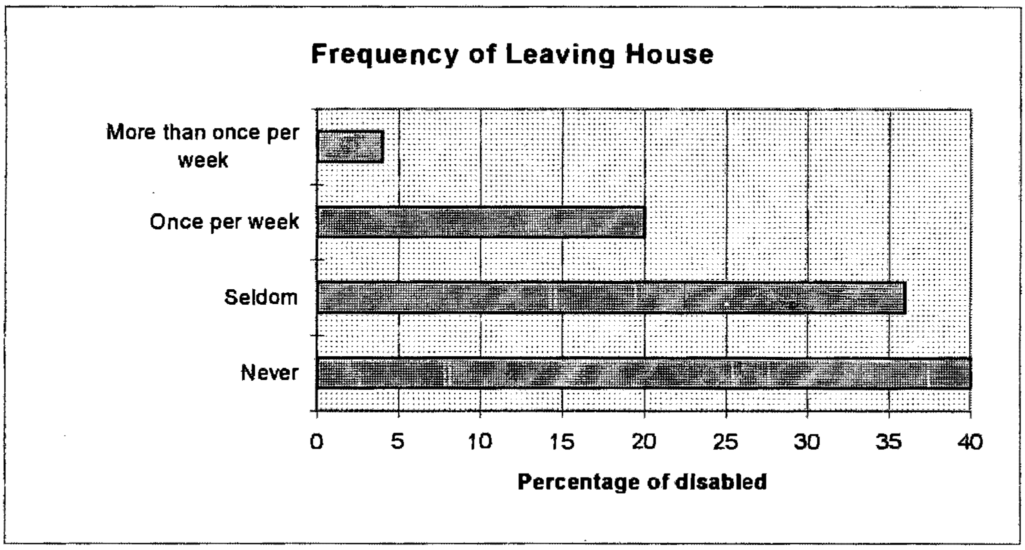


Figure 21: Number of times disabled left their houses

Twenty-three percent of the homes in which the disabled lived possessed televisions. This was a very important factor to the disabled as it was the only means they had of entertaining themselves as many of them were unable to read to a level that could provide enjoyment. For others it was also the only means of contact with the outside world.

Those that possessed a television spent a large amount of their day watching the programmes available, but those that did not have access to a television and could not read complained a great deal of the isolation, loneliness and of boredom they experienced. They were unable to do anything independently and were frequently the individuals who described the number of times they went out as `never' and were amongst those that also expressed dissatisfaction with the amount of contact they had with the community. Those that also had very limited contact with the community, but owned a television did not complain as much of loneliness, isolation or boredom.

8.2.5 CAREGIVER DETAILS

Eight percent of the caregivers were male and 92% female.

The relationship of the caregiver to the disabled person was presented in Figure (16) and the number of caregivers who had received any training in the management of their disabled relatives can be seen in Figure (18).

In the cases where training had been received the caregivers did not remember all the exercises that they had been taught to do for their disabled relatives as they had only had contact with the therapist for one session prior to discharge from hospital and were expected to manage on their own from then onwards.

Having to care for their relatives had placed an enormous burden on the relatives and had affected their lives considerably. Some were obliged to give up their jobs, others who were unemployed at the time were unable to look for future employment. They had no free time and were bound to their houses day and night in case the disabled persons needed them.

They were all pleased with the opportunity for their disabled relatives to receive some help to become more independent and for the opportunity for receiving instructions on their personal management of their relatives.

Even though there frequently were other adults living in the house the burden always appeared to be placed on the primary caregiver. Other members of the family seemed to take very little responsibility for sharing in the duties of helping the disabled on order to assist the primary caregiver.

The caregivers' rating of contact that they had with the community is presented in Figure (22).

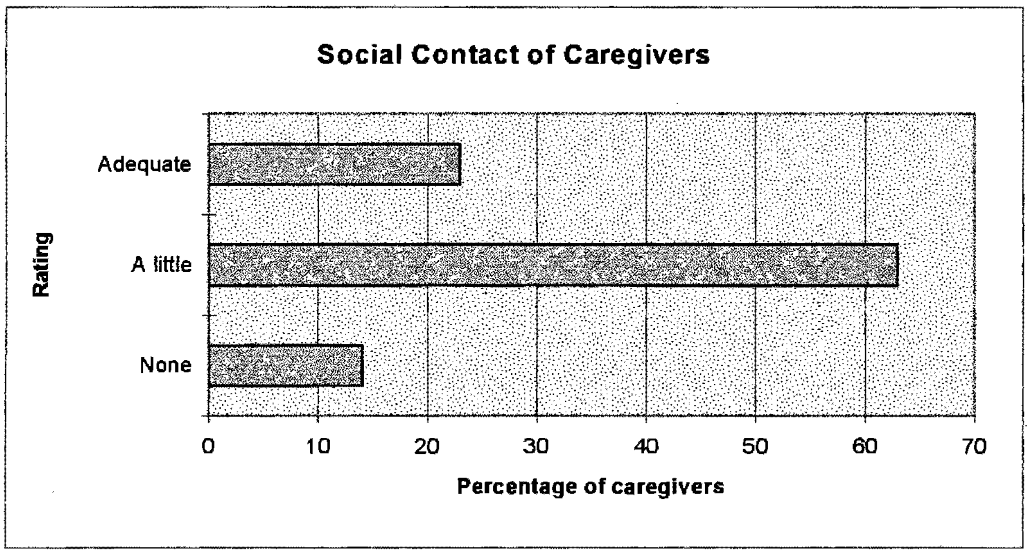


Figure 22: Social contact of caregivers with the community

In relation to the other adult family members sharing the accommodation their rating of the amount of social contact is seen in Figure (23).

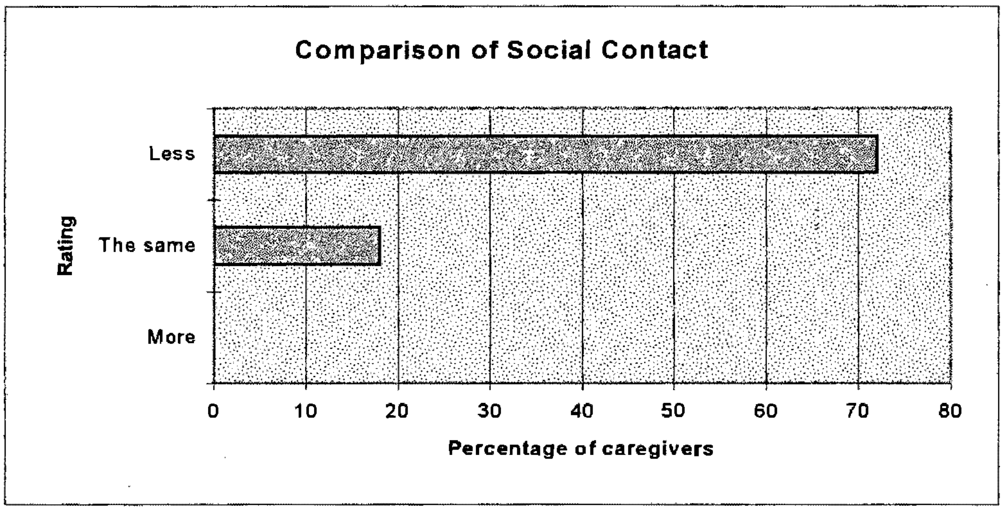


Figure 23: Social contact of caregivers compared to other family members

The level of caregiver burden at the beginning of the programme can be seen in Figure (24).

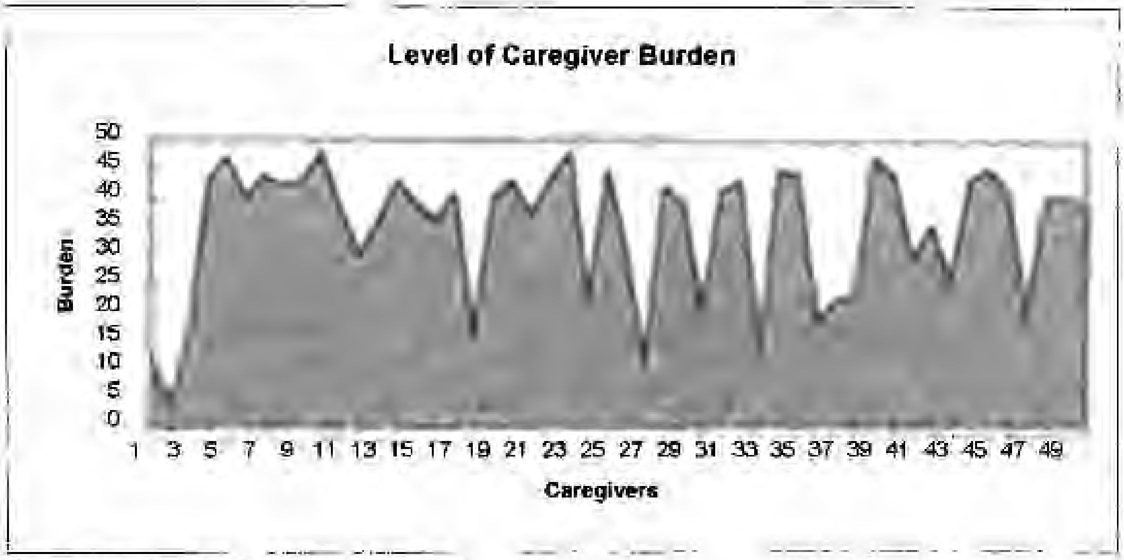


Figure 24: Level of caregiver burden

Pearson's correlation test showed that the level of caregiver burden was inversely related to functional ability (r=-0.5). This finding was not consistent with other studies. Zarit (1982), Zarit et al (1980), Zarit et al (1985) and Lowenthal et al (1967) in different studies found that caregiver burden did not relate to the severity of illness. They maintained that the caregiver's perceived burden depended on subjective factors rather than on the degree of impairment. These included whether the caregivers coped well or poorly with specific difficulties and their resources, namely how much assistance and regular relief they were able to obtain for their caregiving tasks. The findings underscore the fact that caregivers do not find the same problems troublesome (Lazarus and Folkman, 1984; Lazarus, 1966).

A possible reason for the difference found in this study is that it involved physical disability whereas the other studies investigated the effects of dementia, Alzheimer's disease and senile dementia on burden. The other studies were also conducted in the United States where the caregivers had much more access to some form of assistance from the state whereas this was not the case in this study.

When applying the t-test for unequal variances no difference was found between the level of burden for caregivers with disabled whose onset was more than 2 years and the burden of caregivers with disabled whose onset was less than 2 years ($p=0.15$). Again this varied from the findings of Zarit's study on dementia. He found that in a longitudinal study caregivers' ability to tolerate problem behaviours actually increased even though the dementia progressed.

Zarit et al (1986) emphasised the importance of both subjective and objective components when assessing burden. This became obvious when observing caregivers with totally dependent relatives accepting this responsibility as a part of their lives and not as a burden; whereas others caring for relatives who were reasonably independent regarded their burden to be considerable. Sometimes their financial concerns were greater than those whose relatives were totally dependent.

When the caregivers were asked whether they needed assistance from a voluntary worker, not one responded in the affirmative. No matter how bad their circumstances were or how much stress they suffered they simply did not perceive that there was any way in which they could expect any help. They were quite prepared to accept their burden and cope as best as they could.

8.2.6 ASSOCIATED MEDICAL COMPLICATIONS

COMPLICATIONS	PERCENTAGE
Incontinence	8%
Pressure sores	20%
Contractures	24%
Diabetes	20%
Asthma	15%
Arthritis	10%
Mental Retardation	4%
Hypertension	30%

Figure 25: Associated medical complications affecting disabled

Associated medical complications present in some of the disabled and which may have had an influence on the participants achieving their maximum level of function following rehabilitation are outlined in Figure (25).

Many of the contractures and pressure sores were avoidable, but through lack of knowledge, the maintenance programmes had been neglected and this in turn had led to these complications developing.

8.2.7 COGNITIVE ABILITY

84% of the participants achieved a full score for cognitive ability, according to the criteria used by the researcher, as indicated in Figure (26). Although this assessment was very unsophisticated the scores obtained proved to be an accurate indicator of general cognitive ability as affecting the level of potential rehabilitation.

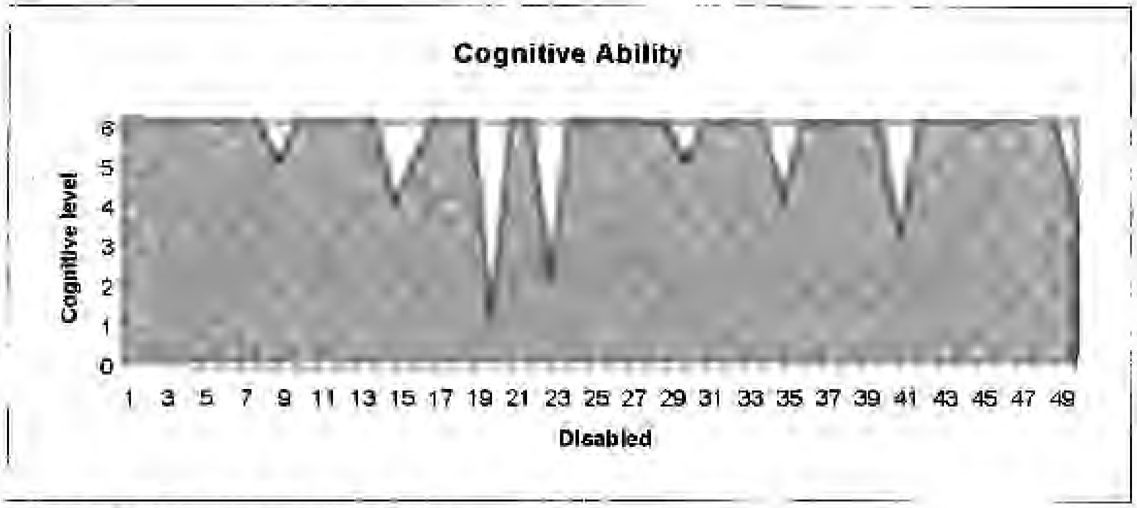


Figure 26: Level of cognitive ability

8.2.8 FUNCTIONAL SCORES

The disabled were assessed in terms of 14 different Activities of Daily Living (ADL). The percentage of disabled achieving maximum scores in the activities at the beginning of the programme can be seen in Figure (27). As could be expected, 'feeding' proved to be the activity in which the least difficulty was experienced (78% of the disabled obtained a full score). Not one person achieved independent 'mobility outside' and 'negotiating stairs'. This was also to be expected as the inclusion criteria specified being bedbound or housebound.

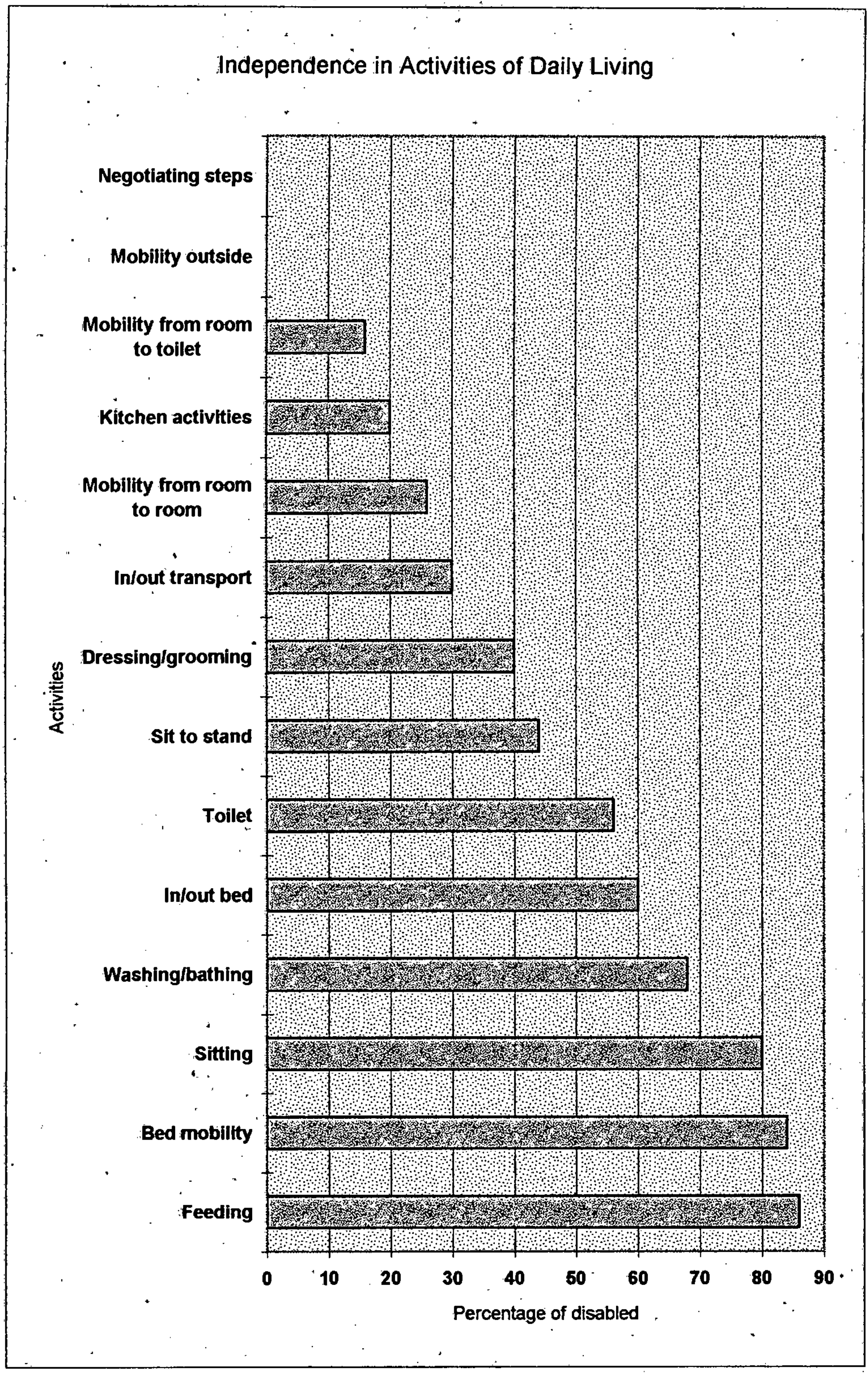


Figure 27: Percentage of disabled gaining maximum score in activity

Individual functional scores at the beginning of the programme are presented in Figure (28). High scores indicate a greater degree of functional independence with a score of 56 indicating total independence as far as activities of daily living are concerned.

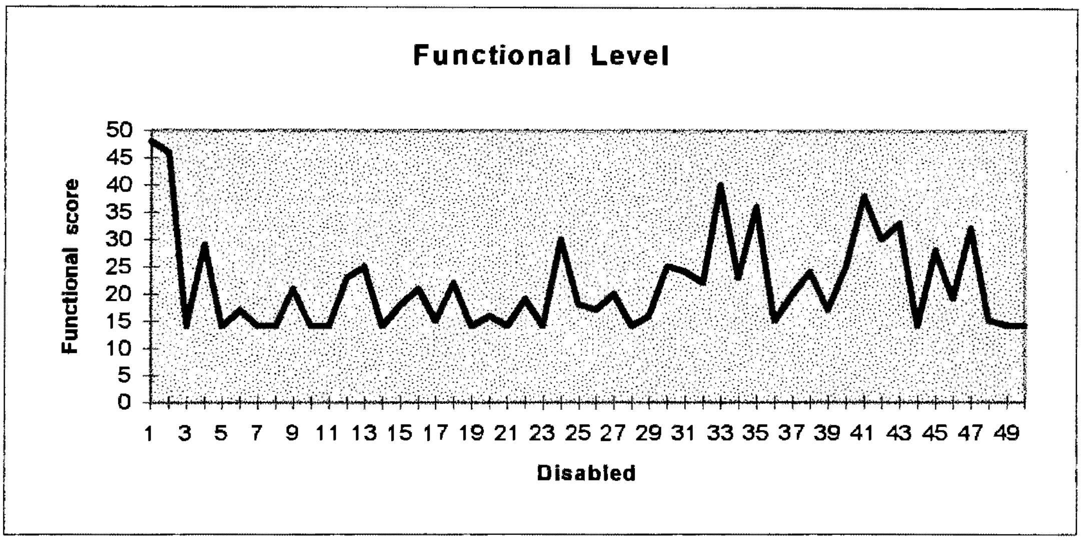


Figure 28: Level of physical function of the disabled

Because of the severity of disability and the length of time from the onset of the disease or injury, it was not possible to judge whether the disabled had reached their maximum potential or not. Therefore, they were all given the benefit of the doubt and were included on the programme.

After the initial assessment the researcher/students considered that 42% of the caregivers required volunteer assistance. This part of the study was implemented immediately and is presented in Chapter Eleven.

8.2.9 FUNCTIONAL APPLIANCES

48% of the participants were in possession of functional appliances. 36% of these had never been used or were no longer required.

Reasons given for never having used the appliances included:

- * The house was too small for the wheelchair to be manipulated.
- * The disabled had never been taught how to use the walking frame in the hospital and was afraid to use it in case he/she fell.
- * There was no space between the furniture in the house and outside the ground surface was of soft sand and the crutches sank into the soil.
- * The wheelchair had been provided for use outside as he/she was reasonably mobile indoors, but the disabled lived on the first floor of the block of flats and was unable to negotiate the necessary stairs to reach ground level.

8.2.10 PHYSICAL ENVIRONMENT

The types of dwellings in which the disabled lived are classified in Figure (29).

DWELLING	PERCENTAGE
Upstairs	36
Downstairs	64
Flat	50
Bungalow	6
House	20
Shack	24

Figure 29: Description of dwellings

There were an average number of 2 rooms per dwelling with an average of 9 people living in the dwelling. Eighteen percent of the dwellings had to share a toilet with other flats.

Access to the homes had to be negotiated by means of the following ground surfaces:

GROUND SURFACES	PERCENTAGE
Steps	60
Rough Ground	56
Sand	22
Pavement	22

Figure 30: Surfaces providing access to homes

8.3 SECTION B

DATA OBTAINED FROM INTERVIEW B AFTER COMPLETION OF THE PROGRAMME

The number of rehabilitation and training sessions provided by the researchers ranged from 3 - 26 visits (mean 12 visits). These were carried out on an individual basis with some participants being visited 2 or 3 times per week and others once or twice per month in order to meet their individual needs and as their rate of progress demanded.

Figure (31) indicates the responses of the disabled when asked how much they had benefited by the programme.

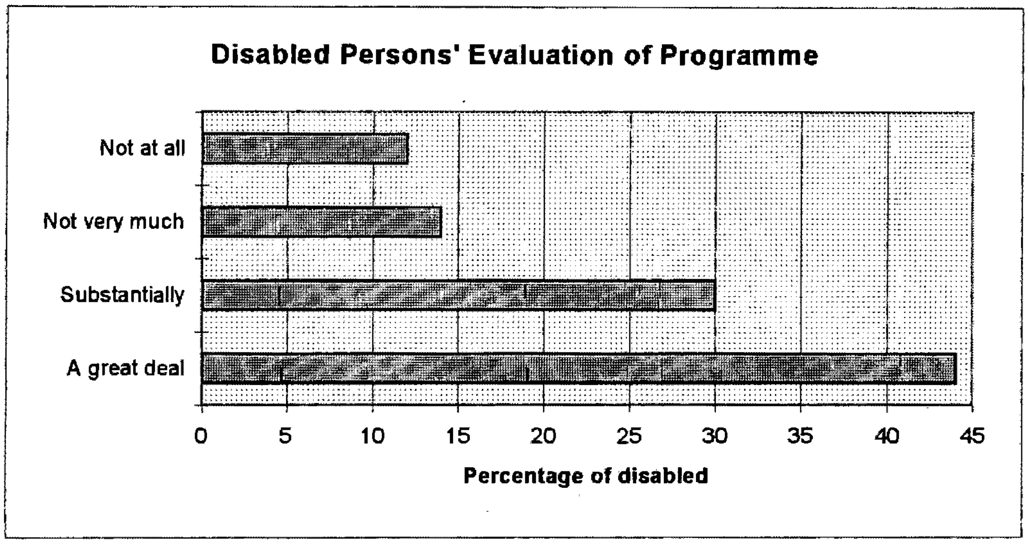


Figure 31: Evaluation of programme by the disabled persons

When asked what the strengths of the programme were most people replied that it was the "help and kindness" that they received.

There were no weaknesses mentioned or changes that anyone suggested to improve the programme.

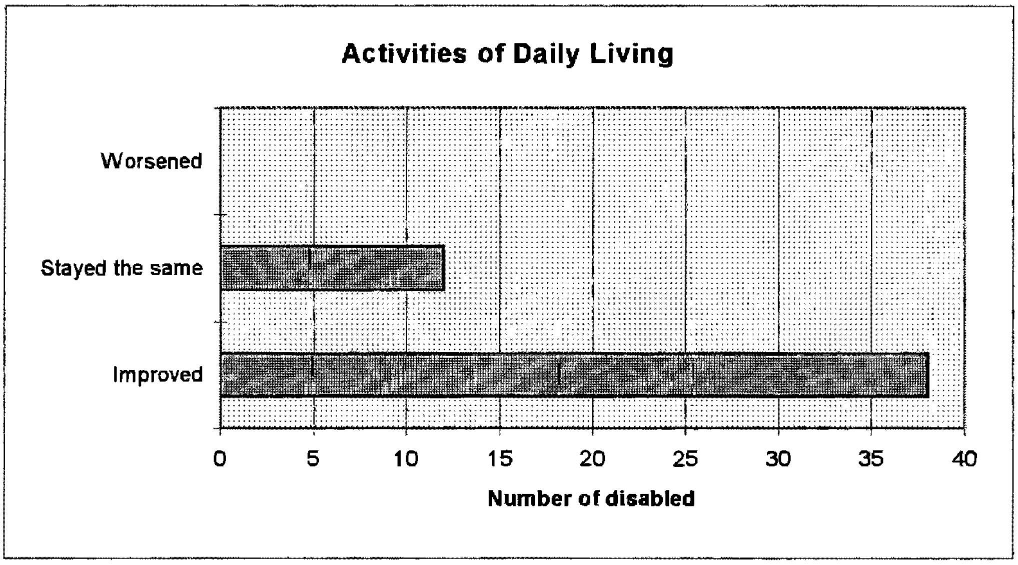


Figure 32: Ratings of their ADL by the disabled persons

Figure (32) indicates how the disabled rated their activities of daily living since the implementation of the programme.

Eighty-eight percent of the disabled stated that their caregivers had benefitted by being taught to help them. The remaining 12% claimed that their caregivers had always managed them well and so they were not able to notice any benefit.

Compared to before the programme the caregivers were rated as helping the disabled to the following extent:

RATING	PERCENTAGE
More	20%
The same amount	40%
Less	40%
TOTAL	100%

Figure 33: Amount of assistance from caregivers

Although the aim of the programme was to make the disabled more self-sufficient it was impossible for 7 to improve their level of physical functioning. The 20% who claimed that their caregivers helped them more usually qualified this rating by stating that their caregivers spent more time with them, were more understanding of their problems and that the quality of their care had improved.

The 40% that claimed that the caregivers helped them less had improved in physical function and no longer required as much assistance.

Sixteen percent of the disabled said they would find it beneficial for them and their caregivers to receive further visits by the physiotherapist. The reasons given were usually that they wanted to be sure that they could not improve more and also that they enjoyed the contact and personal interest shown in them by the researcher and students.

8.3.1 SOCIAL SCORES

Wilcoxon's t-test showed that there was a significant increase in the amount of exposure to the community by the end of the programme (p>0.0001). The difference in the number of times per week that they left their houses before and after the programme is indicated in Figure (34).

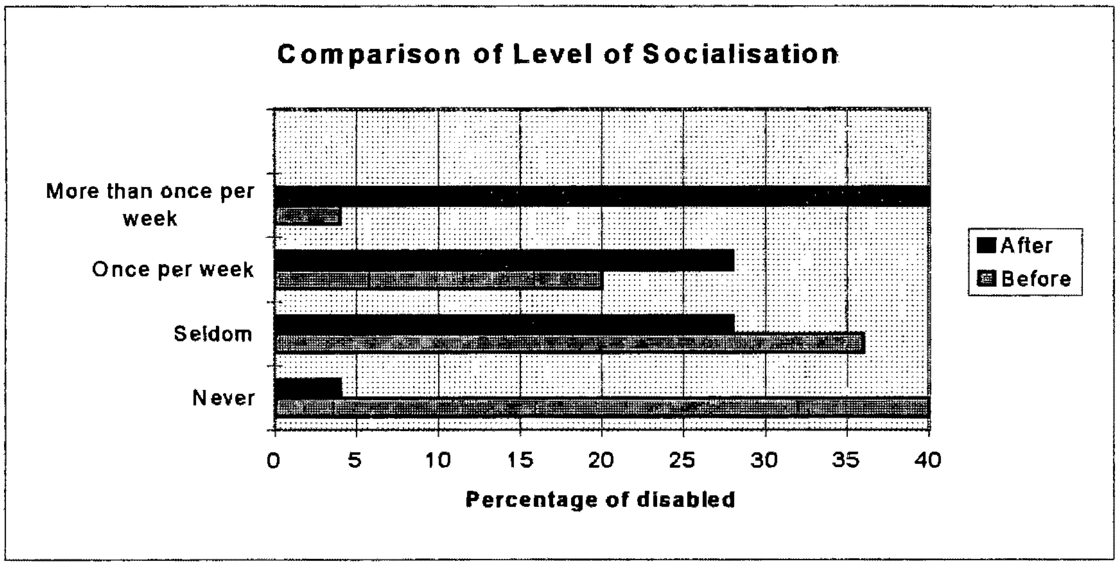


Figure 34: Comparison of the number of times the disabled left their houses

However, this depicted increase of socialisation is not necessarily only a reflection of improvement in the physical functioning of the disabled. Although this did account for some of the increase, most of it was due to education of the caregivers and increased involvement of extended family members, church congregation members and neighbours. Once they were made aware of the importance of the disabled being able to participate in community activities the family members made a greater effort to ensure that they were taken out of their homes.

The response to how they occupied themselves all day was much the same as for Interview A (Appendix iii). A few of them had become more involved in the functions of running their homes. Although many of them had reached the level of being able to be more occupied with vocational training activities these were just not available in Manenberg and there were long waiting lists at the few centres available outside of Manenberg.

8.3.2 CAREGIVER

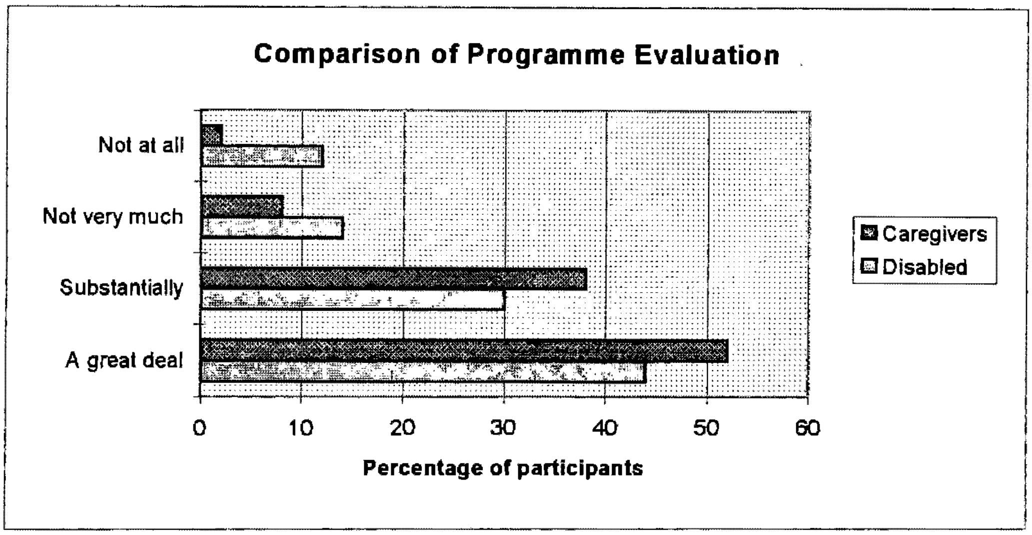


Figure 35: Comparison of programme evaluation by disabled and caregivers

When comparing the evaluation of the programme by the caregivers and that of the disabled (Figure 35) it appears that the programme was more positively rated by the caregivers than the disabled persons.

A probable explanation is that so many of the disabled accepted their disability as one of life's problems and did not realise the burden it created for their caregivers. In addition, no matter how much they improved physically the disabled could not return to any form of work as their level of education restricted them to manual work only which was beyond their capabilities. Even though many of them could have been employed in first world countries there were minimal facilities for sheltered employment in Cape Town and these had long waiting lists for applicants. 92% of the caregivers were female and in a community like Manenberg where the females are given such little recognition in terms of status and decision-making the male disabled considered it to be part of the females' duties to care for them. The female caregivers, in turn, accepted this role without questioning as they had been raised to play a subservient role.

Caregivers' comments on the strengths of the programme were very similar to that of the disabled persons, namely, that it provided them with support and that they enjoyed the interest taken by the researcher and students. They did not identify any weaknesses, but again also recommended that assistance be provided more frequently per week and that the programme be continued.

They described the experience of the home visits as demonstrated below

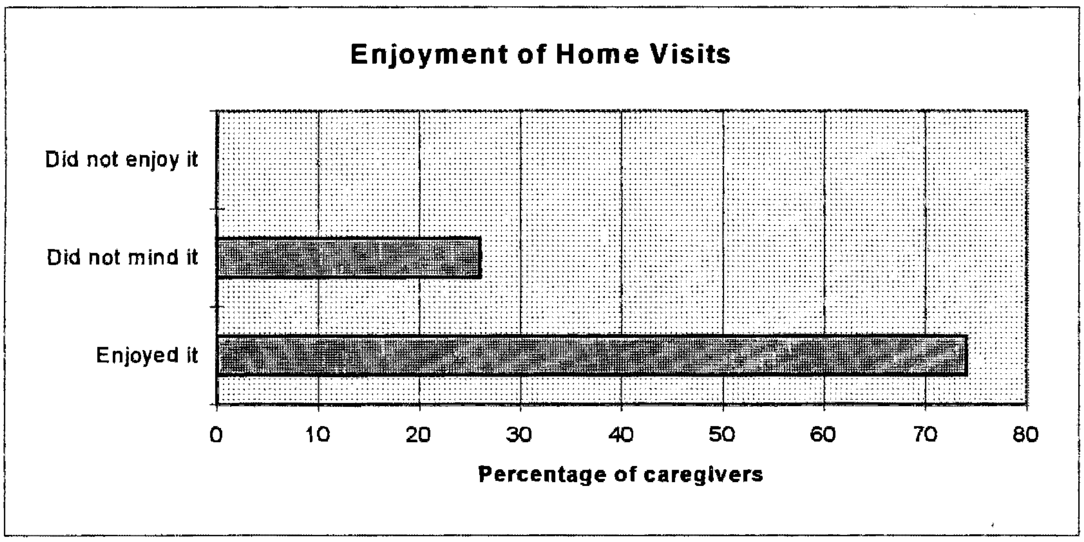


Figure 36: Caregivers' opinion of home visits

Eighty-two percent noted that there had been an improvement in their disabled relative's level of physical functioning. They described the amount of help the disabled person required as being

RATING	PERCENTAGE
More	0%
The same amount	10%
Less	90%
TOTAL	100%

Figure 37: The amount disabled depends on caregiver

Although 90% claimed that the disabled persons were less dependent on them, not all of them had improved in function to the extent that it could make them less physically dependent. However, the fact that the disabled depended on other members of the family to a larger extent (Figure 38) could account for this.

RATING	PERCENTAGE
More	78%
The same amount	10%
Less	12%
TOTAL	100%

Figure 38: The amount disabled depends on other family members since the programme

Ninety-two percent claimed that their handling of the disabled person had improved in that they felt more confident that what they were doing was correct and that they no longer were afraid of hurting their disabled relatives or of expecting too much of them. The improved knowledge and understanding of the medical conditions of their relatives gave them the confidence to deal with their problems (Figure 39).

RATING	PERCENTAGE
More	78%
The same amount	10%
Less	12%
TOTAL	100%

Figure 39: The caregivers' knowledge of the medical condition of the disabled

The amount of contact that the caregivers had with other members of the community had increased since the implementation of the programme. Forty-eight percent were seeing neighbours and members of their church congregations more frequently. Compared with before the programme, in relation to the other family members sharing the same dwelling their social contact was described as

RATING	PERCENTAGE
More	78%
The same amount	22%
Less	0%
TOTAL	100%

Figure 40: Social contact with the community in relation to other members of the family

8.3.3 LEVEL OF BURDEN

There was an even stronger inverse relationship between caregiver burden and functional ability of the disabled persons after the programme ($r=-0.8$) than before the programme ($r=-0.5$). The level of burden was significantly reduced by the programme ($p>0.0001$) (Figure 41). In part, this could be attributed to the fact that the disabled were able to be more independent and by doing more for themselves it relieved their caregivers of physical work. However, Kahan et al (1985:664) claim that increased knowledge about their relatives disability gained from the educational input plays an important part in reducing burden and Brown (1990:460) maintains that the support provided by the researchers also contributes to decrease in burden. Burden also decreased significantly for those caregivers who received volunteer assistance (see Chapter 11). This confirms Brown's (1990:458) findings that where there was service increase burden decreased significantly, but not for those who had no service increase. Zarit (1982) also found that caregiver burden decreased where caregivers were provided with some form of respite from their responsibilities. Caregiver 36 experienced more burden after the programme than before. This was probably accounted for by the fact that her brother had sexually molested one of her children during this period.

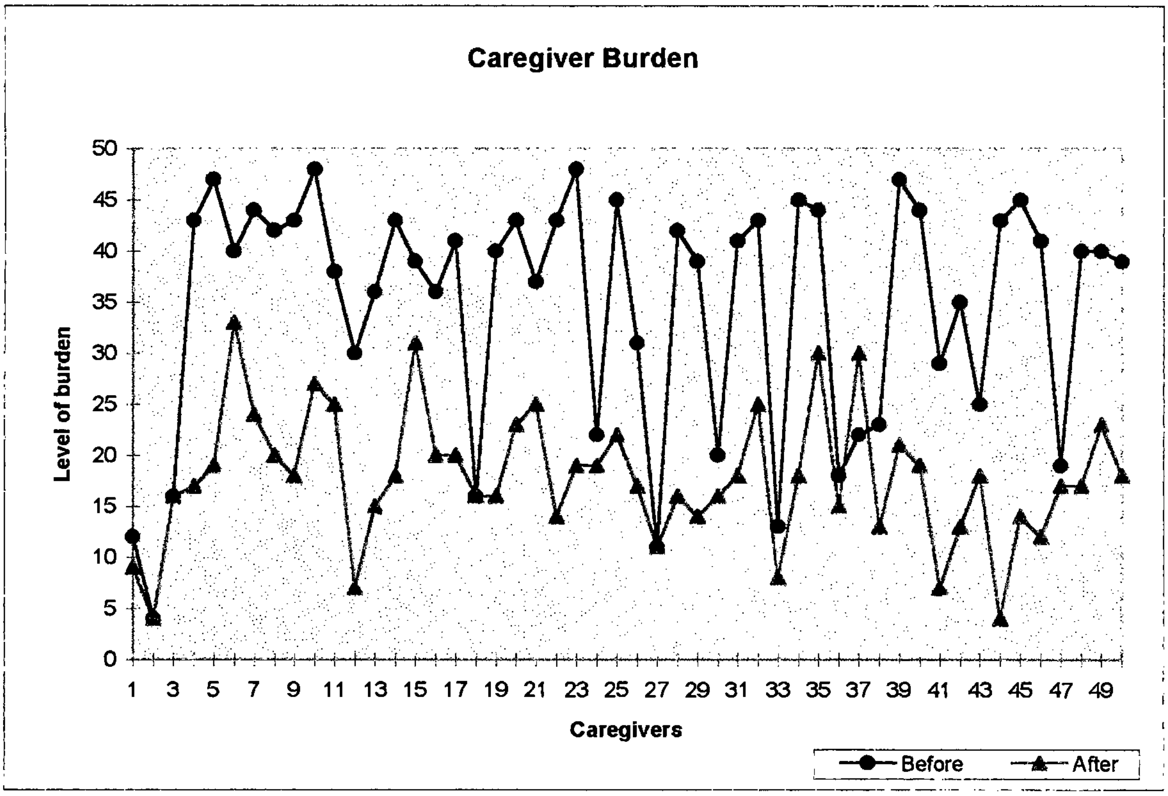


Figure 41: Level of caregiver burden before and after the programme

Twenty-one received assistance from a voluntary worker who helped with the physiotherapy maintenance programmes and/or personal care of the disabled. They rated this assistance of additional help as indicated in Figure (42).

RATING	PERCENTAGE
Nothing	0%
A little	14%
A great deal	86%
TOTAL	100%

Figure 42: The caregivers' rating of the assistance provided by the volunteers

The reasons given for the positive rating were the increased amount of personal time, the decrease in physical work and the increased contact with other community members.

8.3.4 FUNCTIONAL LEVEL

Figure (43) demonstrates the participants functional level before and at the end of the programme. Wilcoxon's signed rank test applied to the ADL scores confirmed a significant improvement ($p>0.0001$). T-tests demonstrated that there was no difference in the amount of functional improvement between the 86% participants who had been disabled for more than 2 years and the 14% participants who had been disabled for less than 2 years. There may very well be an optimum period for improvement, but that does not mean that rehabilitation should not be attempted on the basis that onset of the injury or disease occurred a substantial time ago. Functional improvement was also achieved amongst the disabled who had developed moderately severe contractures.

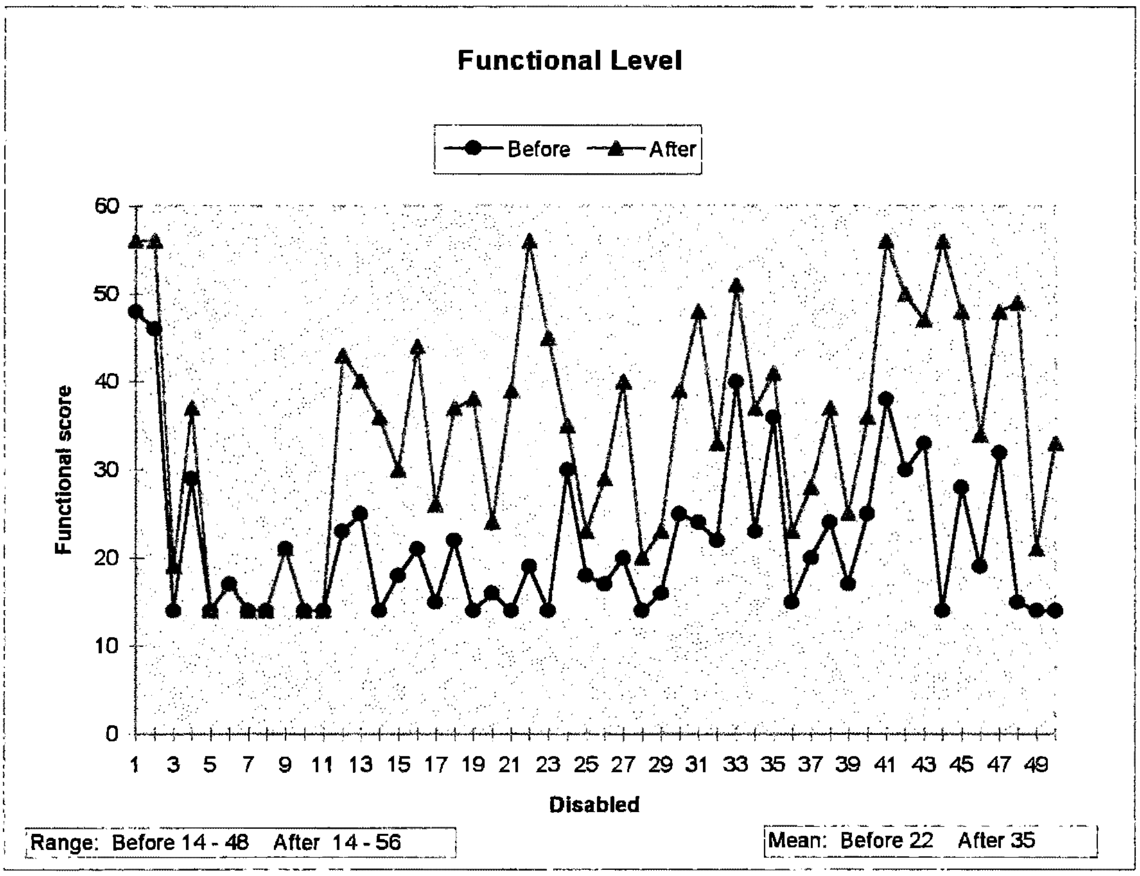


Figure 43: Functional level before and after the programme

Even though some of the disabled finally achieved a maximum score of 56 they still had residual deficits in terms of movement dysfunction or sensory loss. These participants, while remaining disabled, were not handicapped by their disabilities.

Disabled numbers 5 to 11 showed no improvement in physical functioning. This is probably due to the fact that they suffered from quadriplegia and had been fully rehabilitated at

Conradie Hospital and in view of the nature of the diagnosis no further function could be expected.

Figure (44) indicates the percentage of disabled who gained the maximum score for the activity before and after the programme.

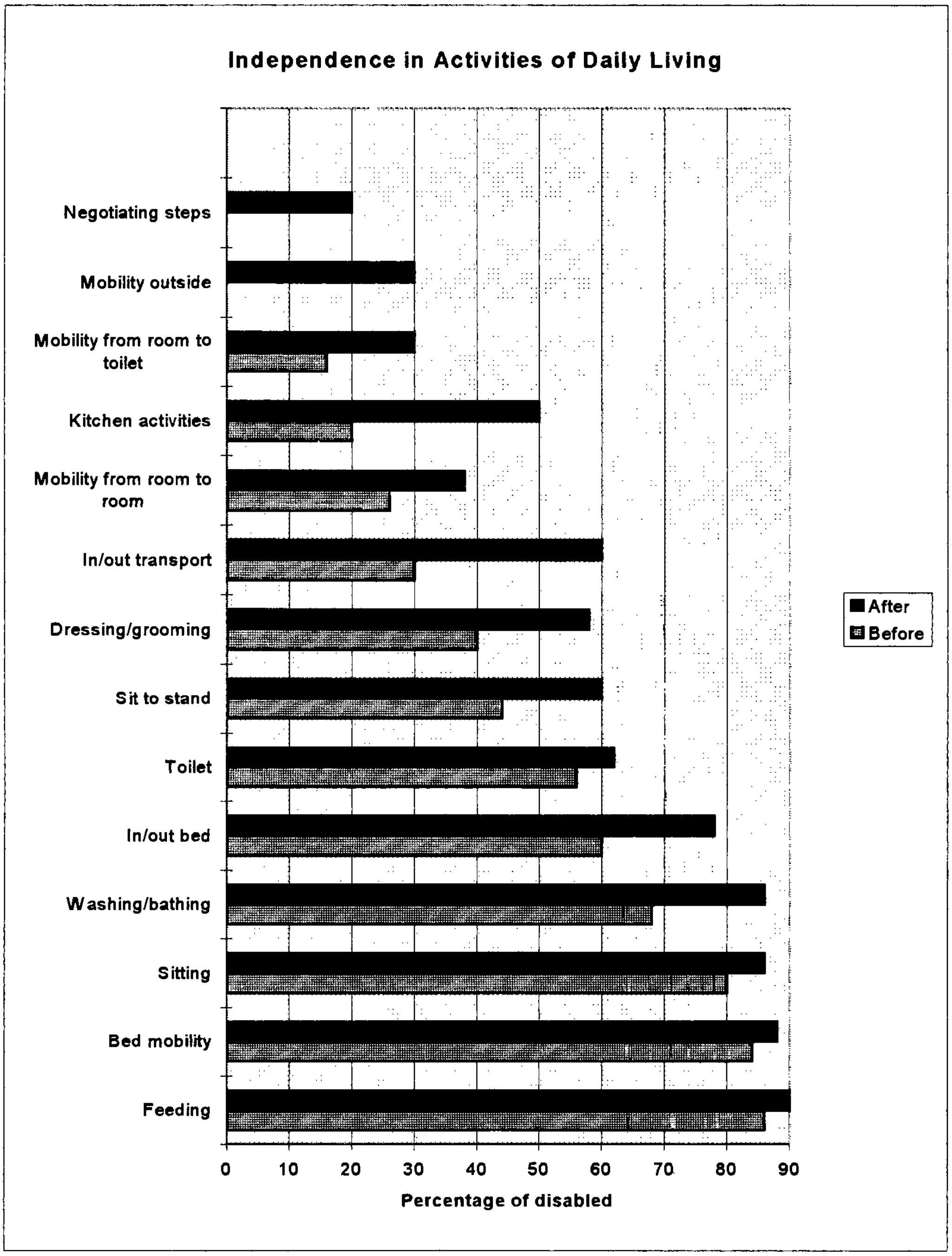


Figure 44: Percentage of disabled gaining maximum score in activity before and after programme

The reasons for the disabled not gaining even greater functional independence are listed in Figure (45).

REASONS	PERCENTAGE
Contractures, pressure sores, etc	20%
Maximum level of function attained	74%
Impaired cognitive ability	6%
TOTAL	100%

Figure 45: Reasons for disabled not gaining even greater functional independence

The disabled benefited from input from the following health team members. However, it was not possible to arrange contact with those categories of health workers included as percentages of "0", although the disabled would have benefited by this contact.

PROFESSIONAL INPUT	PERCENTAGE
Community Nurse	18
Day Hospital	30
Doctor	24
Occupational therapist	0
Speech therapist	0
Social worker	0
Social group	16
Disability group	6

Figure 46: Type of professional input

8.3.5 ADDITIONAL FINDINGS RELATING TO THE PHYSIOTHERAPY

The main difference found to be between the physiotherapy practised in hospitals as opposed to that within the Manenberg community was that of time management. This applied specifically to the amount of time spent in dealing directly with the disabled and the time spent on activities which provided support for the disabled and their families. These activities included education of the participants regarding their medical conditions, assessing and teaching them how to deal with them as well as monitoring their progress and providing psychological and emotional support. Liaison with the CTCC for minor alterations to the dwellings was also very time consuming.

The participants' understanding of the medical condition affecting the disabled was found to be minimal. This was due, in part, to the fact that many of the disabled had never received any form of rehabilitation. It was also a result of not being exposed to any form of explanation by the health professionals at the time of discharge from hospital or due to misunderstanding on the part of the family.

Because of the broad nature of the work it required experienced and mature physiotherapists to deal with the medical conditions, counselling of family members, liaising with other health workers and collaboration with other sectors dealing with health matters in the community. However, once intervention programmes had been established and the disabled required to be placed on maintenance programmes only, these could easily have been carried out by auxiliary physiotherapy staff who were supervised on a regular basis.

A major problem with working within a community like Manenberg on a long-term basis would be to sustain work satisfaction and motivation among the physiotherapists due to the isolation and less-than-ideal environment, for example, standard of hygiene, in which to practise. The constant demands of using initiative to stimulate the participants to solve their own problems was also stressful as there were no other health workers with whom the problems could be discussed.

In order to meet the needs of the disabled and their caregivers it was essential to include their opinions and information regarding the problems they experienced and the ways in which they believed they could be alleviated.

None of the participants in this study would have received any rehabilitation if the MPC had not initiated the study. The most important factor contributing to the total lack of access to rehabilitation available to the community of Manenberg was the lack of transport available to bedbound or housebound disabled.

The resources in the community were exceptional as far as goodwill and enthusiasm were concerned. Offers of assistance were not made unsolicited, but when services were requested the people were reliable and they performed tasks to the best of their ability in spite of their own burdens of living.

SECTION C

8.4 MEETINGS OF THE HEALTH PROJECT COMMITTEE (HPC)

Fitzgerald (1980) states that it is difficult to initiate community development where there is very little sense of community and that this is particularly so in a slum area. However, Manenberg was already a community in transition by view of the fact that the MPC itself initiated their own health project and so had already come a long way in its own development.

In spite of this the researcher found that the most significant finding of this part of the programme was that community development and empowerment was a very slow process. Adams (1990) confirms that in the United States of America programmes encouraging the process of development and empowerment take ten to twelve years.

The researcher learned that one had to become very flexible about time. Meetings always started 20 to 30 minutes after the appointed time and although they were scheduled to last for 1 hour this inevitably extended to 2 hours.

The meetings were conducted in a democratic style and even though the researcher played a key part in the development and encouragement of the participation of all the members it was more in the way of making the participants aware of how much better they knew their own community and could contribute towards the plight of their disabled and caregivers themselves. In order to accomplish this the researcher viewed the community members as resources and not clients, encouraging them to solve the problems of disabled in the community themselves.

A certain amount of conflict occurred from time to time between members of the HPC when the researcher was obliged to act as a mediator. The occasions of conflict were never detrimental to the group as, at that particular stage, one of the members involved in the conflict decided that they had nothing more to offer the HPC and disengaged in good spirit and with no hard feelings on the part of the committee.

Although at the conclusion of the study the researcher had been involved with only a small number of the community this segment became more competent and their apathy was replaced by a determination to improve their own quality of lifestyle by recognising the importance of not waiting for somebody else to do it for them as this was never going to happen.

Throughout the programme the Advice Office, Civics Association and MPC administrators encouraged the mobile disabled from the community to attend the meetings. Only 2 amputees attended, 1 for 2 meetings and the other for 3 meetings. Even though they were encouraged to participate and present their views neither of them ever volunteered any information or perceptions of what they thought could be done to improve the lot of the disabled. It appeared to the researcher that they were passive and accepting of their lot. This could have been as a result of them having being treated under a medical model where they did not ever make any decisions themselves, but this was done for them by the medical team; or because of their low educational level that they felt intimidated and out of their depth; or because they were raised in an environment where they were accustomed to being oppressed and never allowed to make personal decisions themselves. However, this phenomenon of the disabled demonstrating a low level of community participation is also described by Checkoway (1986:278).

SECTION D

8.5 CASE STUDIES

8.5.1 CASE STUDY NUMBER ONE

Ms A, a 42 year old domestic worker, suffered from a stroke affecting the left side of her body in January, 1993. She was hospitalised for 2 weeks and then discharged home to live with her 59 year old mother. They shared their 2 bedroomed flat with 7 other people, but Ms A was fortunate enough to have her own bedroom. She received no disability grant and was entirely dependent on her mother's income derived from accommodation rental.

She received daily physiotherapy treatment while in hospital and at the time of discharge was able to feed and dress herself independently. She was also able to transfer from her bed to a chair, stand and walk around the ward with limited assistance from the physiotherapist or nurse. At the time of discharge her mother had been shown how to assist her to get out of bed, transfer her into the bath and to help her to walk.

She joined the programme in April, 1993. At the first visit she was found in bed in her nightclothes watching television. Her mother did most of the talking during the interview and it was obvious that she regarded Ms A as a helpless child and had taken over all Ms A's responsibilities, including that of raising her children. Ms A had experienced a complete role change from being a single parent breadwinner to a passive nonentity who did not contribute towards any family responsibility.

Ms A had regressed considerably. She had become increasingly weak from inactivity and could only move around the bed and feed herself independently, but could no longer stand, transfer to a chair or walk with assistance. She watched television all day and never left the home. Her mother bathed her and attended to her toilet needs by means of a bedpan. She made very little attempt to communicate with the researcher and it was obvious that she was suffering from a moderate degree of depression.

When inquiring about the advice given to the mother on Ms A's discharge her mother explained that she found Ms A too heavy to get out of bed and that she had forgotten what she had been taught to do. On assessing the bed the researcher found the mattress was very soft and the bed far too low.

When asked what she perceived as her biggest difficulty Ms A stated that it was the isolation and lack of contact with any neighbours. Her mother described her caring role as being physically exhausting as her daughter was obese and this had caused her to have backache which she had never suffered from before.

Both mother and daughter were eager to join the programme and, after a full functional assessment, it was arranged that they would be visited twice per week until Ms A had reached her full functional capacity.

The researcher recommended that 4 large bricks be obtained and placed under the feet of the bed. In addition the position of the head and foot of the bed needed to be reversed so that Ms A's unaffected side was closest to the furniture. This would make it much easier for her to get up as she could assist her mother by grasping the furniture. It also made it easier for her mother as she did not have to bend down so far.

The blocks were obtained from one of the boarders who worked as a building labourer and were in place by the next visit. They had also managed to obtain a wooden board to place over the bath so that Ms A could sit on this instead of getting into the bath as the bathroom was too small to allow her mother to assist her in and out of the bath safely.

During the visits Ms A was taught how to sit, stand and walk with assistance by the researcher. Her mother was taught how to assist her daughter between visits and Ms A was left with a list of exercises to practise on her own. The importance of doing as much as possible independently to gain strength and function was explained to both of them. It was also suggested that Ms A dress herself every day and her mother encourage neighbours to visit and talk to her daughter during the day.

After 24 visits Ms A had reached the stage of dressing herself daily and was able to get off the bed, stand and walk independently inside the house. Although she had a marked limp she felt secure and confident. Visits were continued at fortnightly intervals during which time she was taught how to go up and down the step from her house to the garden and walk independently outside. She was also encouraged to take over some of the household chores from her mother, although cooking was excluded as it was considered to be dangerous as her hands were not strong enough to be safe with heavy saucepans. Although she was capable of visiting her immediate neighbours on her own during the day she could not walk down the road to the shops as she did not feel safe due to the gangster activity in the area. Her mother explained that she would be an easy target for mugging once the gangsters saw that she was disabled.

At this stage it was felt that further management was unnecessary as Ms A was entirely independent, apart from cooking and shopping for herself, and her mother was well aware of the importance of ensuring that her daughter continue to do as much as possible herself. Ms A was cheerful and talkative and her mother no longer responded for her when the final assessment was completed. She was also taking responsibility for ensuring that her children did their school work during the afternoons.

Ms A scored 15/56 for the initial functional assessment at which time she never left the home for social contact. By the end of the programme her functional score improved to 49/56 and she frequently left the home for social contact. Her mother's level of burden decreased from 40/48 to 17/48. Both of the participants rated the programme as being of "a great deal" of help to them.

Whilst visiting another participant in the same apartment block 6 months after her programme had ended the researcher was informed that Ms A had died suddenly of a massive brain haemorrhage.

Discussion: Even though Ms A's mother had been taught how to assist her daughter in hospital her functional capacity had regressed at home because she had been discharged into a home situation which needed a small amount of adaptation. Had a single follow up home visit been carried out shortly after discharge to monitor Ms A's progress the adaptations could have been addressed immediately. Bonner (1972:65) found that the concrete and realistic situation of a home visit was the most persuasive and most effective means of ensuring that functional capacity was maintained and that by being able to demonstrate the disabled person's level of independence in the actual environment it encouraged the family to allow their disabled relatives to maintain their independence.

Essential rehabilitation services provided in hospitals are wasted if there is no follow-up provided outside the acute situation at a time that it is most needed.

It is important to notice how the disabled was affected in an environment which was rendered unsafe by gangster activity. This problem arose frequently in Manenberg in that the disabled were rehabilitated to the extent that they could walk around the community and yet they remained housebound as it was not safe for them to do so.

8.5.2 CASE STUDY NUMBER TWO

Mrs B, a 60 year old lady, suffered a stroke in 1983. She had received some outpatient physiotherapy treatment in 1986, but the hospital transport simply did not continue to fetch her and she had not contacted them to determine the reason for this. She suffered from hypertension, but had not taken any medication since 1986 as she could not get to the hospital.

Mrs B lived in a 1 bedroomed semidetached cottage with her adult son. He had been unemployed for 2 years and looked after her very well even though he was a heavy drinker. They lived on her disability grant of R318 per month. He had recently been involved in an accident and had broken his leg very badly, but, somehow, was still caring for her in spite of having a full leg plaster cast and having to walk with crutches. When he had to go to hospital her neighbours helped her and the church members occasionally visited her and supplied them with groceries.

As their water bill was long overdue their water supply had been terminated and they were placed on a "trickle" system whereby they could obtain only 1 litre of water with the tap open for two hours.

On initial assessment Mrs B was found to have severe contractures of her left arm and was unable to use it even to assist with any activities of daily living. Her left ankle also had a slight contracture, but she was able to get her foot flat on the floor. She had to be assisted with washing, dressing, eating and getting in and out of her chair. Her son assisted her to an inside toilet when necessary by holding her under the arms from the back while she stepped incoordinately without taking any weight on her feet.

She was very keen to join the programme so that she could walk to church again instead of waiting for congregation members to fetch her by car as they frequently never arrived to take her and she lived for her church. She spent the day listening to the religious programmes on the radio. She was obviously popular with her neighbours because they frequently visited her during the day for a short period even though they were much younger and busy with their own families and household chores. Sometimes, during the visits, if Mrs B required something done for the researcher she would merely shout out aloud from her bed for the next-door neighbour who would come around and assist.

Her son was anxious that she should become sufficiently functional to wash and toilet herself and attend to her personal clothes independently as he found these chores embarrassing.

Altogether, Mrs B was visited twice per week for 4 months. She was not able to achieve independent walking as her balance was severely affected and did not improve to the extent that she could manage without a walking appliance. As her left arm was useless, attempts at using any walking appliance were unsuccessful. A walking stick was insufficient and yet she required 2 hands for a walking frame.

It was suggested to her son that he rearrange the furniture in such a way that she could hold on to the various pieces of furniture with her right hand and that there were sufficient sturdy tables and cupboards strategically placed. After a great deal of patience and determination on her part she managed to achieve this independently. Her son and 3 sets of neigbours were taught how to assist her walking by supporting her unaffected side so that she could take all the weight on her feet herself, but they would merely assist her balance. This allowed her to walk to church with a neighbour on Sundays and for Bible Reading once or twice per week.

Although the approach to assist her walking was not one from a physiotherapy textbook, it was a good educational experience for the students to see that under the circumstances the unorthodox approach was acceptable as it was the only way in which the disabled could become reasonably independent. The walking frame was too cumbersome in the small cottage, could only be used with great difficulty and did not improve Mrs B's level of independence.

At one of the Volunteer Group meetings the researcher discussed the plight of Mrs B, her son and his problems with her personal washing as well as the fact that she had not been taking her hypertension tablets regularly and was, therefore, at risk of suffering another stroke. The members discussed different ways in which these problems could be addressed and eventually decided that one of the volunteers would discuss the situation with Mrs B's church minister and request some assistance from a member of the congregation. This was done and he arranged for 2 ladies from the Women's' Auxiliary who lived in the vicinity to visit Mrs B twice per week to assist her with her personal washing and that of her clothes.

Another volunteer contacted the local Health Sister and discussed the fact that Mrs B did not have any hypertension tablets. The Health Sister undertook to fetch these from the Day Hospital herself when she reported there for a meeting. She also placed Mrs B's name on her list of people to be visited so that she could check occasionally on a regular basis to see that Mrs B had a supply of hypertension tablets.

The volunteers liaised with the Advice Office for assistance regarding Mrs B's water situation. One of the members approached the CTCC and her water supply was reconnected with the understanding that she would make a minimal monthly contribution towards this service.

Although Mrs B's functional score showed only a relatively small improvement (14/56 to 39/56) it made a considerable difference to both her and her son's quality of life. She expressed this by saying "I used to get so despondent when I had to wait for help for everything that I wanted to do. Now at least I can manage the private things of my life myself and with just a little bit of help I can walk to church with my neighbours. They don't mind helping me now that I can manage with just a little bit of help and don't have to be dragged around. It is also very good to have the ladies from the church come and do the washing because when they see that the house isn't so clean they help with the sweeping and tidying which makes it better for my son. When one can't come they always get someone else to take her place so that I know there will definitely be someone here every Tuesday and Friday".

The son's level of burden decreased from 37/48 to 25/48. He described the programme as having benefited him "a great deal" and did not find the assistance he had to give his mother during the day as being a problem once she received help with her bathing and washing from the volunteers and neighbours. It also helped to have her go out to church more frequently as it allowed him some time on his own without her as she was of a gregarious nature and expected to be entertained by him all the time he was at home.

Discussion: Mrs B had been disabled for 10 years and, initially, the researcher thought that in view of this and her muscular contractures there would be little scope for improvement in function. In her situation it showed that early rehabilitation may be the optimum period for improvement, but that is not necessarily a cut off point. However, early rehabilitation would have decreased the possibility of Mrs B developing such severe contractures at her shoulder, elbow, wrist and ankle joints. This would have made independent walking a possibility.

Community physiotherapy should incorporate prevention as well as management of disability. For example, it is essential that the disabled be educated to realise the importance of taking their medication regularly to avoid recurrences of their medical conditions.

8.5.3 CASE STUDY NUMBER THREE

Mr C, a 27 year old hawker, became a paraplegic after sustaining a gunshot injury in 1985. He spent 3 months in Conradie Hospital receiving physiotherapy rehabilitation, but claimed that he had never had physiotherapy previously. He did remember receiving occupational therapy and being shown how to stretch his legs to prevent contractures. No family member was taught how to care for him at home.

His arms were very strong and he was able to feed himself and propel his wheelchair independently. Mr C had not done his leg stretches regularly and had developed contractures at his ankles which made it difficult to place his feet flat on the wheelchair footplates. He had also developed pressure sores on his buttocks and suffered from recurrent bladder infections. The Health Sister was visiting him 3 times a week to dress the pressure sores.

Mr C felt he was very independent although his girlfriend, who was his caregiver, said that she had to assist him with most activities to a certain extent except feeding and propelling his wheelchair.

They were both very motivated to join the programme. He wanted to be able to return to hawking which he had not done for 8 years and she wanted to be taught how to help him without causing him further injury.

Mr C and his caregiver were taught how to stretch his legs properly every day to prevent further contractures and also to regain some length of the soft tissues that had been lost. They were educated about the importance of lifting his body at regular intervals to relieve the pressure on his buttocks to prevent further bedsores and was reminded about drinking a large amount of fluids during the day to prevent further bladder infections. He was also given strengthening exercises for his arms, shoulder, trunk and back to do between visits as a maintenance programme.

The researcher visited Mr C every fortnight to progress his exercises and ensure that he and his girlfriend were stretching his legs properly.

When he achieved sufficient strength he was taught how to transfer himself from his bed to the wheelchair and from the wheelchair into his van from which he was going to sell fish to the local community. He managed this safely within a few weeks. He was still not able to manage the step from the front door to the ground independently. His girlfriend was advised to see the CTCC authorities and request that a ramp be built. This was done after a few weeks and Mr C was able to return to his hawking.

No arrangements could be made regarding the use of the outside toilet. Although a ramp would have allowed Mr C easy access from the kitchen, the toilet itself was too small to manoeuver a wheelchair. The researcher also felt that the unhygienic conditions of the toilet were undesirable with his open pressure sores. Four other families had use of the toilet and it was in a filthy state as nobody took responsibility for cleaning it.

Mr C and his caregiver were visited 8 times in total. He expressed his gratefulness for the concern and interest that had been shown to him. Most of what he had been taught he remembered had been taught to him in hospital, but he found that the visits motivated him to do his exercises regularly and the small changes to the furniture arrangements allowed him to become mobile in his wheelchair in the bedroom. He had not been able to adapt this himself as the space in the hospital was so much bigger he could manage very easily, but when he came home he could not do it that way because of the limited space. His girlfriend said she felt very confident about helping him now as she knew that she would not hurt him and now that she understood his medical condition she realised how important it was for him to be reminded of his pressure and bladder care.

Mr C's functional level improved from 23/56 to 43/56 and his caregivers burden decreased from 30/48 to 7/48. He rated the project as having benefited him "substantially" and she as "a great deal".

Discussion: Firth, Wright and Chamberlain (1976:189) found that, as with Mr C, instructions given to patients by hospital staff were frequently forgotten. They have the confidence to perform certain activities in hospital, but lack the confidence to carry them out at home once they have been discharged. With so many different people forming part of the rehabilitation team it is easy for patients to become confused as to which member of the team provided them with which advice or home instructions.

8.5.4 CASE STUDY NUMBER FOUR

Ms D, a 34 year old cashier, was stabbed by her boyfriend and became a paraplegic in 1983. She had spent 3 months at Conradie Hospital and was discharged, fully rehabilitated and with calipers, crutches and a wheelchair. She was able to care for herself and could apply her calipers and walk with her crutches without any help.

She lived with her 2 little daughters, aged 11 and 13 in a 2 bedroomed flat. She lived on her disability grant of R370 and augmented this income by renting one of the bedrooms to a young married couple. Ms D was very enterprising and purchased cheap jewelry in bulk and sold it to the local community from her flat to augment her income.

Ms D did not like living in Manenberg, but was forced to do so because the rentals were cheaper there than anywhere else. She had lived in Lansdowne prior to her accident and wanted to return there "to my own sort of people". She lived in a particularly bad part of Manenberg where there was a great deal of gangster activity and she worried a great deal about her girls when they went to and from school and ran errands for her. She had difficulty in paying her rent as she could not go to the Rental Office herself and when she gave the money to a neighbour he spent it on alcohol.

Ms D had deteriorated significantly during the 10 years since her discharge. She had developed contractures to the extent that she was no longer able to apply her calipers and walk with crutches nor could she get in and out of the bath independently. Her little daughters had to attend to her personal hygiene for her although she realised that this type of caring was very inappropriate and undesirable for them at their age.

The CTCC had provided her with a ramp to her front door and she should have been able to manage the shopping and errands herself, but her wheelchair was in such a dilapidated state she was unable to use it outside as the rubber rings and tyres had worn down to the rims.

After assessing Ms D's level of function and her physical condition it was decided that her hip contractures were so bad that it was impractical to attempt teaching her to walk again. She would have required surgery and extensive hospitalisation to relieve the contractures and the researcher was not sure that Ms D would be sufficiently conscientious to prevent the same deterioration from taking place afterwards.

She was visited once per week for 12 weeks during which time she was taught again how to stretch her legs and given general arm and body strengthening exercises to do on her own. As she became stronger she was shown how to transfer to the toilet and in and out of her bath so that her daughters would no longer have to do these private chores for her.

She was advised to contact Conradie Hospital regarding her wheelchair so that they could organise to have it repaired. Ms D was very resistant to this as she felt that she should not have to pay for anything herself and that everything should be free. After a great deal of counselling and explanation of the actual cost of repairing the wheelchair as opposed to the R15.00 transport cost she would have to pay she agreed to attend the outpatient clinic at Conradie Hospital.

Subsequent to seeing the social worker at the hospital she was given a brand new wheelchair as her old one was beyond repair. During the follow up visits she was encouraged to do her own shopping and errands to reduce the burden on her daughters. She was also encouraged to attend her church on Sundays now that she could get there independently.

At the final visit when the last physical assessment was done Ms D thanked the researchers for the time and effort that had been put into helping her. Although she did not reach the level of improvement that she could have achieved had she not allowed herself to deteriorate she did improve from 25/56 to 40/56. However, this improvement meant a great deal to her daughters who were now relieved of their caregiving tasks. She rated the programme as having helped her "a great deal".

Ms D was attending church regularly and had joined the Women's Auxiliary. She had met a few ladies who lived in the vicinity and with whom she felt comfortable associating and socialising. She was an intelligent and analytical person who explained her deterioration in the following words: "When I came home from hospital I was just dumped here by the ambulance men. I had to look after my children and do the housework and cooking all by myself with no help. I didn't know anybody and I didn't like these people here. They just drink and smoke dagga all day and then they stab anybody who is in their way. The Council put up this ramp for me, but they didn't put up wooden bars in the backyard so that I could practise my walking. The social worker at the hospital told me they would do it for me. I was just so depressed that all I could do was to look after the kids, cook and do the housework. If somebody from the hospital had just come to see that I was doing everything right I'm sure I would have done those things they told me to do every day. By the time I started to feel better and to do things for myself I had got too weak and couldn't even put on my calipers." (sic)

"Now that I can look after myself again I feel better. I have spoken to the ladies at the Women's Auxiliary and they say I should try and get a job at the shop down the road because I can do cashier work and the lady there is going to have a baby soon. One of them said my girls can go to her after school if I get a job. I feel so much happier now that I know these nice people".

Discussion: A great deal of time and money is spent on the rehabilitation of patients with spinal cord injuries at Conradie Hospital. The staff are highly specialised and each patient receives sufficient therapy to achieve maximum level of functioning.

Yet, it is not policy of the hospital for staff to do home visits. Patients are expected to go home to an environment which may need small adaptations if the disabled is to continue to function at the level achieved in hospital. Because these adaptations are not done the disabled cannot function to their maximum level and start to regress.

Patients, like Ms D, feel abandoned and anxious. Had she had one home visit it could have been ensured that her walking bars had been installed by the CTCC and her progress and maintenance of physical function could have been monitored. Werner (1989:14) found that patients monitored at home retain the functional level achieved during their hospitalisation. It also motivates them to continue with an exercise programme that might otherwise appear to be boring and non-beneficial (Rosenblatt, 1986).

Home visits would also have provided Ms D with the emotional support she obviously required at that stage of her rehabilitation.

8.5.5 CASE STUDY NUMBER FIVE

Mr E, a 63 year old unemployed driver, suffered a severe stroke in May 1993. He spent 1 month in Groote Schuur Hospital and 2 months at Lady Michaelis where he received intensive rehabilitation in the Stroke Unit. At the time of his discharge from hospital his medical file indicated that he could function fully independently, albeit slowly, and all that he required assistance with was the buttons on his clothes when he dressed or undressed himself.

The researcher first visited him 4 months after discharge. He had been lying in bed for the three months with his wife and daughter doing everything for him. He spent the day reading his Bible or watching television, but was very depressed as he wanted to return to some sort of work and wanted to be able to attend church again. His wife and daughter had to stop working for 3 days and 2 days per week respectively so that someone could always be at home to care for him.

When questioned by the researcher as to what home instructions the physiotherapist at Lady Michaelis had given him on discharge he could demonstrate his shoulder exercises very well. When he was asked why he had not been doing them or getting up he and his wife both said they were too frightened to carry out these instructions in case he did too much and had another stroke. Although they gave the impression of being apathetic and accepting they were very concerned as they realised that he was getting weaker and was deteriorating physically by just lying in bed.

Mr E was visited twice per week initially as it was very important for him to become mobile as fast as possible to prevent any loss of function. As he was a very heavy drinker over the weekends his visits had to be arranged so that they did not occur on a Monday as he was still suffering from the effects of the alcohol abuse on the weekend and could not contribute maximal interest in his programme.

A great deal of time was spent in counselling Mr S and his wife and reassuring them that functioning would only do him good and not harm. They were both very cooperative and grateful for the visits. She was reminded of the shoulder exercises to do for her husband, taught to her at Lady Michaelis Home, and he was left with exercises to practise for the next visit. After 2 weeks Mr E was back to the functional level at which he was before being discharged.

Mr E was encouraged to help his wife in the kitchen with the dishes and preparation of the food for cooking in order to improve his fine motor coordination. Although he had never performed these tasks he realised the importance of keeping busy and at the same time being of assistance to his wife who was doing heavy physical work cleaning offices during the day.

The home comprised 1 bedroom and was shared by his daughter and her 5 little children. They had use of an outside toilet. They had been on the housing waiting list for 10 years for a larger dwelling unit.

Mr and Mrs E slept on a pull-out bed in the sitting room so that there was not much room in which to move around. The limitation of space was of assistance to Mr E when he first started to walk on his own as it gave him a great deal of confidence being able to hold on to the furniture, when necessary, as he moved around.

As soon as he was managing independently inside, even to the extent of doing his own buttons and writing with his affected arm he was taught how to manage the steps outside his flat and could negotiate these safely within a week.

At this stage the researcher visited him only once per month. During the final visit Mr E advised us that he was able to walk down the road to visit friends, do the shopping and attend Bible Reading at the church twice per week. An unemployed neighbour who was also a friend accompanied him to ensure that he was safe, but he felt strong enough to do it on his own. He and his wife were very grateful for the home visits as they felt they were not able to cope without any support and even though he had been doing most things independently in the hospital they had felt anxious about him doing too much.

Mr E's functional level improved from 14/56 to 56/56 and the number of times he was able to leave home from "never" to "frequently". His wife's level of burden improved from 43/48 to 4/48.

Discussion: Had Mr E received one home visit soon after discharge his progress would have been maintained as the physiotherapist would have evaluated his physical functioning - suggesting how to do things in a slightly modified manner, adapting his home environment slightly and reassuring him and his wife.

It would have been unnecessary for Mrs E and her daughter to reduce their days of going to work and thus decreasing the family income.

It is difficult to envisage that Mr E would have progressed had he not joined the programme as he and his wife were so anxious that he just remained in bed getting weaker and less motivated to get himself going. Mrs E's burden was increasing with increasing financial demands and a decreasing income as well as the increased physical demands on her.

8.5.6 CASE STUDY NUMBER SIX

Mrs F, a 55 year old machinist, suffered a severe stroke in March 1992 as result of hypertension. She had spent 2 weeks in Somerset Hospital and then, although she could not wash, dress, feed herself or walk, she was discharged home to her flat on the 2nd floor where she lived alone. She was divorced and had a son who lived in Manenberg and a daughter who lived in Mitchell's Plain.

She attended Heideveld Day Hospital Physiotherapy Department as an outpatient twice per week for 1 year. The hospital provided transport, but had not arrived for the past month as she was not always been ready for them as she had to rely on her neighbour to wash and dress her. The neighbour had 5 of her own children to whom she had to attend before she could help Mrs F.

Mrs F spent the day in bed and even when she was attending the Day Hospital she was fetched from her bed and taken back to her bed. She was totally dependent on assistance for all her needs.

She was not able to use her left arm at all and her left leg was very weak and could not support her weight. She could feed herself if the food was cut into small pieces, and could assist with her dressing, but could not wash herself properly.

She was very depressed and just lay on her bed staring at the ceiling all day and smoked 30 to 40 cigarettes per day. The neighbour, who she paid R50.00 per month from her R320 disability grant, came in every morning to wash and dress her and to clean her house. She brought her porridge in the morning and left some bread for her to help herself for lunch. In the evening she sent up a plate of dinner with one of the young children. Apart from these brief periods of contact with the neighbour or her children Mrs F saw nobody else. She was a very religious lady and it upset her a great deal that she was unable to attend church.

After the functional assessment at the initial visit the researcher visited the neighbour, Magdeleen, and arranged to meet her with Mrs F the next day. Although Magdeleen was very busy with her own family she was happy to help Mrs F as she was doing. However, she found her very demanding as Mrs F expected her to sit and talk to her all day because she was being paid and she did not have the time to do so. The researcher explained that the whole objective of the visits was to help Mrs F become as independent as possible so that she could eventually manage on her own with very little input from Magdeleen, except for the shopping and heavier housework.

At the first visit a great deal of time was spent in educating Mrs F about smoking as it could have caused her to have another stroke, apart from the fact that she was also a mild diabetic. The programme was also discussed with her and the expectations of what she was going to have to do were made clear to her. She agreed to participate and cooperate as much as she could as she realised it was for her own benefit and that nothing could be achieved without her participation. Magdeleen was taught how to do passive movements to Mrs F's left arm and shoulder to prevent contractures from forming as her shoulder was already very painful. Mrs F was given exercises to practise in bed and advised to try and reduce her smoking.

The researcher liaised with the coordinator of the volunteer group who arranged for a volunteer from Mrs F's block of flats to meet with the researcher at Mrs F's flat at the next visit. Mrs F's minister was also contacted and he agreed to visit her and to contact the researcher again to discuss what the congregation could do to help. He was upset that he had not been informed about Mrs F sooner as she had not been attending church for more than a year and he thought she had moved away from the community.

Mrs F was visited twice per week for 5 months and then once per fortnight and later on once per month just to ensure that she was still managing and to provide a little additional support.

Her functional progress was very slow as she was severely disabled, but the volunteer attended all the physiotherapy sessions and came once more per week to carry out the same programme. This aided matters a great deal as Magdeleen continued to care for Mrs F's feeding and light household chores during this time and another volunteer came in once per week to do the general housework. The minister discussed Mrs F's problem with the congregation and from then on she frequently had visitors from the church and gradually her depression lifted as she became more and more capable and had more social contacts.

One of the volunteers contacted the Community Health Sister to discuss Mrs F's diabetic and hypertension tablets with her and to organise that they be fetched from the Day Hospital when her supply came to an end.

A walking stick was obtained from one of the other participants on the programme who no longer needed it. It was light and Mrs F learned to manage it effectively as it provided her with just the right amount of support.

As she lived on the 2nd floor the final part of the rehabilitation involved teaching Mrs F how to negotiate the stairs. She did not want to relocate to a ground floor flat as she felt more secure from the gangsters in the area by living on the top floor. As the rails did not reach all the way down the stairs the CTCC was contacted and they extended the rails on both sides. Even though her left arm was useless she managed the stairs very well with a small amount of assistance from another person.

Once this stage had been reached Mrs F's psychological condition made a dramatic improvement as she could be taken to church. This was achieved initially by a congregation member fetching her by car, but as this could not be arranged permanently the researcher suggested that a wheelchair be hired at a nominal rate from the MPC for the occasions that they needed to take her to church. She could easily be wheeled to the church, but it was a bit too far for her to walk as she tired fairly easily. Mrs F lived 1 block from the MPC so the wheelchair was easily accessible.

By the final visit Mrs F was able to wash herself with Magdeleen just doing her back for her. She could dress herself and had been taught how to cook her porridge and make sandwiches for lunch with one hand. She could do most of her own housework, including her bed and washing up with her one hand although it was a very slow procedure, but she had all day in which to do it so it was not problematical.

The volunteer had arranged for a second volunteer to fetch Mrs F once per week to take her by wheelchair to a Senior's Club every Wednesday at the local Council Community Centre. She spent the afternoon there socialising with other elderly people from the community.

Mrs F's functional level improved from 14/56 to 43/56 and from "never" leaving the home she now left the home "frequently" for church, Bible Reading and the Senior's Club.

Magdeleen's level of burden decreased from 48/48 to 19/48. She expressed the benefit with which the programme provided her as "a huge weight off my shoulder and my mind" as her husband had started to object to the amount of time which she was involved with Mrs F. She also felt that the R50.00 was more in line with what she was required to do then as opposed to that at the beginning of the programme. She did fear that this might be taken away since she was doing so much less, but Mrs F was very grateful to have Magdeleen to rely on and was very happy to keep the financial arrangements as they were.

Discussion: With the pressure on acute hospital beds stroke victims are frequently discharged prematurely as was the case with Mrs F. Thus her rehabilitation was incomplete and she was sent home totally incapable of caring for herself.

Although she was attending the physiotherapy department as an outpatient this was of little benefit as she was merely returning home to bed and not practising any of the exercises she was learning during her physiotherapy sessions.

The above situations could both have been avoided by a home visit programme instituted immediately after discharge. Even though Mrs F's physical condition did not improve over the period of home visits she was capable of being taught how to function to a level of being almost independent in spite of her disabilities. This could have been achieved much earlier had a home visit programme being established from the time of her discharge rather than 1 year later.

8.5.7 CASE STUDY NUMBER SEVEN

GG, a 13 year old boy, suffered from Cerebral Palsy and associated mental retardation.

GG could talk at approximately the level of a 5 year old child and was able to propel himself around the floor by dragging his legs behind him in a crawling position.

He had severe contractures of his hips, knees and ankles. Previous surgery that had been performed on him at Princess Alice Orthopaedic Hospital to release these contractures had not appeared to have any beneficial effect. The contractures prohibited any thought of rehabilitation towards getting the child to be able to walk independently.

GG spent his day crawling on the floor inside the flat or sitting in the sun on a chair. His mother had to carry him wherever they went and lift him from the floor to the chair and vice versa. He used to have a pram that she could push him in when she went shopping, but he had outgrown this and she was longer able to carry him around with her as he was so heavy. This meant that she either had to lock him up in the flat alone while she was away or she had to carry him to a neighbour who could care for him for the morning.

GG's mother was at her wits end as she was a single parent and had 4 other younger children to care for and she had a very painful back from lifting and carrying GG. She was also very stressed as she wanted to buy a wheelchair, but the family lived off GG's grant of R338.00 per month and she knew she could never afford it.

In the researcher's opinion GG was functioning physically at his highest possible level without undergoing further surgery and long-term intensive rehabilitation at a school for handicapped children. This did not seem to be a feasible option though as all the schools available had very long waiting lists and he had already been on a waiting list at Eros School for 3 years.

The problems of GG and his mother were taken to the next volunteer group meeting. Alternative solutions were discussed and the volunteers decided to contact the local newspaper and place an advertisement for a used wheelchair that was no longer required to be donated to GG.

One of the journalists at the newspaper decided to make a feature of GG. He contacted the volunteer group coordinator and they went to GG's home and took a photograph of him sitting in the sun with a big smile on his face. They covered the story with a two-column feature of the plight of the mother and child. They also described the domiciliary physiotherapy programme and gave contact telephone numbers for volunteers and donations towards other small household appliances that needed to be adapted for disabled persons.

Within a day the coordinator was contacted by 5 offers of wheelchairs. They were all used, but in good condition and were delivered to the MPC. A local ice-cream factory manager telephoned to say that his company would like to donate a new wheelchair to GG. This offer was accepted as GG required an adolescent's chair as he was still too small for an adult wheelchair.

This was delivered to GG and he was taught how to climb in and out of it himself. He was also taught how to apply the brakes and propel and steer the chair himself. He was absolutely delighted as this was the first time in his life that he could be independent. His mother was also very grateful as he could be pushed very easily when she went to the shops and school to fetch his brothers and sisters and she was no longer required to lift and carry him.

Although GG's functional level only improved from 29/56 to 37/56 the number of times that he was able to leave the house increased from "never" to "frequently" and his mothers burden decreased from 43/48 to 17/48.

The remaining 5 adult wheelchairs were kept at the MPC and were able to be hired out by members of the community at a nominal rental of R15.00 per month on a temporary basis.

The researcher contacted the Eros Cerebral Palsied School and explained the urgency of GG's situation and how much he needed to be placed in an environment where he could receive regular physiotherapy on a long-term basis following corrective surgery. The story was the same as that heard by social workers all the time. They had a very long waiting list of equally urgent cases and these children also had far higher

IQ's than that of GG and so would be much more likely to benefit from the schooling and rehabilitation. The waiting lists at institutions for children of lower IQ's was even longer.

At the Volunteer Group Meeting when the researcher expressed amazement at the response to the newspaper feature the volunteers (two of whom followed the Muslim faith) maintained that it was not a surprise to them as the child had a Muslim name and that all the wheelchairs came from financially well-off Muslim families living outside Manenberg. They were convinced that there would not have been the same response to a child having a Christian name.

As a result of the newspaper feature a lady living in the block of flats opposite that in which GG lived, contacted GG's mother and offered her services to care for GG and his brothers and sisters when his mother had to go out to do errands. She was also of the Muslim faith and had previously seen GG been carried around by his mother. GG's mother was overwhelmed by the response of a wheelchair and volunteer assistance.

Discussion: It is difficult to understand the rationale and justification of the costs of the surgery performed and the pain and emotional trauma involved unless GG had been able to attend a special school for physically disabled children where he could have received daily physiotherapy treatment to gain further physical function and to prevent the contractures from recurring.

Had a home programme been in progress the surgery performed could have been a feasible situation with the visiting physiotherapist showing the mother how to prevent contractures from developing again and how to stimulate GG to encourage further physical development.

By the time that the researcher presented GG as a problem to the Volunteer Group Meeting the group had developed to the extent that members came up with various solutions and different strategies of implementation without any input from the researcher. When the wheelchairs were stored at the MPC and one was given to GG they appeared very confident and satisfied with their success.

Five of the group members participated in the planning and implementation of the wheelchair project. This was an accomplishment as, until then, they had worked as individuals and were only involved with the disabled members of the community for whom they were responsible.

8.5.8 CASE STUDY NUMBER EIGHT

Mrs H, a 58 year old housewife, suffered from acute attacks of asthma aggravated by chronic emphysema. She had been a heavy smoker most of her life and for the past 4 years had become short of breath when walking long distances or after heavy physical activity. She had her first asthma attack following a chest infection 3 years ago for which she was hospitalised for 3 weeks. Following this attack she had been hospitalised approximately every 2 months with further asthma attacks resulting from chest infections. In hospital she had received physiotherapy treatment to clear her chest of secretions, but had not been shown how to do this for herself at home and actually knew very little about her chest condition and how to prevent and minimise the asthma attacks, apart from the fact that she should not smoke cigarettes.

Now she was unable to walk to the shops a few blocks away from her flat and had to sleep sitting up in bed as she became very short of breath during the night and coughed a great deal. She was unable to do any housework and any effort incurred while dressing or bathing herself would require a period of rest afterwards. She spent the day sitting in the living room reading and watching television.

Her husband, a heavy duty truck driver, had been forced to give up his job in order to care for her. They lived on an undisclosed income obtained from the rental from a shack in the backyard and 1 bedroom in their house.

Mr and Mrs H shared a bedroom with their teenage grandson. Both Mr H and the grandson were cigarette smokers and in winter the family burned an oil heater in the bedroom for warmth. The heater also emitted smoke when it was burning. They had blocked off the airvents in the house to prevent the wind from blowing through and the rain from entering. This had caused the house to have a damp and mouldy smell.

After the researcher had examined Mrs H's chest and found that she had chest secretions present and that chest expansion was very limited she was taught how to lie with her body over the edge of the bed with her head resting on her arms on the floor whilst her husband was shown how to do chest manipulations that would loosen the secretions so that she could cough them out more easily. They were advised to carry out this regimen in the morning before getting up and in the evening before retiring for the night. A time was arrange for the next visit when the grandson would also be at home so that they could all have an explanation given to them regarding Mrs H's asthma.

At the next visit the researcher checked that they were performing the postural drainage to clear the secretions satisfactorily. Mrs H was shown chest expansion exercises to practise on her own 3 times daily.

The three of them were then told how badly smoke affects the lungs, how it causes irritation and causes the airways to constrict and that it causes increased formation of secretions that become thick and cannot be coughed out because of the narrowed airways. It was suggested that they did not burn the oil heater in the bedroom, but that they kept the bedroom door closed to prevent as much smoke as possible entering the bedroom from the sitting room and that they did not smoke in the bedroom or house and encouraged their boarders not to do so either.

Nothing could be done regarding the airvents as, when the material blocking them was removed, the wind blew in dust and sand which was also bad for Mrs H's chest. However, the walls were mouldy, particularly in the corners behind the beds and it was explained to Mr H how he should wash these down with a detergent for mould removal.

Mrs H was visited twice weekly for 3 weeks. During this time Mr H had washed the walls down and was sweeping the house with a dampened broom and wiping the furniture with a damp cloth to minimise the amount of dust. He was giving Mrs H very effective chest manipulations and she was able to sleep much better once her chest had been cleared. She reported that she felt much better without all the smoke in the house as her husband and grandchild were very cooperative and only smoked outside. They were, however, unable to persuade their boarders to do the same so they kept their bedroom door closed all the time.

Mrs H was taught thoracic mobility exercises to practice on her own in addition to the postural drainage and chest expansion exercises. She was shown how to position herself if she became particularly short of breath and was encouraged to start doing light housework.

Once she was moving around the house without becoming short of breath, in order to increase her exercise tolerance the researcher took her outside to walk on the sidewalk and to practise controlled breathing when walking. She was told to walk the same distance every day for a week and then to increase it gradually until she could walk to the shops.

At the end of 10 weeks Mrs H was able to do a large part of the housework herself and was able to walk to the shops and back without getting breathless. As her chest was clear she was sleeping very well and hardly coughed at all during the night. It was explained to her and her husband that, even though she could manage to do so, she should not try and do the dusting or sweeping in the house or go outside in the wind as this could trigger another asthma attack. She also had to be prudent with her medication and not stop taking the tablets once she felt better as she would regress immediately as it would cause her airways to become narrower and her breathing more difficult again.

By the end of the programme Mrs H's functional level had improved from 46/56 to 56/56 and she was able to leave the house "frequently" as opposed to "never". Mr H was looking for a truck driving job as he felt that the housework he had to do could be done after work.

Discussion: The case of Mrs H is a very good example of how a domiciliary physiotherapy programme can empower people and bring about a great improvement in their quality of life by providing them with the basic knowledge of the medical condition from which they are suffering so that they can apply this knowledge to their personal situations.

It also is an example of how it is not always possible for the caregivers to be taught what to do for the disabled during their stay in hospital as they are frequently prematurely discharged before the physiotherapists have the opportunity of educating the caregivers.

Mr H required to be taught a very simple technique of chest manipulation to loosen his wife's chest secretions. She needed to be taught very simple postural drainage positions, chest expansion and mobility exercises which she could easily carry out herself.

The most important part of the management of Mrs H was visiting her home environment. Without this it would have been impossible to envisage the dusty, damp, mouldy and smoky conditions under which she lived. Teaching her and her family the textbook approach to the causes and management of asthma and emphysema in hospital would have been meaningless. What was needed was the concrete evidence of the dampness, dust and smoke in their home and their practical management within the environment that they occurred.

8.5.9 CASE STUDY NUMBER NINE

Mrs I, an 85 year old lady, suffered a series of severe strokes in 1991. She was bedridden and could not talk. She had been living with her daughter in Mitchell's Plain, but as the daughter and family had had to vacate their house she had come to live with her son and his family.

At the first visit it was obvious to the researcher that Mrs I would not benefit from any form of rehabilitation per sec as she was so badly physically affected and due to the long standing duration of the stroke. However, her daughter-in-law, the caregiver, urgently required assistance with the management of her mother-in-law.

The caregiver was extremely depressed as she had 4 children and a husband to care for and she felt guilty about not spending more time with her mother-in-law who just lay in bed on her own all day. She also felt frustrated that she never had time to either visit friends or to have them visit her. She had felt isolated and lonely since her mother-in-law had come to stay.

Mrs I's situation was discussed at a Volunteer Group Meeting and a volunteer was obtained from the church. She met with the researcher at Mrs I's house and was taught how to assist her with bathing, dressing and sitting. Although the volunteer appeared very keen to assist she came only for 3 weeks and then stayed away as she said she lived too far and the work was too heavy. She was frightened of hurting herself.

The researcher asked the daughter-in-law if she could nominate a neighbour who would be able to help. She could name 3 neighbours with whom she was very friendly, but she requested that the researcher approach them as she was too embarrassed to ask for assistance. This was done and the neighbour agreed to come in on a regular basis twice per week to wash, dress, feed and help Mrs I to sit up.

The caregiver and volunteer were taught how to place Mrs I in the optimum position in bed in order to prevent pressure sores and contractures from developing. They were taught how to turn her in bed and how to move her up and down the bed and how to sit her forward. As they were unable to afford a bedpan they used newspaper very effectively as a substitute. They were shown how to get Mrs I on and off the newspaper. As all these activities involved a great deal of heavy lifting and manoeuvering they were also taught the correct mechanical use of the body to prevent back injuries.

Mrs I received 7 visits spread over a 2 month period during which time the caregiver and volunteer's management of Mrs I was monitored and they were given further advice on handling her. The volunteer proved to be a very concerned and committed friend and incorporated the assistance of another 2 neighbourhood friends to come in during the day for frequent short visits to provide Mrs I and her daughter-in-law with companionship and to assist with any daily household chores being done at the time.

By the end of the programme Mrs I's level of physical functioning had shown very little improvement, from 14/56 to 20/56 and she was still unable to leave the home. However, the burden of the caregiver had decreased from 42/48 to 16/48.

She was extremely grateful for the assistance and stated that much of her anxiety had been reduced by the reassurance that what she was doing for her mother-in-law was correct and that she was doing all that was possible to do. She had also found that by being shown the correct techniques of lifting she no longer felt so physically tired. She felt that the neigbours had become more aware of having a disabled person at home. By them talking to others in the community people were more friendly and sympathetic to her when she saw them out in the shops or streets.

Discussion: Although Mrs I had been living with her son for 7 months and the neighbours knew that her daughter-in-law was caring for her nobody had volunteered to assist her in any way. However, once the researcher approached the nominated neighbour and she, in turn, had contacted other neighbours there was no hesitation in them becoming involved and supporting her. All that was needed was some stimulation of community awareness.

The more neighbours involved the more they made others around them aware of her plight and how they could be of assistance to her. It appeared that all they required was some knowledge about Mrs I's medical problem and this led to some form of community participation as several neighbours assisted in different ways. It also contributed to the daughter-in-law's perception that people on the street were more friendly and sympathetic towards her which provided her with a great deal of emotional support.

8.5.10 CASE STUDY NUMBER TEN

Mr J, a 64 year old retired printer, suffered a stroke on his right side 4 years ago. He had not been hospitalised nor had he been referred for outpatient physiotherapy by the casualty department.

Mr J was severely handicapped and his wife did everything for him. He had a great deal of spasm in his right arm and his shoulder was extremely painful as it had become stiff. He also suffered from gout and was experiencing a moderate amount of pain at the time of the first visit. He spent most of his day reading the Bible, but also watched television as much as he could.

His wife had had to give up her job as a machinist in order to care for him. This meant that they were very short of money as they received only his pension of R600.00 and they had to support a young teenage grandson with this income too. Mrs J was very frustrated as her husband's presence in the house all day irritated her as he called for attention every few minutes. She was unable to get on with her household chores and could not leave him for long to do the necessary shopping as he was nervous of being left alone.

They received no assistance from their grandson as he was involved with the gangs and frequently took drugs. Furthermore, he considered the caregiving role to be part of the female domain and strictly his grandmother's problem.

They were both very keen to receive some assistance. It was suggested they request to be moved to a ground floor flat, but they refused this as they felt safer upstairs from stray bullets from the gangster activity at night. As Mr J had run out of medication for his gout Mrs J was told how to contact the Community Health Sister who would obtain it from the Day Hospital for him. He would not be able to progress to walking without his gout under control because of the pain.

Mr and Mrs J were asked to nominate a neighbour who they thought would be able to assist them. Mr J did not like the idea of someone other than his wife being involved in his physical care, but was happy for a neighbour to sit and share Bible Reading with him twice per week to give his wife some respite. The researcher visited the neighbour on the ground floor who was only too willing to help. She said that she had offered before, but Mr J was such a difficult man he only wanted his wife to do everything for him. Now that he was willing for her to come she would gladly do so.

At the first visit Mr and Mrs J were taught how to stretch his affected arm to avoid further contractures and pain and how to put his arm into a basin of very cold water to reduce the spasm. Mr J was taught exercises to practise in bed so that he could move around and sit up independently.

He was visited twice per week. He and his wife were very enthusiastic and he made rapid progress. Within a few weeks he was able to dress and stand up himself with a little bit of assistance. He wife had to do his buttons and wash his back for him, but otherwise he managed very well. As she had always done his bathing in the bedroom they were advised to get a short wooden board to fit across the top of the bath so that once he could walk to the bathroom he could sit on the board and wash himself. Their grandson was able to obtain this from one of the local rubble sites in the area.

Mr J was taught to walk by holding onto the furniture in the flat and could get himself to the toilet, bathroom, bedroom and sitting room as well as sit and stand on his own. This was a big relief for his wife as she found the physical work a tremendous strain on her back.

Although the researcher did not recommend it due to Mr J's level of disability he was very eager to learn how to negotiate the flight of stairs so that he could walk on the pavement and visit a few neighbours. A walking stick was obtained from a participant who no longer used it and he was shown how to practise walking with it in the flat while the CTCC was contacted to extend the rails on both sides of the stairs right down to the bottom step for Mr J.

Mr J was taught how to negotiate the stairs with the volunteer (who was a much younger and stronger person than Mrs J) standing by in case he needed support for balance. It was a very good learning experience for the students to see how an extremely unorthodox technique had to be used under the circumstances, but that it was not important how Mr J went up and down it was important that he could do so and that it was the safest technique to allow him to do so.

Mr J's level of functional ability increased from 21/56 to 44/56 and the number of times he left the home from "never" to "frequently". He was able to walk up and down the street to visit and chat with the neighbours and to sit in the sun on the pavement and watch the activity of the local children. He was able to get in and out of a car and could be transported to church on Sundays for which he was very grateful as he was a very religious gentleman.

Mrs J's level of burden decreased from 36/48 to 20/48. She was most grateful for the assistance they had received and even though she still had to assist Mr J he was kept busy for long periods of the day with his ADL which gave her time to get on with the housework. She enjoyed the volunteer's company and felt reassured that her husband was safe and happy when she went out for shopping, errands or short visits. This also allowed her some respite from him.

Discussion: The fact that Mr J had not been referred for physiotherapy is a problem that occurs frequently with stroke victims who have not been hospitalised. He could easily have been referred to Heideveld Day Hospital where there was a good outpatient physiotherapy service available. It is possible that had he been referred 4 years earlier his wife would not have had to give up her job and that he would have achieved a greater level of independence. It may have been possible to prevent contractures in his shoulder by receiving advice on how to manage this at home.

The researcher found this regularly with disabled not on the programme when visiting the homes in Manenberg. The disabled were not necessarily disabled to the extent of being bedridden or housebound, but they were walking around the streets with poor walking patterns that could easily have been corrected with teaching and simple walking aids.

This is also a good example of the extent of physical improvement that is possible to achieve even after being disabled and untreated for 4 years.

8.5.11 CASE STUDY NUMBER ELEVEN

Mr L, a 55 year old driver, suffered from 2 strokes 10 years ago and had been bedridden ever since. He had not been hospitalised, but had been given a wheelchair and walking frame by the hospital when attending the outpatient department.

He lived with his wife and adult daughter, both of whom worked. His wife was a machinist and his daughter a shop assistant.

Both wife and daughter left for work at 06h00 and returned at 18h30. They left him with food, a flask of coffee, urine bottle and bedpan at his beside from where he was able to attend to himself during the day. The neighbour had a front door key and she came in to check whether he was in need of anything once or twice during the day. He spent the day watching the ceiling and sometimes reading a magazine.

At the first visit it was very obvious that Mr L's strokes had not been bad and that, had he received any rehabilitation, he would have been capable of being totally independent. He could use both arms equally well and could move his legs independently. However, his hips, knees and ankles had become extremely stiff from disuse in the lying position for 10 years.

Mr L had a very good wheelchair which was used on Sundays when his sons came to visit and they would lift him in and out of it.

Mr L stated that he would like to join the programme so that he could go outside and sit in the sun.

At the first visit he was taught arm strengthening exercises, general body strengthening exercises and exercises to mobilise his legs and trunk so that he could move around the bed. It was obvious that it would take a long time to achieve any improvement due to the length of time that Mr L had been bedridden and so he was given a written programme of exercises to practise and it was agreed that visits would be done once every fortnight.

Mr L obviously worked a great deal by himself because he was very much stronger by the next visit. He was then taught to transfer from his bed to the wheelchair, but as his joints remained very stiff he could not manage it independently and needed a great deal of assistance with his legs as his hips were stuck in an extended position. The neighbour could not manage to assist him with these transfers on her own.

He was encouraged to get dressed every day and was taught how to do this, but it was very difficult for him to get his trousers on as he was unable to bend his hips far enough. However, he was encouraged to persevere until he managed to find an easier means of doing so without incorporating someone else.

The researcher contacted his wife at work and she agreed to stay at home on the day of the next visit as she was unaware that he could do anything for himself and stated that he had become apathetic and fatalistic over the years and had been doing less and less for himself.

At the next visit Mr L demonstrated everything that had been taught to him. The next step would be to get Mr L to be able to transfer to the wheelchair with assistance. He needed a monkey chain fixed to the ceiling above his bed so that he could lift and control his upper body while an assistant lifted his legs onto the chair. Mrs L said that she could arrange for a handyman from the community who could do the adaptation and arranged for him to be there at the next visit.

The monkey chain was erected and Mr L was taught how to transfer to the wheelchair and back into bed and the neighbour and his wife were shown how to assist his legs.

He was getting himself dressed every morning and the neighbour would came in at about eleven o'clock and help him into the chair. He could then propel the chair out the front door and sit in the sun and watch the neighbourhood activity. When he became tired of this he returned inside and watched television or read. His wife assisted him back into bed after she arrived back home from work.

The fact that Mr L could transfer himself in and out of the wheelchair with very little assistance meant that his wife and daughter could take him for walks in the evenings and weekends so that he could be in contact with more people and have a change of environment.

It was not practical to attempt any further rehabilitation with Mr L as his hips and knees would never gain sufficient mobility for him to learn how to get himself in and out of a chair or bath or to manage the outside toilet himself.

Mr L lived very close to the MPC and it was suggested to him that he be wheeled over to the centre one morning a week to join the craft group, but he refused this as he felt that the MPC was politically aligned to the ANC and he would have nothing to do with it.

Mr L's functional level improved from 17/56 to 29/56 and his ability to leave the house improved from "once per week" to "frequently". His wife's burden decreased from 31/48 to 17/48. She mentioned that Mr L was far less apathetic and actually stimulated conversation himself in the evenings in stead of responding to her questions with single word replies.

Discussion: Had Mr L received rehabilitation soon after his strokes it is quite possible that he would have been able to return to some form of employment as he had a reasonable level of education.

The apathy and acceptance that he displayed after 10 years were probably from the isolation and unstimulating life he led. This particular aspect of his personality probably contributed to the fact that he did not become more functionally independent early on even without any rehabilitation as his strokes had obviously been very mild as he was left with no residual muscle spasm and contractures, but rather joint stiffness from lack of use.

The political activity in Manenberg influenced the rehabilitation of many of the participants who perceived the MPC to be an ANC development that encouraged mass action and strikes. They would not attend the craft sessions for this reason as they felt that after every mass action or strike their personal lives had been affected detrimentally by loss of income. Many of them accepted their style of living as their lot that could not be changed and that they simply had to make the best of it.

8.5.12 CASE STUDY NUMBER TWELVE

Mrs M, a 60 year old lady, suffered a stroke affecting her right side 4 years ago. She also suffered from hypertension and diabetes. 4 months ago she had had her right leg amputated just below the knee as she had developed gangrene in her big toe.

Mrs M and her husband shared a 2 bedroomed flat with her daughter, son-in-law and 4 young grandchildren.

She had not attended the physiotherapy outpatient department as she could not afford the transport. In view of her poor circulation and the complication of having no control of the movements of her stump due to the effects of her stroke, the hospital personnel had decided to discharge her with a wheelchair as it was felt that Mrs M would not be able to cope with an artificial limb. She had been taught to walk with crutches in the hospital, but had not done so at home as the space was so confined and she was nervous about trying to do so on her own in case she fell or hurt the stump.

Her son-in-law was unemployed and stayed at home and he physically lifted her from bed to wheelchair and back when needed.

Mrs M was very depressed and her daughter very frustrated. The daughter felt that the mother was lazy and made no effort to do anything and the mother felt depressed as she was made to feel a burden.

On evaluation of her physical condition it was found that there were many things that Mrs M could have been, but was not, doing for herself without any assistance, for example, washing and dressing herself. Some time was spent in counselling the family about their expectations and Mrs M's expectations on what she could and could not do. They all were keen to be taught how to manage Mrs M and how to help her become as independent as possible.

She was shown how to dress and wash herself without assistance. The researcher taught her how to transfer to and from the wheelchair safely by holding onto the dressing table securely. Although she had been walking with crutches in hospital it was an impossible feat to achieve in the flat with the overcrowding of people and furniture. It was decided to request Mr L's walking frame that he had at home and never used.

This was brought to her at the second visit and Mrs M was taught how to use it in the house. She felt very much more secure with it than the crutches and could manage well after a few days practice.

After 5 visits Mrs M became totally independent in the house and was assisting her daughter in the kitchen with the preparation of meals and doing small bits of washing in the bathroom.

When the researcher visited briefly one afternoon about one month later Mrs M was found walking down the road with her walking frame. She apologised for not having time to chat, but said she was off to the Senior's Meeting at one of the Council's Community Centres.

Mrs M's functional level improved from 30/56 to 50/56 and the number of times she was able to leave the home improved from "occasionally" to "frequently". Her daughter's level of burden decreased from 35/48 to 13/48.

Discussion: Home visits done soon after discharge avoid this type of situation where the disabled person is resistant to functioning at the maximum level and the caregivers do not know how much to expect, persuade, encourage or cajole the disabled.

When the home visit is done the caregiver can see exactly what the disabled can do and the disabled know exactly what is expected of them. In this way the caregivers do not resent helping their disabled relative and the disabled do not feel that the caregivers are being unsympathetic by not doing everything for them.

Home visits also overcome the problem of rehabilitation services being inaccessible to the majority of disadvantaged disabled who cannot afford transport costs.

Successful rehabilitation does not only depend on the level of physical disability and the physiotherapists' management, but also on the quality of the social relationships the disabled have with their families and communities. Handicapped people who do not reach their potential functional level place an unnecessary burden on the family and leave the disabled with a feeling of deficiency.

8.6 SUMMARY

This chapter has provided a description of some of the background and lifestyle of severely disabled persons and their families. A summary of the findings will be presented in the next chapter and recommendations for improving the rehabilitation services presently being offered will be made in Chapter Ten.

CHAPTER NINE

CONCLUSION OF DISABLED PERSONS AND CAREGIVER PROGRAMME

9.1 INTRODUCTION

As set out in Chapter One the primary aims of the study were to generate knowledge and insight into the needs of the housebound disabled and their caregivers, to provide them with appropriate rehabilitation and training programmes in order to empower them and to evaluate the effects of the intervention programme. The philosophy underpinning the study was that of community development and community participation.

The programme was effective in rehabilitating the housebound disabled and training their caregivers to manage their relatives themselves. This empowerment increased their capacity to deal with their disabilities themselves and increased the community's awareness of the disabled living amongst them.

As the findings were discussed in detail in Chapter Eight a summary of the major findings will be presented below.

9.2 EFFECTS ON THE FAMILY

Severe disability had a profound effect on the well-being of the disabled person, the caregivers and their families. The disabled relied totally on their families for their very survival. Because of the disabled persons decreased capacity to fulfill their roles it placed additional stresses on the families. This necessitated significant restructuring and changed patterns of communication and interaction within the family.

The programme enabled partial restoration of the family dynamics by increasing the ability of the disabled to perform their roles to the best of their ability and by educating the families to allow and encourage this to take place.

9.3 REHABILITATION OF THE DISABLED

The domiciliary physiotherapy programme was an effective means of providing rehabilitation for the severely disabled people. The level of functional ability of the disabled increased significantly, regardless of the length of time from the onset of disease or injury. This empowerment allowed them to have more control over their own lives and encouraged them to use positive coping mechanisms to deal with their disabilities. Many of the disabled had been using negative coping mechanisms of withdrawal and regression until they started on the programme.

It is important to realise that regardless of how effective the physical improvement was, the rehabilitation of the disabled could not be considered to be complete unless they had returned to some form of employment. But this was not possible in Manenberg due to the low educational level of most of the disabled and the lack of facilities available for sheltered employment or opportunities in the business world.

An essential requirement to achieve holistic rehabilitation for these people was some educational or training centre where they could learn some form of vocation that did not require manual ability. Without the incentive of being able to be meaningfully employed, the motivation to achieve improved physical function or maintain the ability achieved was reduced.

In those cases where physical improvement was not possible the quality of life of the disabled was enhanced by the increased level of understanding that the families acquired. This resulted in the disabled being taken out of the house more frequently and being exposed to more community members by visits from volunteers, church members and their neighbours.

Domiciliary physiotherapy was an effective follow-up system for clients who had recently been discharged from hospital. It prevented deterioration that appeared to occur when there was no form of monitoring and encouragement once they returned home.

In order for the rehabilitation of disabled to be successful, a community multidisciplinary team approach is essential. Members of the team should incorporate doctors, nurses, occupational therapists, speech therapists, social workers, psychologists and community rehabilitation workers. Physiotherapy forms only a part, but integral part of the team.

9.4 CAREGIVERS

The caregivers, many of whom were functionally illiterate, were competent at performing the physiotherapy techniques taught to them. This could be observed by the improvement in functional ability that the disabled demonstrated as the researcher/students only planned the intervention programmes, but the caregivers had to carry out the day-to-day rehabilitation techniques themselves. By being empowered they became self-sufficient in managing the daily rehabilitation and maintenance requirements of their disabled relatives.

The home visit was a means of providing emotional support to the families during the initial period that the disabled was at home after hospitalisation. It assisted them with the day-to-day management of their relatives to ensure that maximum function was achieved early and to ensure that it was maintained.

However, in the researcher's opinion if the programme were to be sustained over a long period of time it would require the input of a community worker to maintain the motivation of both the disabled and their caregivers.

The burden of care that the caregivers suffered was significantly reduced by the training programme ($p<0.0001$). This was brought about by the increased knowledge of their relatives' disabilities as well as the participation of the volunteers and neighbours in assisting them with their chores.

The burden was also relieved by the emotional support provided by the researcher/students and the volunteer assistance.

9.5 STUDENT EDUCATION

The home visits enhanced the students' insight into problems faced by disabled persons in their home environment. This resulted in them having a more holistic approach to client care for both in- and outpatient management.

9.6 PHYSIOTHERAPY

Although transport expenses are eliminated for the clients, when physiotherapy is provided in the community a percentage of the physiotherapists' time is spent in travelling and this reduces the amount of direct client contact. The time lost by travel, however, was gained by the caregivers carrying out the daily rehabilitation with the researcher and students monitoring progress and changing the programme when necessary.

In a country where there are inadequate numbers of physiotherapists to provide intervention services a domiciliary service aimed at incorporating the family and community members is a means of ensuring that the disabled receive some form of rehabilitation and maintenance programmes. This should, however, not be envisaged as an alternative to a community physiotherapy service provided by the state, but as a temporary measure until the necessary community health structures and services are established by a new health policy.

For final rehabilitation of chronically disabled to be achieved home visits provide the physiotherapist with comprehensive knowledge of the environment, family situation and physical adaptation needs of the individual. This cannot be envisaged and planned for from a hospital or outpatient department.

9.7 HEALTH SYSTEM

The health system at the time of the study did not provide adequate health care services for the rehabilitation needs of the severely disabled. There was a big gap as far as rehabilitation services were concerned. The few services that were available were situated in the large hospitals, but were too far from the disadvantaged communities and transport services to reach these facilities were limited and too costly.

Intervention took place inappropriately at the disease level and not where it was most effective, namely, the preventative and promotive level. Many of the stroke victims did not know that it was important for them to control their hypertension to avoid further strokes and several of the participants who suffered from diabetes did not have simple diet sheets to control their blood sugar levels.

There is a need for long term rehabilitative physiotherapy services in the homes of the severely disabled where they are most appropriate. This will avoid the problems of transport costs and reduce the amount of outpatient fees as the families can be incorporated to take over much of the rehabilitation themselves and thus free the physiotherapists so that their services can reach more disabled people.

9.8 COMMUNITY DEVELOPMENT AND COMMUNITY PARTICIPATION

Midgely (1986) claims that community participation is regarded as being a success only when the project is effectively sustained by the community once all external support has been disengaged. However, it is not feasible to expect to achieve this with this study as each disabled person and the caregiver require individually tailored rehabilitation and training programmes specific to their own needs and these can only by formulated in collaboration with and under the guidance of some form of rehabilitation health worker.

Community participation can be measured in terms of the number of people involved as well as the period of time in which they were involved. There was a definite increase in the number of people from the community who became involved with the disabled and caregivers and provided them with assistance when the number of volunteers and neighbours are taken into consideration. By the end of the study the period of time that this included was from 3 to 18 months.

Although it was not possible to measure the actual amount of community development that took place during this study it can be inferred from the amount of physical improvement in the disabled and the reduction in caregiver burden that occurred. These changes were brought about by increasing the capacity of the participants to deal with their individual problems. They also occurred by increased community participation brought about by incorporating the assistance of volunteers and increasing the awareness of the neighbours about the disabled and the burden that their caregivers suffered. Without any knowledge of disability the community previously had not helped the disabled or their families to become integrated in the community.

Community development could also be inferred from the fact that the participants were encouraged to participate in problem-solving for adaptations required in the houses or roles to be altered within the families. Participants were taught how to and encouraged to contact resources themselves, for example, the CTCC and the Community Health Sisters. They were involved in defining their own needs, planning how to solve their problems and executing the plans themselves with some assistance from the researcher/students. This occurred on an individual basis when home visits were done as well as during the Volunteer and HPC meetings.

The development achieved is bound to be sustained given the high degree of involvement which was achieved and the dramatic improvement in the capacity of the disabled persons to function on a day to day basis. The achievements in Manenberg can also be shared by the participants with other communities to snowball into a movement for improving the functioning of disabled in more neighbourhoods, particularly the poorer ones.

It is feasible to predict that the development and problem-solving abilities gained by the empowerment and increased capacity of the disabled and their caregivers could spread to other areas of their lives as the following motto of a staff management training course indicates:

"A mind once stretched by a new idea never regains its original dimensions" (Celebrating Excellence Inc, 1993:1).

CHAPTER TEN

RECOMMENDATIONS

The recommendations that follow in this chapter concern the findings of the first part of the study only. Further recommendations will be presented at the end of the studies on the Volunteer Project and the Student Education Project in Chapters Eleven and Twelve respectively.

10.1 HEALTH SYSTEM

During the reconstruction of the Health System in the Western Cape the various professional bodies involved with rehabilitation should make use of the opportunity to contribute to the planning and development of appropriate rehabilitation services in accordance with the philosophy of the Reconstruction and Development Programme. They would need to include recommendations for the creation of community posts and the provision of training for different levels of health workers.

Medical, physiotherapy, occupational therapy, speech therapy, social work and psychology professions should collaborate and plan an integrated comprehensive rehabilitation service where duplication is avoided.

10.2 PHYSIOTHERAPY EDUCATION

The universities involved with the education and training of physiotherapy students should formulate curricula and provide clinical experience in order to produce graduates that are trained to meet the specific needs of the country.

The basic philosophy of the training should be that of primary health care where students from the various disciplines attend lectures together in community settings. They should also receive adequate exposure to multidisciplinary clinical experiences which prepare them adequately for working in community settings.

Opportunities for students to contribute to the teaching and training of other health workers should also be incorporated in their clinical practice.

10.3 COMMUNITY REHABILITATION WORKERS

South Africa is faced with the problem of a small number of physiotherapists and an increasing population of severely disabled people requiring domiciliary services. Only some of them require specialist help, but there are many that need assistance that could be provided competently by community rehabilitation workers (CRW). The programme conducted in Manenberg is a good example of one that could be sustained by a CRW.

The CRW's would require a much lower level of school education and a much shorter period of training in order to fulfill a most essential service. Training should be structured, but could be provided `on the job' specific to the disabled person's needs.

Having gained the experience of utilising volunteers and the services of a coordinator in this study in Manenberg the researcher recommends that the selection of CRW's be done with utmost care and consideration and that the ideal person is:

* committed to the well-being of severely disabled people
* young, fit and physically capable
* from the community
* respected by the community
* mature, reliable and responsible
* good with interpersonal skills
* familiar with local resources
* sufficiently literate to keep records and basic health statistics
* capable of training caregivers
* in possession of a valid driver's license.

In addition to proficiency in the basic physiotherapy and occupational therapy techniques and skills required to manage the housebound disabled the training should provide the CRW with the skills and knowledge to:

* identify disabled in need of rehabilitation
* know when to consult and refer disabled to a physiotherapist or occupational therapist in order to progress treatment

* recognise situations that are not within the scope of the CRW
* provide emotional support to the disabled and their caregivers.

However, when these CRW's and home services become available the ANC have made it clear that entitlement does not eliminate problems, that the people themselves have to contribute and take responsibility for their own health requirements. The CRW's will not be substitutes for caregivers, but will be able to train the caregivers to take care of their relatives and be a means of emotional support.

10.4 HOME VISITS BY HOSPITAL PHYSIOTHERAPISTS

Until the health system is restructured and comprehensive rehabilitation services are established, home visits could be done by the physiotherapists providing rehabilitation programmes for disabled persons in hospital.

A visit to the homes of the disabled before they are discharged home will allow the physiotherapist to assess the facilities and environment. This will ensure that the appropriate walking aids are prescribed for the disabled and that techniques enabling them to function independently can be tailored to the disabled persons' home requirements.

A further visit should follow shortly after discharge to teach the caregiver how to assist the disabled to function independently as soon as possible, to ensure that the disabled is functioning to maximum capacity and to progress the activities as required.

This will also provide the disabled and the caregivers with emotional support at the time that they most need it.

Periodic visits should follow, if and when necessary, to ensure that the disabled reach their maximum level of function and to ensure that walking aids are returned as soon as they are no longer required.

10.5 THE UTILISATION OF AVAILABLE RESOURCES

There were many non-government organisation facilities within Manenberg which were encountered by chance during the study. These were not utilised maximally as not many participants knew of their existence.

None of the disabled had been referred by the hospitals to any of the organisations operating in the area and yet many of the individuals would have benefited from the facilities which were already established within the community, for example, SHAWCO afternoons for the disabled and the Seniors afternoons held at the CTCC Community Centres.

When disabled are discharged from hospital the physiotherapists should investigate the non-government organisation facilities available in the area and refer the disabled to them.

10.6 THE INTRODUCTION OF A REGISTER FOR SEVERELY DISABLED

A register should be introduced of all disabled who are bedbound or housebound in order to determine the extent of domiciliary services required.

This could easily be initiated by the hospitals when discharging disabled after the onset of injury or disease; day hospitals and hospital outpatient departments when they are seen for follow-up visits; and community nursing sisters who have contact with them during their home visits.

Domiciliary visits could then be planned according to districts so that rehabilitation staff have the minimal waste of time when traveling and transport costs can be reduced.

10.7 FORMATION OF HEALTH CARE COMMITTEES

Other communities should also consider the formation of their own Health Care Committees as was done in Manenberg.

10.8 USING THIS STUDY AS A MODEL IN OTHER POORER COMMUNITIES

This study could be used as a model for physiotherapists to initiate rehabilitation programmes in other poorer communities even though they might not have their own Health Project Committees. Names of disabled can easily be obtained from outpatient registers of the local hospitals and Health Care Centres. Once in a community further names will be obtained by snowballing.

By training the caregivers in the physiotherapy management of their relatives they will be empowered to ensure that the disabled reach their maximum level of rehabilitation and will then be capable of maintaining this level of function.

By utilising the caregivers in the physiotherapy management of severely disabled people it will allow physiotherapists to reach more disabled in need of rehabilitation.

CHAPTER ELEVEN

VOLUNTEER PROJECT: AN INVESTIGATION INTO THE EFFECTIVENESS OF UTILISING VOLUNTEERS TO REDUCE CAREGIVER BURDEN IN FAMILIES WITH HOUSEBOUND PHYSICALLY DISABLED RELATIVES

11.1 INTRODUCTION

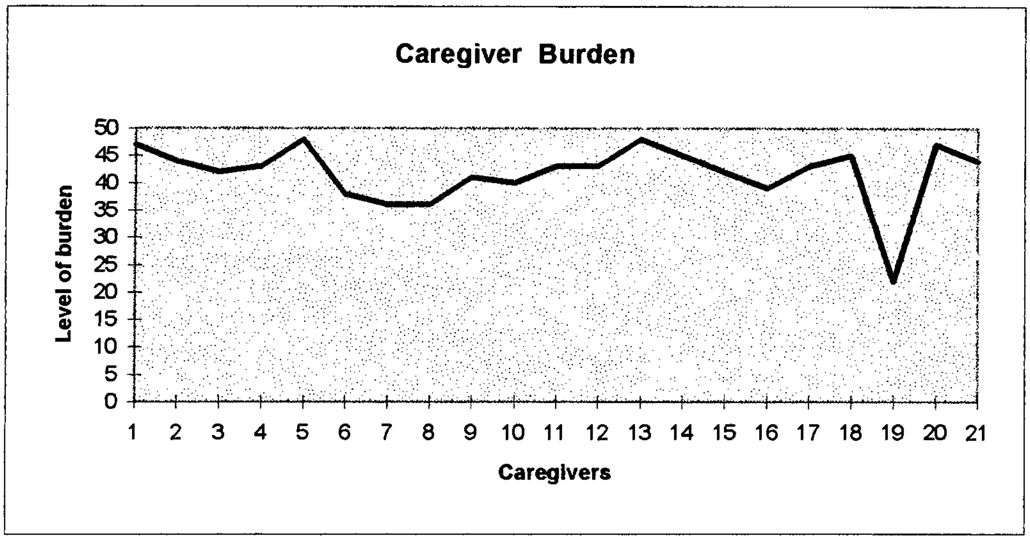


Figure 47: Caregiver level of burden before programme

21 (42%) of the caregivers in Project 1 were found to be suffering from high levels of stress (Figure 47) and were regarded as being unable to cope with their disabled relatives. This was based on statements made by the caregivers themselves verbalising the need for assistance. It was also made by the researcher's/students' observation that the constant demands on the caregiver had led to the disabled receiving inadequate attention and being neglected and that they were simply confined to their beds or homes. (Stokes, 1977:350) sums up the caregivers' predicament in his statement "Overwork, poverty, severe social tensions and sheer exhaustion can make caregiver involvement a demanding proposition in developing countries".

As there was no means of support provided by the state the Health Project Committee (HPC) decided to develop a volunteer system utilising unemployed community members to address the problem. This would incorporate community participation and would be a means of making more community members aware of the plight of the disabled.

Because of improved medical technology the number of disabled persons was increasing and their disabilities were becoming more severe and complex. Their access to money and specialised rehabilitation facilities were inadequate and at the same time the demand for them was increasing. Therefore, volunteers were seen to be a resource that could be utilised effectively as a solution to the caregivers' problems, especially as the envisaged workload would amount to only that which could be achieved in the spare time of the volunteer, but would contribute considerably to improving the quality of life of the caregiver.

Volunteer projects in Nigeria (Ogunkoya, 1982), St. Lucia (Miles, 1982), Botswana and Zimbabwe (Levy and Nyathi, 1984) set up by community-based rehabilitation workers all report difficulties in obtaining able-bodied people with time to spare to participate in assisting with disabled persons in their homes as most family members were employed during the daytime. However, this was not found in Manenberg due to the economic situation of the community and associated high unemployment rate at the time of this study.

11.2 AIM OF THE STUDY

The aim of this part of the programme was to investigate the effectiveness of utilising volunteers to reduce caregiver burden in families with housebound physically disabled relatives.

11.3 OBJECTIVES OF STUDY

11.3.1 To describe the volunteers and types of participation.

11.3.2 To identify the factors that need to be taken into consideration when selecting and training volunteers to assist specific caregivers with their disabled relatives.

11.3.3 To describe how the programme affected the lives of the caregivers and their disabled relatives.

11.3.4 To measure and compare the level of caregiver burden before and after the project.

11.4 ASSUMPTIONS

11.4.1 The people in the community possessed the capacity to be educated and trained in the management of the disabled and support for the caregivers.

11.4.2 A spirit of goodwill and altruism existed in the community whereby there would be support for the disabled and their caregivers.

11.4.3 The volunteers would answer the questions both accurately and honestly.

11.5 VOLUNTEERISM

A volunteer is a person who donates time, expertise or skills for the benefit of others without receiving financial reimbursement. The volunteer has a definite interest in the cause and derives pleasure from serving less fortunate fellow beings with a service. Meaningful relationships are formed with the people they serve and their altruistic needs, often based on religious convictions, are met. Motivation is maintained if the volunteer is clear about the expectations of the tasks, finds these tasks challenging and sees progress being made towards goals that have been set (SANCMH, 1989).

The volunteer learns and develops skills facilitating personal growth in self-confidence by receiving training in essential skills of problem-solving, planning and evaluation. Thus the philosophy of development is a significant prerequisite for volunteer training to ensure understanding, responsibility and commitment in order for participation to take place (Swanepoel, 1989:41). To recruit and sustain services, volunteers need to find their experiences positive and rewarding (Versluys, 1986:57).

Surveys conducted in Washington DC indicate that 1.0% of the caregivers of the working-age disabled population needed some help and that almost all of them needed assistance on a regular basis (Thorncock, 1978:152).

Some approaches of volunteerism focus on providing assistance to the disabled while others emphasise improving the quality of the caregivers' life by providing them with support and assistance (Graham and Jones, 1992; Hardy and Cull, 1973; Versluys, 1986).

In the United Kingdom untrained volunteers have been employed to extend state services with clients contributing small payments towards this additional help. Literature reveals a national trend in this country towards additional help and towards encouraging a life of independence for even the most severely physically disabled by increasing home care supports (Gloag, 1985; Thorncock, 1978).

Chinese families with handicapped relatives were given assistance in the form of home help and day care in order to reduce the burden of care and to prevent the family from becoming isolated (Dixon, 1981).

In South Africa as long ago as 1975 Runnalls (1975) stated that there was a need to train people in physiotherapy skills in order for them to serve as volunteers. This concept was supported by Shirley (1979) who emphasised that by getting the community to help themselves was not to be envisaged as a cheap alternative to replacing professional workers, but was a means of providing a service that would always be insufficient when provided by the professionals due to the extent of the demand. No literature is available on further local research carried out following these recommendations.

11.6 IMPLEMENTATION OBJECTIVES

11.6.1 To train volunteers to perform basic physiotherapy techniques to maintain the physical state of the disabled.

11.6.2 To provide some means of support for the volunteers.

11.6.3 To make more community members aware of the plight of the disabled and the burden of their caregivers.

11.6.4 To foster community participation by teaching volunteers to assist the caregivers, when and where necessary.

11.6.5 To promote empowerment and capacity building by teaching the volunteers how to manage the severely disabled.

11.7 METHODOLOGY

35 volunteers were recruited and consented to participate in the study. 14 of them were obtained by contact with local

church and Mosque groups and by advertisements in community centres. 21 were neighbours nominated by the caregivers themselves as people whom they could trust and whom they would welcome in their homes. Volunteers were considered to be "neighbours" if they lived in the same block of flats or the block of flats immediately opposite the courtyard adjoining the two locks of flats. None of the caregivers living in houses required volunteer assistance.

A meeting was held for all volunteers. The objectives of the project were explained to ensure that everybody was familiar with what the service would entail. This included a commitment of 2 regular 2-hour visits per week when they would be required to assist the disabled persons with bed baths, dressing, feeding, basic physiotherapy techniques and to provide companionship. Volunteers who could not attend the meeting were oriented by the researcher or students at the time of the first home visit.

Volunteers from the church group were matched to the caregivers and disabled according to religious affiliation, distance between their respective homes, nature of assistance required and willingness of volunteers with regard to the specific tasks required of them.

Home visits to the caregivers and their disabled were done by the researcher/students and volunteer together. The volunteers were given a brief explanation of the condition of the disabled and the specific physiotherapy tasks required of them. These techniques were demonstrated on the disabled by the physiotherapist. To reinforce this newly acquired knowledge the volunteers then demonstrated the physiotherapy skills learned so that their techniques could be corrected. Thus all training of volunteers was done on an highly individualised basis. In addition to the physiotherapy skills the volunteers from the church group were taught basic nursing techniques by a community nurse. Each volunteer was given a diary to record the date, time spent and type of assistance given at each visit.

Follow-up home visits took place for 6 months to consolidate the volunteers' understanding, refine physiotherapy techniques performed and assist with problem-solving to overcome any special difficulties experienced with the disabled persons in their specific situations. Initially these were done weekly and later reduced to monthly as the volunteer became more familiar with the expectations and techniques. This form of participatory training was regarded as an important means of capacity building. During this time any potential problems of the caregiver and volunteer having different assumptions about the nature of the service were dealt with by the researcher/students.

When volunteers from the church group withdrew from the programme (reasons for this will be discussed in 11.8.3) they were replaced by neighbourhood volunteers nominated by the caregivers.

Subsequent monthly meetings of all volunteers and members of the HPC took place at the MPC. The object of these was to provide support and educational input as identified by the volunteers themselves and to establish a sense of teamwork. It allowed an opportunity for discussion and sharing of experience and knowledge gained during their home visits. Topics discussed included coping with depression, issues of religious beliefs, looking after disabled people and how to deal with local authorities in order to have minor adjustments made to the homes for ease of managing the disabled persons in wheelchairs. Special needs of the disabled or caregivers were also discussed. For example, one of the mothers desperately needed a wheelchair for her son who had outgrown his pushchair. After discussion the group decided to place a feature in the local newspaper and ask for assistance from the public. This was done and the public responded by donating one new wheelchair and five used wheelchairs. It was decided to hire out the remaining five wheelchairs to other needy disabled at a nominal rental.

After 3 meetings had taken place a coordinator was elected by the group. She was taught how to set an agenda, conduct a meeting and how to coordinate the volunteers and encourage them to continue with their work. She also oriented new volunteers who joined the project and those who replaced those lost through attrition. As the majority of the volunteers had a very low level of education the researcher offered to take the minutes of each meeting. An example of a typical meeting is presented in Appendix (vii).

After eighteen months the caregivers, disabled and volunteers were interviewed to evaluate the programme (Appendices iii, iv and viii). For ethical reasons the volunteers were interviewed at different venues from the caregivers and disabled.

11.8 RESULTS AND DISCUSSION

As set out in 11.3 the aims of this part of the programme were to describe the volunteers, to identify factors that need to be considered when selecting and training volunteers to assist caregivers with their disabled relatives, to describe how the programme affected the lives of the participants and to measure and compare the level of caregiver burden before and after the project.

Religious affiliation proved to be an important factor in matching volunteers and caregivers. Caregivers from the Muslim faith often did not wish to have volunteers from a Christian denomination in their homes and vice versa. There were only 2 volunteers of the Muslim faith, but there were objections to both of their first placements. They were then matched to caregivers from their own faith.

11.8.1 CAREGIVERS

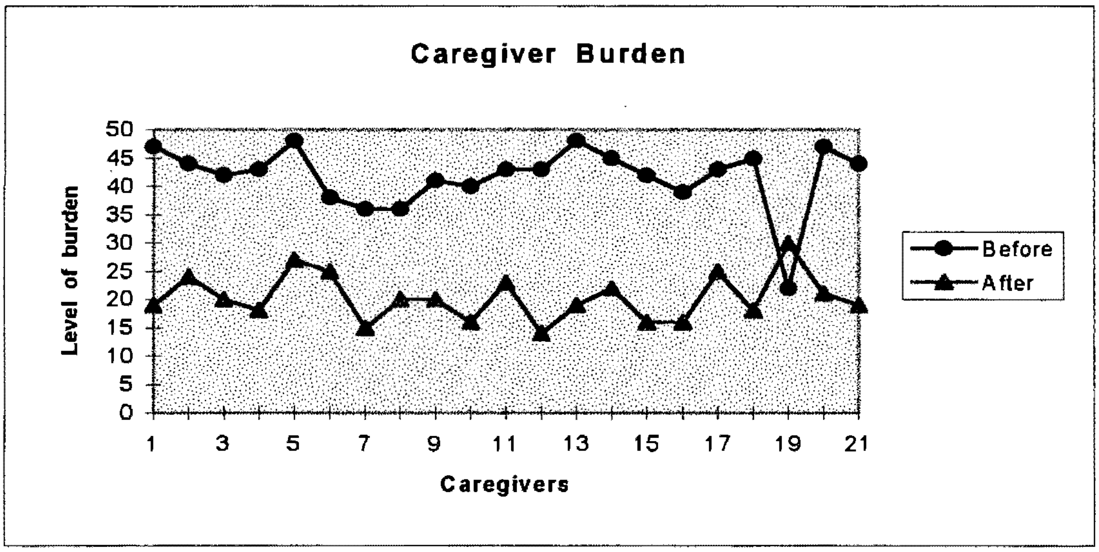


Figure 48: Caregiver burden before and after volunteer programme

Wilcoxon's signed rank test was performed on the levels of caregiver burden before and after the programme. These scores were obtained from Interviews A and B (Appendices iii and iv). Caregiver burden was significantly reduced by the end of 6 months (p<0.0001)(Figure 48) even though the improvement of function in their disabled relatives was not marked (Figure 49). As can be seen from the graph Disabled Numbers 1 to 6 showed no improvement whatsoever and apart from Disabled Number 5 the functional scores of the remaining disabled persons remained very low even at the end of the programme.

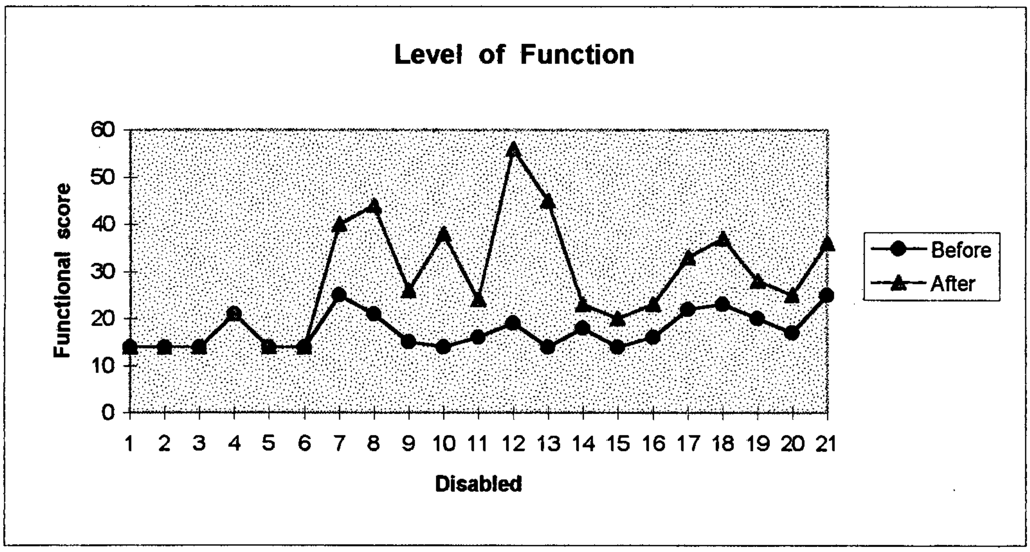


Figure 49: Level of function before and after volunteer programme

The caregivers rating of the assistance provided by the volunteers is shown in Figure (50).

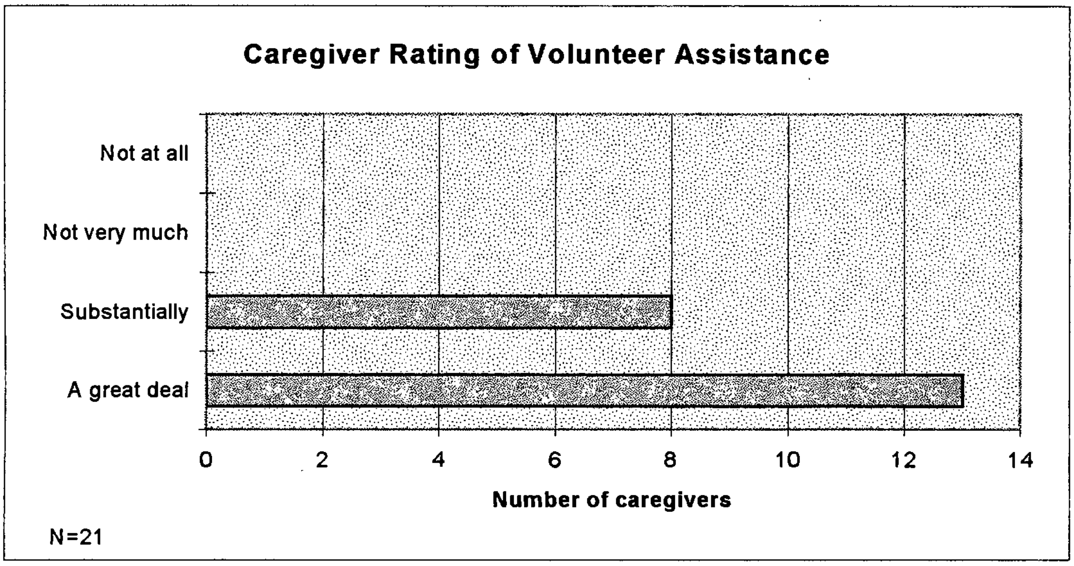


Figure 50: Evaluation of volunteer assistance by the caregivers

The following are some quotes from the caregivers expressing the different ways in which they found the volunteers helpful:

a) "I am able to have some free time to do what I want to do".

b) "It is very helpful to have somebody to help me to lift him in and out of the bed otherwise he has to stay in bed all day long as I cannot lift him by myself and my children are too small to help".

c) I was able to get on with housework when the volunteer came".

d) "While she was sitting with my wife I was able to get out and do shopping or see some friends down the road".

e) "It gave me a break from my husband because he gets very frustrated and this gets on my nerves".

f) "I used to get so tired and stressed when I had to care for him alone. Now I feel somebody else is interested and I feel much better".

g) "I could go out when the volunteer came and not worry about what he was going to get up to without anybody watching him".

h) "She is so kind and we have become good friends. She even does shopping for me and pays the rent and water accounts when I can't get out".

i) "My job is much lighter as it is easier for me to get my mother up and about now.

j) "When she comes it is such a help, but it is a pity she can't come more often".

k) "I don't feel so tired and depressed now as I have help with the work and companionship. Before I never used to talk to anybody during the day until the rest of the family came home".

l) "At least I can get on with the housework without being interrupted all the time now". (The caregiver had poliomyelitis as a child resulting in a deformity of her arm).

m) "I am able to get out and have a break from the house and my husband. I haven't been able to do anything since my husband had his stroke two years ago".

n) "The companionship is very important to me and we also share Bible reading which I miss very much since I can't go to church anymore and leave my mother alone without any help".

The only negative criticism of the project, which was voiced by 8 of the caregivers, was that they would have liked to have had volunteer assistance more frequently than twice per week.

11.8.2 EVALUATION BY THE DISABLED

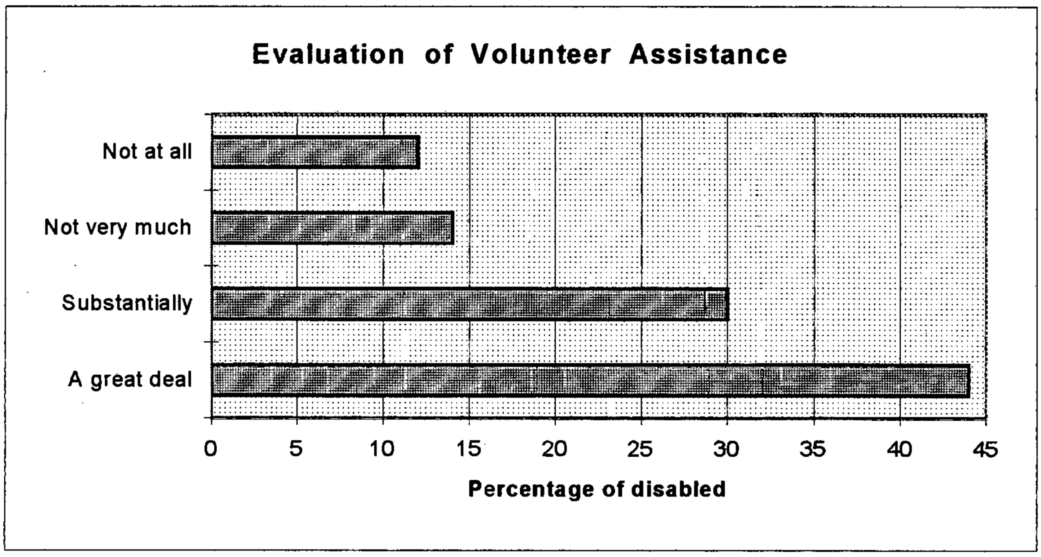


Figure 51: Evaluation of volunteer assistance by the disabled

Figure (51) reflects how the disabled evaluated the volunteer assistance they received.

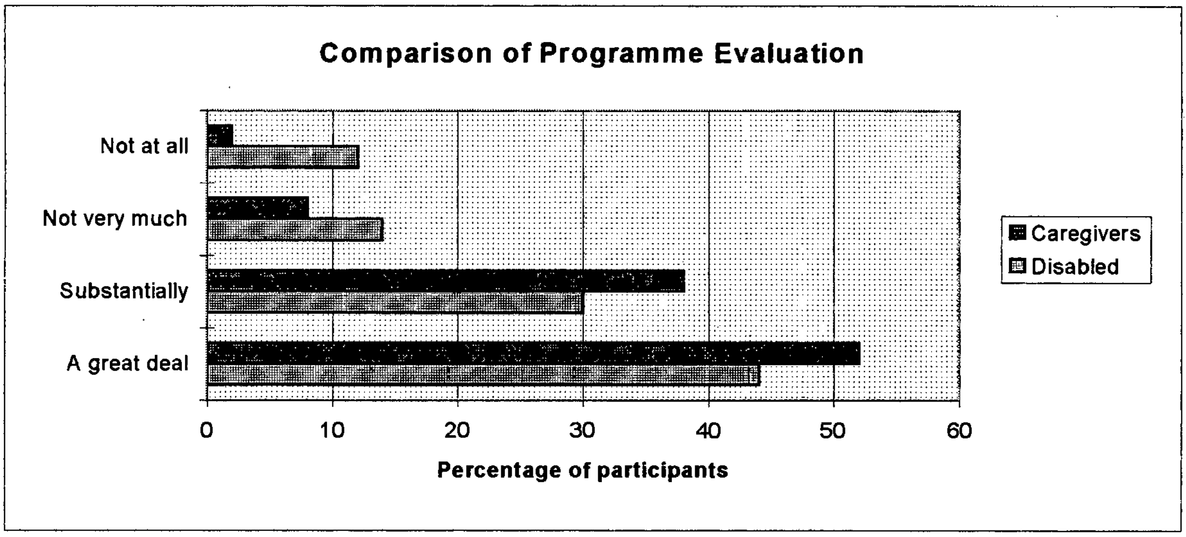


Figure 52: Comparison of caregiver and disabled evaluations of volunteer assistance

The disabled persons did not rate the assistance from the volunteers as positively as the caregivers did (Figure 52).

This may be because the disabled were isolated from the functioning of the family and played such a passive role within the family. Most of them appeared to be completely unaware of the additional work involved in their care and seemed to think that it was an acceptable expectation of their caregivers. This was particularly so in the situations where the disabled were males and the caregivers were females.

As discussed previously, two of the disabled did not feel comfortable with the volunteers assisting them with their bathing, dressing and exercises. They did, however, appreciate their caregivers been relieved of other household responsibilities while they received the care they needed.

All of the disabled commented on their enjoyment of the companionship provided by the volunteer visits. Random quotes are provided below.

a) "It was very important for me to have a friend because my heart was getting very heavy from being so lonely".

b) "I was so happy just to have someone to talk to during the day. I'm alone all day while my family goes to work and I can only lie and look at the ceiling".

c) "I felt pushed aside by my family because they were always too busy to spend time with me, but now there is someone that knows what I need to have".

d) "The volunteer has helped my loneliness and given me moral support. We share Bible reading with her and my wife".

e) "When the volunteer does my exercises then my wife can have a bit of a break. I feel so sorry for her because I'm supposed to look after her and now she has to do all the work and we only have the disability pension which makes life very hard for all of us".

f) "It was good to have someone to chat to; otherwise I never see anybody different".

g) "The volunteer was wonderful - she opened my eyes and let me see that life was not so bad after all. I felt that if she was so good to visit me then I could make an effort to try and help myself more".

11.8.3 VOLUNTEERS

There were 33 female and only 2 male volunteers despite the unemployment rate at the time of the study. Although 4 of the caregivers were males it appears that the men did not regard the volunteer service as part of the male role even though it involved very heavy physical work.

Many of the volunteers were not sufficiently literate to keep adequate written records in their diaries, but were competent at and reliable in carrying out the basic physiotherapy skills required of them.

Of the 21 volunteers who started with the project 14 were lost through attrition and were replaced during the first 9 months. The Health Group of the Institute of Development Studies (1981) in its research also found that after initial enthusiasm volunteer work flagged and rationalised the reason for this being loss of motivation after the skills needed for the task had been learned and the work became routine. In this study, however, the reasons for the difference in commitment appear to be related to age of the volunteer and the distance from the caregiver.

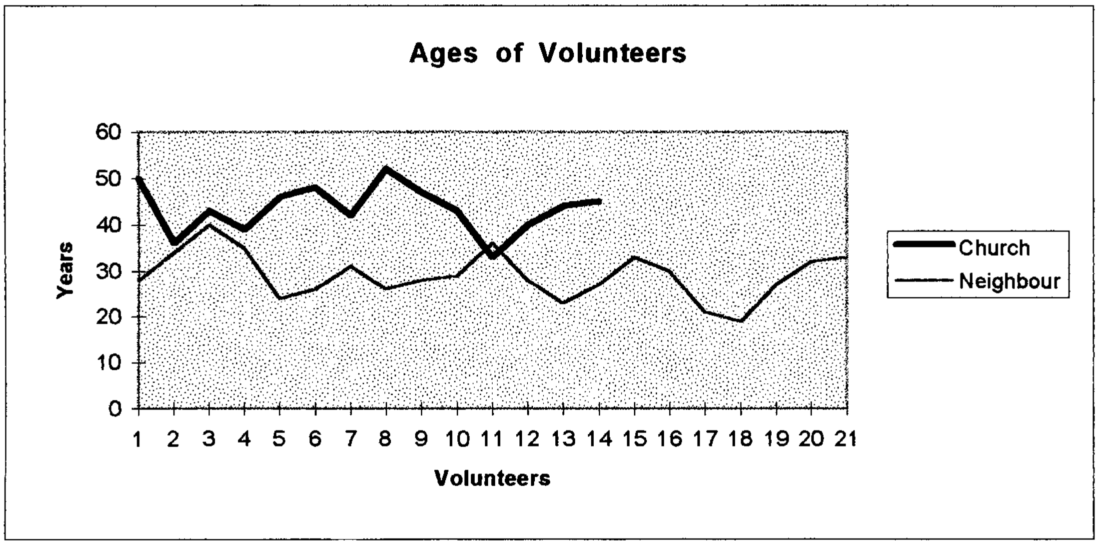


Figure 53: Ages of volunteers

The Mann-Whitney U test showed that the volunteers from the church group (mean 43 years) were found to be significantly older ($p<0.0001$) than the group comprising neighbours (mean 29 years). Attrition occurred only within the older group.

Spearman's rank test performed showed that commitment to the programme was found to be inversely related to the age of the volunteer ($\rho=-0.72$). Although the older volunteers had grown-up children and therefore had more time on their hands to do volunteer work, the nature of the heavy physical work required for this project appeared to be too demanding of the older volunteers. Younger physically fit persons were able to cope more easily.

As stated previously, all volunteers living in the same block of flats or in the blocks immediately opposite the adjoining courtyard of the caregivers were consider to be part of the "neighbour" group of volunteers. Those from the church group lived anywhere from one street block to 2 kilometres away from the caregivers. The distance between volunteer and caregiver was also found to be inversely related to commitment to the project ($\rho=-0.57$). Spearman's rank correlation test was applied to the data obtained from Appendices (iv) and (viii). Although no volunteer lived further than 2 kilometres from the respective caregiver this aspect became an important factor when providing a regular service twice per week as no volunteers possessed their own transport and walking to and from the caregiver sometimes amounted to an additional hour per visit. Again attrition occurred only amongst the church group of volunteers.

Although this was not in the scope of the study and was not established objectively it became apparent to the researcher by means of observation that the volunteers from the church group lived on the periphery of the suburb which is a more affluent area than the central area where the neighbours of the caregivers lived. Thus social class differences may also have accounted for the flagging interest and commitment.

None of the neighbour volunteer group withdrew over the 18 month period. This strong commitment to assist needy neighbours confirms Fitzgerald's (1980:4) findings that "a strong, though dormant, preparedness to give voluntary service exists among the Coloured people". The Health Group of the Institute of Development Studies (1981) also found that it was not unusual for people from the community to commit themselves willingly and reliably to serve voluntarily as health workers.

On the whole volunteers adhered to the original request of providing assistance twice per week, but the amount of time spent at each visit varied a great deal. It seemed to depend on what the caregivers' needs were for the particular day and the time volunteers had at their disposal for that particular day.

Only one of the volunteers described her relationship with the disabled as unpleasant and she withdrew from the project. It appeared that she was unable to accept the values of the family and their style of living, namely, a considerable abuse of alcohol on weekends. The remainder of the volunteers all described their relationships with the disabled and the caregivers as "good".

They all expressed the view that the project was "good" as it "helped other people whose lives were so hard".

When asked how they felt that the project could be improved there were no suggestions. Everyone appeared to be quite content with continuing as they were doing. This, however, only reflects the views of those who remained in the project. Some of those lost through attrition and were able to be contacted thought that transport should be provided and 2 thought that they should receive some form of remuneration. Others reported that they did not enjoy entering the homes of "those types of people" intimating that they were of an inferior social class to that of the volunteer. They frequently spoke in terms of "they" and "we" as though they considered themselves to belong to a different community.

11.8.4 PHYSIOTHERAPY SKILLS

Tasks that the majority of volunteers required to know were passive movements, skin care, assisted walking, lifting of disabled from bed to wheelchair and from wheelchair back to bed.

Most volunteers were found to be very flexible and assisted the caregivers with small household chores and shopping errands when possible in addition to their physiotherapy needs. In 2 cases the disabled preferred not to be bathed or have their passive movements done by the volunteer. These volunteers happily took over the household chores to relieve the caregivers of these tasks and give them the opportunity of carrying out the basic personal hygiene tasks and physiotherapy maintenance programmes for the disabled persons.

The follow-up visits demonstrated that the volunteers were competent at their skills, but the researcher gained the impression that in order to maintain motivation over a prolonged period of time for these routine skills they would need, either to be supported by highly motivated health staff on an ongoing basis or to receive some form of remuneration.

11.8.5 MONTHLY MEETINGS

16 of the volunteers preferred not to attend the monthly meetings. They did not appear to require the support that was initially thought to be necessary for them. They also seemed to be reluctant to take part in meetings as most of them were functionally illiterate and felt inferior and inadequate about making any worthwhile contribution in spite of being reassured that any contribution able to be shared would be meaningful to other members of the group, particularly to the researcher. The reasons they gave for their lack of attendance were family commitments and time constraints. Midgely (1986) confirms this finding by stating that ordinary people have many other commitments and that it is erroneous to think that the poor have an excess of free time on their hands.

For the first 3 months approximately 15 members attended the meetings regularly and then the numbers fluctuated between 7 and 12 per meeting until the group decided to come to an end after 12 months. Biddle in (Fitzgerald, 1980:69) with reference to this phenomenon has the following to say: "Throughout the process, the encourager (worker) will be wise to realise that development is often painful before it is triumphant", and maintains that the phenomenon is normal and desirable provided the members themselves desire it. However, at this time the level of gangster activity was particularly high and the meetings could only take place during the afternoons when rival gang fights took place and innocent residents were frequently caught in the crossfire. The volunteers often expressed their fears about walking to and from the meetings because of their personal safety.

Even though the meetings were discontinued the coordinator continued with her task of visiting the disabled on the programme until volunteer replacements from the neigbourhood were found. She continued attending the monthly HPC meetings and became an important liaison link between the researcher and caregivers once they had completed the rehabilitation and training programmes.

11.9 CONCLUSION

As the findings were discussed in detail in 11.8 a summary of the findings will be presented before recommendations are made in section 11.10.

Caregiver burden associated with the responsibility of caring for severely disabled relatives can effectively be reduced by utilising volunteers where the state provides no service. Neighbours appear to be more reliable volunteers than those living further afield in a community where there is no private transport and costs are a significant factor. Volunteers having to go by foot any distance to provide services do not necessarily have the additional time that this walking demands. In situations where heavy physical work is required, younger volunteers are more likely to be willing and able to cope with the type of physiotherapy tasks required with the maintenance of severely disabled persons.

Utilising neighbours who have been nominated by the caregivers themselves as volunteers avoids the religious, social and cultural barriers that could face volunteers unknown to the caregivers. As they also tend to be of the same social class they can offer companionship rather than just the service.

From the findings, it can be inferred that a certain amount of community participation took place. 35 volunteers from the community, who would not have been involved otherwise, participated in the project. They were empowered to the extent that their capacity for dealing with the disabled and supporting the caregivers increased as a direct result of the training they received. The decrease in caregiver burden reflects that their participation was successful. Their ability to perform basic physiotherapy techniques effectively was confirmed by observation by the researcher and students. Thus it can be inferred from these findings that community development must have occurred to a certain extent.

11.10 RECOMMENDATIONS

In view of the fact that unemployment in this area is so high, income level is extremely low and that there are no permanent health workers employed in the community to provide support and motivation, the researcher recommends that the coordinator and volunteers be paid an honorarium for the tasks performed in order to motivate them to sustain their commitment. This recommendation was put forward to the HPC and overseas funding for this was in the process of being sought, but had not yet been found by the completion of this study.

The HPC should use its networking with other communities through the MPC to share the experiences of this project for purposes of replicating it elsewhere to have broader impact on poorer communities in the Western Cape.

CHAPTER TWELVE

STUDENT PROJECT: TO DETERMINE WHETHER FINAL YEAR PHYSIOTHERAPY STUDENTS AT THE UNIVERSITY OF CAPE TOWN WERE ADEQUATELY PREPARED BY THEIR COMMUNITY PHYSIOTHERAPY COURSE TO COMPETENTLY MANAGE PHYSICALLY DISABLED PERSONS IN A DOMICILIARY SETTING

12.1 INTRODUCTION

It is more cost-effective for intervention of most diseases to occur at their origins than at the stage when curative measures have to be taken. In other words prevention is cheaper than cure and this is the way that education and training of health personnel should take place without minimising the importance of the conventional clinical roles and education (Ritchie, 1994:148).

Clinical education in South Africa has traditionally taken place in hospital settings. With the envisaged essential changes in the health system and therefore delivery of physiotherapy services, increasing numbers of physiotherapists will need to work in the community setting. Parry (1983) and Showstack (1992) state that medical education cannot be separated from the health services of the country and that it should be geared towards the needs of the health system.

The Physiotherapy Department at the University of Cape Town had become increasingly aware of the shortcomings regarding the education and clinical experience of its students within the community at approximately the same time that the HCP committee requested assistance with its programme for the physically disabled.

It became obvious that the aims of the Manenberg community and the needs of the students' curriculum could both be met by establishing a domiciliary physiotherapy programme whereby the disabled could receive rehabilitation and the caregivers could be trained in dealing with their disabled relatives. At the same time the students could gain experience in the community by training and educating the disabled and their caregivers within their social and living environments.

12.2 PHYSIOTHERAPY UNDERGRADUATE TRAINING

Physiotherapy education has traditionally been based on that of the United Kingdom and has been geared toward curative high-technology techniques carried out in tertiary hospitals. These hospitals have been considered to be islands of excellence which encourage specialisation and private practice. This has lead to, in part, the relatively high emigration rate amongst young graduates from South Africa (Lazarus, 1988:35).

Several physiotherapists have, over the years, written editorials and articles regarding the inadequate undergraduate education and training for preparing students to meet the needs of the communities (Davids, 1984:3; Glattaar, 1984; Showstack, 1992). Alt and Basset (1992) found that all physiotherapy student projects carried out in the communities had recommended that their undergraduate programmes contain an increased amount of and exposure to community physiotherapy.

Education and training of health professionals involves service to the community and in order for it to be relevant to the health needs of the communities, students should be exposed to these in real-life situations and not within the walls of academic institutions (Glattaar, 1984; Kock-Weser, 1987; Lazarus, 1988:40; Philpott, 1988:9). Graves (1993:153) went so far as to suggest that it may be appropriate for students to gain experience in community settings before having placements in a hospital to encourage them to develop a community perspective. It allows the student to understand the people's lifestyles and living conditions and the social, cultural, economic, political and ecological factors that influence the health of the individual (Ritchie, 1994:148; Lancet, 1994:613).

Several medical schools have successfully altered their curricula towards community-oriented primary care in Central America, Mexico, Nicaragua, Costa Rica and Australia (Braveman, 1987; Hamilton, 1988; Kock-Weser, 1987).

The profession has debated the fact that should more black students be selected from peri-urban and rural areas it would increase the likelihood of more physiotherapists returning home to work in underserved and underprivileged communities. Although the researcher is aware that selection criteria for physiotherapy students have been biased towards middle class white scholars this matter has been addressed by the Medical Faculty and an extended development programme has been established to increase the number of black students. However, this is not seen to be an answer to providing more undergraduates interested in community work. Experience has shown that, Zimbabwean physiotherapy graduates also have a high rate of emigration to the United Kingdom and United

States of America. This issue is, however, beyond the scope of this project.

12.3 AIM OF THE STUDY

The aim of the study was to establish whether final year physiotherapy students could manage physically disabled persons competently in a domiciliary setting.

12.4 OBJECTIVES OF THE STUDY

12.4.1 To identify topics that had previously been omitted and that needed to be included in the Community Physiotherapy curriculum.

12.4.2 To evaluate the students' ability to manage disabled persons competently in a domiciliary setting.

12.4.3 To identify methods of improving the present method of clinical placements to incorporate community physiotherapy.

12.5 ASSUMPTION

Final year physiotherapy students working under close supervision, would have the necessary clinical expertise to conduct an accurate assessment of the participants and the environment and to provide an effective rehabilitation programme for them. This would involve teaching the caregivers and volunteers handling skills.

12.6 IMPLEMENTATION OBJECTIVES

12.6.1 To provide physiotherapy students with community-based experience oriented toward growth and development of the disabled and their families in the community.

12.6.2 To give the students the opportunity of learning about the general social and environmental problems experienced in poorer communities from the residents and the people employed at the MPC.

12.6.3 To expose the students to the social and cultural environment of their clients and the impact that these factors have on health.

12.6.4 To allow the students to study the progress of disabled persons within their home environment.

12.6.5 To provide the students with the opportunity of assessing the needs of the disabled and their caregivers in their social and home environment.

12.6.6 To provide the students with the opportunity of educating and training caregivers and other auxiliary personnel.

12.6.7 To allow the students to participate in the evaluation of the programme and to make suggestions regarding possible improvements.

12.7 METHODOLOGY

12.7.1 PREPARATION FOR CLINICAL PLACEMENT

In order to meet the needs and demands of the Manenberg community a course entitled "Health Sciences: Community Medicine" was set up by the researcher in conjunction with the head of department in 1992. This course (see Appendix ix for course outline and requirements), comprised largely of workshops, was obligatory for third year students to complete before being allowed into their final year when they would be involved in the project.

One of the workshops was conducted by the coordinator of the MPC in the MPC building itself. He presented a detailed community profile of Manenberg and then arranged for members of the Advice Office to take the class, in groups of five, to visit and meet various residents in their homes in the community. This was done to expose the students to the living conditions of the people with whom they would be working during their final year. Afterwards the coordinator answered questions and a discussion took place on how the living conditions were impacting on the health of residents.

12.7.2 CLINICAL PLACEMENT

40 final year students were involved in the programme over a period of 2 years. Each 4 week period 2 students spent 4 hours per morning in Manenberg.

On the first morning of each block the students spent an hour with the researcher. During this time the aims of the project were explained. Students were given the learning objectives (Appendix x) of the block and this was discussed step by step for clarification to avoid any doubts or misunderstandings. Interviews A and B (Appendices iii and iv) were explained and discussed in relation to the programme aims and needs of the disabled and their caregivers. This process ensured understanding and improved the reliability of the structured interviews.

The researcher repeatedly warned the students at these meetings that they should only go into Manenberg during the mornings and that if at any time they felt their personal safety was being threatened by the gangsters, they were to leave the area immediately.

The students were given a list of names of disabled and their caregivers who were presently on the programme and needed further physiotherapy management and they proceeded to carry out the home visits. Initially they were accompanied by a member of the Advice Office, but once they were familiar with the area and addresses they went independently.

When new referrals were left at the MPC the researcher accompanied the students and role-modeled the interview so that they could become familiar with the depth of questioning that was required of the open-ended questions.

Supervision by the researcher or a clinical supervisor took place once a week in the homes to ensure that the disabled and their relatives were receiving the best possible rehabilitation and education and to progress treatments or make suggestions that the students needed to carry out.

Weekly meetings between the researcher and students continued throughout the block to check physiotherapy records, follow up treatment programmes and discuss unfamiliar problems that the students were facing in the community itself. These included interference by gangsters, substance abuse by family members caring for the disabled and discontinued electricity and water services due to nonpayment of bills.

Students were encouraged to attend the monthly HCP meetings as well as the monthly volunteer group meetings.

At the end of the block each student completed an evaluation of the block anonymously (Appendix xi) and the researcher and clinical supervisor completed a clinical evaluation form for each student (Appendix xii).

12.8 FINDINGS

12.8.1 STUDENT EVALUATION OF BLOCK

The findings will be presented in numerical order according to the Student Block Evaluation (Appendix xi).

1. All the students rated the block as being beneficial. Only one student stated that the block was beneficial, but not enjoyable.

Most of them described the block as a good learning experience because it was the first time that they had been exposed to the living conditions of clients they had been treating regularly in the local hospitals. They described how this experience would change their future treatment plans and home programmes they devised for inpatients as they could see, for the first time, how frequently these had been inappropriate in the past.

The importance of teaching the caregivers became obvious. Although the students had always been taught to do so in lectures they had not experienced the importance of ensuring that the caregivers were educated about the conditions of their relatives and why it was essential for them to perform the maintenance programmes. It also became obvious to the students that so-called `non-compliance' with home programmes taught in hospital was because the caregivers and disabled could not adapt the programmes carried out in the hospital environment to their living conditions rather than ignoring the request to carry out the home programme.

Some students mentioned that they found the hospitality that the community had shown them to be an enjoyable and rewarding experience.

The improvement gained by some of the disabled who had been bedridden for up to 11 years and who had progressed to walking within their homes, assisted by their caregivers, was expressed as a very satisfying experience by 80% of the students. This was particularly gratifying as the students realised that without this programme the disabled would have remained bedridden.

2. Aspects that the students did not enjoy fitted into three categories, all of which were experienced to a greater or lesser extent. These were that they felt physically threatened by the gangsters when walking from house to house, anxiety about the safety of their cars and the transport costs involved in traveling to Manenberg.

38% of the students described their personal feelings of social `guilt' and depression with the social conditions as being unpleasant, but understandable as this was the first time they had been exposed to a disadvantaged community.

3. 95% percent of the students stated that they had negative feelings about the block before they started in the community. These were again expressed as apprehension and fear regarding the violence in the area.

4. 10% of the students stated that their negative feelings after completion of the block remained the same as at the start of the placement.

The remainder described their feelings as being "extremely positive", "a wonderful challenge", "happy to be appreciated by the community" and felt that their physiotherapy knowledge had been broadened.

5. All the students felt that the Community Physiotherapy workshops attended in their third year had prepared them adequately for the rotation. The workshops comprised 6 two-hour sessions. There were no suggestions made as to how these could be improved.

6. Suggestions made to improve the programme included having access to occupational therapy, nursing and social work students to accompany them as they felt that the disabled would benefit more by this additional multidisciplinary input. The provision of walking aids and aids of daily living made available were also proposed.

Two of the students recommended that they thought support groups for both the disabled and their caregivers would be of benefit.

7. 85% of the students suggested that the University provide them with transport and/or insurance for their motor vehicles.

12.8.2 RESEARCHER'S FINDINGS

In areas where there is a high degree of substance abuse and gangster violence it appears that the safest time of the day for home visits to take place is during the morning while the gangsters are still asleep. Their activities and rival gang fights generally started from approximately 15h00 when they began to drink or to take drugs. The homes could not be regarded as safe havens during the afternoons as bullets from the cross-fire of gang fights often penetrated the windows and injured the residents.

During the weekly meetings when the researcher and students met to discuss client progress and problems experienced on the block, it was noted that although the students perceived their Community Physiotherapy course as preparing them adequately to work in a domiciliary setting, there were many topics that the researcher identified of which the students did not have any knowledge. The topics should actually have formed an essential knowledge foundation for community work so that the disabled and their families could be seen as part of a community rather than as independent families suffering from various pathologies. These students were managing the clients from a medical model system and not from a biopsychosocial model. The topics that needed to be dealt with are discussed below.

1. Sociological determinants of health and disease which would incorporate inequalities related to class, race and gender.

2. The history of medical and health care in South Africa. This would include issues of political background to health in South Africa, doctor-patient relations and the status of children, women and the aged as well as the traditional role of institutional care as the place for health intervention and training. The important part that primary health care and its

philosophy of health care as opposed to the medical model would need to be discussed and explained.

3. The health care structures and issues relating to the shape and financing of health services in South Africa. This would incorporate resource allocation issues affecting decision-making as future clinicians and would need an examination of the Reconstruction and Development Programme as well as the ANC's National Health Plan. Disability grants and its effects on health care and motivation for the chronically disabled would need to be discussed.

4. Health beliefs and cultural variations. This would address the issue of health professional-client relations and the distinction that exists between `western' and `alternative' and `traditional' health practice.

5. An introduction to the main religious traditions, their viewpoints on illness, misfortune and health care and how these affect responses to health care. This section would need to include issues on human rights.

6. The philosophy and process of community development and how the emphasis of `treatment' of the individual should be changed to one of capacity building and empowerment of a community.

12.9 DISCUSSION

As set out in 12.3 and 12.4 the aim of the study was to establish whether final year physiotherapy students could manage physically disabled persons competently in a domiciliary setting. In order to do this it was necessary to identify topics that had previously been omitted and that needed to be included in the Community Physiotherapy curriculum and to identify methods of improving the present method of clinical placements to incorporate community physiotherapy at an earlier stage of student training.

While the human resource costs for the project have been extremely high regarding student supervision, the staff involved perceived that considerable advantage had been gained for the students. They were able to rehabilitate the disabled within a realistic home environment and it provided them with the opportunity of becoming acquainted with the home conditions from which most of the inpatients they were treating came. The extent of the poverty, inadequate facilities and burden of care could not have been comprehended without exposure to the home environment. The students could also gain an overall picture of the family problems experienced that they would not have had access to from any subjective evaluation in a hospital in- or outpatient department.

It also allowed them the opportunity to follow the progress of, for example, a person suffering from a stroke in the acute phase in hospital until complete rehabilitation at home. This contributed to their understanding of the many factors that play an important role in achieving independence at home.

The Faculty of Medicine was approached and requested to provide some form of transport and/or insurance for the students' vehicles for clinical practice, but it was not granted. This could have major ramifications on future clinical placements as students might only be able to be placed where there is public transport available. This means that, once more, the very needy disabled living in informal settlements where there is no public transport will not be able to be reached by a domiciliary programme. The public transport system in the Western Cape at present is also a very time-consuming mode of transport.

12.10 CONCLUSIONS

The students have been exposed to a successful community physiotherapy programme which provided the community with a programme of development and empowerment and the students with the experience of working in the community situation and contributing to the development and empowerment processes themselves by managing the disabled and teaching the caregivers. Wolliscroft and Schwenk (1989) maintain that problem-solving skills are often site-specific and that it is essential that they be taught in a setting similar to that in which they will be applied.

The students were exposed to processes of community consultation, community participation and community empowerment. They would previously only have heard about these aspects in lectures, but not seen them put into action. This stimulated social responsibility and political awareness amongst them, most of whom had never previously experienced living conditions in poorer communities. This experiential form of learning allowed them to plan and implement their own interventions which included other sectors within the health care system as well as occasionally outside the health care system per sec.

As was borne out by the significant functional level of improvement displayed by the disabled and the decrease in caregiver burden, it showed that the students were capable of planning and managing a rehabilitation programme competently under supervision. They perceived their Community Physiotherapy course as preparing them adequately for their rotation in the community, but the researcher found that they were managing the clients very much along that of the medical model and were insufficiently aware of the social, political, cultural and religious differences that influenced the lives of the community at large and how these differences impinged upon the health of the disabled and their caregivers.

In other words the scientific medical aspects of their client management was adequate, but they lacked sufficient knowledge of the humanities to change their approach to that of a biopsychosocial model whereby they perceived the disabled and their families as being a functional part of the broader community.

In a country like South Africa where there is increased attention being paid to primary health care and where emphasis is being placed on intersectoral collaboration it would be unrealistic to expect professionals being trained to manage clients holistically without the relevant input.

12.11 RECOMMENDATIONS

1. As the students themselves identified the need for multidisciplinary intervention in the community, it would seem that this should occur right from the teaching level where certain subjects common to the various disciplines could be taught by means of integrated lectures or projects in a community setting. Essential disciplines would include medical, occupational therapy, speech, social work and nursing students. This would allow a greater understanding of the functioning of each discipline and the benefits of interdisciplinary problem-solving learned from an early point in their training.

Future clinical placements in the community should include physiotherapy and occupational therapy students visiting homes together. This should occur from first year and can easily be implemented by a pair of first year occupational and physiotherapy students observing a final year occupational or physiotherapy student. In this way they will become very well acquainted with the nature of the work of the other discipline. It could be continued from second year through to final year with students accompanying each other on selected community or rehabilitation rotations. This could take place immediately. Introduction of medical students from third year to the multidisciplinary clinical approach should be considered as soon as possible.

2. The topics identified in 12.8.2 above should be included in the first year curriculum and should constitute a full year course of lectures, tutorials and fieldwork practice in order for the students to gain a broad overview of their prospective clients. It will also assist them in applying this information to clients in both inpatient and outpatients situations from an early stage of their clinical work. This will have the effect of training the student from second year to think of the disabled as being a functional part of a community to which he/she will be returning with a definite role to play and not merely as an individual with a medical dysfunction that needs to be corrected as far as possible through hospital-based intervention.

Although these topics should be introduced in first year it is important that it not be perceived as a "once-off" course. They should be covered in greater depth from second to final years and should incorporate meaningful community projects each year.

3. In order for the student to have a greater understanding of the ultimate realistic goals for rehabilitation of their clients, domiciliary visits should not be designated at final year only. First year students should accompany final year students during a module in their first year in order to observe living conditions of disabled people in general.

From second year students should accompany clinicians to the homes of recently discharged disabled to follow up their home programmes. This will ensure that techniques and skills learned in hospital can be appropriately adapted to the needs of each disabled person and that they are being carried out effectively. At least 2 home visits should be carried out during each of the 4-week rotations done in the hospitals.

Third and fourth year students should have the opportunity of doing domiciliary visits to recently discharged clients as well as to clients attending as outpatients. There should also be a stipulation of a minimum of 2 home visits during outpatient rotations. Becoming familiar with home environments will help to make the treatment programmes for in- and outpatients more relevant and will also ensure that disabled discharged home do achieve their maximum level of rehabilitation.

4. During the third year of training students should attend a course where they are taught how to make cheap splints of inexpensive materials and how to utilise furniture and household gadgets to make adaptations to the home so that the

disabled are able to function maximally. This is also an appropriate time of their training level for `community development' and `community participation' to be dealt with in detail, preferably by an experienced community worker who is not necessarily medically trained .

5. Students should be regularly supervised in the home situation and be taught to adapt techniques to accommodate the home situation. During this study it was frequently found that the students could not adapt techniques as they felt that they were doing them incorrectly and that this would be evaluated as being wrong by the supervisor. For example, when walking a person with a stroke they are generally taught to assist the person on the affected side, whereas frequently in the home environment it was found to be more beneficial to teach the family to assist the disabled on the unaffected side. When a client had been discharged with a walking appliance, the students frequently persevered with teaching the client how to use it when the home environment was of such a nature that it was far easier and more functional for the client to be taught to hold onto the available furniture in order to move around the house independently. These adaptations need to be taught to the students in the relevant environment otherwise they perceive them to be shortcut sloppy techniques that would be considered to be unprofessional.

CHAPTER THIRTEEN

CONCLUSION OF OVERALL PROGRAMME

13.1 INTRODUCTION

The study set out to evaluate the effectiveness of a domiciliary physiotherapy programme to enable 50 severely physically disabled persons to achieve their maximum level of function and to train their caregivers in the management of their disabled relatives. The intention was not to provide a service, but to empower the participants by increasing their capacity to become self-reliant.

The programme was conducted by the researcher and 40 final year physiotherapy students in collaboration with the Manenberg Health Care Project Committee.

During the implementation of the programme it became apparent that 21 of the caregivers were unable to cope with the burden of caring effectively for their relatives. A volunteer system was instituted to decrease the caregiver burden by assisting them with the disabled persons.

Thus the study comprised 3 separate components, namely, the rehabilitation and training of the disabled and their caregivers respectively; the volunteer training project; and the evaluation of the Community Physiotherapy Course to establish whether it prepared the students adequately for working in the community.

13.2 SUMMARY OF FINDINGS

An effective partnership between the community of Manenberg and the Physiotherapy Department of the University of Cape Town was formed by utilising the model of this study. The disabled and their caregivers received rehabilitation and training programmes respectively. In turn, the students gained exposure to the home environment, the essential experience of rehabilitation in the community and the opportunity of training caregiver and volunteers to provide maintenance and routine physiotherapy regimens. The success of the programme was due to the community's active partnership.

The domiciliary physiotherapy programme was effective in reaching and providing a rehabilitation programme for the severely disabled in Manenberg who would not otherwise have had access to such a service.

Although the programme was viewed as a temporary measure for filling a gap in the health service system, there is also a place for domiciliary physiotherapy in the long-term. Domiciliary visits were particularly valuable when patients were prematurely discharged from hospital before their rehabilitation was complete and for those who did not even reach the physiotherapy department, for example, stroke patients who were not admitted to a ward, but were discharged directly from the Casualty Department.

It provided an effective follow-up system for patients recently discharged from hospital. Frequently the rehabilitation received in hospital was wasted as it was discontinued at home because of lack of knowledge, confidence and motivation. By being more self-reliant and having more control over their lives the disabled were less likely to resort to negative coping mechanisms which put an even greater strain on the family.

Domiciliary physiotherapy provided the caregivers and their families with support and was an effective means of equipping them with the skills to sustain rehabilitation programmes in their homes. Thus it was a means of ensuring more disabled having access to physiotherapy in a system where there were inadequate numbers of physiotherapists to deal with the number of disabled.

Physiotherapy techniques learned in hospital were adapted to the needs of the individual home situation of the disabled persons and were taught to the caregivers. Regardless of their limited educational level they were found to be competent at carrying out these basic physiotherapy techniques. By ensuring that the disabled achieve their maximum level of independence in the home caregiver burden was significantly reduced.

taught to them. Neighbours and volunteers, who previously had not been aware of the problems of the disabled and their caregivers, were also incorporated into the programme and by their involvement caregiver burden was significantly reduced.

This is a feasible model from which to base further rehabilitation programmes in other poorer communities.

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APPENDICES

Manenberg Peoples' Centre
3 June 1993

We the undersigned, being representatives of the Manenberg Peoples' Centre and members of the Manenberg Community, hereby give permission for the information obtained by the Physiotherapy Department of the University of Cape Town from its "Domiciliary Programme for the Housebound Disabled and their Caregivers" to be written up for the benefit of similar health projects in other communities.

We understand that all personal details of the persons concerned will be kept confidential and that any material published will be made available for the use of the Manenberg Peoples' Centre.

.... Mrs F de Vries

.... Mr R Hindley

UNIVERSITY OF CAPE TOWN

PHYSIOTHERAPY DEPARTMENT

REPORT ON THE MANENBERG CAREGIVER TRAINING PROGRAMME

23 MARCH - 30 OCTOBER 1992

To date 128 disabled and their caregivers have been visited.

All the names on the UWC disabled survey list have been visited, but many of the disabled needing assistance were identified by the students themselves whilst visiting homes in the community and talking to the people who knew of disabled in the block or neighbourhood and who were not included on the list. To date only 10 of the 128 disabled have been identified as needing physiotherapy assistance with caring for their disabled relatives.

The students were disappointed at the attendance, namely only 4, at the Caregiver Support Group Meeting on the 20 October as they felt that when visiting and informing the disabled and their caregivers about the meeting and its objectives, there were many more people that were very anxious to form a self-help group. However, the weather was not conducive to a large attendance as well as the fact that these groups do take time to get off the ground. The discussion that did take place amongst the group was very promising and the numbers should grow slowly.

From next year the students will be able to do home visits to the newly discharged disabled and their caregivers. This is, of course, the time that assistance and support is most beneficial and the caregivers will probably benefit a great deal from the others at the Caregiver Support Group meetings.

2 of the final year students are very keen to get a Volunteer Group organised and to match them up with some of the caregivers identified as needing assistance. This will take considerable time as it is not very easily established, but should prove to be beneficial in the future for the use of the MPC.

The students are now doing their examinations and will then be away for the University Vacations. They will resume work in the community from the 11 January 1993.

MJ FUTTER
SENIOR LECTURER

30 November 1992

UNIVERSITY OF CAPE TOWN

DEPARTMENT OF PHYSIOTHERAPY

MANENBERG DOMICILIARY DISABLED AND CAREGIVER PROGRAMME

INTERVIEW A

A. CLIENT'S DETAILS

NAME: ....

ADDRESS: ....

....

TELEPHONE NO.: ....

DATE OF BIRTH: ....

RELIGIOUS AFFILIATION: ....

PREVIOUS OCCUPATION: ....

FAMILY INCOME: GRANT .... OTHER: ....

DIAGNOSIS: ....

....

DATE OF ONSET/INJURY ....

DATE OF FIRST VISIT: ....

1. SOCIAL SUPPORT

Caregivers:

self ☐
immediate family ☐
relations ☐
friends ☐
institution ☐
other ☐

Professional input:
district nurse ☐
day hospital ☐
doctor ☐
occupational therapist ☐
speech therapist ☐
social worker ☐
not required ☐
other ☐

RELEVANT PROFESSIONAL INPUT PERTAINING TO ANY OTHER ILLNESSES CLIENT MAY SUFFER FROM:

____

____

____

2. PREVIOUS REHABILITATION RECEIVED FOR INJURY/CONDITION

Inpatient treatment:

physiotherapy	Y	N
occupational therapy	Y	N
speech therapy	Y	N

Duration: ______________________

Outpatient physiotherapy:

Duration: ______________ Frequency: ______________

If no, give reasons:

not referred ☐
not motivated ☐
unable to attend:
finance ☐
transport ☐
physical condition ☐
accessibility ☐

WHAT HOME INSTRUCTIONS WERE YOU GIVEN BY THE HOSPITAL PHYSIOTHERAPIST?

____

____

____

____

HAVE THESE THINGS TAUGHT TO YOU AT THE HOSPITAL HELPED YOU AT HOME? Y ☐ N ☐

IN WHICH WAY?

____

____

____

____

____

SINCE YOU HAVE BEEN AT HOME DO YOU THINK YOUR ACTIVE DAILY LIVING HAS:

improved ☐
stayed the same ☐
worsened ☐

TO WHAT DEGREE HAS YOUR DISABILITY AFFECTED YOUR PREVIOUS LIFESTYLE?

____

____

____

____

____

WHAT DO YOU HAVE PROBLEMS DOING AT PRESENT?

____

____

____

____

____

ARE YOU HAPPY WITH YOUR LEVEL OF FUNCTIONAL INDEPENDENCE? Y ☐ N ☐

DOES YOUR FAMILY HELP YOU IN ANY WAY?

Y	N

IF YES, HOW?

WHAT ARE YOUR FEELINGS ABOUT THE PHYSIOTHERAPIST TEACHING YOU TO BECOME AS INDEPENDENT AS POSSIBLE?

WHAT ARE YOUR FEELINGS ABOUT YOUR CAREGIVER BEING TAUGHT TO HELP YOU BECOME AS INDEPENDENT AS POSSIBLE?

HOW MUCH CONTACT DO YOU HAVE WITH THE COMMUNITY, E.G. CHURCH, VISITING NEIGHBOURS, ETC?

none ☐
a little ☐
adequate ☐

IN WHICH WAY DO YOU HAVE CONTACT?

ARE YOU SATISFIED WITH THIS AMOUNT OF COMMUNITY CONTACT? Y | N

COMMENTS:

HOW OFTEN DO YOU LEAVE THE HOUSE?

never ☐
seldom ☐
once per week ☐
more than once per week ☐

COMMENTS:

DO YOU HAVE A TELEVISION? Y | N

WHAT DO YOU DO WITH YOURSELF ALL DAY?

B. CAREGIVER DETAILS

RELATION TO THE CLIENT: ______________________________

IS THE PERSON INTERVIEWED THE PRIMARY CAREGIVER? | Y | N |

HOW MUCH DOES THE CLIENT DEPEND ON YOUR HELP AT HOME?

____

____

____

____

____

HAVE YOU RECEIVED ANY INFORMATION OR INSTRUCTIONS FROM ANY HEALTH PROFESSIONAL PERSON REGARDING THE REHABILITATION OF YOUR RELATIVE? | Y | N |

IF YES, BY WHOM? ____________________

WHERE? ____________________

WHEN? ____________________

WHAT WERE YOU TAUGHT TO DO?

____

____

____

____

____

HOW HAS HER/HIS DISABILITY AFFECTED YOUR LIFE?

____

____

____

____

____

ARE YOU HAPPY WITH THE CLIENT'S LEVEL OF FUNCTIONAL INDEPENDENCE? ☐ Y ☐ N

DO YOU FEEL THAT YOU WOULD BENEFIT FROM HOME INSTRUCTIONS ON HOW TO MANAGE THE CLIENT? ☐ Y ☐ N

ARE THERE OTHER CAREGIVERS, OTHER PEOPLE WHO LOOK AFTER THE CLIENT? ☐ Y ☐ N

WHO ARE THEY? ______________________________

IN WHICH WAY DO THEY HELP? ______________________________

____

____

____

____

WHEN DO THEY LOOK AFTER THE CLIENT? ______________________________

____

____

____

____

HOW MUCH CONTACT DO YOU HAVE WITH THE COMMUNITY, E.G. CHURCH, SOCIAL?

none ☐
a little ☐
adequate ☐

IN RELATION TO THE OTHER FAMILY MEMBERS LIVING WITH YOU IS THIS AMOUNT OF SOCIAL CONTACT

more ☐
the same ☐
less ☐

COMMENTS:

____

____

Level of caregiver burden - (FROM ZARIT 1985)

TO EACH OF THE FOLLOWING, RATE ACCORDING TO THE SCALE GIVEN BELOW::

NEVER (0); RARELY (1); SOMETIMES (2); QUITE FREQUENTLY (3); NEARLY ALWAYS (4).

1. DO YOU FEEL RESENTFUL OF OTHER RELATIVES WHO COULD, BUT WHO DO NOT DO THINGS FOR THE CLIENT?	0	1	2	3	4
2. DO YOU FEEL THAT THE CLIENT ASKS FOR MORE HELP THAN HE/SHE ACTUALLY NEEDS?	0	1	2	3	4
3. DO YOU FEEL THAT YOU DO NOT HAVE TIME FOR YOURSELF BECAUSE OF YOUR INVOLVEMENT WITH THE CLIENT?	0	1	2	3	4
4. DO YOU FEEL THAT THE CLIENT IS DEPENDENT UPON YOU?	0	1	2	3	4
5. DO YOU FEEL STRESSED BETWEEN TRYING TO GIVE TIME TO THE CLIENT AS WELL AS TO OTHER FAMILY RESPONSIBILITIES, ETC	0	1	2	3	4
6. DO YOU FEEL YOUR HEALTH HAS SUFFERED BECAUSE OF YOUR INVOLVEMENT WITH THE CLIENT?	0	1	2	3	4
7. DO YOU FEEL EMBARRASSED ABOUT YOUR CLIENT'S PHYSICAL DISABILITY OR BEHAVIOUR?	0	1	2	3	4
8. DO YOU FEEL ANXIOUS OR GUILTY ABOUT THE WAY IN WHICH YOU TREAT THE CLIENT?	0	1	2	3	4
9. DO YOU FEEL THAT YOU DO NOT DO AS MUCH FOR THE CLIENT AS YOU COULD OR SHOULD?	0	1	2	3	4
10. DO YOU FEEL THAT YOUR SOCIAL LIFE HAS SUFFERED BECAUSE OF YOUR INVOLVEMENT WITH THE CLIENT?	0	1	2	3	4
11. DO YOU FEEL THAT THE CLIENT SEEMS TO EXPECT YOU TO TAKE CARE OF HIM/HER, AS IF YOU WERE THE ONLY ONE HE/SHE COULD DEPEND ON?	0	1	2	3	4
12. DO YOU FEEL THAT YOU DO NOT HAVE ENOUGH MONEY TO SUPPORT YOUR CLIENT IN ADDITION TO THE REST OF YOUR EXPENSES?	0	1	2	3	4

TOTAL SCORE [48] ☐

DO YOU REQUIRE ASSISTANCE FROM A VOLUNTARY WORKER?	Y	N

WHAT SORT OF ASSISTANCE WOULD YOU NEED?

1 OR 2 mornings for relief?	Y	N
assistance with bathing, toileting, etc	Y	N
assistance with physiotherapy help?	Y	N

C. PHYSIOTHERAPISTS' ASSESSMENT OF THE CLIENT

Physical condition

Physical impairment affecting level of functioning:

Incontinence	Y	N
Pressure sores	Y	N
Contractures	Y	N
Diabetes	Y	N
Asthma	Y	N
Arthritis	Y	N
Mental Retardation	Y	N
Hypertension	Y	N

Mental Status

DYSPHASIA	Y	N

IF YES, ASK CAREGIVER THE FOLLOWING QUESTIONS WHERE APPROPRIATE. IF NO, ASK THE CLIENT.

COGNITIVE ABILITY:

MEMORY OF 3 OBJECTS:

does not remember	0
remembers some	1
remembers all	2

ORIENTATION (NAME, AGE, TIME AND PLACE):

does not remember	0
remembers some	1
remembers all	2

CAREGIVERS' OPINION OF CLIENT'S GENERAL ABILITY TO UNDERSTAND AND RESPOND CORRECTLY:

poor	0
good	1

TOTAL SCORE [6] ☐

Functional level

DAILY ACTIVITY	INDEPENDENT (4)	INDEPENDENT WITH AIDS (3)	INDEPENDENT WITH ASSISTANCE (2)	DEPENDENT (1)
FEEDING				
TOILET				
WASHING/ BATHING				
DRESSING/ GROOMING				
GENERAL BED MOBILITY				
SITTING				
GETTING IN AND OUT OF BED				
SIT TO STAND				
MOBILITY FROM ROOM TO ROOM				
MOBILITY FROM ROOM TO TOILET				
KITCHEN ACTIVITIES				
CLIMBING STAIRS/RAMP				
GETTING IN AND OUT OF TRANSPORT				
WALKING OUTSIDE				

TOTAL SCORE [56] ☐

FUNCTIONAL AIDS USED:

splints ☐
wheelchairs ☐
walking frame ☐
walking stick ☐
tripod ☐
helper assistance ☐

CLIENT IS CAPABLE OF GREATER FUNCTIONAL INDEPENDENCE ☐ Y ☐ N

IF YES, SPECIFY REASONS:

____

____

____

____

____

IF NO, REASON:

physical disabilities ☐
maximum level of rehabilitation attained ☐
impaired cognitive ability ☐
other ☐

THE CAREGIVER WOULD BENEFIT FROM PHYSIOTHERAPY RELATED TO CARE OF THE CLIENT ☐ Y ☐ N

REASONS:

____

____

____

____

____

THE CAREGIVER WOULD BENEFIT FROM THE ASSISTANCE OF A VOLUNTARY WORKER: ☐ Y ☐ N

For physical assistance with hygiene, transfers, walking, etc ☐ Y ☐ N

Relief in order that the caregiver has some personal free time to perform other necessary household duties ☐ Y ☐ N

COMMENTS:

____

____

____

____

____

THE CLIENT WOULD BENEFIT FROM:

support group ☐
district nurse ☐
physiotherapist ☐
social worker ☐
occupational therapist ☐
speech therapist ☐
old age home ☐
social group ☐
disability group ☐
other ☐

REASONS:

____

____

____

____

____

D. PHYSICAL ENVIRONMENT

TYPE OF DWELLING:

upstairs ☐
downstairs ☐
flat ☐
bungalow ☐
house ☐
shack ☐
other ☐

NUMBER OF ROOMS: ☐

NUMBER OF PEOPLE LIVING IN DWELLING?

family members ☐
others ☐

ACCESS TO HOME:

steps ☐
rough ground ☐
sand ☐
pavement ☐
other ☐

DESCRIBE RELEVANT SURROUNDINGS, DISTANCE TO ROAD, ETC:

____

____

____

____

____

ACCOMMODATION:

TOILET: inside ☐
outside ☐

DOES THE CLIENT HAVE HIS/HER OWN ROOM? ☐ Y ☐ N

IF NO, SPECIFY WITH WHOM THE ROOM IS SHARED:

spouse ☐ Y ☐ N
number of people sharing room ☐

E. SUMMARY

IMMEDIATE GENERAL PROBLEMS OF CLIENT:

____

____

____

____

____

____

____

____

____

____

POSSIBLE SOLUTIONS:

____

____

____

IMMEDIATE GENERAL PROBLEMS OF CAREGIVER:

POSSIBLE SOLUTIONS:

ADDITIONAL COMMENTS:

PHYSIOTHERAPY RECORD

DATE	TREATMENT	SIGNATURE

UNIVERSITY OF CAPE TOWN

DEPARTMENT OF PHYSIOTHERAPY

MANENBERG DOMICILIARY DISABLED AND CAREGIVER PROGRAMME

INTERVIEW B

A. CLIENT'S DETAILS

NAME: ....

ADDRESS: ....
....

DATE OF LAST VISIT: ....

TOTAL NUMBER OF VISITS RECEIVED ....

1. CLIENT

HOW DO YOU FEEL ABOUT THE PHYSIOTHERAPY PROGRAMME IN GENERAL? WOULD YOU SAY THAT YOU HAVE BENEFITED

a great deal ☐
substantially ☐
not much ☐
not at all ☐

WHAT ARE THE STRENGTHS OF THE PROGRAMME?

____

____

____

____

____

WHAT ARE THE WEAKNESSES OF THE PROGRAMME?

____

____

____

____

____

WHAT CHANGES WOULD YOU RECOMMEND TO IMPROVE THE PROGRAMME?

____

____

____

____

____

DO YOU THINK YOUR ACTIVE DAILY LIVING HAS

improved ☐
stayed the same ☐
worsened ☐

IN WHICH WAY HAS IT IMPROVED?

____

____

____

____

____

WHAT DO YOU STILL HAVE PROBLEMS DOING?

____

____

____

____

____

DID YOUR CAREGIVER BENEFIT BY BEING TAUGHT TO HELP YOU? Y ☐ N ☐

IF YES, IN WHICH WAY?

COMPARED TO BEFORE THE PROGRAMME DOES YOUR CAREGIVER HELP YOU

more ☐
the same amount ☐
less ☐

IN WHICH WAY

HOW DO YOU FEEL ABOUT YOUR CAREGIVER HELPING YOU MORE/THE SAME/LESS?

DO YOU THINK IT WOULD BE BENEFICIAL FOR YOU AND YOUR CAREGIVER TO RECEIVE FURTHER VISITS BY THE PHYSIOTHERAPIST? ☐ Y ☐ N

IF YES, IN WHAT WAY DO YOU THINK IT WILL HELP YOU?

HAS YOUR CONTACT WITH OTHER MEMBERS OF THE COMMUNITY, E.G. CHURCH, VISITING NEIGHBOURS, ETC?

increased ☐
stayed the same ☐
decreased ☐

IF APPLICABLE, IN WHICH WAY HAS YOUR CONTACT INCREASED?

____
____
____
____

HOW OFTEN DO YOU LEAVE THE HOUSE NOW?

never ☐
seldom ☐
once per week ☐
more than once per week ☐

WHAT DO YOU DO WITH YOURSELF ALL DAY?

____
____
____
____
____

HAVE YOU RECEIVED ASSISTANCE FROM A VOLUNTARY WORKER?

☐ Y ☐ N

HOW MUCH DIFFERENCE TO YOUR LIFE HAS THIS ASSISTANCE MADE?

nothing ☐ 0
a little ☐ 1
a great deal ☐ 2

IN WHICH WAY?

____
____

____

____

____

B. CARÉGIVER

HOW DO YOU FEEL ABOUT THE PHYSIOTHERAPY PROGRAMME IN GENERAL?
WOULD YOU SAY THAT YOU HAVE BENEFITED

a great deal ☐
substantially ☐
not much ☐
not at all ☐

WHAT ARE THE STRENGTHS OF THE PROGRAMME?

____

____

____

____

____

WHAT ARE THE WEAKNESSES OF THE PROGRAMME?

____

____

____

____

____

WHAT CHANGES WOULD YOU RECOMMEND TO IMPROVE THE PROGRAMME?

____

____

____

____

____

WHAT WAS YOUR EXPERIENCE OF US HELPING YOU WITH YOUR DISABLED FAMILY MEMBER IN THE HOME?

enjoyed it ☐
did not mind it ☐
did not enjoy it ☐

FOR WHAT REASONS?

____

____

____

____

____

HAVE YOU SEEN AN IMPROVEMENT IN THE CLIENT'S ACTIVE DAILY LIVING? ☐ Y ☐ N

DOES THE CLIENT DEPEND ON YOUR HELP?

more ☐
the same amount ☐
less ☐

FOR WHAT REASONS?

____

____

____

____

____

DOES THE CLIENT DEPEND ON THE HELP OF OTHER MEMBERS OF THE FAMILY?

more ☐
the same amount ☐
less ☐

FOR WHAT REASONS?

____

____

____

____

HOW MUCH MORE DO YOU KNOW NOW ABOUT THE CLIENT'S DISEASE/DISABILITY THAN BEFORE THE PROGRAMME?

the same amount ☐
a little bit ☐
much more ☐

DO YOU FEEL YOUR HANDLING (ASSISTANCE WITH TRANSFERS, WALKING, ETC) OF THE CLIENT HAS

improved ☐
stayed the same ☐

IN WHICH WAY?

____

____

____

____

____

WOULD YOU LIKE THIS KIND OF PHYSIOTHERAPY ASSISTANCE TO BE CONTINUED IN YOUR HOME?

☐ Y ☐ N

SINCE WE HAVE BEEN HELPING YOU IN THE HOME, HAS THE AMOUNT OF CONTACT YOU HAVE HAD WITH OTHER MEMBERS OF THE COMMUNITY

increased ☐
stayed the same ☐

IF APPLICABLE, IN WHAT WAY HAS THIS CHANGED?

____

____

____

____

____

COMPARED WITH BEFORE THE PROGRAMME, IN RELATION TO THE OTHER FAMILY MEMBERS OF FAMILY LIVING WITH YOU IS THE AMOUNT OF SOCIAL CONTACT YOU HAVE WITH THE COMMUNITY

more ☐
the same ☐

GIVE REASONS

____

____

____

Level of caregiver burden - (FROM ZARIT 1985)

TO EACH OF THE FOLLOWING, RATE ACCORDING TO THE SCALE GIVEN BELOW::

NEVER (0); RARELY (1); SOMETIMES (2); QUITE FREQUENTLY (3); NEARLY ALWAYS (4).

1. DO YOU FEEL RESENTFUL OF OTHER RELATIVES WHO COULD, BUT WHO DO NOT DO THINGS FOR THE CLIENT? 0 | 1 | 2 | 3 | 4
2. DO YOU FEEL THAT THE CLIENT ASKS FOR MORE HELP THAN HE/SHE ACTUALLY NEEDS? 0 | 1 | 2 | 3 | 4
3. DO YOU FEEL THAT YOU DO NOT HAVE TIME FOR YOURSELF BECAUSE OF YOUR INVOLVEMENT WITH THE CLIENT? 0 | 1 | 2 | 3 | 4
4. DO YOU FEEL THAT THE CLIENT IS DEPENDENT UPON YOU? 0 | 1 | 2 | 3 | 4
5. DO YOU FEEL STRESSED BETWEEN TRYING TO GIVE TIME TO THE CLIENT AS WELL AS TO OTHER FAMILY RESPONSIBILITIES, ETC 0 | 1 | 2 | 3 | 4
6. DO YOU FEEL YOUR HEALTH HAS SUFFERED BECAUSE OF YOUR INVOLVEMENT WITH THE CLIENT? 0 | 1 | 2 | 3 | 4
7. DO YOU FEEL EMBARRASSED ABOUT YOUR CLIENT'S PHYSICAL DISABILITY OR BEHAVIOUR? 0 | 1 | 2 | 3 | 4
8. DO YOU FEEL ANXIOUS OR GUILTY ABOUT THE WAY IN WHICH YOU TREAT THE CLIENT? 0 | 1 | 2 | 3 | 4
9. DO YOU FEEL THAT YOU DO NOT DO AS MUCH FOR THE CLIENT AS YOU COULD OR SHOULD? 0 | 1 | 2 | 3 | 4

10. DO YOU FEEL THAT YOUR SOCIAL LIFE HAS SUFFERED BECAUSE OF YOUR INVOLVEMENT WITH THE CLIENT? 0 1 2 3 4

11. DO YOU FEEL THAT THE CLIENT SEEMS TO EXPECT YOU TO TAKE CARE OF HIM/HER, AS IF YOU WERE THE ONLY ONE HE/SHE COULD DEPEND ON? 0 1 2 3 4

12. DO YOU FEEL THAT YOU DO NOT HAVE ENOUGH MONEY TO SUPPORT YOUR CLIENT IN ADDITION TO THE REST OF YOUR EXPENSES? 0 1 2 3 4

TOTAL SCORE [48] ☐

HAVE YOU RECEIVED ASSISTANCE FROM A VOLUNTARY WORKER?

Y N

WHAT SORT OF ASSISTANCE HAVE YOU RECEIVED?

1 or 2 mornings a week for relief	Y	N
assistance with bathing, toileting, etc	Y	N
assistance with physiotherapy help	Y	N

HOW MUCH DIFFERENCE TO YOUR LIFE HAS THIS ASSISTANCE MADE?

nothing	0
a little	1
a great deal	2

IN WHICH WAY?

C. PHYSIOTHERAPISTS ASSESSMENT OF THE CLIENT

Functional level

DAILY ACTIVITY	INDEPENDENT (4)	INDEPENDENT WITH AIDS (3)	INDEPENDENT WITH ASSISTANCE (2)	DEPENDENT (1)
FEEDING				
TOILET				
WASHING/ BATHING				
DRESSING/ GROOMING				
GENERAL BED MOBILITY				
SITTING				
GETTING IN AND OUT OF BED				
SIT TO STAND				
MOBILITY FROM ROOM TO ROOM				
MOBILITY FROM ROOM TO TOILET				
KITCHEN ACTIVITIES				
CLIMBING STAIRS/RAMP				
GETTING IN AND OUT OF TRANSPORT				
WALKING OUTSIDE				

TOTAL SCORE [56] ☐

PHYSIOTHERAPIST'S OPINION

CLIENT HAS GAINED GREATER FUNCTIONAL INDEPENDENCE ☐ Y ☐ N

IF YES, SPECIFY REASONS:

____

____

____

IF NO, REASON:

physical disabilities
max. level of rehab. attained
impaired cognitive ability
other

COMMENTS: (ON QUALITY OF FUNCTIONAL LEVEL SINCE YOU HAVE BEEN VISITING THE HOME)

THE CAREGIVER HAS BENEFITED FROM PHYSIOTHERAPY RELATED TO CARE OF THE CLIENT Y N

REASON:

THE CAREGIVER HAS BENEFITED FROM THE ASSISTANCE OF A VOLUNTARY WORKER Y N

REASON:

THE CLIENT HAS BENEFITED FROM:

support group ☐
district nurse ☐
physiotherapist ☐
social worker ☐
occupational therapist ☐
speech therapist ☐
old age home ☐
social group ☐
disability group ☐
other ☐

REASONS:

D. SUMMARY

COMMENTS:

M.FUTTER
MARCH 1993
MBERG.DOC

MANENBERG HEALTH PROJECT

MINUTES OF MEETING HELD AT THE MPC ON 2 SEPTEMBER 1993.

PRESENT: As per attached list.

APOLOGIES: R Hindley.

OBJECTIVES OF MEETING:

1. To explain to the volunteers what the project's expectations of them are.

2. To discuss problems arising from home visits.

3. To discuss the agenda for next meeting.

1. **MATTERS ARISING FROM PREVIOUS MINUTES:**

1.1 Debbie Bub had been to see Mrs Hindley and would like to work as an occupational therapist in Manenberg. She will have to find a substitute for herself in her present job at Valkenberg Hospital before being able to start in Manenberg.

1.2 Mr Liddle's rails are on the list of jobs to be done. It might take a few more days and will have to be followed up at the CTCC.
Action: G Hindley.

2. M Futter gave a talk to the group on "physiotherapy" in general as it is practised in hospitals and the roles that the volunteers would be expected to play in the homes of the disabled. An explanation was given as to why it was not possible for a course to be given as in the case of the home nursing course. This was a particular group of severely disabled people and who, because of the severity of the disablement, had to have individual programmes formulated. For that reason each volunteer was assigned to a particular disabled person and would be taught what to do and how to assist this person in his own house. The training would be done by the researcher and/or the students.

3. C Africa gave a description of Mr C's poor home conditions and how his boarder who was his caregiver was struggling to keep him clean. He was incontinent throughout the day and night and she did not have sufficient bed linen to change. A discussion took place amongst the group who decided that they would go around to their neighbours and collect old sheets, etc and take this to C Africa's house to be forwarded. Z Losper suggested that she would contact Sr Frances to request incontinent sheets as well.
Action: All volunteers and Z Losper.

4. It was decided to give the volunteers who did not attend the meetings a tea on 7 October 1993 at 2.00pm in appreciation

for the work they were doing. Each person to bring a plate of snacks.
Action: All.

DATE OF NEXT MEETING	**7 OCTOBER 1993** **2.00pm** **MPC BOARD ROOM**

PRESENT:

G Hindely - Volunteer Coordinator and Chairperson
M Futter - physiotherapist and Minutes
T Nicholson - student
C George - student
S Hilano - volunteer
J van der Speck - volunteer
M Gerbach - volunteer
Z Losper - volunteer
S Dames - volunteer
G James - volunteer
C Africa - volunteer

MANENBERG HEALTH PROJECT

MINUTES OF MEETING HELD AT THE MPC ON 23 NOVEMBER 1993.

PRESENT: As per attached list.

APOLOGIES: F De Vries

OBJECTIVES OF MEETING:

1. To coopt Sr Frances as a representative of the Community Health Nurses.
2. To evaluate the past year's progress.
3. To plan for next year.

1. R Hindley welcomed Sr Frances to the meeting and gave a brief historical summary and report of the progress of the project for her benefit.

S Frances indicated the possibility of involving the 4 local community health nurses who would liaise and assist the volunteers with their respective areas. She would consult with the nurses about this on Friday 26 November 1993. She agreed to be available to serve on the Health Care Project Committee.

She report that a survey was being undertaken re primary health care needs by the CTCC. Every 13th home in Manenberg would be visited. The survey did not include the disabled.
Action: Sr Frances to contact Health Nurses.

2. Progress over the last year included G Hindely becoming the Volunteer Coordinator in June 1993. The UCT physiotherapy department had done 296 visits to date. The number of volunteers had dropped from 11 to 3 people. Reasons suggested may be the heavy physical work involved and many of the volunteers had been older women. Experience was also proving that the best option was to coop the neighbours as volunteers.

Other achievement included volunteers organising the installation of rails, a monkey chain, acquisition of wheelchairs and a Movieland donation of a video contract for funds.

3. Planning for next year. After lengthy discussion on the priority for next year it was decided that it was the need to employ a coordinator early in the year if the project was to succeed. The clinic could assist with recommendations of suitable people from the community when the time came for selection.

Criteria suggested for a suitable candidate included:

- she should be in her early thirties
- have good interpersonal skills
- an ability to perform basic administration tasks
- have a knowledge of the local resources
- be respected by the community
- have an ability to train volunteers
- have a drivers license

Training of the coordinator would be done on the job provided through home visits. Hours would be from 8.30 to 12.30 from Mondays to Fridays. The salary would be just below the tax deductible level.
Action:
*** R Hindley to contact IDT for funding. M Futter to be available for a meeting with the IDT.**
*** M Futter to provide an up-to-date list of disabled persons.**
*** G Hindley to provide a list of volunteers and renew video contract.**

4. To be discussed next meeting: funding for repairs to the many wheelchairs disabled have in the community that are malfunctioning. Repairs are small, but very expensive.

DATE OF NEXT MEETING	**25 January 1994** **2.00pm** **MPC BOARD ROOM**

PRESENT:

R Hindely - Chairperson
G Hindely - Volunteer Coordinator
D Bubb - Occupational Therapist and Minutes.
M Futter - Physiotherapist
S Hilano - volunteer
A Morris - volunteer
J van der Speck - volunteer
M Gerbach - volunteer
M Lewis - volunteer
Z Losper - volunteer
M Domeros - volunteer
S Dames - volunteer
A Foutin - volunteer
F Magreman - C Africa - volunteer
C Africa - volunteer

VOLUNTEER SUPPORT GROUP

MINUTES OF MEETING HELD AT THE MPC ON 2 JUNE 1993.

PRESENT: As per attached list.

APOLOGIES: R Hindley.

OBJECTIVES OF MEETING:

1. To discuss problems arising from home visits.

2. To "match" new disabled on the programme in need of assistance with volunteers at meeting.

1. **MATTERS ARISING FROM PREVIOUS MINUTES:**

1.1 Mrs Lewis was not comfortable doing visits to Mr M's house alone. She did not like the area in which he lived and did not trust the boarders in his house. She felt it was unsafe for a volunteer to go there on her own.
Action: Mrs Olkers to accompany Mrs Lewis in future.

1.2 Mr Leach's rails have been partially installed, but the CTCC have done only 1 rail as the job card only stated 1 rail. Job card needs to state 2 rails and then the job will be completed.
Action: G Hindley.

2. M Futter presented a short "icebreaker" with different coloured balls of wool to demonstrate how communication takes place in a community and how certain members get left out and what their feelings are when this happens.

3. G Hindely presented 3 more names of volunteers from the church. She had also been in contact with 2 Moslem ladies who are very keen to join the group.

4. M Futter gave 4 new names of severely disabled persons whose caregivers were not able to cope and would appreciate and benefit by volunteer assistance. A discussion took place on who was going to take them on and it was decided that volunteers closest to the addresses given would do the initial visits.
Action: Mrs Domerog and Mrs Rossouw.

5. Next meeting will be a discussion on how the group can go about fundraising to have funds available for odd events that they meet. For example, when Mrs Olkers visited Mrs K she had no food in the house as her husband had been jailed and she had no income and 3 small children and her disabled mother to care for. She would have liked to be able to buy some bread and milk for them.

DATE OF NEXT MEETING **4 August 1993**
2.00pm
MPC BOARD ROOM

PRESENT:

G Hindely - Coordinator and Chairperson
M Futter - physiotherapist and Minutes
T Nicholson - student
C George - student
S Hilano - volunteer
J van der Speck - volunteer
M Gerbach - volunteer
Z Losper - volunteer
S Dames - volunteer
G James - volunteer
C Africa - volunteer

UNIVERSITY OF CAPE TOWN

PHYSIOTHERAPY DEPARTMENT

MANENBERG VOLUNTEER PROJECT

QUESTIONNAIRE C

NAME: ....

ADDRESS: ....

....

TELEPHONE NO.: ....

DATE OF BIRTH: ....

RELIGIOUS AFFILIATION: ....

DO YOU LIVE IN THE SAME BLOCK OF FLATS AS THE CAREGIVER? YES/NO

IF NO, HOW FAR AWAY DO YOU LIVE? ....

WHY DID YOU BECOME A VOLUNTEER? ....

....

....

....

FOR HOW LONG HAVE YOU BEEN VISITING YOUR CAREGIVER? ....

HOW MANY TIMES PER WEEK DO YOU REGULARLY VISIT? ....

HOW LONG DO YOU SPEND AT EACH VISIT? ....

....

WHAT TYPE OF ASSISTANCE DO YOU GIVE? ....

....

....

....

DO YOU THINK YOU HELPED THE CAREGIVER? YES/NO

IF YES, IN WHICH WAY? ....

....

....

HOW WOULD YOU DESCRIBE YOUR RELATIONSHIP WITH THE CAREGIVER?

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....

HOW WOULD YOU DESCRIBE YOUR RELATIONSHIP WITH THE DISABLED?

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WHAT DO YOU FEEL ABOUT THE PROJECT IN GENERAL?

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....

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HOW DO YOU THINK THE PROJECT COULD BE IMPROVED?

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MJ FUTTER
1993

UNIVERSITY OF CAPE TOWN

B.Sc (PHYSIOTHERAPY)

111 YEAR

PTH309Z HEALTH SCIENCES: COMMUNITY PHYSIOTHERAPY

1993

Coordinator : M J Futter
Times : Mondays/Wednesdays 13h00 - 15h30

Course Objectives:

At the end of the course the student will be able to:

1. Understand the underlying philosophy of primary health care.
2. Know the different levels of health care with special reference to physiotherapy.
3. Establish community health needs with special reference to physiotherapy by means of a community diagnosis.
4. Arrive at a community diagnosis.
5. Determine physiotherapy objectives in a specific area.
6. Plan and implement a simple community physiotherapy programme.
7. Understand the importance of programme evaluation and record keeping.
8. Be sensitive to the needs of communities.
9. Be aware of the need for developing community partnerships.
10. Be motivated towards a positive attitude to community work.

COURSE SCHEDULE

The course content will be presented by means of workshops, guest lecturers and a community visit and will cover Primary Health Care, Rehabilitation and Community Participation and Development.

Workshop 1

Definitions of health, quality of life, medical and bio-psychosocial models of health, Alma-Ata declaration, Primary Health Care, implementation strategies, levels of prevention, patterns of health care, National Health Goals for South Africa.

Workshop 2

Definition of community, functions of communities, community diagnosis, types of data relevant to a community diagnosis, sources of information, steps in conducting a community diagnosis.
Concept of social needs, Maslow's Hierarchy of Needs, causality of needs, techniques of needs assessment.

Workshop 3

Visit to Manenberg People's Centre.

Workshop 4

Types of data relevant to a Community Diagnosis
Differences between Community-based physiotherapy and institution-based physiotherapy.
Differences between Community Physiotherapy and Physiotherapy in the Community.
Community Physiotherapy:

- philosophy
- target population
- role of physiotherapist
- attitudes required of community physiotherapists
- principles
- planning
- resources
- implementation
- advantages
- evaluation.

Workshop 5

Community Participation, community development, how rehabilitation relates to community development.

Workshop 6

Physiotherapy Assistants and Community Rehabilitation Workers, examples of Community Physiotherapy projects.

Guidelines for writing a project on community physiotherapy.

ASSIGNMENT

1. This is a group assignment and a group mark will be awarded to each member.
2. All members of the group must participate and should meet regularly to discuss the assignment.
3. Students are to assign themselves to groups of not more than four (4) in a group.
4. The assignment should be a succinct and scholarly presentation.
5. **Length:** maximum of 12 typewritten pages using double spacing.
6. The Harvard style of referencing should be used.
7. Use the references given and any other that may be of relevance to your particular assignment.
8. **Due date: 5 September 1993**

Assignment:

Choose any local `community'. Give a community diagnosis and define the target population. Plan and develop a small physiotherapy programme related to your findings in the needs assessment.

The programme must be practical.

The assignment should be a succinct, scholarly paper presented in a precise and logical manner.

N.B. This assignment will contribute 100% towards the PTH309Z Health Sciences: Community Medicine course. It will need to be redone, if unsatisfactory, before progressing to 1V Year.

UNIVERSITY OF CAPE TOWN

PHYSIOTHERAPY DEPARTMENT

MANENBERG HEALTH CARE PROJECT

ROTATION OBJECTIVES

1. Assess the client's ability to function effectively and safely in his/her own home.
2. Enable the client to achieve his/her maximum level of physical function.
3. Teach the caregiver how best to assist the client to function to his/her maximum ability.
4. Teach the caregiver how to handle the client in order to minimise his/her personal involvement.
5. Make recommendations o increase the client's independence at home.
6. Identify where volunteer assistance would be beneficial.
7. Provide training for the volunteer where necessary.
8. Encourage volunteers to attend Caregiver Support Group meetings 15h00 on the first Thursday of the month.
9. Encourage caregivers to attend Caregiver Support Group meetings 15h00 on the first Thursday of the month.
10. Encourage client's exposure to the community at large.

MJ FUTTER
1993

UNIVERSITY OF CAPE TOWN

PHYSIOTHERAPY DEPARTMENT

MANENBERG COMMUNITY ROTATION

EVALUATION OF BLOCK BY STUDENTS

1. What aspects of this block did you enjoy and/or find beneficial?

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2. What aspects of this block did you **not** enjoy?

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3. How did you feel about working in this community **before** you started the block?

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4. How did you feel about working in this community by the **end** of the block?

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5. Did your Community Workshops in 1992/3 prepare you adequately for this rotation? Yes/No

If No, state reasons:

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6. What suggestions can you make to improve the programme for the clients and their caregivers?

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7. What suggestions can you make to improve the block for the benefit of the students?

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UNIVERSITY OF CAPE TOWN

DEPARTMENT OF PHYSIOTHERAPY

ASSESSMENT OF STUDENT'S CLINICAL WORK

tudent's name .... Period worked: From........to........

ear of study (place X in square) Place worked: ....

nd yr ☐ 3rd yr ☐ 4th yr ☐ Clinical staff in charge ....

....

Notes on completing this form

Do not be afraid to give a high or low assessment where it is deserved. You have a responsibility to discuss with your students their shortcomings. It is WRONG and UNFAIR to let students drift on in the mistaken belief that they are giving satisfaction.

Key: E - Excellent; G - Good; S - Satisfactory; U - Unsatisfactory

Performance of treatments

	E	G	S	U	
Always applies theoretical knowledge intelligently					Generally fails to apply theory intelligently
Carries out practical techniques well					Practical techniques poorly carried out
Work is done with attention to detail					Insufficient care given to detail
Performs treatments safely					Does not perform treatments safely
Is responsible ie can be relied upon to carry out instructions					Unreliable unless closely supervised
Is observant of the patient in all respects					Unobservant of patient in all respects
Reports relevant findings					Omits to report relevant information
Keeps good, accurate records					Record keeping poor
In summary, carries out treatments well for a student at this stage of training					Performs treatments poorly for a student at this stage of training

omments:

II Application to work

	E	G	S	U	
10 A keen and willing worker					Half-hearted and indifferent
11 Eager to extend theoretical knowledge					Appears to lack interest in extending theoretical knowledge
12 Eager to improve practical skill					Appears to lack interest in improving practical skill
13 Shows quickness in grasping the importance of essentials					Often fails to grasp the importance of essentials
14 Work is done promptly					Often slow and tends to hold up work

Comments:

III Attitude to patients

	E	G	S	U	
15 Treats patients as individuals, not 'cases'					Does not treat patients as individuals
16 Shows some ability in gaining cooperation of patients					As yet, lacks ability to gain cooperation of patients

Comments:

IV Attitude to colleagues

	E	G	S	U	
17 Cooperative and considerate in dealings with other staff members and colleagues					Uncooperative and inconsiderate in dealings with other staff members & colleagues
18 Responds readily to guidance and instruction					Appears reluctant to accept advice or instruction

Comments:

V Professional behaviour

	E	G	S	U	
19 Takes care to appear neat and well groomed					Careless of appearance
20 Unruffled in all circumstances					Easily 'upset'

Comments:

....

DATE SIGNATURE