

FREEDOM OF ACTION
SIGNIFICANT FACTORS FOR DISABLED PEOPLE

A dissertation presented for the degree

M.Sc (Occupational Therapy)

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ABSTRACT

The overall purpose of the study was the identification of factors which influence the freedom of physically disabled people, within South African society, to make choices that will enable them to conduct their daily lives independently. Qualitative research methods (observation and semi-structured interviews) were utilised to explore the problem from the disabled person's perspective. In total there were ten participants, sampling being purposive and opportunistic. The study was essentially narrative, with the results analysed and grouped thematically.

Factors influencing independence related to the individual's functioning, as well as the social environment and the study's setting in Mitchells Plain, Cape Town. The relative strength of each factor varied at any one time for a given subject, and between the respondents. Overall there was strong agreement amongst participants and with the literature. Recommendations made related to future research, student training and occupational therapy practise.

LIST OF ABBREVIATIONS

A.D.L.	Activities of daily living
C.B.R.	Community-based rehabilitation
C.I.L.	Center for Independent and Integrated Living
D.G.	Disability grant
D.P.S.A.	Disabled People of South Africa
H.I.	Home industry
I.L.	Independent Living
I.L.C.	Independent Living Center
I.L.M.	Independent Living Movement
L.O.C.	locus of control
O.T.	Occupational therapy
P.C.A.	Personal care assistant
P.H.C.	Primary health care
Q.O.L.	Quality of life
S.C.I.	Spinal cord injury
S.H.A.P.	Self Help Association of Paraplegics
U.C.T.	University of Cape Town
W.H.O.	World Health Organisation

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CHAPTER ONE: INTRODUCTION

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CHAPTER ONE

1. INTRODUCTION

Independence in occupational performance tasks is the goal of rehabilitation in general and occupational therapy in particular (Trombly, 1983). This spans the individual's capabilities in self care activities, work, social and leisure time pursuits. When the person is permanently disabled, occupational therapists assist the individual to compensate for his/her losses through the use of adaptive techniques and/or equipment in order to promote optimal functioning. Attention is also given to the psychological needs and adjustment of the disabled person and the re-establishment of a satisfactory lifestyle (ibid., p333).

Banja (1988) has suggested that independence may constitute the ideal rehabilitation outcome (a discussion of the dimensions of independence will follow, see paragraph 6). Certainly any short term gains in rehabilitation can only be truly meaningful if they contribute to independent living and ultimately to the quality of life of the individual. Occupational therapy has a great deal to offer because it strives to affect the quality of life of the individual in a positive way: taking an holistic approach to treatment, therapy aims include teaching adaptive techniques in all major occupational domains of the person's life. Involving patients as active participants in treatment by giving them choice has also been of central importance to the profession since its inception (Rice and Nelson, 1988). Occupational therapy thus promotes the freedom of individuals to act in ways that will benefit their own health and well being.

Traditionally in rehabilitation independence has been equated with the ability to execute so-called "activities of daily living" without assistance. Reviewing the literature has highlighted that it is much more than being able to perform certain tasks.

Lifchez and Winslow (1979) have described independence as a term applied to living a self determined lifestyle; not reduced in any sense by physical dependence upon other individuals or environmental aids. When examining long term outcomes of disability, two variables have been reported by DeJong and Hughes (1982) as being significant for independent living. These are living arrangements (presented as a continuum, from living within an institution, to living with parents and family, to living alone) and productivity. Productivity refers to holding down a regular job, as well as completing housework, voluntary

work, and participation in active leisure and social pursuits. This can be equated with Jagoe and Du Toit's definition of independent living. They see it as "a situation of managing one's own affairs (for the disabled person, this is to the same extent that the able bodied individual manages his), and of active participation in the community" (Jagoe and Du Toit, 1983, p6).

In a study carried out by Rock (1988), six disabled people were interviewed in depth regarding their pre and post institutional living experiences. The intention was to test the hypothesis that independence is an infinitely variable concept, unique to the individual, which concerns control and choice rather than any (objective) absolute measure of competence. Key concepts which emerged included risk taking, privacy, decision making, organisation and control. Independence for these people quite clearly involved choice, control and power in and over the management of their lives and the environment in which they lived.

For the purposes of this study then, independence is seen as the freedom of choice the person has in designing and executing his lifestyle. The essence is not whether the disabled individual needs help, but whether he can take charge of the assistance given. He can thus live his life in the way that he chooses. Of equal importance is that the individual must be living in the least restrictive environment, and be actively involved in community life.

A concept of independence wherein an individual is encouraged to determine his own best interests carries with it important implications. Firstly, the individual must have the cognitive ability to make significant decisions about his life. Banja (1988) has said that for those disabled persons who are in some way cognitively impaired (eg central nervous system pathology), independence will mean becoming more responsible and self reliant in carrying out daily tasks. It will not necessarily include the potential for "self actualisation".

Secondly, the individual must have the opportunity to exercise freedom of choice. Exposure to pertinent information is needed in order for a choice to be made. For example, if the individual is to organise his own free time, he needs to know what leisure pursuits are available. The relationship between socioeconomic circumstances and the level of participation in society is therefore crucial. A certain degree of economic and social well being is a prerequisite

before one can even contemplate participation in the community (United Nations Decade of Disabled Persons, 1986).

1.1. RATIONALE FOR THE STUDY

Occupational therapy (O.T.) involves the treatment of man in totality, through active participation in purposeful activity (Trombly, 1983). In South Africa there are few post structures within the community and virtually no rehabilitation centers (Concha, 1991), thus the majority of therapy takes place within a hospital context.

For the disabled person to attain optimal functioning a graded programme initially emphasising guidance and support at or near the time of injury to increasing autonomy and responsibility as the individual re-settles in the community would be ideal. However within the present economic realities of the country, where hospital expenditure has increasingly been cut, patient turnover is at a premium and in a general hospital such as Groote Schuur Hospital (a tertiary institution in Cape Town) the minority of patients stay longer than a few days (Claxton, 1990). Under such circumstances it is not always possible to provide the traditionally balanced and comprehensive O.T. programme designed to meet the individual's physical and psychosocial needs.

In addition, prolonged out-patient treatment is difficult because patients can ill afford to pay for hospital services and public transport (*ibid.*, p2). Therefore disabled people return, largely without the benefits of adequate rehabilitation and thus potentially ill equipped, to their home environments.

An area of particular concern is the large number of people who draw disability grants. In 1989, there were 15,095 so-called coloured persons living in the Southern Cape Peninsula who were receiving disability grants (South African Association of Occupational Therapists, Western Cape, undated). The majority of these people were dependent, unproductive, and had not had access to rehabilitation. Cock describes these people as "... exist(ing) at the margins of our social and economic life" (Cock, 1988a, p7).

Many believe that the best rehabilitation stems from high standards of general medical care. Within the literature this view is heavily disputed. Nichols (1979)

contends that this is inadequate if the care and counselling do not extend into the social and community aspects of the patients' lives. Jagoe and Du Toit (1983) have stated that only once the disabled person returns to his home and community environment are the full implications of the disability discovered (p6). It is at this stage, well beyond the hospitalization period, that the individual adjusts to his disability and issues of re-integration into the community thus become pertinent. As the majority of South African O.T. services are hospital based therapists would seem then largely unavailable to support the disabled person in a most critical phase following his/her injury.

Cock (1988a) has documented a situation of extreme and urgent unmet needs amongst the spinal cord injured people living in Soweto. She has said that "this would be an extremely depressing picture were it not for the individual qualities of resilience, strength and courage that also emerge from this social context" (p14). DeJong has previously stated that co-operation with professional rehabilitation services is not a prerequisite for independent living. He had noted that "very severely physically disabled persons were achieving independence without the benefits of, or in spite of, professional rehabilitation" (ibid, 1979, p442). What then, allows some disabled people to overcome their difficulties despite many hindrances? What determines the difference between success and non success?

This study is not concerned with independence per se. Rather, its objective is to identify factors which influence the freedom of disabled people to make choices that will enable them to live independently. Are disabled people in South African society free to make decisions that allow them to take on the major responsibility for determining their lifestyle? Are they free to act there-on and thus retain autonomy? Over what areas of their lives do they feel they have control and in what way? By examining what they are doing to manage their lives; that is what choices they are able to make and are making, it is hoped that an understanding of disabled people's experience of their disability can be gained. As called for by primary health care approaches, consumer perspectives can then be incorporated into planning future O.T. services.

If it were possible to determine factors leading to independence, then these measures of success could be used in rehabilitation by groups of disabled people. Knowledge of these factors could help O.T.'s (and others) to develop realistic

goals and strategies with their clients to enhance the potential for independence. Meaningful directions for future O.T. services could thus also be planned.

While reviewing the literature it has been noted that much of the research completed is disability specific. Studies usually focus on one diagnostic group, for example spinal cord injury, stroke, arthritis. This is also seen in services offered for the disabled, for example specific pensions for the blind, support groups for multiple sclerosis versus muscular dystrophy sufferers, and separate protected workshops for the mentally handicapped or cerebral palsy school leaver. Oliver and Zarb (1989) have commented that this fosters artificial divisions in the disabled population, resulting in different groups of people who are unable to coalesce with other disabled people on common issues. This increases the likelihood of the disabled remaining powerless and marginalised. In this study then, people who had a physical disability were considered as one group; subjects were limited to those with motor disability but no further subdivision in diagnosis was made.

Finally, it was an objective of this study to examine the above from the disabled individual's perspective. Several authors have made reference to the need for exploration of the "insider's" view of being disabled (Kielhofner, 1982b; Merrill, 1985; Krefting, 1989). This is in line with what Jagoe, herself disabled and a leader in the South African disability rights movement, has said: "... we know best what our needs are. We are experts in the field of disability..." (Jagoe, 1986, in Cock, 1988a, p14).

1.2. STUDY OBJECTIVE

The overall purpose of the study was the identification of factors which influence the freedom of disabled people, within South African society, to make choices that will enable them to conduct their daily lives independently. Pertinent questions to answer were:

- 1) What control does the disabled individual feel he/she has over his/her life circumstances?
- 2) What opportunities do disabled people have to take decisions about their lives?
- 3) Given choice, how does the disabled individual conduct his/her life?

As is common in qualitative research methods (Merrill, 1985), broad research questions were set. It was anticipated that once data collection and analysis were proceeding, the focus would be narrowed.

1.3. STUDY AIMS

- 1) To identify factors which heighten the disabled person's potential for achieving independence.
- 2) To generate specific hypotheses (factors enabling disabled persons to be independent) for testing in a quantitative study.

1.4 DEFINITION OF TERMS

IMPAIRMENT: Any loss or abnormality of psychological, physiological or anatomical structure or function (W.H.O., 1980, p207).

DISABILITY: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (W.H.O., 1980, p207).

HANDICAP: A disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal (depending on the age, sex, and social and cultural factors) for that individual (W.H.O., 1980, p207).

DISABILITY PREVENTION: This includes all actions taken to reduce the occurrence of impairment (first level prevention), its development into disability (second level prevention) and to prevent the transition of disability into handicap (third level prevention) (W.H.O., 1981, p9).

REHABILITATION: This includes all measures aimed at reducing the impact of disabling and handicapping conditions, and enabling the disabled and 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 themselves, their families, and the communities they live in should be involved in the planning and implementation of services related to rehabilitation (W.H.O., 1981, p9).

COMMUNITY-BASED REHABILITATION: Measures taken at the community level to use and build on the resources of the community, including the impaired, disabled, and handicapped persons themselves, their families and their community as a whole (W.H.O., 1981, p9).

EMPOWERMENT: Process by which disadvantaged people work together to increase control over events that determine their lives (Werner, 1988).

OUTCOME: This refers to the consequence, result or impact of an event or situation. It may be an intended or unintended result (Department of National

Health and Welfare and the Canadian Association of Occupational Therapy, 1989, p9).

INDEPENDENCE: Freedom of choice; being able to make independent decisions; the ability to take on the major responsibility for determining one's lifestyle (Roget's Thesaurus, 1988, p332).

INDEPENDENT LIVING: The ability of an individual to take charge of his/her own life by living in the least restrictive environment that will allow him/her to make significant contributions to family and community life. This includes, if appropriate, securing and maintaining employment (DeJong, 1981).

CHOICE: Exercising one's discretion; opt for; taking up an option (Roget's Thesaurus, 1988, p256).

QUALITY OF LIFE: Attention is focused on the social and psychological being: the individual's performance of social roles, his/her mental acuity, his/her emotional state, his/her sense of well-being and his/her relationships with others (Levine, 1987, p4).

CHAPTER TWO: REVIEW OF THE LITERATURE

Section One:

- 2.1 Approaches to disability
- 2.2 Access to health services
- 2.3 Professional-disabled person relationship
- 2.4 Self help

Section Two: Outcome

- 2.5 Quality of Life
- 2.6 Disability outcome

Section Three: Independence

- 2.7 **Functional Independence**
 - 2.7.1 Technology
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 - 2.9.4 Socioeconomic conditions
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 - 2.9.6 Leisure

CHAPTER TWO

2. REVIEW OF THE LITERATURE

The review of the literature was organised into three main sections. Section one dealt with issues of rehabilitation and differing approaches to disability. An attempt was made to focus on the South African context as much as possible. The next division gave attention to the outcome of disability, defined as the impact, or consequences thereof (Canadian Association of Occupational Therapists and the Department of National Health and Welfare, 1987). The last and most detailed section examined functional, psychological and social independence.

The majority of the literature reviewed was international in origin. In comparison there seemed to be a paucity of research available locally around the above mentioned topics. Published material of the W.H.O. (1976, 1981) and the United Nations (1983, 1986) was first read to orientate the author to current trends and thinking in the provision of services for people with disabilities. Information pertaining to independent living was most frequently found in the American literature; British authors also contributed substantially to the data gathered.

It was noted that in a large number of research studies reviewed the study populations were limited to spinal cord injured persons. This was not ideal as the present study was multi diagnostic in approach and therefore information about a wide range of disabilities was sought. Despite the breadth of the review's sources, the bias remained.

Initially literature pertaining specifically to occupational therapy was gathered as this was the background of the author and the discipline in which the study was undertaken. Thereafter the focus was expanded to include material found in medical journals as well as the social sciences. Information published by disabled people or written from their perspectives was also included in the review.

SECTION ONE

2.1 Approaches to Disability

The prevalence of disability has been estimated variously. The W.H.O. has estimated that 10% of any one country's population may be adversely affected by disability; this increases to 25% if the care and support given by families is included in the calculation. Furthermore, evidence suggests that the prevalence of disability may be higher in third world countries than in first world situations as a strong relationship appears to exist between disability and socio-economic situations. It has been stated that "the highest incidence of disability is found among the underprivileged" (W.H.O., 1976, p69).

The potential benefits of appropriate intervention have been viewed as an improvement in the duration and quality of life for the disabled individual. Rehabilitation also strives to increase the contribution that people with disabilities can make to their community and to decrease the need for caregivers.

Attempts to assess the impact of disability on the lives of disabled persons can be found in the literature. Concepts such as health status, functional status, well being, quality of life and life satisfaction are receiving increasing attention as end points to rehabilitation (Burckhardt, 1985; Decker and Schultz, 1985; Kirchman, 1986; Yerxa and Baum, 1986; Crisp, 1990). It appears that outcome parameters are being expanded beyond survival information and biological data into subjective and behavioral areas.

Traditional concerns of rehabilitation practise and research have emphasized the retraining of disabled people in the execution of so-called "activities of daily living" (A.D.L.), much of which focused on self care. Attention has thus been placed upon treating the functional limitations of the individual. A programme which concerns itself primarily with A.D.L. improvement may be paramount during and immediately after hospitalisation, but this emphasis on acute/restorative care is no longer seen to meet the long-term needs of permanently disabled persons (DeJong, 1979; Acton, 1982; Fuhrer et al., 1990). Increasingly attention is also being placed on the social context in which the disabled person lives, as this is the milieu which largely determines the consequences of disability. This implies taking into consideration the individual's response to his disability, as well as his interaction with family

members and the consequences thereof. Emphasis is given to the psychological and the social adjustments to disability, and to life at home and in the community (DeJong, 1982).

This approach to disability has been emphasised with the growth of the Independent Living Movement (I.L.M.). The core of this movement's philosophy is that disabled persons have both the capacity and desire to be self directing and independent in all aspects of their lives (Cock, 1988a, p44). Two main themes characterise the movement, which started as a product of a number of contemporary social movements in the United States in the 1970's. These are control over their own lives for disabled people, and full participation in the life of the community. It has been described as a continuous process of identifying choices and creating personal solutions (Gloag, 1985b, p371).

In contrasting traditional rehabilitation with that of the independent living paradigm, DeJong (1981) found two main differences. Firstly, in the case of the rehabilitation perspective, disability is perceived foremost as a problem of the individual, and the solution as being primarily to eliminate, reduce or compensate for his/her limitations. The locus of the problem is situated in society in the case of the independent living paradigm, which implies a shift away from emphasizing the characteristics of disease to the social implications of the disability. It also suggests the importance of taking into consideration the individual's attitudes to his disability; his interaction with family members and the community; and the socio-economic factors involved.

Secondly, the solution to the problem is conceptualised as lying in professional intervention in the first case, and in self help in the second. The I.L.M. promotes consumer management; concepts that are synonymous with the movement include advocacy, consumer control, and peer counselling. The responsibility for self care and lifestyle management is therefore shifted from the professional to the disabled individual. As Brooks (1984) has pointed out, this also challenges the traditional expectation that disabled people cannot understand their own conditions or manage the arrangements necessary to meet their needs (p 407).

The I.L.M. has been criticized by a British author on the grounds that it seems to represent only young, intellectually able, white people and that it's emphasis on disabled people's rights ignores economic and political realities (Williams, 1983, p1003). Ben-Sira (1983), a researcher in Israel, has suggested that the movement

is peculiarly suited to an achievement and self-orientated society. Nevertheless, its basic philosophy, which is for disabled people to devise and control their own lifestyles within the scope of their limitations and thus promote autonomy, would seem pertinent to all.

DeJong's perspectives on rehabilitation and independent living appear to correspond with what Finkelstein (1980) and Oliver (1983) have conceptualised as the individual and social models of disability. Jongbloed and Crichton (1990), in examining policy regarding disability in Canada, noted that an individualistic approach to disability had been replaced by a socio-political definition. Although these authors utilise different terminology, all stress the need to move away from focusing on the physical limitations of particular individuals. Rather, they advocate emphasizing the way in which the physical and social environments impose limitations upon certain groups or categories of people. They therefore imply that disability stems from the failure of the environment to adjust to the needs of disabled people and not from the inability of the individual to adapt to societal demands. Discriminatory attitudes and public prejudice have also been viewed as central problems confronting disabled people (Finkelstein, 1980; Jongbloed and Crichton, 1990). Equally important are environmental barriers such as poor access to transportation and inaccessible housing; discrimination in income, education and employment opportunities (Brown, Gordon and Ragnarsson, 1987; Jagoe, 1987).

The realisation of the importance of the environment and of society as factors of handicap is a relatively new phenomenon. DeJong (1981) has suggested that rehabilitation professionals have lagged behind in this because they do not remain intensely involved with the patient beyond the post injury stage. This may be particularly true for occupational therapy services in South Africa where there are few structures for posts available within the community. Two therapists with experience in community based rehabilitation in Cape Town did indeed find that social problems affecting financial security and interpersonal relations in the home could not be ignored when aiming towards independence in all spheres of a person's life (Cameron and Rendall, 1990).

It would seem clear then, that in order to improve the status of the disabled person, attention must be given to the external environment. However, it is questionable whether the occupational therapist's focus should lie with the removal of environmental constraints as urged by independent living advocates, or with the individual's functional and economic skills, as recommended by

rehabilitation professionals. Further research will need to establish what interventions, or combinations of interventions, are most likely to advance the ability of disabled persons to live independently.

2.2 Access to Health Services

Health information has been stressed as one of the main issues to address in the provision of better health for the Third World (Osiobe, 1989, p9). This is supported by Hadingham (1983) who, in examining the needs of the disabled person in the family and in the community, equated knowledge with power (p 40).

In reality not all those needing assistance will at present receive it. Acton (1982) has documented a growing disparity between the number of disabled people who need help, and the facilities available to them (p 147). Several studies specific to South Africa have shown that the disabled population have limited access to medical services, their lives being characterized by poverty and isolation. In 1986 Disler examined the contact that motor disabled people living in certain areas of Cape Town had with health and welfare services. He found that of those living in Bishop Lavis, only 22% had any contact (this was usually with nursing personnel and/or social workers). Eighty percent of motor disabled persons living in Nyanga had no contact with these services. In an earlier study evaluating the care received by non-institutionalised chronically ill persons in the municipality of Cape Town, Dick et al (1978) asked the question: "Are the right people receiving the right care from the right services at the right time?". They concluded that the answer was frequently no, with only 26% of the study participants considered to be receiving optimal care. Cock (1988a) focused on paraplegics living in Soweto, and also found that few participants had access to medical supervision or health knowledge. She concluded that the physically disabled people were discriminated against at both these levels. The author also pointed specifically to the paucity of accessible services with an acceptable standard of care available to the country's Black community, stating "Most black hospitals in South Africa are characterised by overcrowding, inadequate staffing and inadequate resources" (ibid., 1988a, p13).

A manpower shortage of occupational therapists in South Africa has been highlighted by Concha (1990). Taking a disability prevalence of 10% (W.H.O.

1981), the number of black disabled people living in the Southern Transvaal region was estimated. By looking firstly at the number of occupational therapists working within the region (hospital services only), and secondly statistics recording the number of patients treated per month, it was estimated that only 3% of the total disabled population were seen in one year. If just one third of these disabled persons needed occupational therapy services, the percentage being treated at that time marginally improved to approximately 9%. A separate memorandum outlining the situation with regards rehabilitation posts and personnel highlighted the lack of rehabilitation facilities and the scarcity of therapists specifically in the rural areas of South Africa (Rural Disability Action Group, 1987). Again using a disability prevalence of 10%, and the percentage of filled posts in the ten "homelands", a therapist/disabled population ratio of 1:51 000 for occupational therapy and 1:30 000 for physiotherapy was calculated.

It is apparent then, that existing services in South Africa effectively reach a small proportion of the people in need. They are inadequate and within the current financial climate, are likely to remain so for sometime. The manpower shortage is also evident. According to Hammerman (1981), "...even if the entire (world) health budget were to be used for rehabilitation alone, it would take 200 years to achieve the desired result" (United Nations Decade of Disabled Persons, 1986, p 39). Clearly it is necessary to examine all possible and available resources that can be utilized to reach realistic goals together with disabled people.

Occupational therapy in South Africa is faced with the challenge of contributing to the provision of effective, efficient services to all those who are in need of them so as to reach the goal set by the W.H.O., health for all by the year 2000 (W.H.O., 1981). Haynes (1991), an occupational therapist working in the rural areas of Kwazulu, has suggested that the solution is the adoption of the W.H.O. strategies of Disability Prevention and Community Based Rehabilitation (for a definition of terms, see p7). This is in keeping with the current health service emphasis on Primary Health Care, through the use of community-based rehabilitation (C.B.R.). Concha has also stated: "We [occupational therapists] have got to go where the patients are - and that is not in the hospitals" (Concha, 1990, p 9).

C.B.R. is characterized by principles of community level initiative and participation, and family responsibility (W.H.O., 1981). Aiming at social

integration then, rehabilitation takes place within the individual's natural environment and within the home. It is also recognised that important resources exist within the family of the disabled person and his community. This suggests that the occupational therapist should include the individual's support systems in all treatment sessions to ensure carry over into the home. On a more formal level, family and community members are trained as health workers to take care of their own disabled, using local technology and skills. These natural human resources can greatly reduce the demands of professional service systems (Acton, 1982, p 147). The staffing of services by personnel whose training is not as lengthy, expensive or academically demanding as the "medical experts" can also increase the cost effectiveness of C.B.R., and it can contribute to the solution of the manpower crisis (Wasserman, 1986; Keet et al, 1990). In addition, the decreased reliance on professional intervention may contribute substantially to increasing the community's autonomy.

2.3 Professional - Disabled Person Relationship

Disabled individuals have frequently criticized the "sick-role" they are expected to assume in the health professional-patient relationship (Finkelstein, 1980; DeJong, 1981; Sutherland, 1981; Oliver, 1983; Cock, 1988a). When left out of the decision making processes, they see themselves as being forced into passive dependent roles which decreases the ability to function independently. Another way in which professionals are seen to reinforce their client's dependency is by keeping exclusive knowledge for the solutions to the physical and social problems which may confront disabled people. This would seem particularly true of the attitude towards the professionals held by Disabled People of South Africa (D.P.S.A). One spokesperson of the organisation said, "we are no longer accepting the inferior passive role of the recipient" (Jagoe, 1987, in Cock, 1988a, p50). These perceptions appear to have resulted in an "us" (disabled people) versus "them" (professionals) situation, with little genuine listening between the two parties.

Information passed on to disabled people concerning the disabling condition, possible treatment or rehabilitation, and practical input on coping strategies can clearly be an important resource to the individual. The Royal College of Physicians (1986) has stated that once presented with sufficient information, the individual can choose a certain course of action, and thus retain autonomy (p 162). The health professional has also been seen as a potential resource which

the disabled person may choose to utilize in order to enhance independence (Williams, 1982). In this instance, "dependence" on the professional for help may not necessarily lead to loss of autonomy in daily life but rather enhance the potential for independence.

What seems to be crucial then, is the nature of the client-professional relationship. Several studies have shown that disabled people and professionals may differ in their understanding of perceived needs and thus their expectations of the outcome of rehabilitation.

A study by Potts et al (1984), concerning a treatment programme for arthritis, showed that patients were concerned with financial problems and education, whereas the providers emphasized sexual counselling and drug treatment. Other studies have also highlighted this paradox (Thomas and Lyttle, 1980; Jaeckel et al, 1986). The disability rights movement would argue that the disabled person himself is an "expert", and that his identified needs are as important and appropriate as those perceived by the professional. Therefore, in order to achieve patient satisfaction and meaningful outcomes, the disabled person's views may prove most important.

Jago (1987) would also argue for a democratizing of knowledge, where the client and professional are equal partners. This would increasingly give a client-centered focus, which has been described as the "finest essence of rehabilitation" (Meier, 1988, p 11). It would recognise the potential reciprocal nature of the relationship (i.e. the professional may learn as much from the disabled person as the disabled person does from the professional).

The challenge then, is for professionals to give up their monopoly of expertise, knowledge and leadership, and to share information and resources in ways that empower disabled individuals. One way to accomplish this is by involving disabled persons, their families and their communities in planning and implementing services related to rehabilitation. This is recognised by the Primary Health Care approach (United Nations, 1986). A focus on planning and creating services together with the disabled individual would enhance self respect, foster development of initiative, and assist the individual to increasingly accept responsibility for decisions made - all factors which can foster independence. The patient role is then replaced by the consumer role, affording the individual far greater control over his situation.

2.4 Self Help

There are an increasing number of self help groups to which participants are drawn due to the experience of common problems. In the context of disability, the final report of the Mott Foundation of I.L.M. (U.S.A. 1983) defined a mature self help organisation as both a service provider, as well as an advocate for the rights of disabled people in the community (Whitlock and Nkedi, 1989, p1).

Groups may come together because of the recognition of the value in mutual self help and support. The supportive function of a group for people with diabetes has been detailed by Kelleher (1990). The members, by disclosing their feelings about their own experiences, were able to reduce their fears. This was through the recognition that their individual experiences were not unique but were shared by others. They could thus also talk about aspects of having diabetes that they could not easily discuss with others outside of the group setting (eg. doctors, family). Practical advice shared increased knowledge and resources. Robinson and Henry (1977) see the support provided by such groups as giving the individual a feeling of power to cope with his situation.

Some self help groups have begun as a result of disillusionment with existing services, or due to the lack of, or inadequacy thereof. The Self Help Association of Paraplegics (S.H.A.P.) was started by eight paraplegics living in Soweto as a response to the widespread poverty amongst paraplegics within the area (Cock, 1988a). It now functions as a "self-help" factory, providing very practical help through the creation of job opportunities. Several other groups have been started in South Africa as a response to levels of high unemployment (Cameron and Rendall, 1990; Lorenzo, 1991).

A specific form of self help, unique to the disability movement, can be found in the increasing number of Centers for Independent and Integrated Living (C.I.L.'s) being established in many countries. At a most basic level, these offer advice and assistance to the disabled individual in choosing suitable aids/adaptations for everyday life. A wider range of related services (such as peer counselling, transport or attendant care referral) may also be provided (Williams, 1983).

To a large extent, disabled people are exposed to physical, cultural and social barriers which handicap their lives even if rehabilitation is available. According to the Disabled People's International (1981), if problems are environmental and attitudinal in nature, solutions must be "collective self-help" through disabled person's own organisations (United Nations Decade of Disabled Persons, 1986). DeJong and Lifchez have called for "...not more professional intervention but more self-help initiatives leading to the removal of barriers and the full participation of disabled people in society" (ibid., p 31). While these statements perhaps glibly assume that disabled individuals have the financial means to organise themselves and that political or ideological differences can be easily overcome, they do highlight the importance of disabled persons being actively involved in establishing services designed to meet their needs. This allows the individual to retain a degree of autonomy.

While learning and working together, disabled people can combine their power to influence social and political decisions that affect their lives. The South African disability rights movement, Disabled People of South Africa (D.P.S.A.), was launched in 1983. Its aim is "...to fight for equality and full participation (of disabled people) in every sphere of our society. The handicaps which stand as barriers to this are addressed by D.P.S.A. (and member self-help groups)" (Jagoe, 1987, p 33). Founded on self-help principles, D.P.S.A. has grown to encompass over 70 self-help member organisations. It has brought disabled people together, given them an opportunity to view their situation collectively, and has formed a base from which they can take action.

SECTION TWO: OUTCOME

2.5 Quality of Life

Enhancing the quality of life (Q.O.L.) of the disabled individual in the context of his support group and environment has been seen as a fundamental goal of rehabilitation. It has been viewed as important when cure is not an achievable outcome (Meier, 1988, p 7).

It has been documented that the disabled population potentially have a poor Q.O.L. - they often have low levels of education, few marry, and they are more likely than the able bodied to suffer from poverty, be unemployed, and be socially segregated (W.H.O., 1981). However, several studies have shown that disabled people can achieve high levels of subjective life satisfaction. Wacker, Harper, Powell and Healy (1983) followed up 180 former patients of a tertiary care facility for the severely and multiply disabled in order to investigate life outcomes and their perceptions of those outcomes. They found that although most of the subjects lived at home, were financially dependent and were not married, they reported that they were satisfied with their life outcomes and their social activities. The results of three independent studies (Green et al, 1984; Decker and Schultz, 1985; Yerxa and Baum, 1986) indicated that disabled people living in the community are capable of achieving life satisfaction and happiness, along with a belief in personal control over their lives, in degrees that are comparable to those of non-disabled people. This was possible despite higher rates of unemployment and lower income levels for the disabled.

These findings lend support to the adaptive capabilities of human beings; the ability of disabled people to redefine their situations and adopt a value system that allows them to feel good about themselves. Kirchman (1986) explained the results as a consequence of the individual's adjustment of his expectations to his present situation. She expanded this by stating that when a situation is fixed for a person over a period of time, the person tends to accommodate to it, showing gradual increases in satisfaction as aspiration levels recede towards the limits of that situation. The author further suggests that a high Q.O.L. as expressed by disabled people themselves may also be due to the balance of the individual's positive and negative life situations. For example, a good marriage with close family ties may compensate for any disadvantages brought on by disability.

A number of studies have explored factors influencing Q.O.L. for disabled people. Kirchman (1986) followed up patients seven years after discharge from occupational therapy, all of whom had been experiencing problems in the completion of A.D.L. tasks at the time of discharge. In an attempt to measure Q.O.L. through objective means, subjects completed rating scales on general affect (i.e. self perception of Q.O.L.) and measures of satisfaction, and filled in indexes detailing activity participation. A positive significant relationship ($p < 0,05$) was found between general affect and satisfaction with work, use of spare time, standard of living and health. Burckhard (1985) examined the impact of pain and functional limitation on Q.O.L. experienced by people with arthritis. Information was collected using a semi-structured questionnaire. It was found that a positive self esteem, low negative attitudes towards the illness, and perceived support contributed directly to a higher Q.O.L. Severity of impairment was also found to be significant, due to the effect it had on self esteem, internal control of health and severity of pain.

The importance of positive, close and stable social relationships as major determinants of high subjective life satisfaction has been highlighted by several authors (Najman and Levine, 1981; Brooks, 1984; Stensman, 1985). This appears foremost from within the family and also from a supportive social network (eg. friendships). Levine (1987) focused attention on the ability to perform social roles, such as worker, family member, citizen or friend. Stability and conformity to a set of role expectations was seen to potentially help produce happiness and a higher Q.O.L. This was enhanced when choice was available. For example, women able to decide between a housekeeping role, or work outside the home, may be happier than those unable to make such a choice (Najman and Levine, 1981, p 109).

Previous research with non disabled people has supported a relationship between participation in active leisure pursuits and life satisfaction (Flanagan, 1982). Yerxa & Baum (1986), in following-up spinal cord injured subjects living in the community, thus aimed to investigate the degree to which their engagement in activity was related to life satisfaction. Fifteen subjects were compared with twelve age- and sex-matched cohorts. No significant relationships were found between activity configuration and overall life satisfaction. Significant correlations were discovered between satisfaction with performance of certain skills, particularly participation in home management ($r = 0.44$; $p < 0,05$) and social/community problem solving skills ($r = 0.62$; $p < 0.01$), and

overall life satisfaction. The nature of these relationships were however not explored. The sample size was small and limited to a restricted geographical area, thus the results of the study should be generalized with caution.

An interest in Q.O.L. represents a striving towards a comprehensive view of the individual and his/her situation. Occupational therapists (along with other health professionals) have long asserted that their services improve their patient's life satisfaction (Yerxa and Baum, 1986; Kibele, 1989). This is because the assistance and services provided make it possible for the individual to achieve an optimal level of performance as the basis for the quality of his life. Najman and Levine (1981) argue that most health care must be ultimately evaluated in terms of its impact on Q.O.L., and hence the activities and procedures which produce the largest improvement should receive the most support (p113). Occupational therapists may play an important role by discovering areas of performance in which patients report low levels of satisfaction, and then helping them to develop new adaptive skills in these areas. Should satisfaction with performance be increased, such intervention could have an impact on overall Q.O.L.

2.6 Disability Outcome

DeJong (1981), an American researcher central to the development of a formal research model grounded in independent living theory, hypothesized that disability outcomes are affected by:

- i) sociodemographic characteristics of disabled people such as age and sex;
- ii) disability related variables which include the severity and duration of the individual's disability,
- iii) environmental concerns such as the presence or absence of architectural barriers; and
- iv) interface variables which comprise the need for modified equipment.

In a later study DeJong together with Hughes (1982) examined the outcomes of 111 S.C.I. persons discharged from rehabilitation Centers, relevant to independent living. Directed towards the role expectations of a working age adult population group, this focussed on expected living arrangements and activity patterns.

Firstly, a continuum of living arrangement outcomes was identified. The most independent arrangement was considered to be one where the individual lived in his/her own home, with considerable voice in day-to-day decision making. The most dependent, or restrictive, environment was one where he/she lived in an acute-care setting with little voice in day-to-day decision making.

Secondly, the authors expanded the concept of productivity from its usual focus on employment to include the disabled person's overall contribution to community and family life (such as home-making, participation in formal organisations, and leisure time activities). Individual productivity outcomes were thus defined by the activities in which a person was involved, and the degree of participation therein (eg. full-time vs part-time work, active or passive leisure pursuits).

The authors contended that the individual's living arrangements, and productivity are outcome measures that are significant for policy makers to consider. They are also seen as being consistent with the I.L.M. theory and philosophy. As mentioned earlier (see section 2.1, p10) this stresses that environmental variables are as critical as, if not more so than, personal characteristics in determining disability outcomes.

SECTION THREE: INDEPENDENCE

2.7 Functional Independence

There is disparity in the literature on the relative importance of physical rehabilitation tasks in determining independence. Some researchers see physical independence as being able to complete tasks by oneself (Shipham, 1988). Jones and Summerville (1983) in their study of do-it-yourself independent persons (i.e. those who had achieved independent living status without the benefit of rehabilitation services or I.L. programmes) did find that the ability to perform A.D.L. tasks was important for the attainment thereof. These findings contrast with a study carried out by Nosek, Parker and Larsen (1987) which examined the relationship between three dimensions of independence: psychological, social and functional. Focusing on 61 persons with severe musculo-skeletal impairment, they found no significant relationship between measures of functional abilities

and measures of psychological and social independence, even for those with very severe disabilities. It was supported that persons with high levels of independence were able to solicit assistance with daily tasks as was needed. This may have been specific to the population that was studied - it would be expected that people with severe musculo-skeletal problems would be most likely to experience barriers to independence related to environmental accessibility and personal physical limitations and thus would need to acquire the ability to solicit help when required. There were few controls over extraneous variables that could have influenced the results.

The authors concluded that the emphasis on functional abilities which underlies many attitudes and practises concerning people with disabilities is disproportionate. While this dimension is undeniably important, it does not outweigh considerations of psychological strength or social opportunity in determining an individual's general level of independence. It is also a sentiment common among those in the disability rights movement that physical functioning may play little or no role in independence for persons with other priorities (DeJong, 1979). The following quote from a 30 year old disabled person with cerebral palsy would support this:

"I cannot walk, talk or feed myself. I think, so what, if I cannot do these things, I can think for myself and can take responsibility for my life. There are some people without any disability who cannot think for themselves and I feel sorry for them, but I do not feel sorry for me. At least I know what I want ..." (Corbett, 1989, p 156).

The primary reason given in the same and other literature for why little focus is placed on the completion of tasks by oneself or caring for oneself is because the physical demands thereof may not always be worth the time and energy that must be expended (Rogers, 1982, Yerxa & Baum, 1986). For example, taking an hour to dress may not result in the greatest functional independence because by depleting time and energy on basic tasks, the possibility for achievement in work and leisure is reduced. Research has also pointed to the potential negative effects of continual attempts to master physical tasks without help, particularly for severely disabled people. In a qualitative study (Kibele, 1989) five adults with cerebral palsy recalled repeated feelings of failure as a consequence of being unable to meet goals such as walking or feeding without help (this was, in some instances, despite years of ongoing effort).

Williams (1983) views the term independence as ambiguous because it implies self reliance, which he sees as a myth. He stresses that all people are dependent in different ways and that the conduct of life depends largely on a trade off between dependence in some dimensions and independence in others. Williams thus prefers the term autonomy, which suggests the importance of choice but recognises that choices occur in contexts which are a source of power and which are both enabling and constraining. This is evident in the life of a disabled student who became very frustrated when unable to do the things he wanted to. He dealt with this by mentally working out a way to achieve his desire and then asking someone to make or find it. Although sometimes he would not be completely independent even with this new aid, he gained much satisfaction from working out the idea himself (O'Halloren, 1985).

In his article "Disablement and the social context of daily living", Williams (1987) examined why disabled people do not always carry out activities mastered in the hospital once they return home, and why they give priority to some activities above others. He emphasized that certain activities have symbolic value for individuals because of the place they occupy within the roles they perform. For example, a disabled housewife who struggles with the tying of shoelaces may opt for a simple alteration, such as changing the type of footwear. However, should the shoes belong to her children who are off to school where they are required to wear lace-up shoes, the activity now takes on added meaning. The simple tasks of tying shoelaces can be a vehicle through which a social role is thus enacted and a sense of identity confirmed. Activity restriction can therefore be understood in the context of social roles.

2.7.1 Technology

The potential for technology to positively influence disabled peoples' lives is high. The purchasing or making of adaptive equipment and devices, including commercially available items (eg. slip-on shoes, a lightweight kettle) as well as specialised equipment (eg. computerized communication systems, powered wheelchairs) is a solution to overcoming barriers to independence.

Technology is promising because augmenting a person's capabilities through technology increases the opportunity for self direction. It may allow the individual, despite severe disability, to exercise control over meaningful events

and to express basic needs or preference with less frustration, passivity, helplessness and dependency on others. A case which illustrates this is McCuaig and Frank's ethnographic study of adaptation to I.L. of a girl called Meghan. Using familiar equipment and techniques that she had developed over the years, she did all her own personal care, homemaking and shopping. This was despite severe disability: the movements of her limbs were athetoid, she held her head up with difficulty, the severe kyphosis and scoliosis of her trunk affected both balance and posture, and she was essentially unable to speak (McCuaig & Frank, 1991).

Disabled people have stressed that when utilising assistive devices and equipment, individuals should be free to choose what works best for them. Denise, who was blind and has multiple sclerosis, was able to walk but this brought on pain and fatigue. When she finally acquired a wheelchair, "...the sense of freedom came rushing in like a wave" (Brightman, 1985, p 16). Lifchez and Winslow (1979) have also noted that reactions to equipment are frequently very personal. For example, in their predominantly qualitative study looking at the environment and disabled people some of the participants felt that the powered wheelchair was one of the most important factors in developing independence while others felt it was institution-like.

The facilitation of optimal function of the disabled person is central to occupational therapy, and thus the use of adaptive equipment and techniques is of importance. Some authors however feel that technology may also do too much for those with disabilities. Finkelstein (1980) has commented that dependence upon aids can make people with disabilities feel like failures and devalued as members of society. Zola (1982) expanded upon this by explaining that technology may achieve such completeness that by making the individual feel useless, he is robbed of his integrity (p 395).

One way to overcome these possible negative effects of adaptive equipment is to personalise devices. Zola (1982), himself disabled with right sided weakness, sighted an example from his own experience, where he was able to prevent the reoccurrence of a pressure sore by creating a special patch worn over the spot every day. The consequences were two-fold. Firstly, he felt a certain pride in solving the problem when professionals could not. Secondly, he felt that the legbrace, because he had altered it uniquely, had become more a part of himself. He was thus more willing to make use thereof.

2.7.2 Personal Care Assistance

Gloag (1985) has observed that obtaining adequate personal care is the biggest problem for many severely disabled people, especially those wanting to live on their own (p 370). She sees this as being possible through the use of sophisticated aids, and with the assistance of professional and voluntary support. A disabled person has commented, "P.C.A.'s (personal care attendants) are my frontline defence against the obstacles imposed by severe disability" (Brightman, 1985, p 23).

The conceptualization of personal care services is highly congruent with the choice making concept of independence. The fundamental premise is that the provision of care is directed and monitored by consumers rather than by providers. Thus, independence is fostered when consumers have the responsibility of hiring, and managing their attendants. However, not all disabled people will have the financial means necessary to acquire P.C.A.'s.

The need for companionship and personal security has also been found to be a legitimate use of a personal care attendant's time. A study by Spencer (1991) compared 12 settings in which housing, attendant assistance and transportation were shared by clusters of young adults with physical disabilities. A conclusion reached was that residents frequently asked for attendant visits because they wanted social closeness rather than the performance of physical tasks. Observations of disabled persons' life experiences made by Lifchez and Winslow (1979) also highlighted the potential for friendship between the disabled individual and the attendant caregiver - particularly in the light of shared intimate and personal moments.

2.8 Psychological Independence

2.8.1 Facilitation of Adaptation

2.8.1.1 Duration of Disability: The reactive models of disability have emphasized the importance of the passage of time to alleviate patient distress. Adjustment has been viewed as a sequential staging process involving three to five naturally occurring stages. This theory is supported by Richards (1986) who found that scores that measured hostility, depression, and problems associated with S.C.I. dropped steadily and significantly over one year following discharge from rehabilitation. Woodrich and Patterson (1983) in their study of S.C.I. persons also found that as time passed after the onset of the subjects' disability, the greater was their acceptance thereof.

A study by Frank and Elliot (1987) supported an alternate view, stressing the importance of previous life stresses and resources for coping. They focused on 53 S.C.I. persons, aiming to investigate the impact of life stress on psychologic well-being following injury. Their results suggested that disabled persons who were experiencing higher subjective levels of lifestress at the time of injury displayed more distress than those reporting lower levels of life stress. The findings were not mediated by the passage of time since injury. Patient distress was therefore affected by experience of life stress regardless of time since injury. A later study by Buckelew et al (1991) also revealed little support for the stage theory. Their research focused on 106 subjects from two samples, differing in time since completion of rehabilitation by two years and once again limited to S.C.I. persons. The results suggested that to better understand the characteristics of the disabled who coped well, efforts should be directed towards looking at individual characteristics within the disabled population, such as locus of control. A specific limitation of this study was that the sample was comprised primarily of male Caucasian subjects.

The above studies were limited to assessing adjustment relatively early after injury (between one to five years); longitudinal studies to assess coping strategies and adjustment across a longer time span and targeting a larger range of physical disabilities are also needed.

2.8.1.2 Self Concept: Research has been directed towards the ability of people with disabilities to redefine themselves (ie their values and perceptions) as part of the adjustment process. Schultz and Decker (1985) in their study of S.C.I. persons on average 20 years after injury, asked their respondents if there had been any purpose or positive meaning that the disability had in their lives. Sixty-four percent of the subjects responded YES. The most frequently mentioned types of meaning were those related to personal growth such as increased awareness of self, becoming a better person and value changes. However sampling issues again affect the generalisability of the findings; although the sample was a reasonable size (n = 100) it was also fairly homogeneous.

Weinberg (1984) conducted semi-structured interviews with 30 physically disabled adults in an attempt to study the quality of their lives. Subjects had a variety of diagnoses, but the majority were disabled from birth or childhood. The author found that part of their adjustment process had involved value considerations, as well as physical adaptations. They needed to challenge societal beliefs (eg. strength, independence and appearance are essential aspects of self worth) and to adopt other values. The importance of being kind, intelligent and a productive person had come to assume new significance, and intellectual pursuits as well as personal qualities were increasingly stressed. These adaptations were not easy; respondents sighted periods of loneliness and depression before coming to terms with their disabilities.

In the literature there is a discrepancy about the relationship of severity of disability to self concept. Woodrich and Patterson (1983) in their study of S.C.I. persons found severity of injury to be of no importance. Burckhardt (1985) on the other hand has recorded that the greater the level of impairment for people with arthritis, the lower their self-esteem. This was due, in general, to the functional restrictions imposed on the individual by arthritis, and was compounded with increasing age. The differences between the study results may be explained by the fact that in the former study the disability (S.C.I.) is static whereas in the latter (arthritis) it is episodic, often painful and may be progressive.

Several authors also point to the importance of the individual's attitude towards his/her disability (Burckhardt, 1985; Strudwicke, 1991). In her book, "Ordinary Moments" documenting the experiences of disabled individuals Brightman quoted Don, disabled with cerebral palsy, who stressed the need to be positive

and to take responsibility for the situation with this statement: "I am responsible for my current reality; you are responsible for yours" (Brightman, 1985, p 47).

2.8.1.3 Locus of Control: Locus of Control (L.O.C.) is a tendency to believe that outcomes either are or are not related to one's own actions (Kielhofner and Burke, 1980). Internally orientated persons believe that their well-being can be controlled by their own actions and consequently will be more active as they trust they possess the necessary skills to meet the demands placed upon them. Individuals with external orientations believe their well-being is under the control of powerful others, chance or fate. They are thus passive, believing that they have no influence on what happens to them and merely perform tasks as they are directed or required to do (Burke, 1977, p 257). L.O.C. is usually viewed as a continuum between these two extremes. It has increasingly gained support as being inherent in the process of adaptation.

Parks (1984) has reported that internal scorers not only experienced less distress than external scorers but that they also achieved better outcomes. It would seem that if the individual's behavior results in the desired outcome, the individual will develop a sense of having an effect and experience feelings of success in controlling the environment (Burke, 1977, p 256).

The relationship between L.O.C. and post hospital outcomes has been examined by DeJong (1981). He found that amongst a group of S.C.I. persons, "internals" spent fewer days in hospital due to medical complications, scored higher on the life satisfaction index, and spent more time in educational activities, community work and paid employment combined. This suggests that individuals with internal control are more likely to take social action to improve social conditions. In contrast, a study by Currie-Gross and Heimsach (1980) found that those disabled people living in the community who saw their environment as controlling them through chance, fate, or other people in power reported generally greater problems in mobility, self-care, employment, and independent living than those disabled individuals who saw themselves as controlling their environment through their own actions and decisions.

Maas, DeJong and McKenna (1988), in reviewing the literature on adaptation to physical disability as a function of L.O.C., documented that responses to stress may be modified by L.O.C. It appears from their article that individuals with

external L.O.C. may be more distressed by disability than people with an internal orientation. With regards to long-term disability, individuals with an internal orientation have been documented to cope more effectively and to be better able to adapt to their new situation than those who are externally controlled (Parks, 1984). This is supported by a study of occupational hand injuries which found a significant relationship between psychological health status and internal orientation (Lee et al, 1985).

In a study conducted by Decker & Schultz (1985) which examined life satisfaction and depression amongst S.C.I. persons aged 40 - 73 years, it was found that the perception of control was the variable most strongly associated with psychological well-being. The authors constructed an index consisting of five likert-type items to measure perceived control over various circumstances. Subjects with high levels of reported depression also had low levels of perceived control. Severity of disability was found to play a role: in this study the perception of control was lowest amongst persons experiencing the most severe injuries (eg. complete quadriplegia). The consequences thereof were feelings of powerlessness to cause a change in their present life circumstances.

2.8.1.4 Social Support: The literature suggests that social support is crucial in enabling the injured person to make physical, social and life changes (Decker and Schultz, 1985; Swanson, Cronin-Stubbs and Sheldon, 1989).

Swanson, Cronin-Stubbs and Sheldon (1989) in their review of the literature on social support suggested that supportive relationships promote adaptation to physical disability by buffering the deleterious effects of environmental stresses. For example, information from supportive others may influence the individual's self-concept by reaffirming a sense of personal worth. A longitudinal study of 583 non-institutionalised physically disabled persons by Patrick, Morgan and Charlton (1986) supported this buffering hypothesis. Self-report measures of social contact and adverse life events (eg death of a spouse) were examined in relation to physical and psychological health. They found psychosocial dysfunction to be highest in persons who had experienced adverse life events and had low levels of social contact. Those who had low levels of social contact but had experienced no adverse life events showed no deterioration in health status.

Decker and Schultz (1985) view social support as facilitating adaptation to physical disability by fostering a perception of control and feelings of competence within the individual. Based on a number of studies, they conceptualised social support as consisting of three areas:

- i) **Instrumental Support**: This is the provision of tangible assistance (eg. help with A.D.L., financial, transportation).
- ii) **Cognitive Support**: This is the communication of information that will help the disabled individual to negotiate his world (eg. knowledge of available resources, education on adaptive techniques).
- iii) **Affective Support**: This is the communication of direct positive affect (eg. receiving of feedback that the person is loved, providing encouragement).

Social support is discussed further under Sections 2.9.2 and 2.9.3, pp 37 and 38.

2.8.2 Personality Characteristics

Research has stressed the importance of personality factors in determining independence. Cay (1985), in examining psychological aspects in rehabilitation, has stated that the individual's pre-disability personality is important; not in terms of personality type but whether or not the individual has coped well with other problems or adult life before the disability (p 12). The main finding of a study by Nosek, Parker and Larsen (1987) was that for a population (n = 61) with severe musculo-skeletal impairments, psychological factors (specifically certain personality traits) were more characteristic of psychologically and socially independent persons than functional abilities. They found differences in personal and demographic characteristics between disabled persons with high versus low levels of psychological independence. Specifically, persons with high levels of psychological independence (including assertiveness, self assurance and self sufficiency) tended to be female, their personalities were more outgoing and they tended to perceive themselves as independent. They tended to live in less restrictive settings, were more likely to have hired attendants and to have more options in transportation. On average these disabled persons had fewer months of formal rehabilitation, were in good health and had fewer communication problems. A specific question which seems logical to follow on from this but was

not addressed in the study is: What are the influences which precipitate the development and expression of these personality factors?

Rogers (1982) believes that the personal requirements for independence are competence and autonomy. She views competence as implying adaptability in organising skills into integrated courses of action to serve innumerable purposes. She described a repeated sequence which leads to mastery: thinking about what to do, making a choice from available options, implementing a plan of action, and then evaluating. Autonomy was seen as requiring an accurate appraisal of one's competence to accomplish a task. Choices are made that are culturally and socially bound. Obstacles are viewed as challenges and effort is sustained until the task is completed. Thus autonomy is the self confidence to regulate one's daily life.

2.8.2.1 Challenges: When disabled people are able to perceive change as a challenge to their development, independence would seem to be promoted. Denise, disabled with multiple sclerosis, has said: "I have found that the struggle to overcome some of my disabilities has, at times, been exhilarating or energizing" (Brightman, 1985, p 28). Lifchez and Winslow (1979) have commented that what seems to be required for the disabled individual seeking independence is a certain degree of challenge in his personal and physical environments. The authors believe that if everything is made accessible and useable without the intervention of the user or inhabitant, there is little sense of competitive achievement. Rogers (1982) would support the notion that too often professionals protect disabled people, doing too much for them, and therefore prevent the experience of normal developmental stresses.

An important element of accepting challenge appears to be the need for disabled people to be exposed to risks. According to Zola (1982), an issue of great concern when activities and devices are designed for those with disabilities is often safety; the protection of the individual from unnecessary harm. He has rejected this, quoting from the psychological literature where risk taking is viewed as essential to the growth and development of all individuals. The need for risktaking was confirmed by a British study where the meaning of independence for six disabled individuals who had moved from institutional to community living was explored (Rock, 1988). The participants, during unstructured interviews, cited examples of risktaking which were important to

them, such as being able to go out alone, cooking and possibly injuring oneself, trying new tasks and developing new skills.

2.8.2.2 Individual Independent Living Skills: Jagoe and Du Toit have defined I.L. skills as "... skills which develop in the quest for and maintenance of independence" (ibid., 1983, p 6). In their article "Skills for Independent Living", these authors discussed the following issues which have been important in their own experience as disabled people:

- i) **Asking for, and accepting help.** When living with a severe disability, these skills were seen as crucial for survival. It was not important whether the individual required assistance, but rather that feelings of helplessness and dependency which undermine confidence were not internalised. The essential element lay in taking control of the situation, for example initiating the helping process, choosing the helper and clear and concise communication of needs.

Dependence on others for basic needs can produce frustration, a sense of powerlessness, and real fear of losing the services and protection provided by the caregiver (eg. should the person become ill). Rogers (1982), in her article discussing the philosophies underlying independence, concluded that for disabled people the growth of autonomy is ultimately connected with learning to adjust to being the recipient of help (p 74). As the individual is receiving assistance with very personal activities, the need to ensure a degree of privacy (eg to work through emotions by indulging in quiet reflection) has also been stressed by several authors (O'Halloren, 1985; Corbett, 1989; Rock, 1989).

- ii) **Planning Skills.** The disabled person may have required the assistance of mechanical, electrical or human aid to carry out daily activities. Thus a shopping expedition or making effective use of attendant care may have required complex planning. Related skills may have included crisis management, setting priorities, making choices, assessing risks and problem solving. Several other authors have reinforced that time spent on fostering such skills is at least as valuable as that spent on developing physical skills (Cole, 1983, Neistadt and Marques, 1984; Frieden and Cole, 1985).

- iii) **Interpersonal Relationship Skills.** This included employer skills (eg. obtaining a care attendant), relating to medical professionals, managing the assistance of a stranger on the street.

Brown and Ringma (1989), in reporting on the setting up of a home in the community for four severely disabled persons, also stressed the importance of interpersonal relationship factors. The home followed a "consumer-directed empowerment model", whereby the members were given responsibility, and were involved in management from the beginning. The consumer-staff interface emerged as critical to consumer empowerment. The degree to which consumers were able to direct their own care, and develop their preferred lifestyle was dependent on staff willingness to respond to consumer direction. However it was also reliant on the disabled person's ability to effectively articulate needs and preferences. The household member needed to feel comfortable with the staff member before being able to tell him/her what to do.

- iv) **Personal Skills.** These included learning to over-come potentially handicapping situations eg. invasion of privacy (in receiving assistance with basic self-care), being stared at in public places, coping with day-to-day matters that sap time and energy (i.e. transport, maintaining health, maintaining essential equipment). Suggestions made include developing confidence through exposure, and developing personal discipline through a goal directed focus.

Jago and Du Toit stressed that the essential responsibility for developing I.L. skills and acting thereon rests firmly with the disabled person himself/herself. The acquisition of such skills is viewed as a process, with greater proficiency developing as the individual is exposed to situations when he/she can make use of them.

2.9 Social Independence

According to the W.H.O. (1981), disabled people generally have lower incomes than able bodied persons, and are more likely to suffer from poverty. Social segregation is also widespread. The I.L.M. has suggested that several key environmental variables such as unmet attendant care needs, architectural barriers in the home, transportation barriers and the potential loss of public benefits affect critically the level of I.L. of disabled people (DeJong, 1981). Other environmental barriers documented in the literature include decreased employment and education opportunities, and lack of access to housing, transportation, public facilities and community services (Sutherland, 1981; DeJong and Lifchez, 1983).

Physical access to the able bodied community does not necessarily guarantee a positive experience. According to DeJong and Lifchez (1983), "the ultimate and most pervasive environmental barriers are the attitudinal ones, particularly the view that disabled people are helpless, pathetic victims deserving of charitable intervention" (p35).

Studies specific to South Africa have shown that the physically disabled are socially disadvantaged in numerous ways. An article by Cock (1988a) outlined a number of environmental constraints experienced by S.C.I. people living in Soweto, including discrimination at the level of independent family life, social attitudes and social participation. The Department of Community Health (UCT), during an earlier study conducted in 1984/1985, attempted to answer the question: To what extent are disabled people integrated and coping in society? They found that, in the so-called coloured area surveyed, few (15%) disabled people in the economically active age group were working. Most others were receiving disability grants, the amount small and insufficient for more than the basic requirements. Few were involved in worthwhile recreational activities (42% did nothing except listen to the radio or watch television; 43.4% a little housework). Almost all saw the unavailability of suitable work as the greatest deterrent to obtaining employment. Transport also appeared significant in influencing occupation and recreation, with only half of the disabled and 22% of handicapped people able to use public transport. It was concluded that the local disabled were not able to participate fully in, and contribute to the development of, the society in which they lived (Disler, 1986).

2.9.1 Living Arrangements

Research favours living within the community as being compatible with an independent lifestyle. DeJong (1981) proposed a living arrangement index based upon where and with whom the person lived. This included a range of living arrangements from living with a spouse to living within an institution (see section 2.7, p).

A Canadian based researcher expanded upon DeJong's concepts; firstly, by testing the model empirically (Dunn, 1990). A random sample of 300 clients stratified according to age and living arrangements within an adaptive housing scheme in New York City was used. The sample was limited in that no subjects resided in institutions and only a small number were employed; nevertheless it spanned a far greater diversity of disabled people than the work completed by DeJong, which focused on S.C.I. persons only. Data collection was through a postal questionnaire. Multiple regression analysis was utilised to test the impact of socio-demographic characteristics, disability related variables and environmental barriers upon I.L. outcomes. Dunn found that five independent variables were predictors of the respondent's living arrangements. These were age, communication problems, marital status, household income and hours of paid personal care attendants. Once again it was clear that environmental conditions play an important part in allowing disabled people to live productively in the community.

Secondly, Dunn evaluated the specific impact of housing adaptations upon independent living. It was reported in qualitative interviews that even minor adaptations to the home provided the disabled individual with increased ability to perform a task on his own eg. using the modified bathroom without help, doing chores alone. Interviewees also commented that once barriers were removed in their homes, they were able to spend less time in bed and more time in the community. For example, one senior citizen needed two attendants to carry him down the stairs whenever he went to see his doctor. Once his front door was made accessible, and he received an outside stair glide, the respondent reported feeling far more independent: he could now get out by himself and go to the doctor, or shopping alone.

2.9.2 Family Influences

With the move towards de-institutionalisation of disabled people, a trend had developed to look towards the family to provide care and support.

According to the literature cited by Brooks (1984), when family relationships are positive individuals are more likely to adjust positively to their chronic condition (or disability) and would therefore be more likely to practise active coping measures and self care (p 406). She also stated that this benefit of the family towards health promotion is assumed to arise primarily from routine lifestyles and socio-emotional nurturing. The support provided by a warm and loving family is said to moderate the psychological distress associated with disability and to assist in a satisfactory psychological adjustment.

Schultz and Decker (1985), in their study of 100 middle aged and elderly S.C.I. persons who were living in community settings, found that spouses and children were the most important sources of support for the disabled individual. Research has suggested that the psychosocial functioning among S.C.I. individuals is strongly associated with maintaining the marital relationship (Urey & Hengeller, 1987). Where marriage is sustained, it greatly enhances the chances that the disabled person will have a more independent lifestyle (DeJong, Branch & Corcoran, 1984).

Several studies have shown that being married enhances the chances that a disabled person could be living in a less restrictive environment (DeJong, 1982; DeJong, Branch and Corcoran, 1984). Oliver (1983) has noted that the most common reason for the disabled individual to enter residential care is family breakup, and the refusal or inability of the carer to continue with his/her task. Therefore research has suggested that marital status is a powerful predictor of living outcome variables.

The family has not always been viewed favourably, especially for the younger disabled. Parents and relatives can inadvertently prolong child-parent dependency and thus the individual can be institutionalised at home as much as in a nursing home. Cay (1985) has documented that when family are worried, frightened or over anxious about the disabled individual, they react by becoming overprotective. I.L. is then challenged as care takes on a "mothering" quality and reciprocation is impossible.

2.9.3 Friendship and Peer Support

Social interaction is considered to have a strong normalising function when relationships between consumers and attendants, service providers, neighbours and other disabled people expand to the full range of social roles (Brooks, 1983).

Sutherland (1981) believes that isolation is a major factor in the oppression of disabled people, and that a primary tactic is therefore for them to come together to support one another. The intervention of a disabled peer can significantly accelerate the transition towards independence for disabled people (Saxton, 1983). The readily identifiable benefit is the realisation that the peer counsellor has had to confront similar issues and can therefore empathize with what the individual is going through. There may be a greater sense of safety in sharing feelings and identifying personal issues. For example, in depth interviews carried out by Pearson and Klock (1989) with ten paraplegic men showed that one area for peer counselling is in sharing sexual difficulties and solutions following injury. The authors described the context of the study, ie Hong Kong, as being fundamentally a conservative society. The validity of the study was possibly enhanced because the interviewer himself was in a wheelchair, and this potentially contributed to the frankness characterising the information given. This in turn lent support for the use of peer counselling.

Peer counselling is frequently chosen by I.L. programs as a primary method of teaching I.L. skills. The counsellor is used as a role model; the disabled individual gains assistance from a peer who has successfully resolved many of the problems he faces in establishing an independent lifestyle (Lifchez & Winslow, 1979; Cole, 1983).

2.9.4. Socioeconomic Conditions

There is a well documented connection between poverty and disability. Economic barriers confound the individual's ability to overcome both environmental and personal barriers because they restrict the range of possible solutions. Shearer (1982) has described some remarkable successes in I.L., but the going is often tough. She believes that if severely disabled people had control of an adequate income, they would be independent of all welfare

services. Crucial needs identified included money and advice. However these factors are most often lacking.

In a South African study of black S.C.I. persons in Soweto, informants stressed that their lives would be far easier if they had money. As one informant said, "I can't afford to buy the things I need to lead an independent life" (Cock, 1988, p). The majority of the sample had been injured in a direct violent assault of some kind, yet only a small proportion (17%) had received any form of compensation. At the time of the study, only 56% were receiving disability grants.

In a study conducted by Brown, Gordon and Ragnarsson (1987), it was evident that adequate access to resources can decrease the impact of the disability. They compared the activity patterns of 22 S.C.I. men with a matched group of able bodied men. The results showed that the S.C.I. men with high levels of education, good incomes and access to private transport had activity configurations very similar to the able bodied group. The resources (eg. having a car) affected directly the roles adopted by the individual (eg. return to work), and his activity patterns (eg. participation in recreation outside of the house). Thus, money and other resources were seen as the "great equalisers". A limitation of the study was that 18 years was the median time since onset of disability, thus this group of disabled persons had access to resources over a lengthy period to reach a high level of functioning which perhaps would not be possible for a newly disabled person. The activity patterns of disabled persons with low levels of resources were not examined and the study was therefore biased towards a specific socio economic grouping.

An earlier study did find similar results which lends support to the above mentioned research. Ben-sira (1986) in his study of 545 disabled Israeli war veterans showed that successful coping, or satisfaction with life areas, was predominantly affected by personal resources, such as occupation and financial status.

A national social policy can considerably alleviate the effects of economic disadvantages, but it is difficult to remove them completely. In Sweden for example, which is considered to have one of the most comprehensive programmes of financial support and rehabilitation, a relationship prevails between relatively disadvantageous economic conditions and disability (United Nations Decade of Disabled Persons, 1986). Of all the Swedish people suffering

from a mobility disability or reduced eyesight cited, only 17% were salaried employees and 52% were considered to be working class.

Independence and participation within community life are possible only where there is at least a minimum of resources available. According to Brown, Gordon & Ragnarrson (1987), these can be viewed as residing in three contexts. Firstly, within a societal context examples include accessible public facilities and legislation protecting the rights of disabled people. Secondly, resources may pertain to the individual's immediate environment eg. available transportation, household income, hired assistance. Lastly, internal variables are important, such as the disabled person's motivation, coping mechanisms.

Important resources for the individual are existing community services within the home areas. It has been documented that disabled people are low users of community services and agencies (Decker & Schultz, 1985) - this may be due to, at least partly, a lack of knowledge thereof (Cock, 1988, p 13). However, where services are apparent and available, their positive influences have been documented. In a study with stroke patients, DeJong (1982) found that the number of services received from various non-medical organisations was a positive predictor of independent living for the group as a whole. When examining factors related to independence, Jones and Summerville (1983) conducted a needs assessment survey of 60 clients with physical disabilities, and found an emergent group who had achieved independent living status without assistance from a formal setting. This group differed on several factors from individuals who had received assistance. Specifically, they identified that the group of "do-it-yourself independents" exhibited more awareness about the types of resources available to them than individuals who had received help from I.L. programs. They were better informed about sources of financial aid for attendant care and tended to be more aware of where to locate equipment that they needed.

2.9.5 Employment

The benefits of employment are numerous, and include the ability to be self supporting, a sense of personal achievement, increased self-esteem, and social status (Lifchez, and Winslow, 1979; Turner, 1987). It is often seen as a sign of

success in overcoming the limiting effects of a disability, and is considered the end goal of medical rehabilitation.

Research has pointed to factors which enhance the chances that the disabled individual will become employed. These include demographic data (eg. age, education, diagnosis), psychological variables (eg. motivation) and social influences (eg. previous occupation, job availability). In a follow-up study of 307 subjects two years after admission to a rehabilitation Center, Granger (1985) found that functional independence correlated positively with occupational status. He found that when a subject scored low on the Index, they stood a 1 in 10 chance of being employed. The chance rose with an increasing score on the Index. McClaren (1979) identified social factors determining motivation to become employed post disability among black unilateral lower limb amputees living on the Witwatersrand. Factors found most significant (at a level of 0.05%) related to the degree of responsibility the amputee had to his family: those amputees employed were married, had a number of adult and child dependents, were head of their families and were the major breadwinners in the household.

Work is highly valued in society, but studies have shown that disabled people have restricted opportunities and limited choice in vocational activities. The percentage number employed has also been cited as low; in some instances as low as 13% (Granger, 1985; Kuh et al., 1988). However, although it has been noted that it is important for the self image of the individual to feel productive, unemployment need not be equated with poor vocational and personal adjustment (Crisp, 1990). In addition the small number of disabled persons gainfully employed would suggest the need to explore their potential for alternate social roles.

Lifchez and Winslow (1979) believe that an important part of the disabled individual's adaptation process is to learn to value the contributions that one is able to make within society, focusing on the abilities rather than the disabilities. They emphasized the exploration of personal potential, hence work for disabled people may never fit the typical image. The most well-suited involvement may be part-time, voluntary, temporary or sporadic. In their study they quoted a disabled individual as saying "I chose not to work at a job". He felt that his time was more productively spent through his involvement in voluntary projects, and counselling. Crisp (1990) interviewed 60 persons with S.C.I. on average 11 years after onset of disability. Questions asked, amongst others, concerned the ability

to cope with vocational decision making. The findings suggested that persons with disabilities who return to work may do so only after years of social and psychosocial adjustment. Voluntary work could then be useful as a stepping stone towards improving or maintaining skills and preparing for future employment. In South Africa specifically, for those unable to find work in the open labour market, informal sector activity has also escalated as a major source of income (Randall, 1988, p66).

2.9.6 Leisure

Meaningful leisure has for many disabled people, of necessity, become a substitute for employment. The benefits thereof are apparent. Physical gains acquired include increased strength, endurance and mobility (Jackson, 1989). This improved physical capacity may in turn lead to proficiency in performing A.D.L. tasks and thus increased function independence (for example, improved upper arm strength and sitting balance as a result of participation in sporting events may result in increased wheelchair dexterity, thus making the individual more mobile).

Recreational activities can provide opportunities to redevelop social relationships; they can foster self esteem, elevate mood and be a source of fun (Valliant et al, 1985; Cotton, 1987). Developing talents and personal interests contribute to a sense of identity and as such can ease the experience of disability considerably (Brightman, 1985).

Cotton (1985), in discussing recreation and people with physical disabilities, has also stated that the excitement and stimulation provided by leisure time pursuits is likely to lead to a more motivated individual who seeks to actively explore his own immediate world (p 3). This is supported by the experiences of Stephen, who is disabled with a right above knee amputation. He found that the confidence and pride gained by excelling at skiing spilled into other areas of his life. He came to realise "...that I could do anything I really wanted to do; my self doubt was easing ...".

CHAPTER THREE: METHODOLOGY

- 3.1 **Study type**
- 3.2 **Study population**
- 3.3 **Research setting**
- 3.4 **Location of participants**
- 3.5 **Setting up the fieldwork**
- 3.6 **Data collection**
 - 3.6.1 Observation
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- 3.7 **Analysis**
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CHAPTER THREE

3. METHODOLOGY

3.1 STUDY TYPE

The study was conducted using qualitative research methods. The concern was with understanding disabled persons' experiences from their frame of reference. Two main field strategies were employed; namely systematic observation techniques (derived from traditional anthropological methods) and unstructured interviewing. The data was collected over a period of six months by the author first hand.

3.2 STUDY POPULATION

The study focused on physically disabled people with a motor disability. The following parameters for inclusion were set:

- 1) Participants were limited to individuals with an acquired disability.

A distinction was made between individuals with congenital and acquired (adolescent and adult) disability in keeping with the literature, where they are documented as two distinct groups. Neistadt and Marques (1984) have described individuals disabled later in life as being psychosocially delayed or disrupted. They may have developed a number of community living skills which are now arrested while they adapt to the disability. However, these basic life coping strategies are derived from the person's psychosocial development prior to injury. On the other hand, for the congenital disabled the disability may be a more integral part of the individual (Weinberg, 1984), but the person may never have had the opportunity to develop a repertoire of life skills. Neistadt and Marques described this latter group (ie the congenital disabled) as psychosocially deprived.

- 2) All participants were people who had been disabled for at least two years.

Duration of disability was thought to be significant because time is needed to adjust to new life circumstances. As suggested by DeJong (1981), for the

individual to have achieved some degree of stability in his life, a minimum period of two years was stipulated.

- 3) Participants were limited to those living in the community rather than those within institutional care.

Qualitative researchers have stressed the importance of the environment in which the subjects live (Schmid, 1981; Kielhofner, 1982a). An emphasis was placed on community living because as Jagoe and Du Toit (1983) have pointed out, it is only once the disabled individual returns to his home that the full implications of the disability are discovered. There has also been a shift away from institutional care to a focus on rehabilitation within the community and the home (United Nations, 1986).

- 4) Age criteria were set as 18 - 45 years.

Study participants were limited to individuals who were of an employable age which provided the potential for financial independence. This was thought to be important because as mentioned in the literature review there is a well documented connection between poverty and disability (United Nations Decade of Disabled Persons, 1986). Access to adequate resources has also been found to decrease the impact of disability (Shearer, 1982; Cock, 1988; Brown and Ringma, 1989).

- 5) Due to the nature of the methodology, with its emphasis on observational techniques, all subjects were required to speak the languages of the researcher ie. English and/or Afrikaans.
- 6) As the chosen methodology required that the researcher spend time with disabled people in their immediate home and social environments, all participants had to voluntarily agree to take part in the study.

3.3 RESEARCH SETTING

The study was conducted in Mitchells Plain, a so-called coloured community situated 25km from the Center of Cape Town.

A geographical region of focus was chosen for two reasons. Firstly it was felt that all participants residing in one area would have been subjected to similar environmental influences, resources and constraints. They would all be members of a particular subculture. Secondly, a region was selected for practical purposes: to save on time, energy and financial expenditure.

Mitchells Plain was chosen for convenience. A recent study (Rendall et al., 1991) estimated, excluding those employed, a crude disability rate of 3.9% for the region. The community-based occupational therapy service which is active in the area afforded a readily available sample of disabled persons. Lastly, Mitchells Plain is comprised of several distinct areas which vary considerably in their socio-economic conditions. This would allow for potential inclusion of participants from a variety of lower to middle class backgrounds. The context from which the subjects were drawn is described in greater detail in appendix D (p 217).

3.4 LOCATION OF PARTICIPANTS

Targeting a specific population is common to qualitative research, where sampling is usually small and most often opportunistic (Krefting, 1989). Sampling was thus purposive; no pretence was made at randomization.

Selection was on the basis of the set criteria and accessibility to the author. At no point did the author wish to sacrifice quality of data for breadth of scope. However an attempt was made to choose subjects who represented a broad perspective on the issues being studied. It was felt necessary to reflect the potential diversity of experiences of the disabled population within the identified area. This was accomplished by attempting to bring variability into the demographic data of the sample; particular emphasis was placed on variety in diagnosis, length of time since onset of disability and employment status. Problems experienced were documented in chapter 4 (see p 64).

Finding disabled people to take part in the study proved to be a difficult and time consuming process. There was no disability register listing suitable candidates. An immediate problem was therefore how to locate subjects. The most logistically straightforward and cheapest way appeared to be via people working in community organisations and through existing groups within the

community. Initially, two main sources were approached. Firstly, the Mitchells Plain community based occupational therapy project (for a description thereof, see Cameron and Rendall, 1990). Services are usually offered during the normal working day, and thus potential participants were most likely to be unemployed. The project's home industry co-operatives allowed for the possible inclusion of individuals working from home.

Secondly, the Rehabilitation Centre, Association for the Physically Disabled (situated in Bridgetown, Athlone) was approached. The aim of the Centre is to provide rehabilitation for physically disabled persons so as to enable them to enter and compete in the open labour market (see Holland, 1990). Drawing subjects from this source would thus have provided individuals who were employed.

No problems were experienced in obtaining permission to utilise the occupational therapy project for names and addresses of participants. The majority of the sample were located through this source (see p 65). It was however not possible to utilise the Rehabilitation Center client records because although access was granted, this was conditional: no visits were to be made by the researcher to the subject's work place. This was contrary to the chosen methodology which by its very nature necessitated spending time with the individual at work. It was felt essential to include disabled people who were employed in the study; as a group they could differ vastly from the unemployed (eg daily activity configuration, financial circumstances). Therefore to obtain the final sample it was necessary to consult a wide range of services. These included the Association for Physically Disabled social workers, the Groote Schuur Hospital work assessment unit, social and sports clubs (eg St Giles), disabled persons' own organisation (eg DPSA -Disabled People of South Africa) and private occupational therapists working in Mitchells Plain.

A total of eight participants was chosen, given the depth of data sought and the time constraints of the study. They were selected in two stages. The field work commenced with observation of five subjects; as the study progressed three further subjects (screened for their employment status) were included. In addition, two key informants were selected to take part in the interview stage of the study. They were chosen according to the sample criteria, but specifically for their ability to articulate their experiences, their standing within the disabled community and their perceived high level of independence. They were included

as "resource persons"; to sensitize the author to the experience of disability, and to highlight any prejudices, misconceptions or areas left out of the interview guide. This brought the final number of participants to ten.

3.5 SETTING UP THE FIELDWORK

Contact was made with the community organisations detailed above, and names and addresses of suitable candidates were obtained. Potential subjects were then telephoned: they were briefly informed as to who the caller was, how she came to acquire their telephone number and why she had contacted them. Permission was sought to visit the individual at home, the purpose of which was to explain the research study and to gain the disabled person's co-operation. A time was agreed upon. Where there was no telephone number the first home visit formed the initial contact.

At the first meeting the purpose, methodology and practical implications of the study were made clear (for information shared with the potential subjects, see appendix A, p 207). As the disabled people were to be active, voluntary participants, it was necessary to be open and explicit. There needed to be no doubt about what was required from them. Particular stress was placed on the confidentiality of the data, and the choice involved for subjects; participation being voluntary. It was also made clear from the outset that the author, in spending time with the participants, would refrain from offering professional advice or undertaking any professional activity. The intent was to leave the professional caregiver role behind, and to reverse the patient-therapist relationship to that of the researcher learning from the disabled person.

The subjects were then given time to consider participating in the study, and to discuss the idea with relevant family members and if applicable, employers. Where possible the family was included in the initial discussions. Although not the main focus they were indirectly involved because of their interactions with, and influences on, the disabled person. Permission was required to visit participants who were employed at the workplace and the employer was thus important from the beginning. In most instances the author was directly responsible for informing significant others of the nature of the study, however the disabled individual was always given the option of how and when this was done. Subjects could not be included if they were willing but the family and/or

employer were unwilling. This was due to the nature of the methodology which required observation of daily activities, both in the home and work environments.

Following further telephonic contact, a second meeting was arranged with subjects who consented to participate. A verbal contract was entered into. The disabled persons agreed to allow the researcher to spend time in the home and the community, to make notes of observations and to tape record the interviews.

During this visit the practical arrangements (eg observation times and settings) were also worked out. Participants filled in a brief personal details sheet, which documented basic demographic data (see appendix B, p 209). This was important because the information influenced the roles and activities in which the individual partook. The author could then plan observation, in addition to general times, around specific events. The verbal collection of personal data was also seen as a useful period during which initial barriers could be broken down and a rapport fostered. A discussion of the participant's daily programme then followed, and the nature and scope of activities to be observed was agreed upon. Thereafter the first observation date was set.

Visiting, explaining the study and seeking information was all in keeping with the pattern of polite discourse which discourages haste and relishes exchange. In accordance with the practises of community occupational therapy (Bumphrey, 1987), it was anticipated that time would be needed to build up a rapport and to establish the credibility of the researcher. Therefore setting up the field strategies was a time consuming process. Two, and in some instances three weeks lapsed between the initial contact and the start of the observation period. This was prolonged when no information other than the disabled individual's name and address was available. In these instances the first exchanges with potential subjects served as a screening, to see if they matched the sampling criteria. In total 18 physically disabled people who were contacted did not do so and were thus found unsuitable for the study (eg most were older than 45 years of age; a few had been disabled since birth and others had been injured within the last two years).

3.6 DATA COLLECTION

3.6.1 Observation

Rationale

According to Kielhofner (1982a), qualitative research "... seeks to understand and portray the social life of a particular group within its own physical, social and cultural context" (p 69). An assumption common to both occupational therapy and this research approach is that human behavior is influenced by the psychological and physical environment in which it occurs (Schmid, 1981). Consequently, to understand this contextual influence, the researcher observed the subjects in their own environment.

It was thought that being around in a household at certain times of the day would provide opportunities to note routines and events of daily life. Participants were not screened for their ability to articulate experiences; the potential richness of observed versus reported behavior was evident.

The study was essentially explorative; it was felt that commencing with observation would give focus to the interview stage of the research. With time in the field, trust and confidence built up would increase the likeliness of open and frank communication during the interviews. It has also been reported elsewhere that what people say is not always reflected in what they do (Krefting, 1989). Observation was thus used as a strategy to validate, and expand upon, what the subjects later verbalised.

Preparation

Prior to the commencement of the fieldwork, a day was spent with each of two disabled people. This was felt to be essential preparation to increase the researcher's familiarity with qualitative research methodology. These individuals were chosen to meet the criteria for subject selection, but they were not part of the final study sample. Emphasis was placed on observing daily activities.

The experience gained during this preparation period assisted the author in working out the practicalities involved in spending time with disabled people (eg length of observation periods, recording of data, types of activities to observe). Potential obstacles and problems came to light. Insights gained caused the researcher to consider carefully her role in the setting. Following this there was

no other way to overcome initial nervousness and anxiety than to plunge straight in.

Procedure

Setting: Observations were carried out within the participant's home and social environments. Subjects were requested to continue with their usual routine or activities and to not make any special arrangements for the researcher, who would fit in with their plans for the day. The settings varied considerably and were very much subject specific, depending on what daily occupations the individual performed. For example when participants were employed most of the time was spent at the workplace. In contrast the majority of observation periods with the unemployed, or the housewife, took place within the home.

Time: The subjects were followed for varying lengths of time and intensity according to their wishes. It was not possible to observe the execution of self care tasks, particularly washing and dressing, as these were considered by all participants to be intimate and private. Observation times thus usually started later in the morning, not earlier than 8:30 - 9:00 am. Other personal moments, such as working out finances, settling accounts, or time spent in the bedroom, were also respected and then excluded from the fieldwork when so stipulated by the participant.

Observation periods spanned weekdays and weekends. They were limited by the researcher to day time only; the latest departure from the field was 5:30 - 6:00 pm. Sessions varied between 1 - 4 hours, at the most spanning a morning or afternoon depending on the field conditions. They were more lengthy when observing a variety of activities (eg the preparation of a meal) or a complex social setting (eg attending a sports group), and shorter when little variety or change in activity was evident in the field (eg participant spending afternoon reading in the sun). Exceptions were made: because of the distance and time involved when observing one subject at Stellenbosch University, these sessions then usually lasted for a full day. Subjects were visited between 1 - 3 times weekly at pre-arranged times. Surprise visits were also carried out; these potentially added to the richness of data obtained. All participants were made aware of the likelihood of such visits, and prior consent was obtained.

Observation periods were initially randomly chosen to span a wide range of different activities, occurring at a variety of times in the day or week, and with

various people. Later sessions were more systematically chosen; specifically to fill in gaps where certain events had not been observed, or where too little focus had been given. Times and duration thereof were thus chosen to provide the researcher with access to a range of daily activities and situations specific to the lifestyle of the individual.

Observation: There were two stages to the observation period. Firstly an activity study was carried out. The three areas of occupational performance (activities of personal management, productivity and leisure/social) were borne in mind. Observations were made of daily routines, social relationships, and special events. Over time, this allowed the researcher to discover stable patterns as well as changes.

The second stage was questioning. Informal "little chats" were held with the participants. The purpose thereof was to understand the motives and meanings behind observed activities. Conversation topics brought up by participants, or between members of the social setting, were also recorded. According to Kielhofner (1982b) such information is natural and spontaneous, and "... provides insights into the kinds of things natives consider relevant to ask and know about the person or situation involved" (p 154).

Role of Researcher: The literature documents four types of participant observation, varying according to the amount of participation on the part of the researcher (Kielhofner 1982a; Krefling, 1989). In this study the researcher played the role of observer with very little participation involved. However, participation took place where it seemed most natural and appropriate. For example, when visitors came to the individual's house it helped to put everyone at ease if the researcher joined in the conversation and did not make notes; on the insistence of family members the author would engage in the playing of T.V. games. Time was also spent talking to subjects about what they were doing and more generally about their lives. Where participation appeared to alter or directly affect the setting, a description of these effects was included as part of the recorded data.

Time Log: The researcher was too obvious an intruder and an object of curiosity to be able to observe unobtrusively. She was frequently treated as a visitor: only allowed access to the sitting room, provided with tea/coffee, and expected to engage in polite conversation for the duration of the session. This was despite

numerous attempts to encourage participants to continue, as usual, with their daily tasks. Subjects where this frequently occurred were thus asked to complete a time log; that is to record all activities performed in a specific 24 hour period. The purpose was twofold. Firstly, the researcher could see, by comparing what the participants were doing during observation times with what they engaged in when she was not there, if she was getting a true reflection of the daily routine. Secondly, the time log also brought to light whether there were times when specific events occurred that would be valuable to observe. Subjects were invited to make any comments about the activities in terms of feelings, reasons for doing them, and who assisted or participated in these activities. The time period was chosen by the individual, who also noted the typicality thereof.

Recording of Data

According to Merrill (1985) field notes serve as the bridge between observation and analysis. They should therefore be systematic and complete. In this study data for analysis was collected using two approaches. Field notes, using pen and paper, were made in narrative form using no predetermined categories. Checklists and categories were decided against because it was felt that this would inhibit the researcher from obtaining qualitative data structured in ways that were not anticipated. Notes were for the most part recorded during the observation periods. Where this was not possible (eg while travelling from one setting to another; data overload) key points were kept and elaborated upon immediately thereafter. The general format of the notes was as follows:

- mapping of time and space (eg physical setting; time of day);
- noting of others in the setting (eg relationship to the participant; present location; involvement in the setting);
- systematic recording of the participant's behaviour and activity participation (eg type of events, activities and interactions). Typical as well as spontaneous practises and special occasions were documented;
- noting of topics of conversation and where relevant, content; and
- lastly, recording of any further questions, queries or insights arising from the observation period.

An ongoing field log (or diary) containing notes on methodological concerns, personal thoughts related to the researcher's experiences and personal reflections was also kept throughout the study. This served as a record of the author's questions, problems, frustrations and insights concerning the overall

research process. It was to be used in the analysis and evaluation phases of the study.

3.6.2 Interviewing

Rationale

While observation formed a major source of data on behavior, interviewing was employed to provide more detailed information on the explanations and rationale behind these actions. This is in accordance with what Schmid (1981) has stated; namely that human behavior goes beyond that which can be observed, and lies in the perspectives and meanings held by the individual in a particular context.

It was not possible to observe all areas of function. The fieldwork was limited to day time only, and excluded for the most part personal care activities. During the interviews all areas of occupational performance were to be covered. The individual's disability history, which was largely unfamiliar to the researcher, was also to be included so that the influence of past events and experiences on present functioning could be explored.

Interviews and observation are considered complementary methods of testing the completeness and accuracy of data obtained from one or other methods (Buzzard, 1984). Loosely structured, free flowing interviews were thus conducted during the last two months of the fieldwork period.

Interview Guide (see appendix C, p 210)

This was drawn up to provide a general framework for the researcher and to thus ensure that all the relevant information was obtained. It guided the course of the interviews, but within each of the sections flexibility was exercised and the participants most often provided direction (for example, the sequence of questions was not rigid; depending on the individual's lifestyle, emphasis could be placed on different parts). The content and categories to be included were drawn from previously cited literature; the author's personal experiences and thoughts as an occupational therapist; and predominantly from themes emerging from the observation period which needed further exploration.

The interview guide was designed to cover physical, psychological and social aspects of disability. It also examined past, present and future functioning. Both

exploratory questions, and probes were included. The phrasing of questions was important; they had to be simple, uncomplicated, non judgemental and free from jargon. They also had to be sufficiently broad so as to permit the individual the freedom to introduce material, and the researcher questions, previously unanticipated. Questions were laid out, within each section, to permit a flow from general to specific information. For example, when discussing the social environment, participants were first asked if there had been certain people in their lives who had been particularly helpful. Later questioning then prompted them to focus on family life and friendship. Probing was used to ensure the desired information was obtained, to increase the detail thereof and to gain clarification when needed.

The interview guide consisted of the following sections:

- 1) Disability History This was largely unfamiliar to the researcher, as the first part of the fieldwork concentrated on present functioning. The objective of this section was to examine changes in function, activity patterns, social relations, attitudes, and feelings from the time the individual was first disabled until the present time. The author wished to explore how the patterns had developed.
- 2) Function This section covered all areas of occupational performance. It was divided into the use of time, physical functioning and the execution of personal care tasks, and participation in the community (ie work, leisure, community organisations). Specific questions to answer were:
 - What activities do people who have a disability participate in? How did they come to be involved and how do they execute these tasks?
 - Is participation in some activities more important to the individual than participation in others? If so, why and which activities?
 - Are people with a disability able to extrapolate what they learn in hospital and integrate this information into their home lives?
- 3) Social Environment This section explored social integration and isolation, including the individual's interaction with family, friends, and other disabled people. It focused on how people react and relate to the person who has a disability; the type, frequency and quality of interactions and the importance of significant others to the individual.

- 4) **Physical Environment** The emphasis here was if and how the environment enabled the participants to manage without help or to do what they wanted to do. This was both within the home, and the broader physical terrain of Mitchells Plain. Environmental concerns such as accessibility, transport and public attitudes were considered, with the focus on how the individual dealt with these potential obstacles. Included in this section were the economic environment, and the role of professional health services - both considered to be important resources.
- 5) **Feelings and Adaptation** This was the first section dealing specifically with the psychological aspects to disability. The most important information to gain was how the disability affected the way participants felt about themselves, how satisfied they felt with their lives, and whether the disability had any purpose, or positive meaning in their lives.
- 6) **Future** This part of the guide explored the individual's future plans, as well as any long term goals. A specific objective here was to see whether the participant's saw the usual adult tasks (such as forming intimate relationships, marriage, work) as being part of their future.
- 7) **General** In the last closing section, participants were invited to make any comments on independent living, and to offer advice to other disabled people in similar circumstances to their own. They were also given the freedom to make suggestions on what they would like to see happen in the future for people who have a disability.

Preparation

Prior to commencing this stage of the fieldwork, interviews were conducted with two disabled people who were living in Mitchells Plain but who were not part of the study sample. The purpose thereof was twofold. Firstly it exposed the researcher to an unfamiliar method, providing both practise and confidence. The author was able to improve her interviewing technique, such as reflecting information back to the interviewee, probing for clarification, making use of silences. Secondly, it provided an opportunity to test out the interview guide and to revise it accordingly.

All field notes made during the observation stage of the study were also read through before interviewing the participants. This was to assist in providing focus: to locate important areas and to formulate questions specific to the lifestyle of the individual.

At the beginning of the field work all participants were made aware of the interviewing stage of the study. Nearer the time their co-operation was re-affirmed. Consent for tape recording all interviews was confirmed and the respondents were once again assured of the confidentiality of the data. At the opening of the first interview it was made clear that the individual was under no obligation to answer the questions or to discuss a specific area if they chose not to. They could also ask for the tape recorder to be switched off at any stage - this was to alert them that they were in control of the interview situation.

Procedure

Setting: Criteria for choosing the venue were that it should offer privacy and comfort, and be quiet enough to allow the interviews to be taped. The setting was jointly agreed upon by the researcher and the participant. This was usually chosen for convenience; to be the least disruptive to the individual's usual routine. The majority of the interviews were therefore carried out in the home, and in two instances they were conducted in the work environment (this was feasible as both the participants were working alone in office settings; one from home and one in her father's business).

Time: Interviews were carried out at times which were chosen by, and thus suitable for, the participants. Factors which influenced their decisions included making time during their usual routines (eg over week ends for individuals who were employed full time; delaying the interview date until after an examination for the participant at university), and finding times which ensured the greatest degree of privacy or the least likelihood of interruptions (eg choosing days when a spouse was working; interviewing in the morning while children were at school or in the late afternoon when the work setting was the quietest).

Length: During the preparation period it had become clear that at least 2.5 - 3 hours in total needed to be allocated per participant. Given the depth and scope of information the researcher wished to cover, and to prevent fatigue, it was also anticipated that the interviews would span a number of sessions. The interview

periods were thus planned to range between 45 - 90 minutes (ie corresponding to one or two sides of a 90 minute tape). This was dependent on circumstances (eg interruptions) and the participant's responsiveness (eg mood, fatigue). The interview guide was roughly divided into three sections (ie disability history and function in personal life skills, work, leisure and the community; the social and physical environment; feelings, adaptation and future plans); each to be focused on in a different interview.

The time between interviews was planned to be at least long enough to allow for a preliminary listening to the tape recordings, but short enough so participants could remember the subject matter from the previous interview. A maximum time period of 10 days was stipulated.

Interviewing: All interviews commenced with the participants detailing their disability history; ie early function and feelings until the present time. They were loosely structured, allowing the interviewee considerable space for talking. They were also not usually combined with observation periods. The expectations on the individual differed vastly in each part of the fieldwork and they were thus kept separate to help the participants in making this distinction.

The researcher made sure that all areas on the guide were discussed during the course of the interviews. The exact format was not important, and direction was most often given by the participant. Not all the questions were put to all the participants, particularly as a rapid firing of questions was to be avoided. Where individuals were more talkative or volunteered information with little prompting, less questioning was necessary. The researcher's primary role was then to ensure that the interview remained centered around independence. The guide was followed more closely with quieter or more reticent participants.

Initially the interviewer allowed free flow talking; the assumption being that the participants would volunteer and talk about important issues. Later the interview became more focused, with the researcher probing for detail or clarification of issues. This included asking for explanations of specific actions and events observed in the first part of the fieldwork.

The interviews were carried out in the language of the participants. On occasion reflective summaries were used as a method of validating what was heard (particularly during afrikaans interviews, the author's second language). They

were useful to check that the interviewer had understood correctly, and as points to lead further discussion.

Recording of Data

All interviews were tape recorded to provide a much more detailed account of discourse than could be accurately recalled.

It was initially thought that all recorded interviews would be transcribed verbatim. However, this proved to be beyond the time and financial bounds of the study. As an alternative, the author listened to the recordings as soon after the interviews as possible, making summarised notes. This written data provided for ease of analysis. The original tape recordings were also kept and could be referred to at any stage.

Field notes were written at the conclusion of each interview, to document the researcher's general impressions thereof. These included comments on the privacy of the setting, the individual's mood, responses to phrasing and content of questions, the need for clarification, etc.

Leaving the Field

After spending six months with the participants, leaving the field was not an easy task. From the beginning they were made aware of when this would happen, and the researcher also gave timely reminders. Withdrawal was slow; the time spent in the field with each individual was gradually decreased and the intervals between visits was at the same time increased. The researcher also initiated discussions on an emotional level, eg why the individual had agreed to participate, whether their expectations had been met, how they felt about the researcher withdrawing. They were not paid for their participation, but each was given a token gift.

3.7 ANALYSIS

Data analysis in qualitative research departs dramatically from the traditional quantitative research designs. It is cyclical, ongoing and cumulative (Kielhofner, 1982b; Merrill, 1985; Krefting, 1989). For this study, it began with the first observation, continued throughout the data gathering process, and culminated in thematic analysis once the fieldwork had been completed.

There were two phases to the analysis. During the data collection period preliminary analysis involved reading through field notes, or listening to tape recordings, as soon after a session as possible. The purpose thereof was to formulate further questions, to determine areas needing elaboration or to identify specific gaps which existed. This gave direction for further sessions. For example, time was spent with a participant while he attended lectures at Stellenbosch university. After observing that he made use of a number of people to assist him daily, several questions arose: How did he set up the supportive network? Who did he ask for assistance? With what tasks did people help him? How did he become acquainted with the various people? How did he feel about asking others for assistance? These questions were then later explored in an interview situation.

A separate, summarized list of emerging themes was kept from early on in the observation stage of the data collection. This was crude and simplistic but was a start at grouping the information into meaningful categories. Headings such as "environmental influences", "use of assistive devices", and "hope of further recovery" were then followed by examples which were recorded when spending time with each individual. Once again this gave direction to future sessions. The researcher was also able to begin to see similarities and differences in the information gathered from the various participants.

After the fieldwork was completed thematic analysis was undertaken. In this stage of the analysis, the author needed to generate categories from within the data which would allow the logical classification thereof. This involved reading, and re-reading all the field notes.

Each segment of the data was coded using one or more categories developed by the researcher. Coding has been defined as involving the identification of words, phrases and ideas which seem significant to the subjects' thinking (Walker, 1989, p500). Codes used were firstly concrete, and later, conceptual. Initially the focus was placed on words used by the participants themselves (for example the family being 'obligated' to provide assistance; it was seen as their 'duty'), and the coding begun in the first stage of the analysis. As this progressed, the information was categorised using more abstract concepts which linked the earlier, cruder codes together (for example, from the above came the idea of 'kinship bonds' between family members).

Categories developed from repeated and varied contact with the data. There was constant reflection on the information that had been gathered. For example, once a new section of the data had been analysed, this was compared to previous observation periods and/or interviews to see how consistent or common emerging categories were. In this way information was also linked together. Differences as well as similarities in the data obtained from the participants were examined. The frequency of the various themes in the total body of the data was thought to give some idea of the power thereof.

As a category developed, the next step was to collect instances (either supporting or challenging) for the emerging hypotheses. This became possible once the researcher began to make sense of the accumulated information. The process of reading and re-reading the data, while continually searching for disconfirmation, qualification or confirmation of results was re-iterated until the themes and hypotheses were clear.

The focus in the analysis was on distinguishing factors which would yield to rehabilitation influence, and not on features which are largely dependent on political, economic or cultural influences of the sample population.

3.8 TRUSTWORTHINESS

The trustworthiness of the results was established through the consideration of several factors. To obtain a comprehensive picture of the social setting, an attempt was made to sample all possible natural settings. Persistent observation was thus carried out across different social settings (eg varying time, day of week, venue), and during interactions among different social groupings.

Other important information, affecting the social setting, to note was the credibility of the participants (eg their motives, knowledge), the context of the data received (eg whether information was directed or volunteered), and the researcher's relationship to the participants or extended social group.

The existence of different types of data collected from several sources (ie observation, interviews, informal conversations) was to allow cross checking of analysis and research impressions for discrepancies and variations. Information from one source could verify information from at least one other source, and

weaknesses of one method could balance out against the other method. It was also felt that the triangulation of methods could contribute additional data that may not be obtained from a single approach.

Credibility is supported when interviews or observation are internally consistent, ie where there is a logical rationale about the same topic. To assess this, the researcher repeated observations of the same events; during the interview process questions were also reframed or repeated on different occasions. In addition, when developing a theme consistency across a number of participants was also sought.

The author's field log (see p 52, paragraph four for a description thereof) recorded possible assumptions made which were clarified with the subjects. Thus potential influences of her background on the research process were noted.

Another important component to trustworthiness is the documentation of methodological procedures involved in the collection, analysis and interpretation of data. Thus the field journal contained chronological notes discussing methodological concerns and decisions. In the final write up of the study, the methodology was then described in detail, with reasons for choices also given.

The analysis of the data was completed by the author independently, without peer assistance or examination. Therefore, in an attempt to increase the dependability of the data, segments were recorded and then re-analysed at a later stage. The results obtained were compared for consistency.

To ensure there were no unexplained inconsistencies between the data and the interpretations thereof, the field notes were searched for disconfirmatory results. When needed, this resulted in the modification of the emerging categories, themes or hypotheses.

Central to credibility is the ability of informants to recognise their own experiences in the research findings. The results were therefore discussed with two participants; they reviewed a draft summary of the major findings.

Further information on the trustworthiness of the data is given in the following two chapters (see sections 4.3 and 5.1, pp 66 and 144).

According to Miles and Huberman (1984), the researcher's skill and familiarity with the qualitative research process also warrants attention. Several steps were thus taken to increase the author's own trustworthiness.

Both methodological and investigative papers using a qualitative approach were read. Particular emphasis was placed on occupational therapy publications to increase the relevance of background material to the topic undertaken. Due to a lack of published qualitative research in South Africa, this literature was predominantly American.

Where possible, all talks or practical courses given pertaining to qualitative research were attended.

Prior to, and during the research process, the author discussed the study with representatives of people who have a disability in the Cape Town area (eg U.C.T. Disability Unit, Western Cape branches of People for the Awareness of Disability Issues and D.P.S.A.).

The study was also discussed with occupational therapists working in the community, particularly concerning its feasibility.

Pilot observations, and interviews, were carried out before commencing each part of the fieldwork.

Methodological concerns, as they arose, were discussed with a researcher familiar with qualitative research methods.

CHAPTER FOUR: RESULTS

4.1 The participants

4.2 The setting

4.3 Organisation of the results

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4.4.1.3 *Use of previous experience*

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4.4.2 A change over time: decreasing expectations

4.4.3 The Individual's responsibility

4.4.3.1 *Self motivation leading to improvements in function*

4.4.3.2 *Taking the lead in relationships*

4.4.4 Taking risks versus fear of failure

4.4.5 Self growth and autonomy: meeting the challenge of a changing environment

4.4.5.1 *Rising to the demands of the situation*

4.4.5.2 *Perseverance*

4.4.5.3 *Cognitive appraisal: the challenge of prejudice*

4.4.5.4 *Building on positive experiences*

4.4.6 Adaptation to disability: a process of reorganizing the self

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4.4.6.2 *No going back*

4.4.6.3 *Adaptation is ongoing*

4.4.7 Adaptation to disability: reflections on the purpose

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4.4.7.3 *Measurable steps*

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4.6 ASPECTS OF RECEIVING HELP

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4.7 THE COMMUNITY OF MITCHELLS PLAIN

- 4.7.1 A desire for safety
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 - 4.7.2.1 *Contact with friends*
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- 4.7.5 Problem solving through networking

CHAPTER FOUR

4. RESULTS

The primary purpose of this study was the identification of factors which heighten the potential for people with physical disabilities to achieve independence. It focused on the life experiences of eight physically disabled people living in Mitchells Plain. Two key informants were also included in the second (interview) phase of the fieldwork.

Data collection was carried out during May - November 1991. The author spent time with subjects while they went shopping, cooked meals, sat down to eat with their families, attended lectures, completed housework, fetched their disability grants, joined in social groups, sat in the sun, read, looked out of the window, played with their children and participated in a host of other everyday tasks. She also bore witness to crisis moments, such as one participant coping with the unexpected death of her mother, and turning points, for example the excitement of an individual starting a part time job, and money from a third party claim coming through for another subject.

In total, three hundred and twenty three hours were spent observing the daily lives of the participants. During the interview phase time spent with each subject ranged between four and a half hours and ten hours (total time spent was fifty four hours).

This yielded a vast amount of raw data.

The participants all described traumatic early experiences as disabled people. On discharge from hospital, most remembered feeling physically weak and seven subjects, despite having previously mastered at least basic self care activities, were fed, washed and dressed once they returned home. Although they initially rarely left the confines of their home environment, all but one subject got out of bed daily. Psychologically the subjects remembered being easily angered, frustrated, and often withdrawn. One participant stated, "*I hated the world; I hated myself*". Another's despair was clear in his thinking at the time, "*Dit sou beter gewees het as ek dood was*".

The participants described a very different picture during the course of the study, between two to eleven years later. The majority felt they had moved forward with time and eight subjects expressed satisfaction with their lives.

The results document, in themes, the enabling and constraining influences which have shaped these changes and led (potentially) to increased independence or inhibited the attainment thereof.

4.1 THE PARTICIPANTS

The demographic details of the participants were summarised in Table I (see p65).

All the respondents were disabled as a result of an injury. Six had been involved in car accidents, one a bicycle accident, one in a diving incident and two had been shot. A possible bias was that seven of the participants had spinal cord injuries. This was the diagnosis of the majority of the disabled people known to the organisations from whence the respondents' names were obtained. Despite this however, there was variety in the functional limitations experienced by the individuals. Five of the participants were ambulatory and five were wheelchair bound (one utilising an electric wheelchair). Upper limb function was affected for seven of the subjects, of whom three had very little arm and virtually no hand function, two had the use of one arm only and two respondents were able to use both arms although the functioning of one hand was compromised. In total, three participants had all four limbs affected by their disability, three presented with a hemiplegia, and three had lower limb- and one upper limb-involvement only. It was felt therefore that there was a reasonable distribution of physical disability.

The majority of the participants (six) were located through the occupational therapy community project which is active in Mitchells Plain, four of whom regularly attended the programme. Furthermore, two respondents were contacted with the assistance of occupational therapists, another via the Association for the Physically Disabled (an ex client of the organisation) and one through Disabled People of South Africa (D.P.S.A.). The location of the subjects through these sources posed several limitations.

TABLE I: DEMOGRAPHIC DETAILS OF PARTICIPANTS (N = 10)

AGE	SEX	EDUCATION LEVEL	PHYSICAL DISABILITY	LENGTH OF DISABILITY	MARITAL STATUS	LIVING ARRANGEMENTS	PRODUCTIVITY	INCOME
22	male	std 10	C3 incomplete quadraplegia	2 years 2 months	single	sister, husband and children	unemployed	disability grant (D.G.)
30	female	std 5	right hemiplegia	7.5 years	widowed; daughter (11) son (8)	mother's house with family and 3 siblings	housewife	maintenance grants (x2)
39	female	std 6	C5/C6 incomplete quadraplegia; wheelchair bound	3 years 3 months	married; daughter (18 and mentally retarded)	husband and nephew in own house	housewife	husband supports
32	male	std 7	T12/L1 incomplete paraplegia; wheelchair bound	4 years	married; daughter (12) son (10)	wife, children and boarder in own house	woodwork home industry (K.I.)	D.G.; K.I. income
21	female	std 8	left below knee amputation with prosthesis	2 years	single	stepfather and siblings (middle child of five)	receptionist in father's business	salary
30	male	std 5	complete paraplegia; wheelchair bound	4.5 years	married; daughter (12)	wife and daughter in council house	woodwork K.I.; O.T. community project	D.G.; K.I. income
26	male	std 6	C2 Brown Sequard type lesion	3 years	married; step children x2 (14; 9 years)	wife, children and boarders (x2) in own house	woodwork K.I.	D.G.; K.I. income
22	male	std 10	C5 complete quadraplegia; wheelchair bound	5 years	single	parents	Stellenbosch University student (first year)	D.G.; bursaries
32	female	std 10	C4/C5 incomplete quadraplegia; wheelchair bound	6 years	single; daughter (12)	daughter, nephew, and live in maid in own house	People for the Awareness of Disability Issues	D.G.; work as voluntary
25	male	std 10; 2 years university	left brachial plexus lesion	11 years	single	parents	work study officer	salary

It is possible that disabled people who are linked to welfare and service organisations are a specific subset with different characteristics to those not receiving assistance from professional intervention and there is an over representation of the former group within the study. This may also have accounted for the high level of jargon used by some respondents when describing their situations. Few ($n = 2$) of the participants were in full time employment; this was not unexpected given that disabled people attending the occupational therapy project's day time groups were most likely to be unemployed. A larger representation of disabled persons who were working was sought but proved difficult to obtain because the author had no means of locating potential participants (four were identified through a snowballing effect, however their respective employers were not willing to allow the researcher to carry out observations at the work place and thus they were excluded from the study). Lastly the average length of time since onset of injury was 4.8 years (ranging from two to eleven years), the study being slanted towards the relatively newly disabled person. This possibly arose because those people who had been disabled for a longer period were no longer linked to the organisations from where names for the study were obtained, or they had been injured before the

community project was started in their home area. It should also be noted that the majority of the participants were young, varying between 21 to 39 years of age.

Notwithstanding the above, and the size of the sample, the author considered that the participants exemplified sufficient variety and breadth that allowed the results to serve as a beginning in the exploration of independence for disabled persons from their perspective.

4.2 THE SETTING

The fieldwork was carried out in Mitchells Plain; predominantly in the participants' homes but also within other contexts where they spent their time, such as the work environment, social groups, and their immediate neighbourhoods. The settings varied considerably in socio-economic conditions; four of the respondents could be said to have middle-class backgrounds and the remainder lower socio-economic backgrounds.

4.3 ORGANISATION OF THE RESULTS

The results of the study were lengthy. In total 22 themes were identified. In an attempt to organise the data to facilitate the reading thereof, they were divided into four main sections (see points 4.4.- 4.7). Within each section the relevant themes were then documented. For the purposes of presentation and clarity each theme was given an introduction and a concluding summary. Where topics were particularly lengthy, headings were given to sub-divide the information.

Again for clarity, the results of the study were displayed linearly. It must be noted that in reality the individual's potential for independence was determined by a complex interplay of these factors; the relative strength of each varying between the participants and changing over time for each person.

Direct quotations and observations made during the course of the fieldwork were included to support the data presented. It was an objective of the study to examine factors related to independence (for which purpose the group acted as representatives only), and not to emphasise individual traits. For this reason

examples given were not matched to specific subjects. In most instances the number of participants who contributed to a specific topic were also not given, as the author was concerned with quality not quantity of data.

Three respondents were particularly able to articulate their experiences more than others and utilised a considerable amount of jargon terminology in doing so (this may have been due to their high levels of education and involvement with professional services). However care was taken to include responses from as many of the participants as possible or to document incidents which were observed in a variety of settings. In reality it is probable that seven subjects contributed substantially more to the data than the remaining three respondents. Within one theme quotations and observations given were also drawn from the experiences of different participants and no subject contributed more than one example per topic. Due to the lengthiness of the data, illustrations given were limited to two or three per theme and subsection thereof.

In order to achieve the study purpose, emphasis was placed on influences which enhanced the potential for independence. Many more positive experiences were thus documented, rather than problems or difficulties experienced by the subjects. This was a bias placed on the data by the researcher and is not necessarily indicative of a high level of autonomy, or suggestive of positive coping mechanisms, amongst the participants.

It should be noted that although all the data collected was analysed, not all the information has been included here. The results that were recorded were the topics and incidences most frequently mentioned by different participants, and the influences which they expressed as having been most powerful in shaping their experiences. To ensure the credibility and trustworthiness of these choices made by the author in presenting the data, draft copies thereof were reviewed and discussed firstly with two participants, and secondly with two disabled people who were external to the study. The question of representativeness was also always borne in mind when quoting sections of discourse, and any inconsistencies in the responses of the participants then highlighted.

The results should be viewed in the context of the greater environment of Mitchells Plain, and may thus not be the most important factors influencing independence for other disabled people in a different setting.

4.4 INDIVIDUAL CHARACTERISTICS

This section consisted of eight themes. Individual influences on the participant's motivation, adaptation and coping strategies were reported.

4.4.1 Starting Points: Premorbid Functioning

In discussing the respondents' present functioning and activity participation, it emerged that these were substantially influenced by their premorbid personalities, lifestyles and experiences.

4.4.1.1 Premorbid Personality:

In this study it was difficult to differentiate between coping mechanisms that individuals developed through the experience of being a disabled person, and behavior that was part of their premorbid personality. The following however suggests that at least to some extent patterns of coping were dependent on premorbid functioning.

One subject described the personality traits that he felt had helped him to deal with daily life as a disabled person as firstly determination and secondly patience. Both these he felt he had inherited from his parents; he viewed his father as a fighter who did not give up easily and his mother as being the patient one.

Another participant described herself as the kind of person who tried to do tasks to the best of her ability. She felt that this had been longstanding and had continued after her accident.

One subject thought that he had always been able to motivate himself, explaining that he had learnt to push himself when needing to get fit to play competitive sport. Following the onset of disability, he displayed this same perseverance in exercising to improve his physical functioning and his determination in struggling to complete self care tasks until he became competent.

The respondents reported that they began to exhibit their coping mechanisms from early on, in some instances whilst in hospital. As one

subject said, "*Ek was van die begin af, outspoken*". He had previously been living with his in-laws and wanted his own house. Therefore, in his own words, "*ek het die dokters en die social worker geharass, lastig geval*". Other respondents relied on their previous interpersonal skills by asking questions and verbalising their feelings to staff.

Another participant, on returning home from the hospital, experienced that people felt sorry for him. He described the situation as being as if they were preparing for the dead (eg family came to ask for his bicycle, they wanted his clothes). His response was, "*...ek het somme gou van my laat hoor!*".

The influence of the physical disability on the individual's premorbid personality appeared to be to exaggerate specific traits. One subject stated this when she generalised from her own experiences and her work with other disabled people and said:

"When you become disabled, your natural personality and character traits don't fall away. If you were abrupt, a rude person before, you carry it over. Perhaps worse".

This statement was supported by other participants in the study. One subject said that she had always been shy when meeting new people; her appearance played a large role in this (she was markedly overweight) and now that she was physically disabled this had worsened. Another described himself as outspoken; he felt this had increased through necessity after his accident in response to the prejudice and barriers he encountered within the environment.

4.4.1.2 Return to Premorbid Lifestyle:

Participants volunteered repeatedly that the way to cope with being disabled was to continue, as far as possible, with one's premorbid lifestyle.

"I always said to myself: The only way I'm going to get over this, the only way I'm going to be myself again, is by doing what I always used to do".

"I got myself right by sticking to my old routine: I got up when the others [the family] did; I did the housework as before".

[When asked what advice she would give to a newly disabled person in a similar position to her own] *"I would encourage them to be like they were before, to continue with the same lifestyle, or maybe try and make it better. Because that's exactly what I did. The thought crossed my mind, being just isolated - but then I couldn't because... I mean... I wasn't like that before".*

A desire to return to a familiar lifestyle was evident in the respondent's daily routine, especially in executing self care and work tasks.

The subjects appeared more likely to strive to be self reliant if they had been used to helping themselves. One subject began trying to wash and dress herself a month after she returned home. When asked why she had started attempting these tasks she replied, *"Ek was gewoon om myself te help; ek was nie gewoon daaraan dat my ma vir my moet help nie".*

Another subject explained that she found it particularly difficult to ask for, and accept help as she had never had to do so before. The participants then, in accordance with their previous lifestyles, all chose to be as self reliant as was possible.

It appeared that subjects who had been employed prior to their injury were potentially more likely to want to work again. This was evident from the experiences of one participant who voiced that he found it difficult to understand why other disabled people were happy remaining at home and receiving disability grants. His point was that he had always worked; from the time that he had left school he had never been without a job for more than a week. After his disability he continued to be motivated to work.

Another respondent, when speaking of the advice he would give to a fellow disabled person, said that he would tell the person to be hardworking. He then qualified the statement, stating that it would depend on their premorbid lifestyle, and continued as follows:

"Jy kan nie vir 'n man sê hy moet hardwerkend wees nie en hy sit in 'n rolstoel, as hy nie voor daai tyd gewerk het nie. Dit sal verskil as jy met 'n persoon wie tevore gewerk het praat. Dan kan jy sê: probeer om hard te werk en alles sal regkom, jy hoef nie te worry nie..."

Female participants who were involved with housework described themselves as always having been houseproud and were therefore motivated to continue with whatever tasks they could manage. Male participants who completed housework also commented that this was not a new pattern. Those that assisted their spouses or family had been willing to do so before their injury and those that did not had never been involved in the execution of household chores.

Therefore it seemed that after the onset of disability the subject would, if possible, return to familiar patterns and routines.

4.4.1.3 Use of Premorbid Experiences:

In some instances participants were able to make use of past experience and old skills to assist them in new situations.

One subject who was initially quite weak in his left arm and leg was able to strengthen them through exercising. He had previously done sport regularly and used this as a basis for drawing up his own exercise programme.

Another participant used his knowledge of woodwork to build a ramp outside his front door. He then went on to utilise his skills in assisting other disabled people in his area to build ramps.

A younger subject described how, before his accident, he would ride his bicycle without holding the handle bars and do other tricks such as standing on the cross bar while the bicycle was in motion. It therefore seemed very simple to him to ride and control the bicycle with one hand after his left arm became paralysed.

Participants appeared more likely to feel confident about completing an activity if they had been involved in a similar situation before the onset of disability. When they could make use of familiar skills, the potential to take a risk and attempt the task was greatest.

In this study the three disabled individuals who were driving their own cars had all done so before their accidents. The first time they drove after the onset of disability was thus not particularly stressful because, having driven before, they felt they knew what to do.

When female participants started preparing meals again they felt secure in the knowledge that they had done so before. The skill involved had previously been mastered and therefore the task was familiar to them.

4.4.1.4 Developmental Stage at Time of Injury:

It was evident from the above that the activities in which respondents chose to participate were individually orientated. Choices made also appeared to relate to the subjects' age and thus developmental stage at the time of onset of disability. This was clearly seen in distinguishing subjects who were then in their teenage years or early twenties from those who were disabled later in life (ie, late twenties and older).

Younger participants all mentioned concerns with body image; as teenagers they were highly conscious of their physiques. This acted as a strong motivating force to encourage them to master basic self care tasks such as eating, dressing and washing. In the older than 25 years age group, none of the participants mentioned this as a major contributory factor to motivate them to help themselves.

A desire to be socially accepted, part of a group and to lead an active social life were also high on the agenda of the younger subjects. One participant who was injured in a cycling accident began riding, using one arm only, three years later. He did so because this was the mode of transport used by his peers, and when his closest friends had started taking part in competitive cycling, he had felt left out. The subject had been involved in the sport prior to his accident and with time this started again. The reason he gave for this was, "*I started fighting back because I mean I hated the fact that I was left out of everything*".

Another participant remembered how he had always asked his physiotherapist: "*Wat kan ek doen om my 'image' te verbeter?*". His desire to be "in", and not to be seen as different, was evident in the plan he made to prevent him from falling out of his wheelchair. He initially used a strap, positioned in the same way as a seatbelt. This was acceptable when he attended a special school, but not when he became a student at university. Modelling from his fellow students, the subject thought of using a money belt tied around his waist and wheelchair which effectively served the same purpose and to the individual was far less noticeable or stigmatising.

Older subjects displayed different priorities. They placed a greater emphasis on the importance of the family. A female participant who was married verbalised that her sole motivation to try to help herself, and the reason she persevered in her attempts at walking with calipers, was for her child. Her eighteen year old daughter was mentally retarded and had been put into an institution at the time of her injury. The subject looked forward to the day when this child could once more live at home, which she felt would definitely be possible once her own functioning improved.

Another participant thought that it was easier for disabled people if they were married as in his experiences this gave him a reason to come home, and a reason to try to help himself. He said:

"[If you are married] ... *dan voel jy rêrig... hier MOET 'n man staan hier.. hier... . Jy voel: jy's 'n man. Hier's nie 'n ma of pa of iemand wat vir jou vertel; hier's jy self die man*". He went on to explain that as the man of the house, it was his duty to provide financially for his family and this motivated him to work.

In summary, it was apparent that premorbid functioning affected the respondents' present lifestyles. Participants therefore continued where feasible with a familiar routine after their injuries. This meant participating in tasks with which they previously had been involved. In this way they were able to capitalise on old skills, being more confident in initiating and executing

activities where these could be utilised. Priorities differed as individuals were motivated to complete their age appropriate life tasks. It also seemed that the individual's premorbid personality remained for the most part unchanged after the onset of disability .

4.4.2 A Change Over Time: Decreasing Expectations

During the interview phase of the study, the author initiated discussion about the participants' dreams and goals for the future. This centered around the fulfillment of adult life tasks; there was strong agreement amongst the individuals. The participants most frequently volunteered finding a partner, being married, owning a home, and being employed as important. However, they expressed difficulty in turning these plans into reality.

In many instances participants devalued themselves. This was particularly evident when they were newly disabled. An example of this was seen when a participant, while in hospital, told his wife that he would no longer be able to work or complete many tasks, "*soos 'n volle man nie*", because he was going to receive a disability grant. De-valueing themselves was most common in relationships, where participants could not imagine another person showing interest in a person with a physical disability. It was also seen in work related tasks; for example being unsure of what sort of work they could do, or not believing they could get a job.

A common experience of participants was that they did not take part in activities because they could not imagine, with their physical limitations, how they were going to manage. In many instances they were also convinced that they would no longer enjoy tasks they had previously taken part in - particularly leisure and social activities. They therefore tended to accept their present circumstances as best they could. This is clear in the following quotations which were derived from different participants in relation to a number of situations - not being able to maintain their premorbid lifestyle, being unemployed and having to make do with a disability grant, and going out less than they would have liked to:

"Ek moet maar seker net lewe soos dit voortgaan. Soos die lewe is moet ek aanvaar".

"Miracles kan nie by my gebeur nie, dit weet ek. So ek vat die lewe soos dit kom".

"Dis swaar, maar wat kan ek maak?"

To adapt, and to be able to feel satisfied with life, participants then appeared to begin to expect less from life, and to be content with whatever came their way, until something better came along. As an illustration of this, a participant who found himself always waiting on others to help and who had previously worked but since his accident spent most of his time at home, said of his circumstances, *"That's life"*. A subject who had not made any new friends since her injury occurred stated: *"So I'll just hang on there..."*

Thus when subjects could not see how participation in an activity was possible, they could not create the opportunity to do so. They appeared then to resign themselves to the situation, seeing little chance for change.

A participant summed this up when she described her first two years after she became disabled as consisting of eating, sleeping and watching television (T.V.), and said, *"You just fit into whatever is there for you. When you're out of it, then you wonder how you managed. Watching T.V. never bothered me at that time, because that's all there was. Now that I have so much more, I wonder why I didn't go mad"*.

4.4.3 The Individual's Responsibility

Several participants expressed the belief that it was up to the individual to determine his/her own lifestyle. These respondents felt they could be active in deciding what tasks they participated in, and how this was done. They also verbalised the importance of making their needs known to others.

4.4.3.1 Self Motivation leading to Improvement in Function:

There was a strong feeling among participants that the desire to increase function needed to come from themselves.

"Ek glo nie dat jy moet net terug sit nie. As jy net jou eie motiveering insit, en probeer, dan sal jy uitvind dit werk".

"Be hardworking and never underestimate yourself. Ultimately its your decision what you do with your life".

There was a belief among participants that if they put effort into doing a task, it could be accomplished. Some respondents thus frequently credited improvements in function to the direct result of their own efforts to help themselves. One subject demonstrated this when she verbalised that she felt her physical ability could improve further; she qualified this by saying, *"... dit hang net van myself af".*

Another example was seen when a participant spoke about the increased strength in her affected arm:

"Elke dag het ek gedink: ek moet probeer. Dit gaan nie werk nie as ek altyd hulp soek. Toe het ek self hierdie hand reggekry".

4.4.3.2 Taking the lead in relationships:

Subjects volunteered the importance of verbalising when they were unhappy or when their needs were not being met. This was paramount in three situations. Firstly, when they felt prejudiced against, for example someone feeling sorry for them, talking down to them or being over-involved and assisting the subject when help was not desired. Secondly, when asking for assistance. Thirdly, speaking up was valuable in breaking out of a pattern of being passive, of having tasks done for them which the participants could manage themselves, and wanted to try to do.

There was a strong feeling among participants that it was up to them to teach others about their disability and their related needs. When others were uncomfortable around them, it was their responsibility to act as the role model for how they wanted to be treated.

A participant described how anxiety provoking it had been for her if friends visited unexpectedly - for example if they should arrive on a day

when she had taken tablets to evacuate her bowels and thus could potentially have an accident. The subject found that she was able to relieve a tremendous amount of stress when she began telling people when they could visit and when they could not - as well as why without feeling embarrassed. Forewarning visitors of the likelihood of an accident when they did arrive at an unsuitable time also helped to lessen her anxiety.

Participants described the varying reactions of people when they met them for the first time. Some people would greet the subjects, others stared and yet others appeared decidedly uncomfortable. Several participants then saw it as their responsibility to put the other person at ease. One respondent described a workshop he attended where the other participants initially remained apart from him. His response was to initiate conversation, and to use humour as a way of diffusing the situation. In this way he hoped to show them that he was "okay".

Another participant explained that when he met new people, he tried to make the person feel as comfortable as possible by finding common interests to talk about. This helped to make the conversation flow - and even if they didn't accept him, he felt that it became easier for them to communicate with him.

This theme was summed up by a participant when he drew on his own experiences of how he had increased his activity participation and stated:

"In the end, it's up to you and your own efforts..."

4.4.4 Taking Risks versus Fear of Failure

Several participants emphasised the importance of being prepared to take risks when striving towards greater independence. This appeared to relate to a positive self image. Respondents less likely to initiate change by taking a risk seemed to doubt themselves.

Participants acknowledged the need for risk taking in the following quotations.

"Voor jy enige verhouding begin, is dit ook 'n kans wat jy waag. Enige belangrike besluit om te neem is 'n kans wat jy waag..."

"Miskien kan 'n mens nie alles voluit bedink nie; jy kan nie al die antwoorde hê nie. Jy moet tog iets aanpak en die kanse waag en dan so leer..."

Several participants attributed their willingness to take risks and face challenges to a positive self image.

A respondent who led an extremely active life said this was *"because I feel good about myself"*.

Another participant explained how he had felt after he had verbalised his feelings to a girl whom he had liked when he said: *".. ek het die moed gehad; dit wys ek het self vertrou want ek het myself nie teneergedruk nie om te dink dit sal nie uitwerk nie. Ek het die kans gewaag en ek is nie spyt nie"*.

One participant, when asked what she would like to see happen in the future for disabled people, answered:

"Yes! I'm all on about equal rights. But no one will treat you as an equal unless you start treating yourself, or believing that you are an equal. Therefore you can't start with educating the public. You've got to start with motivating [disabled] people to have confidence and believe in themselves..."

In contrast, when participants lacked confidence in their abilities, or feared failure, they were less likely to risk partaking in activities. One subject was scared to go out of the house when she first received her prosthesis as she was not sure of her mobility and ability to walk up stairs.

Another respondent, observed predominantly within his home environment, appeared to the author to be extremely confident. However, when seen in another situation - an evaluation session for employment purposes - he became anxious about his performance and was unwilling to initiate participation in the various duties assigned to him unless directly ordered to do so.

Yet another participant described how her physical functioning was often far less of an obstacle than her emotions. As an example, she spoke about her sexual functioning - although she knew that this was physically possible (her intellect told her it was possible as she knew the facts) - emotionally she was unsure and thus the subject avoided entering into intimate relationships, concentrating her energies on her work.

It was therefore evident in this study that it was not always concrete barriers that limited participants in taking risks or participating in activities, but also their subjective view as to whether they would manage. The result of an individual's poor self confidence was that an activity was either cut out altogether, or he/she withdrew from society. On the other hand a positive self image resulted in the individual being more willing to take chances or face challenges.

4.4.5 Self Growth and Autonomy: Meeting the Challenge of a Changing Environment

"Ek sal sê, die omstandighede laat jou 'self concept' groei, of inhibeer ... dit is iets waaroor jy nie beheer het nie, omstandighede; jou omgewing beheer dit".

A change in the environment, over which the participant had little or no control, often brought an increase in independence. This was because opportunities opened up that had previously never existed and provided the individual with the option of participating in activities he/she had up until then thought were not possible. More often than not respondents verbalised having found that when they were in a new situation which demanded more of them, they were able to rise to the expectations put on them.

In the simplest of situations this was caused by a change or break in the usual routine of the subject. One participant, who was exhibiting signs of depression and showed little interest in doing her housework, showed a change when her niece unexpectedly telephoned and arranged to visit. This provided, in the short term, something for her to look forward to. It also lifted her spirits considerably, and she uncharacteristically volunteered to organise and cook a family luncheon in honour of her niece.

More common however, opportunities were provided through a change in the social circumstances of the participant. A change in the environment pre-empted a change in function. For example, a participant began to contemplate attending university after his father became employed there. It was possible as several obstacles had been removed. He would not have to pay fees therefore finance was no longer a problem; he could travel to the campus with his father thus any potential transport problems were solved; he was reassured by his father's presence in case an emergency situation arose.

Another participant who had looked unsuccessfully for employment finally met with success when her father opened up his own business and offered her a job.

A third subject, when his money from his third party claim came through bought a car. Up to that time he had spent the majority of time at home; thereafter with readily available transport he chose to go out far more often.

4.4.5.1 Rising to the Demands of the Situation:

Participants volunteered that the first time they attempted tasks was most often when a need arose and there was no-one available to assist them. It was therefore not by choice that they became engaged in certain activities, but by necessity.

It was a common perception that the involvement of, and support provided by, others was most acute when the individual first returned home. Participants felt that this declined with the passage of time and therefore individuals found it was increasingly necessary to attempt tasks themselves. A subject summed up the situation as follows:

"Unless you start fighting for yourself, unless you are yourself, people get angry at having to do things all the time. Initially people feel sorry for you. As they get to know you or time passes by, they forget and just go back into a normal routine. So help fades after a while".

Improvements in function then were evident around a crisis point, when subjects suddenly found themselves left to their own devices. One participant felt that the time when his wife left him for three months due to marital discord was when he became self reliant, as he was forced to see to his own needs.

A participant described how after her relationship with her boyfriend ended, she was forced into new situations. She commented further, "... *and it was 'do or die'. It was then that I decided 'to do', and to take control of and responsibility for my life and the unavoidable situation I was in*".

When given the space to help themselves, subjects found they became more willing to attempt tasks and were able to improve their function, often to their surprise. This was clear from the experiences of one participant whose mother lived with her for almost three years following her injury. During this period she never had the chance to cook and tried for the first time once her mother left. Initially she was very hesitant; as a housewife with an incomplete quadraplegia she was afraid of burning herself. But she felt she had no choice (she was not willing to rely on neighbours for help; her husband worked and she doubted his culinary skills; and financially full time help was not an option). The participant, on attempting her first meal the day after her mother left, discovered that she could manage when assisted by her nephew. It was also observed during the study that although her nephew routinely completed specific activities (eg chopping onions, placing rice on the stove) and assisted with basic self care tasks (eg emptying her urine bag), if alone at home she then completed these tasks herself.

In most instances ideas to overcome potential obstacles came once the respondent was in the situation. This was because only then were the individual's needs most apparent. One subject explained this in terms of the benefits he found between receiving therapy at his special school, versus initially in the hospital. He found that once at the school issues such as dealing with volumes of work or the use of a device to type became pertinent, and thus it was only at this stage that he began to spend more time finding solutions to these problems.

A wheelchair bound subject, on purchasing a car two years after his injury, asked a neighbour to fetch it for him. The next day he wanted to go shopping but could not find a driver. The subject therefore devised a way to use a stick to press down on the pedals while he drove. He managed in this manner for the next two years until when parking the car he drove

into a wall. At that point he decided it was necessary to adapt the car and thus had hand controls fitted.

A participant summed up her experiences as follows:

"Another thing is, I made a lot of improvement with regards my daringness to try when he [her live in boyfriend] was gone ... because he cushioned me. We never even used the wheelchair in the house because it was easier for him to carry me to the bed, chair, toilet, car - he's a big man. So I didn't even need to try to transfer; it was quicker for him to just pick me up than to facilitate, stand and facilitate - you know, that sort of thing. So in that sense it was a blessing that he had gone. I mean, life wasn't easier but ... NOW, I realise that ... because I spent more time in my wheelchair ... because if someone wasn't close by it was necessary that I TRIED to lift myself ... which is the only thing where I think the strength came from, that I can now do that. Because I tried".

4.4.5.2 Perseverance:

Many of the subjects discussed their perseverance and determination to overcome obstacles. Most often this was expressed through the words, "... en ek het gefight..." or "I started fighting back when... ". Another subject gave the following advice to others which had been helpful to him:

"When faced with a problem, keep trying. Try figure out a way to get around the problem. Don't just give up; there IS a way to do it..."

Yet another subject said: *"Don't just give up when things go toughly. Put yourself in the situation, and try your best to let it succeed"*.

Respondents who were able to visualise their participation in certain activities were those able to problem solve and devise solutions to potential problems or barriers. Some subjects were able to approach situations with creativity, seeing options, ideas, solutions - and thus turn the situation to their advantage. This ensured that they persevered even in the face of seemingly insurmountable obstacles.

As an example, one participant said that when faced with apparent obstacles, he lay awake at night thinking of alternatives and solutions.

Another subject saw himself as a person who thought through situations thoroughly before reacting to them. He gave the example of how his relationship with his parents had improved after his accident. He attributed this to his continual careful appraisal of the consequences of his actions; if he thought these would be positive then he would carry out the behaviour.

Another subject verbalised his use of problem solving skills as follows:

"A lot of the things that I've ever done, I've actually thought about first. I spend a lot of time daydreaming about what I can do and what I ... or what I could do better, if I did it this way or that ...um ... I do a lot of creative thinking and that ..."

Respondents gave examples of where they had successfully thought of solutions that would keep the activity within their reach. A participant described the adjustments he needed to make when he started riding his bicycle after his accident. *"I had a good athletic build and I was strong, so I could compete with my friends. But I did have handicaps and had to compromise and find solutions. For example, you use your arms to climb a hill. I've developed increased strength in my legs because I can't use my arms for power at all"*.

In some instances then, participants were able to partake in the activities they had done before their injuries because they had persevered and found solutions to the problems facing them.

4.4.5.3 Cognitive Appraisal: The Challenge of Prejudice

Participants described the situations they hated the most as those in which it was clear that they were being pitied. It was often expressed that unless people knew the individual, they saw him/her as handicapped. As one subject put it, *"... and that's how people perceive me, you know: 'Ag shame'. They don't realise you're still a person. You still feel, and you don't like being felt sorry for. I hate it - that is the worst thing"*.

It became clear that when people underestimated the respondents' abilities or had lowered expectations and were therefore not supportive of their attempts at tasks, several participants deliberately set out to prove these misconceptions wrong. There was a feeling that it was the responsibility of the individual to show others what they were able to do. When it was suggested that subjects would not manage a task, this challenged them to try and show that they were capable. In these instances the prejudice acted as the catalyst to motivate the participants. The following quotations illustrate this.

"I often try and do things that many people only think two handed people can do, and will be difficult for a disabled person. So I often do things which will shock people".

"Toe ek besluit het om universiteit toe te gaan, het baie min mense vir my ondersteun - in my idees, om my aan te moedig. Ek het agtergekom hulle sê net: 'oh!' Maar in hulle kop is hulle nie baie positief nie. Toe het ek probeer om hulle verkeerd te bewys. En ek het!"

"... a friend told me I was making excuses, being lazy. I saw this as a challenge; I hate to be called lazy. I think this is what makes me do things, when people say I can't. When I say I can't, then I can't. If someone else says I can't, then I can - that's just this stubborn streak in me".

Furthermore, participants also verbalised that when people doubted their ability, it made them also doubt themselves. They therefore also needed to prove to themselves that they could manage tasks. One participant described how he exercised in secret, in his bedroom, to improve his function. Only when he was confident in his abilities did he show his family that he was able to do more than they had thought.

Another participant expressed that he took part in seemingly dangerous sports (eg cycling races and rock-climbing with the use of one arm) to:

"... in a sense shock the world. But in a sense to prove - not to shock but to prove to myself that I am alive ... but it also proves to me that I'm still capable, I can still do things".

4.4.5.4 Building on Positive Experiences:

In observing and interviewing participants it was clear that positive experiences were self-perpetuating and reinforcing. The first experience may have come from an unexpected opportunity, but when attempts at doing tasks or participating in activities were successful (often to their surprise), subjects showed a high level of motivation to repeat the behaviour.

A participant described her surprise at discovering that she was able to complete handwork, an activity she had never attempted when she had the full use of both her hands. The experience led her to feel good about herself, particularly as she had initially struggled but had with effort mastered crafts such as macramè and crochet work. The consequence was that thereafter the subject persevered with tasks even when she was clumsy or struggled. She commented, "*Tot vandag: as ek iets wil doen en ek sien ek kry dit nie reg nie, dan doen ek dit oor*".

Another subject stated that his leisure activities prior to his injury were camping and going to the beach. After his injury he took part in neither activity, as he felt that he would not enjoy himself. Three years later he was persuaded by friends to accompany them to the beach. He went along despite reservations. To his surprise, the outing was extremely pleasurable; largely due to his friends who included him in all the day's activities with ease. Thereafter he went regularly to the beach and the same year he went camping for the first time after his accident.

This ripple effect, whereby success in one activity motivated the individual to repeat the behaviour, was also seen when the situation per se provided a variety of new opportunities that previously had not existed. For example, the participant who attended university also went to the cinema for the first time during his first year as a student. This had become possible as the campus was very close to the town centre which was accessible for wheelchairs. The subject was able to make use of other facilities within the town; he could go shopping whenever he chose, return videos or make an appointment at the local optician should this be necessary. Usually, at home, he had relied on his parents to do these tasks for him.

Another participant, when she started working, found to her unexpected delight that she was able to, for the first time since her injury, make new friends. This was purely by chance; although she worked alone, her office was situated in close proximity to three small shops. The employees had become friends amongst each other and automatically included her in their circle when she started work.

Achieving success also led to increased **hope and optimism** for the future. Positive experiences led participants to persevere in difficult situations because they foresaw that their dreams could potentially become reality.

One subject said: *"Kyk, dit raak al hoe beter vir my. En hoe beter dinge vir my raak, hoe beter voel ek oor myself"*. This participant was describing his work situation; initially he had thought that he would not be able to work again but opportunities had come his way and he thus felt hopeful for the future.

One participant had mentioned the possibility of getting a part time job the following year. He later spoke of wanting a larger monthly income; it was queried whether he thought this was possible in the light of the potential work offer. His reply was:

"Miskien. Miskien is dit nie eers die werk nie. Maybe ... miskien iets anders sal gebeur, you never know ... want so baie dinge het al vir my uitgewerk, so hoekom nie meer nie? Miskien iets beter... "

Another participant volunteered that she was shy in meeting people, especially men. She could not imagine someone accepting and wanting her as a wife because of her artificial leg. In an interview (two months later) however she stated that marriage was a definite possibility. When this was queried she replied that she now had a boyfriend, and thus felt confident about the future.

Positive experiences thus helped motivate subjects to persevere to achieve their goals. They were able to endure difficult situations or struggle with tasks when there was hope of improvement in the future.

Therefore in summary, a change in circumstances or the environment provided a chance for the participants to increase their autonomy. This was because of the expectations which existed within the new environment. Independence was potentially promoted when subjects responded to the increased demands placed on them.

4.4.6 Adaptation to Disability: A Process of Re-organising the Self

Participants who had been able to adapt and adjust to their new status as a disabled person appeared to have gone through a process of re-organising their values, lifestyles and perceptions of themselves.

In some instances this was a result of a direct, conscious choice. For example, subjects volunteered that after having gone through the severe trauma linked to becoming disabled they had began to think more about the meaning of life. This resulted in two participants becoming religious. Another participant felt that she knew herself better after her accident than before. She commented:

"I've had to stop, and look at my inner being. Before, it was run, run, on the go all the time. Now I've been stopped. Which is a blessing as otherwise I wouldn't have found the things that I have now".

In other cases changes occurred as an indirect result of the disability. As an illustration of this a participant described himself as a much softer, caring person after his accident. This he attributed to the fact that he was now less involved in sport than he had been previously, and thus had more time to focus on developing relationships.

Three of the male participants who were married also commented that their relationships with their spouses had improved because they spent an increased amount of time at home and thus saw problems, as well as their contribution to them, that they had previously been too busy to notice.

4.4.6.1 Acceptance of Change as Normal:

"Ek probeer nooit om te vergelyk, hoe ek voor my ongeluk was en nou nie, en probeer om dieselfde te wees. Want ek kan nie terug gaan na daai tydperk

nie. Ek as 'n persoon - my behoeftes - het ook verander soos ek verander het".

The above quotation serves as an illustration of an attitude demonstrated by several participants. The majority verbalised that they spent their time very differently after they were disabled. Respondents explained that because their needs and circumstances had changed with time, they viewed a change in activity configuration that had occurred as natural. They therefore did not attribute changes in lifestyle, or negative experiences, as necessarily being linked to the disability itself.

For example, one participant volunteered that he saw very few of the friends he had before he became disabled. He stated that he had expected this; at the time of his accident they were reaching an age where people were likely to start drifting apart - from school to divergent career choices. Therefore although they might keep some contact with each other, he would not expect the relationships to be as before.

Another subject spent the majority of her time in work related activities. She volunteered that she had given very little attention to developing leisure pursuits or building new friendships, because she had felt that her priority had been, at the time, to build a career. The participant anticipated that this would change in the near future as her work was now well established and she had begun to contemplate marriage again.

The acceptance of change in their lives as normal, and not as a direct result of the disability, was also evident when two subjects discussed the reasons they felt caused changes in their personalities. One participant felt she had changed from being a quiet reserved person who spent the majority of her time at home, to a much more outgoing and friendly person. This she attributed to the ending of her marriage; she described her husband as having been extremely oppressive. The other subject felt he had generally become less aggressive and more even tempered as a result of his increased involvement with the church.

4.4.6.2 No going back:

Contrary to the above, some participants were unhappy with the changes that had occurred after they became disabled, and displayed a desire to return to their former lifestyles if they could. On probing this appeared to relate to unfulfilled needs - respondents wanting to be more productive and socially active than they were. The feeling was that if they could approximate their previous life circumstances, they would be more contented.

In this study three subjects were able to do this, but found that it did not make them happy. One participant moved from staying with his sister to his parents's home as this was in the area where most of his friends stayed (he had felt isolated at his sibling's house; both because of the geographical location and the absence of a telephone). He returned after one week. To his surprise, the subject had found that he no longer wished to go out as often and for as long as his friends did; he was content to spend more time at home and to concentrate on his studies.

Another working participant spent a week at home after the death of her mother; she was relieved to return to work as she had felt non productive while at home. Prior to this experience the subject had considered giving up her job as she had thought she would enjoy staying at home, as a housewife.

A third participant had contemplated moving back to East London, her home town, because the majority of her family were there and she reasoned that there would then always be someone readily available to provide assistance. She had the opportunity to visit for a few days on a business trip and hated it. The subject found that she felt quite isolated as having lived in Cape Town for four years, she had been able to set up a supportive network. Her family were no longer the prime contributors to this.

Therefore in summary, participants who attempted to reverse changes that had occurred within their lives after their injuries to a previous state found the experience less positive than they had anticipated.

4.4.6.3 Adaptation is Ongoing:

A participant stated: "*Alles [ideas for solutions] kom nie op een sitting nie*". This serves to illustrate that adaptation was ongoing; with time new ideas were added to the old, thus changing or modifying the earlier solutions.

A participant with limited hand function described the splint made for him to enable him to hold the telephone. At that time his parents dialed the number for him. His next plan was therefore to mould a place on the splint for a knitting needle, with which he could dial the number himself. The needle slipped against the numbers; he therefore added plastic tac to the bottom. Later he realised that if he pressed the numbers with his hand in a certain way, he did not need the needle. These changes occurred within a space of the year.

Physical and task improvements were noted over time. A participant said: "*As jy 'n bietjie kan doen, dan doen jy 'n bietjie meer*". He had initially been told by the doctor to expect little physical improvement following his discharge from hospital. Early attempts at exercising were difficult and slow, but with perseverance this became easier. He described doing one press-up the first time he tried, two the next. Within the week this had increased and after two months his arms were sufficiently strong not to limit him in doing this exercise.

Another subject stated confidently that her physical function was still going to improve, 11 years after her head injury. When asked why she felt this way, she replied, "*Want ek kan dit voel. Dit voel asof dit verbeter. Spesiaal met my regterhand want ek kan nou stryk met die regterhand. Dit voel sterker*". The subject felt that she was still progressing and thus saw no reason why this should not continue.

Adaptation was therefore ongoing, as participants find out about new ideas or worked out new solutions to presenting obstacles. One participant, five years after his accident, came across the ideal bowl to use for eating; it was a dish his mother had bought to use in the microwave. Another subject said, from his own experiences:

"Jy leer iets, en dan leer jy om dit makliker te maak.."

4.4.7 Adaptation to Disability: Reflecting on the Purpose

There was a strong feeling among the participants that it was up to individuals to decide how they wished to view their situation. They could either dwell upon the accident, or move on to viewing life more positively again. This is expressed in the following statements made by three participants:

"Jy kan nie jou gedagtes daarop sit nie en net dink nou is ek gestremd. Dit sal jou meer swakker laat voel...".

"I had to let my life continue and just forget about the fact that I couldn't do certain things".

"You control who you are: if you're negative, you've decided to be negative...".

There were several strategies which assisted participants to take the focus off their disability, view their circumstances positively and continue progressing with their goals or plans. These are documented in this theme.

4.4.7.1 Focus on Abilities:

Virtually all the subjects volunteered that in order to remain positive, they focused on activities they could do, and not what they could not manage or struggled to do.

A participant, when asked whether she ever felt there were tasks that she wished to complete but could not because she was physically disabled, replied: *"No. That's wasting time. That's wasting energy. I get on with the things I can do"*.

Another participant had great difficulty thinking of an activity which he could not do because of his paralysed arm. But he spoke continuously for an hour on what he could do. This was indicative of his philosophy; focusing on the positive aspects of his life rather than the negative. He commented:

"[always] Look at what you can do. I mean I can think; even if I was paraplegic with no arms I can still write poetry, read. I mean there's such a lot to learn and so ... I haven't stopped living yet. When you're alive, you're alive. And living is so important. And if you have a disability and are alive,

a living person, why not live? Otherwise you might as well kill yourself and that's that. You've always got an option. I took a good look at where I was at, what I could do, and then when, where I could go forward, and do other things. So look around, try new things - if it doesn't work, too bad".

Respondents pointed to possible influences of **professional staff on the self concept** when they attributed the foundations for an attitude of thinking positively to being laid within the hospital setting. One subject expressed this as, "*.. as jy daai 'self esteem' kan in die hospitaal kry om te dink kyk hier, ek kan dit doen, dan kan jy dit doen*". They felt this was determined in the relationships held with the professional staff. Some had perceived staff to be extremely negative, displaying limited expectations for the individual - in these instances they had been discharged with low expectations for themselves. Others described having been encouraged; helped to see the pros and cons of situations, but with a focus on their abilities. A participant described his relationship with his physiotherapist as being extremely helpful because, "*Sy het nooit iets negatief gesê sodat 'n mens down voel nie, sy het nooit ... sy was nooit 'bad luck' nie ... ek het nooit gevoel soos 'n hassle nie, soos 'n las. Sy was altyd positief*".

The subjects' obvious pride in their accomplishments no matter how small, was clear. A respondent verbalised that she had never worked on an overlocker or completed craft activities before her accident. She said: "*Vandag kan ek dit doen. En dis wonderlik, alles wat ek nou kan doen. Ek meen, nou dat ek verlam is ...*".

Participants therefore reduced self doubt by concentrating on their potential, and not limitations.

4.4.7.2 Retrospective Appraisal: Making Light of Hardships:

Another way in which participants managed to cope with the hardships they experienced was by making light of negative or difficult experiences. This was often seen when a participant described an experience in retrospect. For example, one subject explained that he had been

bedridden, in pain and highly frustrated at not being able to do tasks when he first returned from hospital. He then summed up the situation in this obvious understatement, "*Well, I didn't enjoy life then*".

Another subject's marriage underwent tremendous strain as a result of his injury, to the point that he later attempted suicide. He described the situation as, "*en daar's mos jou ups and downs*".

Humour was also employed in some circumstances as an alternative to anger. This was particularly seen when participants were met by prejudice. Seeing the funny side of a situation helped them to be able to dismiss it as inconsequential. A participant described a situation where she was shopping with her sister and the saleslady completely ignored her, despite the fact that she was answering all the questions. After the incident she laughed about this with her sibling which then diffused her irritability.

Another subject was discharged from hospital wearing a neck brace, causing people to stare at him. His friends would then joke that he could earn a living begging; he verbalised that their humour helped to decrease the emotional charge in the situation for him.

4.4.7.3 Measurable Steps:

A less mentioned theme although paramount to some participants was the setting of small goals by which they could measure their progress and thus see that they were moving forward. Breaking down the problems into containable and achievable units helped subjects to see them as being within their reach.

One participant said that he had been in tremendous pain when he first came home from hospital, and thus was bedridden by choice. He began to increase his mobility with the assistance of his brother who helped him in setting measurable and achievable goals - first to stand, then to walk to the basin in his room to brush his teeth, then to walk to the toilet etc. Another participant remembered the sensation and movement he felt for the first time in almost two years after he went for tests following two operations performed to stabilise his paralysed shoulder. This motivated him to try to use the arm as much as possible because he felt as if function

was returning. A third participant found that when he recorded and paced his daily exercises designed to strengthen his weakened arm and leg, he could push himself to do a little more each day.

Short term goals were of value because participants were able to see their progress, which served to maintain their motivation and hope to keep trying to improve their functioning. The apparent success acted as a motivator for them to continue.

4.4.7.4 Focus on the Future:

Three of the participants felt that one way to remain positive despite hardships was to focus on the future. They would advise a newly disabled person not to concentrate on the past, or problems, but to rather think forward to the future and build on their increasing abilities. Two quotations illustrate this:

"Daar is baie dinge om oor te dink. Dink hoe dinge sal wees wanneer jy regkom. Dink: ek sal weer my werk kan doen, of dink: Ek sal weer dit kan doen... "

"If you don't dream big, you won't get anywhere".

Not all participants were able to think about the future; and four subjects stated specifically that they did not believe in planning ahead. This was clearly related to the vulnerability they felt, caused by the suddenness of the onset of their disabilities. This was an event over which they felt no control, and which had led to dramatic life changes. In the light of this, they developed a philosophy of taking one day at a time.

One participant gave her reasons for not planning her future as follows: "Nie in my toestand nie. Want ek weet nie waar ek sal wees volgende jaar nie. Want dinge gebeur en verander so gou...".

Another subject said: *"Ek vat een dag op 'n slag. Elke dag vir homself. Ek weet nie wat more gaan gebeur nie. My gesondheid kan miskien verswak en dan kan ek nerens toe gaan nie. So ek vat net elke dag soos dit kom".*

In summary then, participants made use of a variety of strategies to maintain a positive outlook and nature. Emphasis was placed on strengths and abilities, while minimizing difficulties and pain. This was assisted when progress was noted. Some respondents also made use of future goals to maintain their motivation.

4.4.8 Adaptation to Disability: Development of a Routine

Subjects repeatedly stated that advice they would give to a newly disabled person was "to keep busy". This was because a common experience described by participants was that spending the majority of their time at home, with very little to do, they tended to constantly think about their physical condition, its limitations and how it had affected their lives. This emphasis on negative thoughts led to feelings of unhappiness, sadness, and depression. However when they were occupied, they found that the activity distracted them from reflecting on themselves and they reported being far more satisfied with their lives.

The above is clear from the experiences of two participants; one of whom joined a sports group and the other a work group. The first subject had been used to working prior to his injury and found sitting at home, with very little to do, made him feel as if he would go mad. When the opportunity came to join a sports group, he was willing. He found that the sports group gave him a reason to get up early in the morning, and gave him an outlet to focus his attention on other than his disability. The second participant explained why the work group to which he belonged was important to him, even though it did not provide a regular income when he said:

"... omdat dit verhoed dat jy net by die huis sit en dink... die ongeluk, die gestremdheid. En dit is wat jou verswak..".

Loss of a routine therefore resulted in an overconcern with the disability. By taking up opportunities for work or leisure when these came along respondents maintained a focus to their day, and they then thought less about their physical limitations.

Routines were developed through experimenting, through trial and error.

"... mainly my life has become .. sort of ... um .. what I do I do now, and I have learnt most of the things. Unless something really new comes into my life now and I have to change.. "

A participant explained how he had initially struggled with housework, particularly washing and drying dishes. With time he was able to work out the best way to hold a plate without dropping it.

Another participant verbalised that initially her sole focus had been to worry about basic self care tasks, for example her bowel evacuation was a problem as it was erratic. Thus she was embarrassed if people popped in to see her, and seldom left the house for fear of an "accident". Once she developed a routine and her eating, sleeping and bowel habits became more predictable, she developed far more peace of mind. This left her free to concentrate on other tasks which gave her more satisfaction and fulfillment.

There were several ways in which the routines used led to increased independence for the participants.

Firstly, participants chose to have assistance from people who knew them well and knew how best to provide the appropriate and necessary assistance. Their main reason was that they found instructing numbers of people on how to help them both tiring and time consuming. Subjects verbalised that they wanted to focus on managing basic self care tasks as little as possible. Relying on the same people daily meant a routine could, with time, be established which was virtually stress free for the subject.

Secondly, subjects through the use of routine became aware of how long an activity would take to complete. They could then plan their time effectively and organise the day appropriately. One participant verbalised that she found herself having to get up earlier in the morning than before her disability, as it now took her longer to prepare herself for work. Another respondent attending university stated that his subject choice had been influenced by the time it took to travel between the various faculty buildings on campus. A third subject sighted how much of her day was taken up in basic self care. A part of this was her bowel

functioning - she used to resent the amount of time spent sitting on the toilet, as it was both boring and frustrating for her. Later she managed to use the time more effectively and to her advantage; the participant deliberately left her correspondence to be completed during the times she spent on the toilet!

Important routines observed were those which made use of the human body. Most often participants were no longer aware of the choices they were making, or that they had a choice. In time function became automatic. For example, wheelchair bound participants automatically reached to apply the chair's brakes when they were stationary; a participant holding onto the chair with one hand maintained stability while reaching with the other.

Participants with one impaired arm were observed to have developed a routine of only using the stronger arm. This was established early on, when they first came home from hospital. At the time they were generally weak and had not been able to use the disabled arm, or had struggled profusely when attempting to do so. It was functionally easier to use the other, stronger arm and with time, they became used to doing this. The disabled body part, through lack of use, remained awkward and the use thereof never became automatic again but required a conscious effort - participants described it as a heavy or different feeling, and as not being able to rely that readily on the disabled side for function.

Two examples illustrate the above. One participant's right arm was completely paralysed when she came home. She therefore used her left hand to feed herself. Initially she struggled but later it became easier. Once her right hand began to increase in function, the new pattern had already been established and she thus never changed back to the full use of her dominant arm. Another participant described why she continued to use her non-dominant, but stronger arm in preference to her impaired side when she said, "*... want ek is so gewoond aan hierdie hand, en hierdie hand werk beter*".

Despite this neglect of the affected side it was observed that the impaired limb was used when the task required bilateral hand function. One subject, when asked why he used his left (affected) arm so little in function replied: "*... want dis amper so te sê, dis buite werking*". He however did work bilaterally in performing certain tasks, such as washing and drying dishes. When this was pointed out, the subject answered, "*.. want dis 'logical', jy het twee hande nodig om dit te doen*".

The use of a routine therefore assisted the subjects to plan their time effectively, and familiar daily patterns decreased stress. Re-establishment of a routine served to reduce the participants' pre-occupation with their disabilities. With time patterns of function became automatic.

4.5 SOCIAL ENVIRONMENT

"It's easier to accept your disability when others accept who you are. I've accepted the way I look because others have accepted who I am".

"Ek sal sê hoe ander mense jou sien, of hoe jy dink ander mense jou sien, bepaal wat jy van jousef dink".

"[after the onset of disability] I thought I had changed. I realised I was the same as before by the way my family and friends treated me - taking me out, including me in things".

The above quotations serve as an illustration of the emphasis subjects placed on the social environment in determining how they viewed themselves and the activities in which they partook. The role of the significant people in influencing what they expected of themselves and therefore the potential for involvement in activities was reported in the following five themes.

4.5.1 People as External Motivators

"There will always be one person who believes in you; get closer to that person".

The encouragement provided by others made participants begin to attempt tasks and to take risks; it was also the motivation for them to continue with activities.

In most instances this was attributed to the encouragement provided by family members and for some respondents, close friends.

A participant answered when asked how he had managed to overcome obstacles and improve his function, *"dis meestal te danke aan [sy vrou]"*. She had inspired

him by verbally telling him that he would manage the task if he tried; for example if he wanted something from the top cupboard, she would decrease her assistance and make suggestions as to how he could get there himself.

Another subject explained how he initially did not want to go out, as people stared at him and this worried him. His parents helped him overcome this as they refused to let him have his way, including him in the activities that they did. He said, "*Hulle het my nie een kant in 'n kassie gebêre nie; van die mense weggesteek; skaam gewees vir my...*".

A third participant said: "*I don't know what the transition was, I mean why ... what made me fight back. I think maybe it was... my parents... . Basically um... my Dad's a real fighter ... um... in spirit. So he would always encourage me to do things...*".

Other participants mentioned similar experiences; they would begin to take risks because of the presence of a spouse, parent or friend who was there to spur them on with inspirational phrases such as 'you can do it', or 'come on, I know you can do it'. In these instances, with the continual encouragement, they would persevere with the task. Participants were thus encouraged when they themselves lacked confidence.

Respondents volunteered further that they had discovered hardships were much easier to get through if there was **someone with whom to share the experience**. This was seen in the home industry work groups run by the community occupational therapy project. Despite difficulties, the members maintained interest therein as they supported each other through the hard times.

Another participant described a friend who stood by him, coming every morning to get him out of bed. Sometimes he had just got out of bed, and then the friend would leave. At times he did not want to get up; he saw no reason to as there was nothing he was going to do that day. Then the friend would insist and push him until he was dressed.

Participants expressed being extremely sensitive to the responses of those around them when they first attempted tasks. If they were given **positive feedback** for

what they had achieved, the encouragement motivated them to persevere or to repeat the behaviour.

A participant explained the role his parents played in spurring him on to keep trying tasks:

"They encouraged me to do things by praising me and being proud of me when I managed. For example, recently my father came to me when I built the wing of a model aeroplane and said, 'You know, I just don't know how you get it right'. That kind of encouragement does build one up a lot".

Another way that people motivated the participants was through the expectations they placed on the subject. When others verbalised that they believed a task was within the individual's capacity, the respondents began to believe that too.

A participant gave the example of when she started her work within the disability movement. Initially she was unsure of herself; but she was encouraged by a colleague who verbalised that she was willing to carry her as much as she needed. The participant explained, *"She really just encouraged me so much. So I thought okay, if you believe I can do it, then why don't I believe I can do it?"*.

The faith of the other person served to decrease the subject's own self doubt. Another participant verbalised how he had expected the student information service to react negatively to his wish to study at university. He had thought they would advocate UNISA as a more viable option for a disabled person. To his surprise however, they were encouraging, and told him about the experiences of other disabled students on campus. He described the consequences thereof as follows:

"Dit het my laat goed voel om te kom. En dit het my meer aangemoedig om die besluit te neem om universiteit toe te kom; om aan te gaan met my besluit".

Particularly inspiring relationships which served to motivate (especially younger) individuals to achieve greater independence were **relationships with the opposite sex**.

A participant volunteered that it was a relationship he maintained with a girlfriend that first caused him to risk doing tasks. He commented:

"Sy was altyd ondersteunend; dit was lekker om vir haar altyd te vertel van dinge wat ek gedoen het. Ek het 'n rede gehad waarom ek dinge doen. So op 'n manier het sy my gehelp om 'guts' te het. Nie om iets te bewys nie, maar om gerespekteer te word. Jy voel nie ... alleen nie".

Another subject described how dependent he felt on one of his relationships when he stated:

"I spend a lot of time talking about how I'm feeling, and a lot of that time is because of my arm. For the past two months I've been in almost constant pain everyday. So how I'm feeling relates to my arm and so we talk about that. If she wasn't there, or someone like her wasn't there, then I'd crack. So, in a sense, she's my analgesic...".

The support and encouragement provided by significant others was thus a critical factor for the participants. This was summed up by a respondent who spoke about her relationship with her boyfriend and caregiver as follows:

"I must say, thank God for John, because he would say: 'I'm not going to let you die'. Often I'd say: 'Just leave me, just go away, just go and find someone else and just leave me'. Because that's really what I felt. I felt useless, I felt hopeless, I didn't feel I was worthy of a boyfriend. I was feeling just like a burden. And he said: 'No, I won't let you die. You're not going to die on me'. And he wanted me not to die more than I wanted me not to die. And I must say that really strengthened me a lot". They exercised every day together; the subject feeling as if he really pushed her. "I would try and meet him halfway: he feels good about me, and I don't feel good about me, but let me try for his sake. And I must admit, it worked".

4.5.2 Participants Accepted for being Themselves

A valuable role played by outsiders was to show the disabled participant that a task was within their reach.

It was common for participants to devalue themselves; they used words and phrase such as *"minderwaardig"* and *"kan niks doen nie"* to express this. For example subjects verbalised having thought that, as a disabled individual, they would never work again or would never have the chance to be involved in an intimate relationship. However, through the involvement of others and their positive attitudes, the subjects were able to once again realise their potential.

One participant spoke very highly of an occupational therapist through whom he became involved in a work group. Up to that point, he had been at home and had not worked for the past two years. He felt that she did not see his wheelchair and perceived that she treated him no different to everyone else. He stated, *"she opened my eyes to what I could do, and that I could do something"*.

Another participant attended a sewing course organised by the occupational therapy community project, and continued then to sew from home. Although this later fell through, it was his first attempt at a work activity following his accident. Up until that point he had thought work was no longer possible; thereafter however he continued to be involved with other activities from home. The initial sewing course had once again instilled a desire for a productive lifestyle, and he then saw it as being within his reach.

Participants doubted themselves most in the attainment of intimate relationships. In almost all instances they had initially ruled them out as a possibility. However, much to their surprise, experiences were often positive.

A participant said: *"Ek het nie eers geweet dat 'n vroumens sal nog in my belangstel nie. Ek was baie verbaas om uit te vind dat meisies nogsteeds belang gestel het"*. Thereafter the subject had become far more active in seeking out a partner.

Another participant documented her experiences as follows: *"I thought a male will probably never look at a female with a false leg. And I've experienced that that is not really it. You do find people that will discriminate against it. But then on the other hand, you'll find that people take you for the inner you, and not really for the appearance"*.

Therefore, only once within the situation could participants see the relationship as potentially turning into reality. This was due primarily to the responses and

attitudes of the other person within the environment. If they were favourable, participants then began to view the situation more positively. A final illustration of this was seen when a participant verbalised that it had been hard for her to imagine marriage as a possibility. But she had recently met a friend with whom she felt at ease. She stated further, "... *and yes, since I've met him, I've decided it's possible*".

In the above mentioned examples, the initiative came from the family or friends; they provided the opportunity for participation rather than the disabled individual being proactive and creating the situation for himself/herself. Clearly, participants de-valued themselves, they were assisted towards greater independence when others accepted them for being themselves.

4.5.3 The Family: An Extension of the Disabled Person

In the study all the participants were living with immediate family members; in their own or the family's place of abode. Four were staying with their parents, four with their spouses and two with siblings. For seven of the subjects this was the same arrangement as before they became disabled. The presence of family members within the home substantially influenced the subjects' activity configurations and daily routines.

All but one of the participants reported having required assistance with basic selfcare tasks at some stage following the onset of disability. This was always carried out primarily by a spouse or parent, and secondarily a sibling. The majority of care which was necessary therefore became the responsibility of the family.

This theme documents the integral involvement of family members in the life of the disabled individual.

4.5.3.1 Community Living possible due to Family Assistance:

Living in their own home, where they had control over the daily routine, was important to the subjects. This was clear in the following two quotations.

"This is my home and my house. Who would give up her home and house to live with other people? Never".

"My eie wooning ... ek is my eie baas ...".

Severely physically limited participants were able to remain within their own homes because of the presence of significant others. Participants volunteered that they were thus extremely relieved that they had families and homes to return to when discharged from hospital - so that living in an institution had never been an option for the subjects.

When one of the subjects needed help that the immediate family could not provide, it was expected that the extended family member came to live with the disabled person, rather than vice versa. This was extremely common. The mother of one participant lived with her for almost three years following the subject's accident, primarily initially because she was extremely weak and needed assistance with all basic self care tasks. Her husband was in the army and often away; later he was employed closer to home doing shift work. He could thus not provide the necessary support.

In another example a subject relied heavily on her sisters for help; they moved from Port Elizabeth to Cape Town to live with her. When one of the sisters was married she moved out of the house and the participant employed a char to assist with basic self care tasks. However, whenever she experienced a crisis (eg, the char left and she needed to train a new person) both her sister and brother-in-law would move back in for the interim period.

Participants verbalised that for them to move and live with extended family members was never an option (the two respondents staying with siblings had done so before their injuries). Despite the fact that there would potentially be more caregivers available to assist the individual, or even to provide social support and company during the day, they viewed this as being a compromise of their autonomy.

In the cases where participants were residing with their parents or siblings, this was due to financial reasons rather than the disability itself. Only one

subject, a widow with two children, expressed having wanted to live on her own but being constrained by her physical limitations. She was unhappy with the living arrangements as the house was crowded; however her mother had convinced her not to move out by stating that she would struggle with her children, and that no-one would be there to assist if she became sick.

Two of the three participants who altered their living arrangements after the onset of disability did so primarily to be closer to the hospital. One subject perceived she would receive a high standard of care from the particular centre. The other wanted to be able to reach the hospital quickly should an emergency have arisen. The third participant moved from staying in a room with his in-laws to a council house when he was discharged from hospital. Whilst an in-patient he had stopped going home for week-ends as his in-laws complained about having to move the furniture to accommodate his wheelchair. This led him to discuss the possibility of a council house with the social worker and it was subsequently arranged for him.

4.5.3.2 Expectations placed on the Family to Provide Assistance:

Participants in this study expected the family to be there to assist them where necessary. There was a belief that family members were obligated to help each other wherever they could.

It was expressed by respondents that they felt they could not "burden" friends or neighbours and ask for help. They were reluctant to do so, not wanting to appear as a nuisance. There was also a feeling that one could not ask too much of others as they would have their own obligations to fulfill. This was evident in the following two quotations:

"And when I have to go away, she [her sister] takes off work to go with me. Just because there aren't any other reliable people. My sister just got married now, in August. But you see, who else am I going to go to? I suppose I could go to you and ask you to do it, being a person I know in the community. But you've got your job, other commitments and things, so why must you take the time off? So how much is the community prepared to do this?"

"On monday the maid stole my clothes and left. I had started menstruating the week before; my catheter was leaky. So it was bloody and messy and wet and everything. I had to 'phone my sister and say come home from work. Who else in the community can I say come home and help me? You know. So family takes up most of the burden of a disabled person".

In contrast to the reluctance to rely on the community for help, it was expressed repeatedly that family were **obligated** to provide assistance. One participant volunteered that she felt better off as a "non-white" than a "white" disabled person, as she perceived herself to be in an extended family-type set up. In this context it was viewed as natural to receive help from other members, and natural for the family to help one another.

A participant described his family's philosophy as, *"ons help mekaar so. As een nie het nie, dan gee die ander"*.

Another respondent with quadraplegia, who relied heavily on his parents for assistance in carrying out physical tasks, tried to help them financially whenever he could. His reasoning was *"... om ook 'n bydra te lewe aan die familie, want ek het gevoel ons is 'n span; ons is 'n eenheid. Almal moet probeer wat help kan bring"*. Family members were thus seen as interdependent.

There was an expectation that family should offer assistance, and not necessarily have to be asked. A common statement was *"hulle kan sien ek sukkel"*. One subject expressed anger that her sisters were not sensitive to her needs. She never requested assistance directly, expecting them to volunteer but as this was not forthcoming perceived them as unwilling.

Moreover, participants also volunteered that it was part of a family member's duty to help, and to not expect something in return. Another subject described her sister as *"... she's just a funny kind of person, expecting something for whatever she does. And I just feel I'm not obligated - probably because she is family so she shouldn't expect something from me. On the other hand, I was the one who looked after her daughter from eight months so in the light of that, I feel she shouldn't expect something from me. She should gladly offer to do something so because of that, I just don't even ask"*.

Two exceptions contrary to the feeling that family were obligated to provide assistance were noted. Firstly, two participants recognised that bearing the burden of care could be physically and emotionally demanding for family members, as well as disruptive to their lives. Both were quadriplegic subjects and had been exposed to the idea of paid attendants, which they stated they would prefer. An obstacle was finance. One of these subjects did periodically make use of an attendant, but she had yet to find a suitable permanent attendant who stayed long enough to become familiar with her needs. As she put it, *"If I could find someone who is there all the time, and whom I didn't have to constantly teach, I would prefer that person because it gets rather heavy on family"*. The other subject in thinking ahead also realised firstly that his parents would not necessarily always be around to assist him, and secondly that the only way to realise his goal to be free from his dependence on them was to pay someone to assist him.

Secondly, not all participants were positive about their relationships with family members, and were thus less likely to rely on them for help. One subject in particular stated *"Jy moet jou familie uitskakel. Want hulle is altyd die mense wat iets te sê het"*. His experience was that they (in this case his mother and siblings) interfered with his marriage. This caused problems in the relationship with his wife, and made him feel negative towards himself. He felt that his family were wanting to be overinvolved, not letting him make decisions for himself, and thus wanted minimal contact with them.

4.5.3.3 Family influences on Activity Participation:

The availability of a family member influenced **what** activities the individual participated in. An example of this was seen when a subject found herself forced to play a mothering role to her younger siblings when her own mother went into hospital for a week. Following an operation her mother passed away; thereafter the participant began taking her siblings on a weekly outing which increased the amount of time she spent outside of the home.

Another subject who was assisted by her mother in basic self care tasks stopped attending her social support groups after her mother returned to

her own home. This was because there was no-one available to wash her in preparation for the outing.

The family of a younger participant underwent severe financial problems beginning shortly before he was discharged from hospital. His father lost his job, they had bought a new house and their car was stolen. Therefore the subject spent almost all of his time at home initially. He could not partake in the usual family outings such as shopping because of lack of transport.

Participants also appeared to fit into the activity patterns that were acceptable to the household as a whole, and that others were involved in. A subject was observed to sleep very late - almost all morning. However, this was the same pattern shown by his sister and brother-in-law when they were on holiday.

Another described how she would spend her days helping her mother with the housework while the rest of the family worked. She slotted in daily with her mother's routine.

Unemployment among family members was high, and it was thus common for them to work from home to earn extra money. In these instances the participants would join in, for example a subject assisted her mother in the sewing of linen and children's clothes and another helped his wife in the selling of food items from their home.

The presence of significant others also determined **when** participants were able to carry out specific tasks. For example, a participant verbalised that she would have liked to get up later in the morning, but she needed to be helped into the bath by her sister before her sibling went to work.

It was common in this study for employed family members to do shift work. One participant planned her shopping expeditions around the days her husband was off, as he could then push her to the shops. Another participant explained that when her sister had been unemployed, she could ask her to take her out at a moment's notice. Once her sister started working, she planned the bulk of her activities outside of the home

to correspond with the weekend, when her sister would be free to provide assistance.

4.5.3.4 Family as Facilitators to Assist in Function:

Common early experiences of participants were that their families or caregivers became over involved with their lives, doing all tasks for them and giving the subjects little opportunity to help themselves. One participant described his situation as, "*Ek is maar 'n robot*". Another subject viewed her situation as follows:

"At the beginning, I had little say over anything. Even what I was going to wear. My sister would come and wash and dress me and I'd see what I was going to wear. I felt like I was being a bother, saying give me this or give me that. I thought: it's hard work for them to be doing this or that for me, so let them get on with it without me still going against the grain with whatever they feel they want to do. And I was that passive for a long time. I even had no choice in what I was eating".

However, not all families took over and completed tasks for the disabled person. In some instances they expected the participants to take part and do as much as they could.

A respondent verbalised: "*... and my family helped me quite a lot. Because they were the ones that said: 'come with us, and do this with us, and do that for me' and that is how I started doing things*".

One participant felt that she was initially quite dependent on her family, but that they gave her very little chance to feel like that as they encouraged her to pull her weight within the house. "*And even if I wanted to be pampered, they wouldn't. And there were times I didn't want to do the dishes, or get out of bed, or get up early to help my brother prepare for school. Many times. But that was my duty and I had to do it. My mother wouldn't get up early and do it for me. She'd say: 'no, you do it yourself'*".

One way in which the family provided assistance then was by including the respondent in activities which were happening within the environment at a given time. It was observed that another way in which the caregiver

assisted the participant was to structure the environment so that they could manage to help themselves, rather than doing the task for them.

A participant described how his parents laid out strips of toilet paper for him as he had difficulty tearing the sheets.

Another subject was able to climb in and out of the bath independently because a chair was placed next to it.

A third participant explained how she was able to complete cooking tasks although her physical endurance and mobility were limited. A family member would prepare the environment for her by carrying the necessary ingredients from the cupboards or fridge and lay them out on the table where she was to work.

In the above examples, the family was heavily involved, but were supporting the individual without actually doing the task for him/her. By preparing the environment they acted as facilitators to allow the participants to do as much for themselves as was possible.

It was beyond the scope of this study to examine the knowledge and motives of the caregivers, but it was noted that in two instances participants attributed the caregiver's approach to having been influenced by the counsel of a professional person. They had been forewarned that the disabled person was likely to struggle with tasks initially, and perhaps appear clumsy - but if they persevered this would improve. In a third case the family had prior experience of dealing with a disability, as the participant's grandfather had also had a similar injury.

In summary then, the respondents' families influenced where they were likely to live, and what activities they would potentially participate in. Family members were most likely to be called upon to assist in the completion of tasks when help was needed; their presence and attitude towards the provision thereof directly influencing the individual's autonomy. Providing assistance was considered both a duty and a natural process, with members expected to be interdependent. For these reasons the family was viewed as an extension of the participant.

Whether a constraining or enabling influence, they played an integral part in determining the individual's daily activity configuration.

4.5.4 Friendship between Disabled People: Role Models and Shared Experiences

Participants came into contact with other disabled people through several channels. The most common were via time spent in hospital together (either as in-patients or at out-patient clinics), groups run by professionals and the disabled peoples' own organisation, Disabled People of South Africa. Less common channels were friends or family members who had become disabled.

In this study participants were positive about the role other disabled people had played in their lives; specifically how they had influenced their achievement of greater independence. The reasons therefore, and the observed benefits thereof, were discussed in this theme.

4.5.4.1 Peer Support:

Participants expressed feeling a common bond with other disabled people, which helped them to feel less alone. Knowing others had gone through the same experiences was supportive in itself. There was a strong feeling that another disabled person would understand their situation better than an able bodied person, and thus several participants expressed that they would specifically seek out and befriend another disabled person.

A participant verbalised that, "*Enige gestremde mens voel meer gemaklike met nog 'n gestremde mens*". He had personally found it easier to speak to a disabled friend about issues such as toileting and sexual functioning than to his wife.

Similarly, a subject volunteered how free he had felt to express sexual concerns in a group situation with other paraplegics rather than with a social worker and his wife. Again there was an expectation that a fellow disabled person would naturally understand, due to the shared common experiences.

Knowing that others (with similar disabilities to their own) took part in specific activities also gave participants hope that they too could do so. There was a feeling that if others could manage a task, despite physical limitations, so could they.

A participant remembered her mother telling her stories of how her grandfather had coped with the same disability. She said, *"It made me feel as if I'm not alone ... you know ... there's someone in the family who's got the same problem, who had the same problem. And they coped with it and I'm much younger so how can I not cope?"*.

One participant remembered seeing physically disabled people driving themselves to their out-patient appointments while he was still in hospital, a memory he recalled later when he bought his own car.

Another participant verbalised her early thinking before she had her car fitted with hand controls as, *"[X]'s a quad' and he's driving, so why can't I? [Y]'s a quad' and she's driving, so why can't I?"*.

4.5.4.2 Resources:

Participants were assisted by other disabled people through the advice and suggestions made to overcome practical problems. They were helped to see how participation in a task was possible. For example, one subject experienced difficulty transferring independently onto the toilet as his bathroom was narrow. After learning how another paraplegic individual managed to do a forward transfer, he experimented and was able to work out his own solution.

Another participant attended a support group with his parents for spinal cord injured persons. Here he was given "tips" to make his daily routine easier. One of his major concerns had been how his parents would cope with turning him in bed every three hours, every night, for the rest of his life. The group suggested sleeping on a sheepskin, which he found to be effective in decreasing the potential of pressure sores and thus he did not need to be turned as frequently as before.

Another less common way in which disabled people acted as resources for the participants was by putting them in contact with specific people or

organisations who could be of help to them. In this study examples of this included a participant being told where she could have her car adapted, suggestions of disabled people whom they should contact who had the same diagnosis as the participant, and the names of possible support groups to belong to. In all these instances this networking was completed through the disability movement operating in South Africa, D.P.S.A..

4.5.4.3 Comparisons as a Measure for Progress:

It was extremely common for participants to compare themselves to other disabled people they knew or with whom they came into contact. The comparison was usually in terms of progress made in performing basic physical tasks. A participant would explain that he could bath alone and at the same time cite cases of other disabled people who received help in the task.

Another subject compared himself to the individuals he had met in hospital, and verbalised how much further he had progressed than they had in the interim. He felt proud of being able to walk unaided whereas one of his peers still relied on calipers for support.

By comparing themselves to other disabled people, participants gained a **sense of achievement** as they used the comparison as a measure for progress. They felt proud of their accomplishments, which also served to decrease their sense of disability. This was because although they acknowledged their limitations, subjects were quick to point out that they could manage more than another disabled person. This served to make them feel, "*not that disabled*".

Another way in which participants used comparison to their advantage was by using the experience of other disabled people to **guide their own choices**. This started as early as their hospital period for some subjects. For example a subject who initially presented as a quadriplegic after his accident was encouraged to maintain a positive outlook by seeing that other patients who could not use their arms were able to be cheerful.

Another subject witnessed ex-patients returning to hospital with pressure sores and noted the long healing process. This motivated him to be

meticulous in his own routine as he did not want to be re-hospitalised for an extended period again.

A third subject who maintained contact with two disabled friends expressed a desire not to make the same mistakes he observed them make in their relationships. He thus specifically worked on improving the communication with his immediate family.

Participants had not always felt positive about mixing with other disabled people. Three subjects volunteered that they had been particularly reticent to do so when they were newly disabled. The reason was that being involved with other physically disabled people meant, at the very least, acknowledging their own disability and they were not ready initially to do so.

Firstly they were not yet that ready to accept their disability. A young participant had been encouraged to talk to others with a similar physical limitation but had not. He remembered not wanting to see himself as, or accept himself being, disabled. A participant who knew a disabled person living in his street found the contact depressing because when together they focused solely on their physical limitation, pain and tablets, and no relationship was formed. This again made him feel disabled.

Secondly, participants carried with them the stereotypic views and prejudices held by the general public which they did not wish to apply to themselves. This was clear in the reasons given by a subject as to why she initially rejected numerous invitations to join a support group. She stated:

"The idea of mixing with other disabled people wasn't my idea of fun. I thought if I mixed with so-called crippled people, my mind was going to become crippled. That was my view of disabled people; they were mindless".

However, it was interesting to note that all three of the participants who were initially reluctant to be involved with fellow disabled people, verbalised that they themselves now wished to be involved in helping others. They were motivated to pass on their experiences so that the newly disabled individual did not have to go through the traumas they felt they had. Five participants gave this as their

reasons for agreeing to take part in this study. Of these, three participants (including two of the initially hesitant subjects) had also chosen helping disabled people as their future career direction. Clearly they had at some point recognised the value in relationships between disabled people!

In analysing the change in attitude, it was apparent that this was due primarily to personalized contact between people. In the above mentioned example, the participant reluctant to attend the support group finally did go because of the encouragement given by two of the members she became acquainted with outside of the group situation. She therefore reasoned at the time that she was going because of a personal invitation, rather than to associate with a "bunch of cripples". Once involved, the subject experienced the value thereof. The participant who found speaking to a disabled person in his road depressing maintained a close relationship with a friend who became disabled after his own accident. The difference here was that they had more in common than just a disability; they were in fact friends. Participants who were initially hospitalised for extended periods and were amongst other disabled people during this time expressed similar views. Together they shared the rehabilitation process, but once they left the hospital they stayed in contact with very few of the people; only those with whom they had formed relationships that went beyond a focus on the disability.

Therefore, it was clear that participants valued and learnt from the assistance given by other disabled people. However, this was most acceptable to the individual when there were other bonding factors such as friendship, rather than purely the disability itself.

4.5.5 Religious Beliefs and the Power of Faith

Religion played a role in the lives of almost all the participants. It was common for the participants to attribute their source of motivation and perseverance in helping themselves despite obstacles, to religious beliefs.

"My geloof is my bron van energie; my bron van uithouermoe; my ... um ... ek moet se as dinge verkeerd gaan dan keer ek altyd terug aan my geloof en as dinge goed gaan dan is ek bly om my God te dank, dat ek goed oor myself kan voel".

"If God didn't exist I don't think I would have been able to cope [with my disability] because what's the use of living basically ... generally? What's the use of struggling if there's nothing?"

"Soos ek sê, die enigste ding wat vir my help is om te bid".

The four participants who had strong religious convictions prior to their injuries described their early feelings as being ambivalent. They remembered being angry with God, questioning why the accident had occurred; yet at the same time clinging to their faith to find meaning in what had happened. Three further subjects described a renewed or strengthened faith for the same reason. Beliefs such as the onset of disability was a test of faith, that it had happened for a reason, or that it was God's will, helped them to accept the situation.

Participants in many instances attributed the process of starting to think positively about their disability to their faith. One participant went so far as to volunteer that she felt much more positive about her life after her accident than before, verbalising that it could easily have gone the other way. She saw her attitude as a reflection of her faith, stating, *"I feel good because of the promises in the Bible. My religion makes me feel like someone special"*. In her case the disability had been a catalyst which deepened her religious beliefs, and they in turn helped her to see positively into her situation.

Two other participants echoed her feelings when they volunteered the following:

"How do I manage to change my attitude when some people just rot away? My basis for operation is the strength that I get from the Lord Jesus Christ, nothing else".

"Religion is my anchor. And that's where I draw my strength from; that's where I get all my positive thinking from".

The subjects with strong religious beliefs volunteered that early prayers were directed at asking for recovery and increased physical strength or movement. This was particularly evident when people around them did not think improvement was possible. Through faith in the power of prayer they were then able to maintain a degree of hope. An example of this was seen when a

participant described how he put his faith in God and prayed "*to come right*", despite being told by the hospital staff and doctors that he would not walk again.

However, the subjects did not pray without accepting some responsibility for their recovery. In the above example the participant also described exercising intensively. As two participants said, "*God helps those that help themselves*". They therefore first prayed for strength and determination, and subsequently exercised with the belief that their physical condition would improve.

Religious beliefs thus helped to provide meaning and gave encouragement to the respondents. A participant summed up with the advice that he would give to a newly disabled person:

"[Jy moet] ... *baie bid, krag vra, en... dinge sal regkom*".

4.6 ASPECTS OF RECEIVING ASSISTANCE

There were two schools of thought related to receiving help expressed by participants. In some instances subjects were opposed to relying on others for help; on the other hand there were circumstances when participants chose to have assistance, without feeling compromised. The following section consists of four themes and details these views. It should be noted that the use of assistive devices has been included here (section 4.6.4), as they were seen as a form of inanimate help.

4.6.1 Assistance as a Strategy for Increasing Involvement

Receiving assistance when they first returned home from the hospital was seen by almost all participants as natural and desirable. This was usually because initially their physical function was poor; they struggled and became frustrated when trying to perform even the simplest of tasks. In addition it was common that subjects felt overwhelmed within the new situation. They were not prepared for the reality of being at home; they had either not thought about it and had

not anticipated a change, or it was different to what they had imagined. Many participants also expressed feeling tearful, depressed and withdrawn. To some it felt as if their lives were worth nothing. They therefore had no interest in trying to help themselves.

Participants thus welcomed the assistance and attention given by others. It was only if the involvement of family or caregivers continued past this initial uncertainty and unhappiness, that it then caused resentment. As an example, one participant, when asked whether family members took over, said: *"Yes, I struggled with that. I struggled that they always wanted to do things for me. Not right at the beginning, because then I was very passive. But once I started fighting back: this was not on, I didn't want them to do things for me"*.

This theme documents the reasons why participants were willing to be assisted in tasks.

Many participants expressed that they chose to have assistance with tasks with which they, due to their physical limitations, either struggled or performed at a slower than average rate.

"Sommige kere was ek vir myself maar die merdere kere moet my vrou vir my was om gouer klaar te kry".

"Tying knots is difficult. For example, tying the bikes to the roof racks. I can do it, if I have the time and patience. I have got the patience; so it depends on the time. It just takes that much longer as I have to haul with my mouth and that sort of stuff".

Respondents felt that receiving assistance with time consuming and difficult tasks freed them to take part in activities that were more meaningful. They could then put emphasis where they wanted to, rather than where the physical disability dictated. One participant with quadriplegia explained this using the example of why she stopped trying to type with the aid of a stick:

"The thing is, even if I don't stop trying to do things in my mind, I stop wasting time trying to do things when I could be doing something else. You know what I mean..."

I'm wasting time with that stick - I could be using my brain for something else and get someone else to do the typing for me".

Another participant explained the situation as follows:

"I found an ADL focus both frustrating and tiring as I had no energy left for much real living".

Another reason participants continued to receive help after the initial phase of being disabled was because they felt this allowed them to participate in activities that would otherwise have been out of their reach. This was particularly seen in relation to social activities.

One participant always invited his brother and family to join him when he went camping. This was because he anticipated needing assistance, such as getting into the ablution blocks or being pulled through the sand on the beach. Receiving assistance was acceptable to him because it allowed him to continue with a leisure time activity from which he derived much pleasure. As he commented, *"Dit [receiving help] maak nie saak nie, so lank ek maar net enjoy"*.

Another participant, when visiting friends in Mitchells Plain, had found that most houses were not wheelchair accessible. An acceptable solution for both the subject and his friends was for him to leave his chair at home and for them to carry him into their homes. It was important for the subject to continue socialising and therefore he was content to receive help without feeling compromised in such situations.

A less universal reason why some participants were happy to receive assistance was dissatisfaction with the quality of their own performance. This was seen in cooking tasks, when participants with limited fine motor co-ordination had difficulty with slicing vegetables thinly or peeling potatoes. It was also evident in the context of household tasks, for example digging a deep enough hole for the planting of trees.

Another participant cited an example related to personal care when he said: *"I can't cut the nails of my left [his injured] hand as I can't keep the fingers stiff*

enough to cut. I can, but I do a terrible job. My plan? Mom! Or somebody else to help".

Therefore respondents chose to receive assistance if this saved time and aided their participation in more fulfilling tasks or improved the performance thereof. It was also clear that participants did not feel compromised in receiving help if they knew that should it be necessary, they could manage the task themselves. Two examples illustrated this. One respondent verbalised how he felt when he was in a rush to make an appointment and his father assisted by tying his shoelaces. He said, *"I couldn't care - I could do it"*.

Another participant verbalised her elation at peeling six potatoes for the first time five years post injury. It took her two hours; now that she knew she could do it, she saw no reason to continue as it was too time consuming a task to make it worthwhile.

4.6.2 Passive Acceptance of Help: An Expectation of the Carer as Perceived by the Participants

A dominant concern of participants was not to become, what they perceived to be, a burden on others. Subjects verbalised, particularly when they needed frequent assistance, *"Ek voel soos 'n las"*. However at the same time they became frustrated at the passivity expected of them; as recipients of care many felt they had little control over when or how tasks were completed.

Respondents felt a **nuisance** if they received negative feedback from others. Not all individuals were willing to provide assistance when this was requested. Common experiences of respondents were that if they wanted to contribute by making suggestions of how or when a task was done they were viewed as demanding, ungrateful, or that they were wasting the helper's time. For example, a participant described her experiences as follows:

"It's crazy, but it's like this: people want to do everything for you, even decide for you, or they want to do nothing for you. If you say you're capable of doing this, they say oh? You can? Okay, go ahead and do it. They don't want you to do the 90% that you can do, and lend a hand with the 10% you need help with. They either want to

do everything for you, or they want to do nothing for you. And that's exactly what happened here. I would say: why don't you let me go so far, and that 10% I can't manage, then I'm going to say help me in whatever - even if it's to decide to paint my room pink or blue or whatever. They couldn't understand this; they thought I was being ungrateful. We're doing all this for her and here she comes along and doesn't appreciate it".

One of the difficult adjustments to disability the participants described was finding themselves always **"waiting on others for help"**. They found that people would assist at a time which was convenient to them, and not necessarily when the participants desired the task to be done. A common scenario described was the disabled person requesting assistance and the helper replying, *"I'm coming now"* or *"I'm busy, I'll come in a minute"*.

As a result of the above, some participants were inspired to become more self reliant. This started very early for the subjects, during the hospital period. One respondent described how at meal times there were many patients to be helped and he would generally have to wait his turn. This led him to request that the food be placed in front of him whereupon he tried to manage independently. At home the same subject was usually assisted by his wife in dressing or washing tasks; however when she was busy he managed himself.

Another participant was assisted in her meal preparation by her nephew. On days when he was not home at the time she wished to begin she either had to wait for him, or try herself. The participant continued:

"Dan dink ek: nee man, ek gaan dit [peeling and chopping onions] self doen. Dan sukkel ek maar. Dan is dit 'n uur wat verby is ... maar as hy uiteindelik huis toe kom, is die kos al klaar. So as jy weet jy kan dit miskien self probeer dan moet jy probeer. Want as jy sit en wag vir daai persoon om te kom ..."

Another reason participants appeared to try and help themselves was because tasks were not done to their satisfaction. This particularly applied to housework. Three of the female respondents chose to do their own cooking as they preferred the taste of their own food. One of these subjects also preferred to struggle with

cleaning and laundry tasks because she felt her nephew, who otherwise completed these chores, was not thorough.

However, some participants also very often stopped doing tasks if they perceived themselves to be a burden. A participant explained that when he first came home from hospital, he spent all of his time in his bedroom. When asked why, he responded, "*Somme so*". On probing it became apparent that his mobility was poor, and he had thought that it would be a nuisance for others to assist him in and out of the house.

Another participant, on overhearing a conversation where her sister was complaining about how long tasks took if she gave input (for example, if she suggested what to wear, or what should be cooked), promptly stopped voicing her needs and passively accepted the care given. In these instances then, because of the way they perceived others would feel, subjects decreased their participation in tasks with which they required assistance.

Therefore in summary many participants struggled with being the recipients of help. They expressed feeling like a burden, and feeling frustrated with having to rely on others to decide when or how tasks would be done. The results were twofold; namely some respondents became more self reliant and others decreased their participation in activities where they needed to be helped.

4.6.3 Legitimate Assistance: Maintaining a Measure of Independence

Subjects described when and why they chose to receive assistance. Some participants also had no choice due to their physical limitations. This theme documents how the participants legitimised receiving assistance, and how they managed to do so without feeling that their independence was compromised.

4.6.3.1 Reciprocation:

Subjects were able to keep an autonomous position when they were able to offer something in return for assistance given. If this was not so, they were never sure whether the help given was done out of pity or charity - a position they chose not to be in if at all possible. Reciprocation also allowed them to avoid being "mothered" by the helper.

Three of the participants who owned their own cars were not able to drive themselves. They thus relied on other people to do so. As they could meet the helper halfway by making use of their own car and petrol, they then felt comfortable asking someone to act as a driver.

Another subject felt strongly that his wheelchair was his "round feet" and that he did not require assistance to be mobile. He thus usually refused help when people offered to push the chair. However, there were occasions when, on returning home after a shopping expedition, the wind would be blowing hard and make mobility difficult. If help was offered under these conditions he would accept; and in order to help the person in return he would offer to relieve him/her of the shopping parcels by placing them on his lap.

Within the family, reciprocation was also seen through the interchanging of roles. For example, male participants not working would undertake to complete the greater part of the household chores if a spouse was employed. Another subject was willing to see to the toddler, whom his wife looked after during the day, for short periods when she needed to go shopping.

A few participants volunteered that one way in which they met helpers half way was by choosing to lessen the demands made on the caregiver. They were motivated to decrease what they perceived to be a potential overburdening of their helpers. This was seen particularly with the more severely limited participants, who by necessity relied heavily on others for assistance. The thinking of these subjects is summed up in the following quotation:

"... ek het altyd in ag geneem, die persoon wat vir my help ... dat dit nie vir hom .. um .. so veel is om vir my te doen nie. Ek het altyd die maklikste uitweg gesoek vir die persoon wat vir my help. Dat dit nie moeilik vir hom is nie want ek vat dit so: hy help vir my so dit moet vir hom maklik wees en dit moenie moeilik wees om vir hom te verduidelik; dit moenie moeilik klink nie..".

When participants were able to pay for help given, this also legitimised requesting the assistance. There was a strong feeling that being able to pay for services made the situation natural and acceptable. This is evident in a statement made by one subject; namely "*...even able bodied people hire others to help them with a job; even the simplest of jobs*".

Another severely disabled participant who required substantial help with her self care agreed to pay her sister if she was willing to live with the subject and to provide the necessary care.

4.6.3.2 Verbalising Needs:

It has previously been mentioned that participants felt they were expected to be passive recipients of care (see section 4.6.2, p120). They found frequently that they were unhappy in such situations, becoming resentful and angry towards the helper. This was rectified in situations where they verbalised their needs.

Respondents felt they remained in an autonomous position when receiving assistance if they maintained involvement in the decision making process. A participant explained how he was able to view himself as independent despite needing substantial help to perform tasks because he decided what his needs were, and how others were going to help him. He gave an example of when he wanted to go out, and relied on friends to drive him. The subject said:

"Eintlik kan jy sê, tot 'n mate is ek onafhanklik as ek uitgaan want dis my besluit waarnatoe ons uitgaan; dis my besluit wanneer ons terug kom en so aan. Die enigste iets waarop ek afhanklik is, is iemand moet die kar bestuur. So nogsteeds kan 'n mens sê dat ek maak wat ek wil maak, maar ek het net iemand nodig om die motor te bestuur".

Another respondent explained why he went to great lengths to always make his needs known when he said: "*En deur om net te voel dat jy daar is, sê jy iets. Om te weet dat dinge gedoen word soos jy wil hê...*".

Participants were also able to maintain control of a situation when they changed the nature of their role therein. One participant described how

she managed to do her own cooking by using the people around her to act as her "*hands and feet*". She decided what to make, which spices to put in, etc, and others did the physical tasks such as fetching, carrying, stirring, etc. This was a common pattern noted during the observation period. Participants would comment that they for example, were able to do their own cooking, housework. In reality, "doing" meant directing helpers to carry out manual tasks while the disabled individual took responsibility for the necessary planning and decision making.

4.6.3.3 Network of Support:

Participants, when they had a number of people to rely on for assistance, felt far less apologetic about needing help and could request this with confidence. When they could rotate the people on whom they depended, they no longer felt like a burden or nuisance because they then only infrequently asked the same person for help.

The participant who was a quadriplegic and attended university managed on a day to day basis because he had set up a supportive network throughout the campus. In each of the buildings where his lectures took place, there was at least one person, usually a staff member of the cleaning or maintenance departments, whom he regularly approached for assistance. He was however careful not to overutilise one source; for example he might receive help in one building to empty his urine sack and then travelled to the next before requesting any further assistance from a different support system. In the same way the subject was aware of a number of students on whom he could rely to, for example take out or pack away books, open doors and he again took care not to rely too heavily on specific people.

Access to a supportive network also allowed individuals to go to places that would otherwise have been beyond their reach. One participant described how he was able to continue attending matches at Newlands Cricket Grounds or club rugby matches because at both places he had met people who either worked there or attended matches regularly and were willing to assist him. He therefore did not feel vulnerable and could be dropped and fetched by a family member, but otherwise left to cope alone.

Another subject explained that the reason he was able to go camping was because he utilised the other campers as helpers. Most camp sites were not fully accessible to wheelchair users but this was of little consequence to him as he firstly always organised outings together with his brother and family and secondly, the campsite afforded a readily available supply of people to assist him where necessary.

Participants maintained a degree of privacy by limiting those who provided assistance. As one subject said, "... *dit hang van my af: wat, waar, en deur wie ek dinge laat doen*". Most often help needed in self care tasks was provided by immediate family members only. This was predominantly a spouse or parents.

The subject who attended university found it reassuring that his father worked there too. He was comfortable in receiving assistance from students and university workers for almost all tasks, but considered his genital area to be private. Therefore, if he wet himself or was worried that his condom had come off, he would always call his father.

A participant who received help with bathing would, rather than ask an outsider to assist, change his daily routine if his wife needed to go out and was thus not available to help him at the usual time.

Participants also recognised the contribution others made in allowing them to keep a degree of privacy. In some instances subjects felt that family members were particularly sensitive towards their needs, keeping a distance when they wanted to be alone or decreasing the assistance given if they were uncomfortable. An example of this can be seen in the following quote where a participant describes the situation with his mother:

"I actually found, later on... well dressing especially... my mother always used to help me, and it was a problem because I was an adolescent and I had to face that but... um... she sort of held back after a while. When I started trying to button shirts myself, she stopped helping".

It is evident therefore, that having a number of people forming a network of support on whom to rely increased the participant's potential for independence. However, the majority of subjects in this study felt an absence of suitable people, outside of the family, willing to be of assistance. Participants described having in the past been let down; this made them reluctant to ask for help the next time around. The consequences were that this led to individuals feeling that they could not rely on others - if they could not manage the task themselves then it was simply beyond their means.

It appeared that where participants were able to utilise a network of support was when group situations occurred naturally within their environment, and where they were part of the group. Examples from this study were participants belonging to the occupational therapy community project and its groups, youth or church groups, and peers within a class at school or university.

In summary then there were several ways in which participants were able to legitimise the receiving of help. A measure of independence was maintained when they were able to promote an interdependency with the helper, verbalise their needs and thus direct the care given, and make use of multiple assistants.

4.6.4 Disparaging Views of Assistive Devices

Participants, when they had initially been given assistive devices remembered being willing to use them because they were open to all ideas which could potentially have made their lives easier. They also accepted the advice from the professional because the latter was perceived as a person with expertise. One participant explained this by stating, "*Wel, hulle is die mense wat voorskryf en ons as die pasiënte kan mos nie teen dit werk nie*". However, once in their own homes, they exercised their own power by deciding whether to use the devices or not.

Only one participant stated that he was actually opposed to the use of assistive devices to aid function; he had always tried to get around using what he called

"gadgets" and to date been successful. The majority of subjects were not opposed to the use thereof, but they were disparaging about the assistive devices that they had been given. Very few had in fact (beyond the initial phase) continued to make use of them. Their reasons were multiple.

Subjects described that they felt slower and clumsier with the assistive devices, and often struggled to carry out a task when using one. They found the devices to be cumbersome and time consuming, and saw no obvious increase in their functioning when they made use of them. A participant explained that she never used the built up fork given to her because it was awkward and she ate too slowly; it was simpler for her to use her left (unaffected) hand. In the same light she said of the backwasher given to her, "*Nee, ek kon nie klaar kom met daai ding nie*".

Similarly a subject who had been given a vegetable board with a spike to stabilise an onion or potato found that she rarely if ever used it, preferring to call for assistance than struggle with the board.

Participants felt that the devices they had been given were ineffective: they simply did not work and were often more trouble than they were worth. A participant who was given a fork, knife and spoon all in one so that he could eat one handedly found that the serrated knife edge was either too sharp to go into his mouth or too blunt to cut the food.

A subject stated that the sponge on her longhanded back washer had been too soft to scrub her back effectively. She later found a perfect function for it - cleaning the outside of her first floor windows!

A common reason participants gave for not using assistive devices was because their use was initially awkward and they gave up trying to manage without assistance before becoming practised. This was illustrated in the experiences of a subject with a vegetable board who said, "[dit was] *ongemaklik want ek was nooit gewoond daaraan nie. Kyk toe ek my twee hande kon gebruik ... dit was 'n groot verskil vir my*".

No participants remembered having persevered with the use of an assistive device that was initially cumbersome until it became easier.

There was also a feeling that relying on devices was in some instances not practical, particularly if they needed to be used outside of the home environment. A participant explained how he initially coped with his schoolwork after he injured his one arm. He used a filing system for note keeping and a drawing board for tasks such as drawing straight lines. He continued, *"It was great, I could use it, but I would have to carry it to school everyday. It was a big thing to lug around from class to class, it took over the whole desk. Pages kept getting torn out of the ringbinders. It was too cumbersome; in standard eight I reverted back to an ordinary notebook"*.

In contrast to their reluctance to make use of assistive devices situations where participants were willing to do so appeared to be when they had been able to negotiate some control over the attainment thereof; either by adapting the device in some way or through the purchasing of a commercial item.

Respondents expressed a more positive view towards assistive devices given to them when they had been **involved in the making thereof**. Taking a standardised item, or way of doing things, and adapting it to suit their own needs personalised it.

A participant sited as an illustration of the above a splint he was given to assist him in eating. He had no say in the creation thereof, being told that the maker had previous experience of similar situations and thus knew the best way to make it. The subject's major concern was that the splint was difficult for a helper to attach to him. He used it very little, most often being fed. Later the subject attended a special school where another splint was made, this time incorporating his ideas. Following this he was motivated to use it and began to eat with minimal assistance.

Participants were also observed to be using far more **commercially available** devices than those given to them in the context of the hospital, specifically designed for disabled people. (The devices were considered adapted because of their specific characteristics and application which allowed participants to

complete tasks without assistance). When questioned, subjects gave two main reasons for their preferential use.

Firstly, they felt that commercially manufactured items were most often more effective than home made articles. One participant bought a back brush with a long handle and a firm sponge attached to assist in washing.

Another, although struggling financially, bought a shredder/slicer with a rubber suction pad in place of the vegetable board she had been given. She was now able to prepare meals within an acceptable amount of time and with little frustration, by herself, despite limited function in her dominant arm. This obvious increase in function justified the expenditure for her.

Participants also commonly had push buttons on their telephones, which removed the need of a device to assist in dialing. Commercially available items were successful in promoting independence, because they worked.

Secondly, commercially available devices or equipment were often far more acceptable to the subjects. The use of conventional items meant that they were orientated to the mainstream of culture, and not the subculture of disability.

In some cases participants were not even aware that equipment or tools they were using could be seen as adapted, because these were commonplace items used universally (by disabled and nondisabled people) to complete tasks. This was especially noted with the use of sophisticated technology, such as typewriters, computers, modems. One participant could not think of any devices that he used to aid function. Later it was observed that he used a clipboard to stabilise paper when writing and a metal ruler with a metal weight to assist in the drawing of straight lines as he worked one handedly.

Participants appeared to have developed ingenious ways of using the body as a tool to aid function. This allowed them to compensate for physical limitations without the need for assistive devices. Examples included holding onto the wheelchair with one hand while reaching forward with the other to prevent loss of balance, or making the drying up of dishes a one handed activity by holding the plate against the body.

Participants also illustrated this usage in basic self care activities - they described placing a facecloth on a leg and twisting their arm into awkward positions in order to wash the non-affected side, or rubbing the whole body against the side of the bath with a face-cloth inbetween.

Two parts of the body frequently acted as substitutes for the holding function of a hand; namely the mouth and feet. Participants sited examples of placing a toothbrush in the mouth while pressing out toothpaste, or pulling with their mouths to tighten a knot, tie a shoelace. One subject utilised his feet to aid function; by placing nail clippers on the floor and pressing on them with his foot he was able to cut the finger nails on his non affected hand.

It would seem then that participants did not favour the use of assistive devices. This was primarily because they found them clumsy, awkward and frequently ineffective. There was little evidence of subjects persevering with a device until they became more skilled in its use. In situations where they had some control over choosing or designing the item, the use of a device was viewed more favourably.

4.7 THE COMMUNITY OF MITCHELLS PLAIN

Activity patterns were influenced by cultural factors; choices made by the participants were closely influenced by social and physical constraints or resources within their residential area. Although not exclusive, the following section documents the most important influences apparent in this study. It is divided into five themes.

4.7.1 A Desire for Safety

Attention was focused on safety by the participants, both in- and outside of the home.

Respondents appeared to want people around them, rather than to be left alone. This was for safety reasons; they wanted a back-up system available to them at

all times in the event of an emergency. In practical terms this meant that they chose never to be alone in a building. A subject illustrated this when he said:

"n mens voel 'n bietjie ... bekommerd as jy alleen is op 'n manier dat ... wie gaan nou help as iets gebeur?"

It was noted that subjects who did not want to be left alone tended to be the most physically disabled of the group. However there were two quadriplegic respondents who were content to remain alone at home for extended periods, because they had immediate access to assistance in the event of an emergency. This had been pre-arranged and was telephonic; if help was needed they could call a neighbour or family member to come to their aid.

Two other participants also commented that they had had telephones installed specifically for emergency purposes.

Outside of the home, participants felt they were easy targets to be attacked or robbed. They reasoned that as physically disabled people, it would seem obvious to the aggressor that they were limited in ability to run away or defend themselves. This was stated in the context of discussing violence and crime in Mitchells Plain; predominantly due to the prevalence of gangs within their home areas. Concerns for safety thus influenced how they spent their time.

There were certain times when the subjects chose to stay at home. For example, going out at night or visiting specific areas in Mitchells Plain over weekends was considered particularly dangerous and thus best avoided by some participants.

It was common for a family member or friend to be taken along when respondents went shopping, fetched their disability grant, or when they needed to make use of public transport. Their prime concern was not to be robbed, particularly when carrying money.

A need for safety governed the use of public transport. The travelling by train was considered ill advised by all participants; and some subjects also verbalised not wanting to ride in taxis because they were fearful of being attacked. Options were thus using a bus, or paying for private transport, unless they had a car of their own.

Three participants also verbalised wanting to change their residential area because of the incidence of violence there. However as housing was at a premium, this had up until the present time not been possible.

In response to the focus on safety, another common strategy used was that of concealment. Participants attempted in some way to hide or minimize their physical limitations, so as to appear less vulnerable and to decrease the chances of being singled out as a target for potential attackers.

Two participants who were given walking aids from the hospital stopped using them when outside of the home because they then appeared less conspicuous. Another subject described how he deliberately slowed down his gait pattern when going out as his limp was then less noticeable. For the same reasons he walked with his affected hand within his pocket.

Thus participants volunteered that in many instances, their actions were motivated by a need for safety.

4.7.2 Isolation versus Community Integration

In talking to the subjects it became apparent that when they had initially been discharged from hospital, they had chosen to spend the majority of their time at home.

A reason participants gave for wanting visitors to come to them, rather than to go out, was that they felt self conscious and uncomfortable if people looked at them. A participant described her feelings one and a half years after her disability as, *"I liked myself in my home, but not outside. People would look at me, and stare at me. I hated that"*. Within the confines of their home however, she felt less exposed and vulnerable.

A subject described that being at home and having people coming to her rather than going out built her confidence as she did not have to worry about problems such as leaky catheters, accidents etc. She initially insisted that the physiotherapist treated her at home because here she felt comfortable about

going to the toilet in the middle of the session; she did not feel happy doing that at the physiotherapist's practise, and could then not relax.

Another participant said: *"I had a lot of friends then [when he first became disabled], and they were great. I belonged to a youth group; my friends would come round so I did not need to go out much ... "*. He therefore had no reason to go out and was content to stay at home.

The participants' home environment was thus extremely important to them as this was where they, to varying degrees but in all cases initially, spent the majority of their time. One subject who moved to be closer to the hospital chose the house she bought because it had a swimming pool and lovely garden. She commented further, *"At that time I wasn't going out ... so I thought if my house is nice, I didn't need to ... people could come to me and I wouldn't have to go out"*. She was satisfied with her choice, even though it became apparent that it was inaccessible for a wheelchair (the house had a sunken lounge), because it had a comfortable, pleasant atmosphere.

With time, the desire to spend more time outside of the home and to be involved within the community became more paramount. Much to their dismay, respondents found that they were for the most part isolated from regular support systems, with little opportunity to lead a productive lifestyle.

4.7.2.1 Contact with Friends:

The value placed on friendship by participants has been documented elsewhere (see section 4.5.1 to 4.5.2, pp 98 and 101). However, in reality, support was most often provided by family members, and not a peer group.

Save for one participant who had a core group of friends from the youth group he continued to attend, subjects found that their circle of friends had diminished after they became disabled. Many friends had stayed away and were not supportive. In some cases they had lost contact with their entire peer group.

"Dit lyk vir my nadat ek gesteeek is kom daar nie meer vriende nie. Of hulle kom, en dan is hulle weer weg".

"Om die waarheid te se het ek almal nuwe vriende wat my situasie kan verstaan, wat my kan aanvaar".

The participants gave various reasons why they thought this had happened; some within their control (eg, they had felt like a burden if they telephoned friends asking for assistance or thought that they might be seen as such and thus the contact faded) as well as not within their control (eg they no longer had access to resources such as money, a car, alcohol, and so the friendship faded).

Making new friends was also not easy for the participants. When they had been able to make new contacts, this had usually been unplanned, and unexpected. Subjects tended to make friends in the places where they spent the majority of their time. For example, one participant who worked within the disability movement verbalised that all her support systems were part of the movement. She stated, *"And I suppose again because that takes up the larger part of my life, that those people happen to be there. Should the circumstances change, I suppose I'll draw from other walks of life"*.

The most frequent places where friends were made then was through contact at work, and where participants belonged to groups within the community (for example, O.T. groups, St Giles, the Church, youth groups).

Participants who were not employed and spent the majority of their time at home, were quite isolated. Unless they belonged to an existing group within the community, they had virtually no regular contact with other people during the day other than with the family.

When asked whether there were people with whom they felt comfortable about sharing their experiences and problems, the participants most often quoted family members. Two subjects also said that they could not think of a single person on whom they could rely for support (ie someone with whom they felt comfortable to share problems and experiences), family included.

When asked about their motivations for taking part in the study, five of the participants expressed that they were seeking company, with three having looked forward to speaking about their feelings. In addition, two other respondents quoted the author specifically as an important person with whom they felt comfortable; in the first instance she was one of two confidants and in the second the participant verbalised that the author was his only 'close friend'.

4.7.2.2 Contact with Community Organisations:

At the time of the study all participants save one were able to sustain involvement in activities outside of the home, including work and/or leisure, to the extent of at least half a day per week.

Such involvement however, seemed to have been possible to arrange in Mitchells Plain because of the presence of the community occupational therapy project active within the area. Five of the participants were involved in the work, social or sports groups run by the project. When this was excluded, six of the subject were noted to spend almost all of their time within the home environment. Their participation in the community life of Mitchells Plain was minimal.

Apart from the occupational therapy project, the church was another major support system within the community. One participant volunteered that attending church and a prayer meeting were her only two regular and guaranteed weekly outings.

A subject had recently joined a new congregation during the course of the study and attended meetings five days a week. He had nothing else to do with his time and saw this as a way to meet people and form new friendships.

Younger subjects were also involved in youth groups; one utilising the church music group as a creative outlet.

Other groups that individuals attended were linked to the disabled community itself; for example St Giles, support groups run at the Independent Living Centre for spinal cord injured people. These were

held outside of Mitchells Plain; the participants knew of no other support systems within their own community with which they could potentially link themselves.

4.7.2.3 Contact with Neighbours:

A sub culture of sharing between neighbours was observed during the course of the study, for example the borrowing of basic food items or a family without a telephone giving out the neighbour's number in case they needed to be contacted and expecting to be called if it rang for them.

However, when questioned respondents expressed a reluctance to rely on neighbours for help. The reasons given were twofold. Firstly, some participants felt that their neighbours were not the kind of people they wanted to be involved with, or befriend. They expressed disapproval of a lifestyle which involved heavy drinking or taking of drugs, and in some areas these were common weekend activities. As one participant aptly put it, "*Dis nie my soort company nie. Ek meen ek is gestremd, maar ek kan at least my vriende pick, ja?*".

Secondly participants expressed that they did not want to rely on their neighbours for help because of past bad experiences. They had perceived a reluctance on the part of others to provide ongoing assistance. A participant sighted an example where she had asked a neighbour to wash her hair. That day the neighbour had planned to go out, the next morning she was sleeping and the following afternoon the subject was still waiting for an answer. She felt unable to site a neighbour on whom she had consistently been able to count.

Another participant occasionally asked neighbours if they would go shopping for her. However her experience was that unless they were already going for themselves, they would not make a special trip. In these instances she was forced to go without what she needed. Neighbours had also frequently asked to be paid when they did tasks such as shopping for her, which she could ill afford.

Therefore, participants were not prepared to rely on neighbours for assistance other than to borrow small items such as a spade or cup of sugar. As this was common amongst people generally in the neighbourhood, they did not feel compromised in doing so.

There were two exceptions to the above. One situation where participants were willing to ask for assistance from neighbours was when they needed transport. It was again common within the context of Mitchells Plain for people to hire a driver or a driver and car when they needed to go outside of their immediate environment. For the disabled participants who were not able to use public transport, this was a most viable alternative. It did allow them to go out more than they otherwise would have; however it was generally expensive to hire a car and thus finances remained the major constraint. One participant said, "*..dis niks om te vra maar die koste is te veel*".

Two participants were also actively involved with their immediate neighbours. The basis for this was social contact and friendship. One subject had formed a supportive relationship with her neighbour and could go to her to discuss problems. In the second case the neighbours were also family friends and were involved in providing physical help for the disabled individual.

Therefore in summary, participants in this study had limited contact with friends, neighbours and community organisations. Although they expressed a desire to be more integrated, they had found that opportunities were few. The sense of isolation felt by some respondents was clear in one subject's reply when asked about his support systems, "*Daar's niemand nie. Ek is maar op my eie*".

4.7.3 Employment: Support and the Informal Sector

There was a strong feeling amongst the respondents that working (whether paid or voluntary) confirmed a person's value in society and provided a focus for one's life. One participant went so far as to say that when he had been put off work, it had made him feel, "*Ek is klaar met die lewe*".

Subjects also felt that work was an activity which had the potential to minimize differences between being disabled, and the able bodied. One individual expressed this as, "*work helps you see there is nothing different between me and him; just the body. I'm in a wheelchair, you're not*".

Another respondent said: "*...as 'n mens net kan werk... jy is in 'control' van jouself. Jy het jou 'ability back'; jou 'self esteem back'*".

Therefore work was highly desired by participants. An increase in the work opportunities available for disabled people was also the most common need expressed by them. In reality, in the context of Mitchells Plain, few opportunities existed for them to be employed.

Job availability limited participants' firstly, in finding work, and secondly in changing work. Only one had been able to find work on his own accord. He was very unhappy with his job, but was unwilling to change. He said: "*... just because the job market isn't so great. Let alone for people just out of school or varsity with two usable arms. But someone who only has matric and one or two years of varsity - which isn't anything really... AND then a paralysed arm...*".

None of the other respondents had been able to create their own work opportunities and those that had approached government or welfare organisations had met with no success.

Those who were employed had all found work through personal contacts and networking, within their own available community or subgroup. One had been employed by her father. Another had been encouraged to start a project when she approached a contact within the disabled people's movement. Three further subjects were involved in the work groups, doing sub contracted woodwork, which are linked to the occupational therapy community service operating in Mitchells Plain.

What was common to all these situations was that participants maintained relationships with the person who linked them to the work opportunities. In the first two cases a bond (family, and friendship) had existed. For the latter three subjects, although they were first introduced to the O.T. project via the social worker of a welfare organisation, in all three instances they formed a tie and became acquainted with the professional concerned before being offered the work positions. Therefore, again it was via personal contact.

In the context of Mitchells Plain, it was common for individuals to work from home. The informal sector was a popular alternative to regular employment. This option was also available to participants in the study. However for a home based project to be a success and to be long lasting, two prerequisites were clear.

Firstly, it was not a case of "anything is better than nothing". If subjects had no real interest in the type of activity or task, they chose not to become involved or if they did so initially, this faded with time. Examples of this were seen when participants described how they started home industry activities (for example, leather work, sewing, hawking from home) but stopped as soon as they faced problems. Four of the subjects had gone this route; one describing that with three previous work ventures he had undertaken, he lost interest as soon as he realised they were not "*his line*". Another described a leather home industry he had been taught in hospital which he stopped when obtaining supplies became too much effort. In contrast, a participant involved in the sub-contracting woodwork group explained that he continued with his work despite little money and many frustrations because, "*Ek 'enjoy' myself. Ek hou van die werk*".

Secondly, those participants working from a home base were not doing so alone. Common to all of them was the presence of a supportive network which had intimate knowledge of the work, as well as the potential difficulties and frustrations. In the woodwork group, this was provided by the other disabled members of the group. For example, peer pressure was applied if one member did not do his fair share of the work; they were able to motivate each other to take part when fluctuations in interest occurred, and because they had varying disabilities, tasks the one struggled with were done with ease by another - this then lessened the difficulties and frustrations. The participant who was involved in the setting up and running of People for the Awareness of Disability Issues (PADI) from her home, had two major supports. She made use of volunteers from the Volunteers Bureau to act as helpers in physical tasks - typing long documents, fetching and delivering items. She was also encouraged to continue with the work by the local disabled peoples' organisation and network, who were there to offer advice and to praise her attempts.

It was clear then that the use of personal contacts facilitated the potential for employment of the respondents. The supportive nature of working within a group in the informal sector assisted in the maintenance of motivation for the

work. Notwithstanding the above, the individual had to be interested in the type of employment for the venture to be a success. As a subject said:

"... [it] doesn't matter, disabled or able, one is willing to try something out and if you find that you don't like it, you will stop".

4.7.4 Transport as a Barrier to Participation

A major obstacle hindering participants in going out was the availability of suitable transport (for information on transport services in Mitchells Plain generally, see appendix D, p 217). The use of public transport was limited because of safety factors and accessibility. It was also expensive; in some cases more so than it would be for the average commuter. For example, one subject had experienced taxi drivers who saw taking him and his wheelchair as a "special trip" and who had then demanded that he pay double fair or on several occasions, for the whole taxi.

Without the availability of transport, participants were limited in where they could go. Outings were mostly within their own neighbourhoods, such as visiting family or attending the occupational therapy groups. Most often they were limited to routine rather than pleasure trips, for example going shopping for groceries or fetching a disability grant. These places were within walking distance of the majority of the participants' homes; in the case of the groups, transport was arranged by the project.

Activities which happened outside of their immediate environment were most often beyond their reach. For example a participant, after he had been at home for three years, was offered a job by the brother of his doctor. However, he was unable to take up the position as the offices were approximately 25km outside of his home area and he was unable to organise regular affordable transport.

Another participant described a regular sunday outing as picnicing with his brother at the beach. They would catch a bus and then walk to their favourite spots. After his injury the participant no longer continued with this; initially because utilising public transport had been difficult and later because decreased endurance limited the distance that he could walk. He did not have access to private transport of his own.

Almost all of the participants who spent the majority of their time at home said they would go out if they had access to a car. In this study four subjects had either received or were waiting for the settling of third party claims. In each case a priority had been to buy a car. These participants (and those that had access to private transport) described going outside of their immediate environment, on outings such as picnics, braais, visits to the beach or for sunset drives. In some instances the subjects had waited up to two to three years for the money to come through; and during this period had spent almost all of their time at home. Their patience was finally rewarded; the availability of the transport then afforded them far greater control over the frequency, type and distance of outings away from the home environment.

A participant summed up the situation facing most subjects when he said:

"Om uit te gaan is niks, maar die vervoer...".

4.7.5 Problem Solving through Networking

Seven of the subjects relied on disability grants as their income (R 318-00 per month); this left very little money for possible expenses related to their physical limitation, such as buying of equipment, assistive devices or adaptation of transport. Several respondents had been able to take care of their needs which potentially incurred high expenses, in addition to waiting on M.V.A. claims, through the use of an informal network of assistance.

The subjects' response to problems that arose was to verbalise their needs to as many people in their social circle as possible (including family, friends and professionals). One participant was assisted financially by his ex-employer through the donation of the necessary materials to pave his sandy frontyard. A friend then assisted in the actual paving.

Another participant explained that he was able to come home for weekends while in hospital because his ex-employer provided the transport.

One participant made use of a formal funding organisation to help pay for equipment he needed - a motorised wheelchair, typewriter and computer. He learnt about the organisation while attending a special school.

A second participant, through her work in the disability movement, was able to request the necessary equipment she needed from official sponsors.

None of the other participants were aware of any organisations or bodies to which they could apply for financial assistance of any kind.

Another way in which networking and making their needs known benefitted the participants was through the suggestions and generation of ideas or solutions to situations. This was clear when a participant described how he had wanted his car adapted with hand controls but he had not known where to have this done, or if he could afford it. After mentioning this to a professional who was active in his life, she put him in touch with her husband who was also in a wheelchair and could advise him as he had adapted his own car himself.

Another subject described the sequelae following his initial exposure to computers. He had worked on a computer by chance when he attended a centre for evaluation purposes as part of his third party claim. Thereafter he thought about this as a career option. What started as a vague idea began to seem like it would turn into reality after he discussed it with his sister and she told him of a training course within his home area, and a vacancy at her workplace.

Therefore participants, in an endeavour to increase their independence, made use of all opportunities to make their needs known and to gather practical help or advice from their social contacts. They were nevertheless as a group poorly informed about existing resources.

CHAPTER FIVE: DISCUSSION OF RESULTS

5.1 Evaluation of the methodology

5.1.1 Observation

5.1.2 Use of semi-structured interviews

5.1.3 Influences of the researcher

5.2 Discussion of the results

5.2.1 Discussion of the major findings

5.2.2 Discussion of the remaining findings

CHAPTER FIVE

5.1 EVALUATION OF THE METHODOLOGY

5.1.1 Observation

Time allocated for the fieldwork was perhaps ambitious for the study purpose. The author needed to obtain a focus in the study within an extremely short time. This was difficult, because of the exploratory nature of the work and unfamiliarity with the method. The author had no previous contact with Mitchells Plain and thus the study environment was also new. Given its qualitative nature, an understanding of the context from which the respondents came was important. The demands of the study method also required that the author spend time observing the participants in their natural environments. However the personal time constraints of the researcher necessitated that her orientation to the area was concurrent with the time spent with the subjects. Little opportunity was available therefore to explore the area and its resources in general, before targeting specifically on the study's respondents and their immediate environments. Ideally a longer period spent in the field would have allowed for an initial orientation phase which is thought to be vital to contextualise the study.

Observation in its true sense, whereby the researcher is part of the community and notes observations unobtrusively was not possible as she was obviously external to the environment, not living or working there. Therefore the fieldwork was not a natural and spontaneous process but took place in an artificial setting created by the author specifically to meet the study purpose. This required that considerable time was spent firstly identifying potential subjects and secondly a lengthy contracting period when participants were informed of the study and its practical implications for them (see appendix A). Thus although the author did not share their lives on an intimate daily basis, she was able to gain an understanding of life as a disabled person in Mitchells Plain through this negotiated entry into different settings.

The artificiality of the method posed several drawbacks. It was not possible to observe respondents taking part in all activities of daily living; tasks such as self

care were viewed as private by the subjects and thus information pertaining to the performance thereof was gathered in the interview phase of the study only. The author was also too obvious an intruder to observe inconspicuously and for the most part she was treated as a visitor in the home. Four participants almost always left the tasks they had been involved in prior to the author's arrival to make tea and sit in the lounge, whereupon she was expected to initiate and maintain the conversation for the duration of the visit. Collection of data was then hindered because access to different settings (ie varying environments) was prevented. Attempts to overcome these obstacles were documented in the methodology section of the study, for example the drawing up of a time log which detailed how participants spent their time and thus suggested to the author when best to visit in order to observe varied activities. However, despite numerous re-iterations as to the study purpose and the respondents' commitment to it, the problem persisted.

The constraints of the methodology necessitated that the author be highly organised in her time management, choosing when to visit participants carefully. As a disciplined researcher she was able to achieve this. However many arranged visits did not happen because the individuals concerned were not home at the agreed upon time. It is possible that because no routine to the visits was established, the respondents were not able to cope with the flexibility with which the author appeared to come in and go out of their lives. Although attention was initially focused on contracting with the participants and ensuring that they fully appreciated the demands the study would place on them, feelings of ambivalence may have arisen. These perceptions were verbalised to subjects at various stages, but no clarity as to why they disregarded confirmed appointments was gained. These experiences were particularly frustrating and de-energising for the author.

Note taking of the observations made was not always possible in the field. Participants displayed a natural curiosity and degree of anxiety as to what was being recorded. In some instances showing them the notes allayed these feelings; however where individuals remained suspicious and continual attempts at recording information in their presence served only to promote tension, this was stopped. In addition it was not always possible to record observations while with some participants because of the nature of the situation, eg walking to the shops, going to visit a friend. Thus recording of the observations were by necessity completed after the time spent in the field. This was not ideal because it relied on the ability of the researcher to recall accurately and in detail

the events or interactions which had occurred. Where possible then, brief notes in point form were made during the observation period. These served as memory aids for the detailed notes written thereafter (this was also done as soon after the observation period as possible). These practical considerations created much time consuming additional work for the researcher, which had not been anticipated.

Observations made of the participants was limited to a relatively short period (six months) and therefore focused on present functioning. A time span of at least a year would have allowed for the observation of factors which naturally change over time (eg age, socio-economic circumstances, family configurations) on independence. Viewing of special events, for example celebrations around birthdays or Christmas would also have then been possible. The interviews proved vital for the supply of this information and was thus used to provide a more complete disability history.

Notwithstanding the above, the observation period was a vital part to the study. Its primary usefulness was as a sensitizing device; orientating the researcher to the context in which the participants lived (see appendix D for a brief description thereof). A growing understanding of the environment (eg housing, transport, employment etc) provided increased insights into the influences external to the individual which affected function. The experience thus provided an intimate and vivid knowledge of life in Mitchells Plain which could only be gained firsthand. This examination of the broader context of the study was thus essential as a framework for adequately understanding responses given in the interviews.

Observation was also critical in providing a sound basis for the interviews. Participants became familiar with the researcher during this period, and issues of trust and ambivalence were addressed. It is unlikely that the same quality of data would have been obtained during the interviews had this initial phase not been included. A clear illustration was seen on one occasion when a participant discussed her marital problems, and began by stating that although this was hard for her to do, the researcher had no doubt already noted the problems and thus she felt comfortable about raising the subject.

Observations made provided a focus for the later interviews; questions and queries arising out of the time spent with the respondents formed the basis of the interview guide and could thus be explored in depth during the second phase of data collection.

The two methods used in this study were clearly complementary of one another. Information gained during the different phases was cross checked for consistency as a way of ensuring internal trustworthiness. As stated previously, the artificiality of the observation period influenced the quality of the data gained and thus information collected during the interviews contributed substantially more to the formation of the results. This was reflected in the themes described in chapter 4 where emphasis was placed on direct quotations from the interviews, and fewer examples from the observation phase of the study were given. In addition most of the illustrations from the time spent with the respondents also came out of the informal and spontaneous conversations held with them, rather than pure observation of function.

However it was also noted during the second phase of the fieldwork that it was difficult for some participants to verbalise their feelings or experiences. For example, they could state that a relationship had changed and that they were unhappy therein, but struggled to articulate how or why. The researcher's therapeutic background was then useful in drawing out respondents, but this was not always successful. In these instances the time spent with participants within their natural environments proved most important. This was because the author was then able to highlight specific interactions she had observed and raise them for further comment, thereby helping subjects to focus their thoughts. She was also able to draw her own conclusions from observations made, and then reflect these back to the respondents for verification or clarity.

5.1.2 Use of Semi-Structured Interviews

The interview guide was comprehensive and detailed, resulting in lengthy interviews and the collection of a considerable quantity of information. Its content was guided primarily by the observation phase of the study (ie areas that emerged as important influences, information that needed clarity or further exploration) and its structure by occupational therapy's holistic approach to

rehabilitation, each section having been designed to explore a different component of function (ie physical, psychological and social). No participants added further sections or information to the guide; but differences were noted in where individuals placed emphasis. This then provided the parameters within which to systematise thoughts.

In the majority of cases interviews were conducted within the participants' homes, although one was carried out in a work setting and two were completed at neutral venues specifically chosen to ensure privacy. This was particularly where there were many people in the home. Times were chosen carefully, to minimize interruptions and again to ensure the greatest amount of privacy (eg when the spouse was at work and children at school). It was felt that all but one participant was therefore able to speak freely (in this case he was not alone at home and it is possible that the opportunity of his wife to listen in to the interview influenced the information he shared).

Interviews spanned a number of sessions with each participant, primarily because of the lengthiness thereof. Time between each visit was kept short to facilitate recall and continuity. There was some advantage in interviewing each participant a number of times. Firstly this minimized the possible influences of general mood or health at a particular visit. Secondly the participants were able to reflect on their responses and could then potentially add to the information given in a subsequent interview. It also allowed for a gradual pacing towards more sensitive and personal issues.

The initial part of the interview guide (documenting the participants' disability history) was vital because the author had been observing present functioning, and needed to gain insight into understanding the processes which had shaped the observed behaviours. All interviews therefore initially focused on the individual's life as a disabled person, up until the present time. Thereafter the interview guide was not strictly adhered to; emphasis and sequence of the discussion was given by the disabled person and thus varied considerably between the respondents. This flexibility proved suitable to the study although it complicated the analysis phase because the data first needed to be organised before the analysis could begin.

The interviews were conversational in nature and slowly paced. The researcher's primary task became to assist the participants to explore their initial responses further. With the quieter respondents the use of silences worked well to facilitate the gradual sharing of experiences.

It has been documented in the literature that many disabled people have a poor quality of life, with few being employed or marrying after injury (W.H.O., 1981). When participants expressed a view alternate to this, questions which worked well were those phrased to include these common sequelae of being a disabled person and exploring why the individual viewed his/her situation differently (for example, 'Many disabled people don't see marriage as a possibility, why do you?').

Questions themselves gave insight. For example, unexpectedly participants struggled when asked what advice they would give to another person in a similar position to their own. Respondents expressed that no two disabled people could be regarded as the same, and thus there was no specific solution which would work for everybody. One participant phrased this as, "*I'm not them and they're not me*". Although it had not been the intention of the author to suppose this, the example illustrated how active the respondents were in highlighting what they considered to be important.

Although the guide was considerably detailed, this did not impede the flow of the interviews. During the piloting of this stage the author became familiar with its content and thus seldom had to refer to it while with a subject. It was studied more closely between sessions to guide subsequent interviews so that all necessary areas would ultimately be covered. As there was no immediate pressure to conclude the interviews they continued until this was achieved with every respondent.

It was an assumption in the study that the participants would be able to give accurate and perceptive data. This subjectivity was required for the fulfillment of the study purpose. However it was common for participants to minimize problems or difficulties they had experienced in the past, particularly when recollecting their experiences closer to the time of their injuries. Initially they seemed to give a slightly romanticised and abbreviated version of the past; probing and detailed exploration of areas they brushed over served to decrease

this. The study was still limited by the memories and retrospective interpretations of the respondents. One way to accurately capture and highlight changes in function over time would be to conduct multiple interviews with the same participants 6 months or one year apart.

Perhaps one of the reasons why the interviews with each respondent were so lengthy was because information given was often in the form of examples of previous experiences. These reminiscences proved fascinating and could perhaps have been thought of as a third method of data collection.

The tape recordings of the interviews were lengthy and time consuming to transcribe. It was therefore not possible, as was anticipated, to do so word for word. Notes made were recorded in summary form, and supported by relevant direct quotations. This was felt appropriate as where possible during the interviews reflective summaries had been made to ensure that information was correctly understood, and these formed the basis of the notes written. All original recordings were maintained for later cross checking - this was done in some instances to ensure the accuracy of quotations which had been transcribed.

5.1.3 Influences of the Researcher

The data was collected by the author first hand which allowed for uniformity and control in the method used.

A possible limitation in the study may have been the researcher's clinical background. With some prior knowledge and experience in the field it was perhaps not always possible to have remained totally objective and to have ignored all preconceived ideas about the topic being studied. The potential for bias was always foremost in the author's mind, and a diary was kept where likely assumptions were highlighted. These were then verbalised to the participants; the author was aware of two occasions when a respondent challenged her viewpoint of a situation. This was a humbling experience and served to further sensitize her to the need to constantly question assumptions.

In other situations the author became aware of how little insight she, as a trained professional, had into some of the realities of life as a disabled person. This was

particularly in the performance of practical, everyday tasks (such as the amount of time spent on bowel functioning and how disruptive this was to daily life, or how to deal with menstruating and the fear of accidents). In these instances the participants were most clearly the teachers.

The researcher's background also had a positive influence on the study. As an occupational therapist in training she received instruction in interpersonal skills, including interviewing and counselling. Thereafter in her clinical responsibilities the author was for a year involved in carrying out weekly screening interviews which explored the work potential of selected people with disabilities. It was therefore with some existing skill on which to build that she undertook the present study. The attention given to enhancing her specific knowledge of qualitative research methods was documented in chapter 3 (see pp 61 and 62).

The author was also able to utilise her interpersonal skills gained as a therapist to establish relationships with the participants in a relatively short space of time. This was valuable given the time constraints of the fieldwork. The extent to which this had been successful was seen firstly when selective individuals included the author as one of the people with whom they felt comfortable to share what was on their minds and secondly it was reflected in the difficulty experienced in withdrawing from the field. All respondents had been aware from the start of the temporary nature of the research. However it was not possible, having made every effort to form close trusting relationships with the participants, then to suddenly withdraw after the interviews were completed. Closure of the data collection phase therefore took place over a protracted period, and in two instances participants were referred elsewhere for ongoing support.

From the beginning it was also made explicit that the benefits of the research would not be mutual; participants were told that their relationship with the researcher would hold little or no benefit for them other than they would have the undivided attention of a patient, non critical listener. However it was not always possible to remain uninvolved as frequently participants sought advice (all were aware of the professional background of the researcher) or included the author as a resource person (eg, asking for letters to be posted, requesting that a wheelchair be pushed or for an object to be passed to them). As the emphasis

was on observation and not participation, these situations initially placed the researcher in a dilemma. She did not want to become caught up in the role of therapist, or make the participants in any way dependent on her, however minor it may have been.

With time it became apparent that being involved in the setting could be viewed as positive. Some participants made use of a number of people to assist them in doing tasks and by including the researcher in this process, they were demonstrating a coping mechanism that they would usually employ; namely requesting help from those within the immediate environment. Thereafter the author felt freer to participate when assistance was asked for, and the exact nature of the visits varied depending on the needs of the individual or the relationship with which he/she felt most comfortable (it was also always questioned as to who would help or how the participant would manage if the author was not there). Advice was never given unless directly requested.

5.2 DISCUSSION OF THE RESULTS

The findings of the study were based on the experiences of 10 physically disabled participants. The discussion which follows centered around the results recorded in the previous chapter (sections 4.4 - 4.7). It was divided into two sections. Firstly the findings and themes which emerged during the course of the study and considered to be most important were discussed. The second division focused on the remaining results. Here the information was presented for the most part in a similar sequence to that used in the results section. Within each section subheadings were not used; the reader's attention is drawn to the use of two different typesets. When moving from one topic to the next the proceeding sentence or paragraph was highlighted thus delineating the beginning of the discussion of another issue.

Attention was given to integrating the findings with the results of previous studies and thus it was noted whether issues were confirmed or disputed by the literature. Possible explanations for differences and similarities were given. The

implications of the findings and any indications for future research were also discussed.

Much of what emerged from the study was essentially not new, and was supported by earlier research and existing theories. However as stated previously, the literature reviewed was predominantly international in origin. This study placed the information into a South African context. To date the author was also unaware of other local (published) studies in occupational therapy which have been approached from the perspective of people who have a disability.

5.2.1 Discussion of the Major Findings

The promotion of independence amongst the respondents was complex and multifactorial. A high priority was given by participants to the social and physical environments in influencing the potential for greater independence. This would at first seem to support a social approach to disability. Authors such as Finkelstein (1980), DeJong (1981), Oliver (1983), and Jongbloed and Crichton (1990) have emphasized the way in which the environment imposes limitations on the individual. The social context in which the individual lives has been seen as the milieu which largely determines the consequences of disability (Jagoe and Du Toit, 1983). However, while environmental issues are undeniably fundamental influences on the disabled person's functioning, individual characteristics also emerged as central to the promotion of autonomy.

The results suggested that in order to understand how disabled people adapt to their physical limitations, attention needs to be directed towards the individual. This was not in the sense of the participants' physical limitations. Previous research, such as work done by Jones and Summerville (1983), has tended to suggest that disabled people who achieve high levels of independence have fewer or less severe physical impairments. In this study the respondents' disabilities were of less importance than their personality traits and psychological functioning (eg coping mechanisms, motivation, self concept). These inner resources determined how the individual responded to external enabling or constraining influences.

For this study then, environmental variables and personal characteristics were both critical in determining disability outcomes. Behavior was thus in general a function of three interrelated influences; the individual, his/her immediate environment and social support networks, and the community or context in which he/she lived. This lends support for occupational therapy theories which suggest that the enhancement of function requires knowledge and consideration of the individual within daily life contexts.

Adaptation to disability was clearly longterm and ongoing. There was no point reached when the participants could be said to have "made it" and to have then become "independent". Solutions were seldom permanent; the individual constantly building on previous learning and adapting accordingly. Independence in this context could be viewed as a dynamic process, with function changing over time and being constantly modified by the existing environmental influences.

It is questionable whether there was a sequence to this adaptation. Some participants did appear initially to be most content within the confines of the home environment and only later began to want to go out more. There was however no direct support for a stage theory to adaptation, whereby the individual passes through various sequential stages which, with the passage of time, alleviate stress (Woodrich and Patterson, 1983; Richards, 1986).

Premorbid ability was found to influence present functioning. Participants showed a desire to approximate patterns of function after their injuries similar to that of their premorbid lifestyle. They thus appeared motivated to take part in activities if these had premorbidly been important to them. In this way subjects seemed to be exhibiting specific values which were of significance to them, regardless of the presence of the disability. It was also apparent that existing coping mechanisms and personality characteristics did not fall away after injury. Rather, the influence of the disability appeared to be to exaggerate specific traits.

The literature would support the above. A study focusing on S.C.I. persons found that subjects who were experiencing higher subjective levels of stress at the time of injury displayed more distress than those reporting lower levels of stress

at the time of injury (Frank and Elliot, 1987). The results emphasised the importance of previous life stresses and resources for coping as affecting present functioning. Cay (1985) also pointed to the importance of, when looking at adaptation to disability, examining how the individual had coped with previous problems or adult life prior to the disability.

Therefore in order to motivate disabled people to participate in activity, attention should be paid to their premorbid functioning. Examining their lifestyles prior to injury would help in the identification of priorities and interests. Focusing on previous coping strategies would provide clues to the presence of potential resources for coping. In addition age at time of injury was an indication of choices made in activity participation, as respondents were motivated to take part in the developmental tasks of their age group (for example younger subjects emphasised the importance of friendship and forming intimate relationships; older respondents focused on work and the family). The need to integrate treatment with the developmental timing of the disabled individual was evident.

All the participants appeared to have gone through an initial period when they were dependent on others for help, and when they chose to spend the majority of their time at home. This was regardless of the level of functional ability attained while in hospital or the extent of the physical limitation, and was suggestive of poor self esteem. Whereas in the literature the severity of the physical disability has been found to be positively linked to self esteem (Burckhard, 1985), this was not supported in the present study. Rather, it would appear that the presence of any physical disability by its very nature was enough to engender changes in the self concept. Thus the re-organisation of values and perceptions of the self appeared necessary for the individuals to cope with their new status as disabled persons.

Research has previously highlighted the ability of people with disabilities to re-define themselves as part of the adjustment process (Schultz and Decker, 1985; Weinberg, 1984). Most often changes resulted in a shift away from physical abilities to an increased focus on personal qualities and intellectual pursuits as being important. The present study also pointed to the need for participants to find some purpose or positive meaning in their disablement. On the whole it appeared that religion particularly was able to provide this kind of meaning,

participants needing to feel that there was a point to their suffering. In this way the individual was able to view his/her situation more favorably.

The first voluntary attempts by participants at helping themselves were most often around a crisis point, when no-one was available to assist them. At other times it was difficult for the respondents to always plan ahead and imagine the circumstances; once therein by necessity they had to cope. Thus it was not by choice that the subjects initially began to improve their functioning, but through forced independence. It was interesting to note that in all examples given, they were also able to meet the requirements of the situation, and to cope. A limitation of the study was that it did not explore if there were times or circumstances in which they had not coped. Therefore it was not clear if subjects left to their own devices would cope, or if and when the experience would be too overwhelming. The results of the study suggested that participants were more often than not able to rise to the demands of all expectations placed on them. Further research would need to explore this.

Perceived control over their circumstances developed through the participants' experiences of overcoming an obstacle. When attempts at completing a task or doing what was important to them were positive, respondents appeared motivated to repeat the behavior. This would seem to be because success in one situation led to expectations of success rather than failure in future situations. After a positive experience participants displayed increased belief in their abilities and this provided hope that goals could be achieved. The importance of hope has been stressed by Callahan (1988) who said that "all things are enduring if the demands of the situation are finite in depth" (p325).

It was clear from the study that an important way in which other people assisted the participants towards greater independence was through the creation of opportunities. On one level this was by acting as resources, for example by giving ideas, making suggestions, placing the subject in contact with a work or social contact. This has been labelled by Decker and Schultz (1985) as 'cognitive support' (ie the communication of information that will help the disabled individual to negotiate his world). For some participants the realisation of the part others could play in assisting them led individuals to begin to make use of all possible contacts when wanting to become involved in an activity.

On a second level, significant people created opportunities because of their expectations for the subjects. When participants were self-doubting and unable to see taking part in an activity as possible, they were shown the way when family or peers believed in the respondents' abilities and automatically included them in activities. It was also seen in the forming of intimate relationships, which many participants had ruled out as a possibility. The other person thus showed them, by accepting them for who they were, that finding a partner was indeed possible.

Participants therefore assimilated the views of others into their own self-esteem. The consequences of the above were that participants began to have increased hope and higher aspirations for the future. They were less willing to simply accept their present situations but sought rather to find ways to make events happen as they would have liked.

It would seem then that other people, including professionals, have a role to play in the creation of opportunities for disabled people which will lead to successful experiences and thus increased feelings of autonomy.

5.2.2 Discussion of the Remaining Findings

Participants were not always able to achieve or obtain what was important to them. This appeared to relate to poor self-confidence and a poor self-image. In particular, newly disabled respondents most often severely underestimated their abilities and social attractiveness. Behavior was therefore not solely determined by what tasks they could physically perform, but also their own belief in their abilities.

When participants were self-doubting, they were not able to see themselves participating in activities as desired. This was because they could not imagine, given their physical limitations, how they would be able to do so. With time, as their function or activity participation remained relatively unchanged, some respondents then appeared to begin to resign themselves to their situations. They verbalised having to be content with their present circumstances, and feeling little ability to change it. There was thus a strong feeling among the participants that they had to make the most of their existing situations.

Theories of motivation have focused on the consequences of the individual's adjustment of his/her expectations to his present situation. Kirchman (1986) reported on the learned helplessness theory and explained that when a situation is fixed over a period of time, the person tends to accommodate to it, showing gradual increases in satisfaction as aspiration levels recede towards the limits of the situation. The results of the present study would lend support for this theory.

Participants who resigned themselves to their existing circumstances therefore believed that they had little control over events, showing a low level of personal causation (Burke, 1977). This could have been due to the sudden onset of disability, which in all cases was traumatic. When their lives had been altered so dramatically without their control, this could have led to feelings of vulnerability and lowered confidence. It was then difficult for participants to be able to imagine having autonomy over their futures. They were not able to set goals for themselves or work towards the achievement thereof, as they felt little hope for attaining the desired result.

As subjects were not always able to control their circumstances or environment, their greatest sense of choice became how they responded to opportunities which arose. It has been documented that when a desired outcome is achieved, the individual develops a sense of having an effect and feelings of success in controlling the environment (Burke 1977). Perhaps then, it was not so important whether respondents were able to create opportunities for themselves but rather their responses to situations which arose.

Perceiving change or difficulties as a challenge promoted independence. As it was not always possible for participants to think ahead and preplan all events, a willingness to take risks therefore emerged as an important character trait. This is highly congruent with the literature, where it has been stated that challenges are needed for the development of a sense of competent achievement (Lifchez and Winslow, 1987). Several authors have also said that too often disabled people are protected as too much is done for them and they thus have little chance to experience normal developmental stresses (Rogers, 1982; Zola, 1982).

When obstacles were seen as a challenge the participants remained motivated to persevere until the task was completed. This would imply a need to believe in

their own ability to succeed. The converse was clearly seen; namely that respondents who doubted themselves and feared failure were more reticent to take up challenges. Rogers (1982) believes this is because individuals lacking in self assurance frequently interpret obstacles as personal deficiencies and thus readily give up when challenged.

Several participants did voice the opinion that it was their responsibility to make good events happen in their lives, as a result of their own efforts. This suggested that some respondents did feel they had power over their circumstances, in contrast to feelings of helplessness and a poor sense of personal causation. It is possible that participants who felt this way inherently had an internal locus of control (see p38, section 2.8.1.3 for a description thereof). The literature has suggested that these individuals (namely those with an internal orientation) are better able to adapt to their new situations than those who have an external locus of control (Parks, 1984; Lee et al., 1988). Perhaps then, these participants had been able to successfully overcome initial feelings of vulnerability and to cognitively appraise their situations in order to adapt.

An area where participants felt a high level of autonomy was in relationships. There were strong feelings that communication was a two way process and thus in relating to others subjects emphasized their role, particularly in verbalising when they were unhappy or wanted their needs to be met. Jago and Du Toit (1983) have previously called the ability to ask for and accept help an independent living skill which, when mastered by disabled people, helps them to take control of the situation and not to lose power. This would imply a high level of interpersonal skill, particularly assertiveness. Although this may come naturally for some individuals, others may need to acquire such skill.

Perhaps therapy time would be well utilised if focus was given, in addition to working to improve physical function, to the acquiring of such skills. This approach to disability is implied in the philosophies underlying O.T. practise, where attention is given to psychological and social needs as well as the individual's physical ability (Trombly, 1983). An examination of the person's premorbid personality and coping mechanisms would provide insight into

existing abilities and this could direct the amount of time spent on improving interpersonal skills.

Perceptions of power to direct their daily activity configurations thus varied amongst the respondents. This seemed dependent on the premorbid personality as well as positive experiences. The relative strengths of these factors, or the degree of inter-relatedness thereof, is not clear. It is hypothesized that the disabled person's motivation (and therefore likelihood of participating in a task) would at the very least be enhanced through the experience of success. This in turn would lead to a greater sense of control over the situation.

An interesting finding of the study was that **participants organised their days into fairly routine patterns of behavior.** This developed with time, as they adapted to their new ways of carrying out activities and these became more familiar patterns. A previous study examining the adaptive abilities of a person severely physically limited by cerebral palsy also noted that the smooth handling of events was made possible by planning, use of familiar people and a known environment, all of which were based on long term strategies (McCuiag and Frank, 1991).

Routines had a potentially positive influence on independence: knowing how long an activity took to complete or whom to rely on for assistance would have allowed for more stable and predictable patterns of function and thus possibly reduced stress.

Use of routines also had a potential negative effect. It was observed that few participants made use of the affected limb (particularly when one side of the body was compromised) in function. This they explained as being due to early weakness and awkwardness. As time passed they became used to performing tasks without (or with minimal use of) the body part. It would seem therefore that coping without the use of a limb became a habit. To re-learn to use the body part would then require conscious effort; having adapted once to accommodate the disability it would possibly be difficult to break the now well-established patterns of functions.

As part of their daily routines, respondents highlighted the positive effects of engaging in meaningful tasks. This confirmed the appropriateness of the value given in occupational therapy to purposeful activity, including work and leisure.

Participants placed considerable emphasis on the influence of the social environment on their autonomy. There were several reasons for this, including the creation of opportunities for participation which has been mentioned previously (see p211). The support and encouragement provided by others in particular helped respondents to persevere during difficult situations or when problems seemed overwhelming. In addition, how others treated them influenced the subjects' views of themselves. Positive feedback promoted a positive self concept and motivated the individual to attempt to do more for himself/herself. When respondents doubted their abilities and could not see participation in a task as possible, they frequently credited the support and encouragement provided by others as being the catalyst leading to changes in these perceptions.

The literature also places high value on the importance of social supports. It has previously been noted by several authors that positive, close and stable social relationships are a major determinant for high subjective life satisfaction (Najman and Levite, 1981; Brooks, 1984; Stensmen, 1985). Decker and Schultz (1985) called the communication of direct positive affect (eg encouragement, positive feedback) 'affective support'.

It would seem then, from this study, that the importance of the social environment is to provide an emotional climate conducive to the perception of control and a positive view of the self. This has been supported by previous studies; Decker and Schultz (1985) viewed social support as facilitating adaptation to physical disability by fostering a perception of control and feelings of competence within the individual. Another study which examined the development of a positive self-esteem among persons with cerebral palsy also identified relationships and opportunities as factors which led to changes in the self concept (Magill-Evans and Restall, 1991).

The literature has shown spouses and children to be important sources of support for the disabled person (Schultz and Decker, 1985; Corbett, 1989). The support provided by the family is said to moderate the psychological distress associated with disability and to assist in a satisfactory psychological adjustment. Corbett (1989) has also stated that a positive interdependence of family networks can provide a Q.O.L. which a bleak and lonely independence might lack.

The results of this study would seem to support the above. Family members were frequently cited as prime motivators and encouragers. More than this however, the family have been viewed as an extension of the disabled individual. When assistance was needed in A.D.L. tasks, family members were the most frequent helpers. As all respondents were living with their families, members contributed substantially to their activity participation. This included whether a task was done for the disabled individual or if the participant was encouraged to help him/herself and who if anyone was available to offer assistance. The attitudes of family members affected whether involvement in household tasks was encouraged and whether respondents were taken outside of the home. The family's social circumstances influenced the resources available to the individual, and again the potential for independence.

A unit of self-support appeared thus to be formed by the participant and his/her immediate family, and not the individual alone. Members clearly played an integral part in shaping the disabled person's daily activity configurations.

In view of the large influence the immediate family had on the respondents, when providing rehabilitation services it would seem most appropriate to work with, and incorporate into the treatment process, the primary caregivers. The family could be an important resource ensuring carry over of rehabilitation into the home. The development of family centered strategies (such as incorporating exercise and activity into the existing routine of the home) rather than individual programmes would perhaps achieve longer lasting effects. Increasingly involving the family together with the disabled person in rehabilitation has also been stressed in Primary Health Care and community based rehabilitation, which emphasises the importance of family responsibility and recognises the family as an important community resource (W.H.O., 1981).

Not all research has viewed the family of the disabled individual as favourable. Parents and relatives have been seen to prolong child-parent dependency and to

be overprotective (DeJong, 1981; Cay, 1985). Respondents tended to be less critical or negative towards their families. They were far more accepting of the help provided.

This could have been influenced by the fact that all participants were living with their immediate families. Possibly they had little choice as to who assisted them because there were few or no options available to them other than to rely on their kinship. This would seem to have been supported when participants named the family as their major support system, and were unable to list many friends, neighbours or other people who fulfilled this role.

It is questionable whether the relationships between family members always fostered choice, self direction and a gradual cultivation of the disabled individual's capabilities. In some circumstances this would seem so, when tasks were laid out in such a way as to facilitate function. Respondents also described situations where caregivers were over-involved and opportunities for decision making were limited (particularly when they were newly disabled). Previous research has noted that disability affects the balances in family power. It has been stated that irrespective of past relationships, the question of control is likely to be different when households revolve around disabled relatives (Borsay, 1990). More research would thus seem indicated to evaluate the degree of interdependence between members, and the degree of autonomy afforded to the individual. The elements found in this study to be important in legitimising the receiving of help could be focused on; namely reciprocation and direction of assistance given (ie asking for help when needed, stating what or how this was desired). It would be interesting to study the changes in the relationships from overprotectiveness to the allowing of more autonomy. In addition, given that the family were central in providing assistance for the participants and influencing their daily routines, research focusing on their perspectives of providing care would seem paramount.

Of particular concern was the small number of support people outside of the family named by respondents. Respondents who were not linked to community organisations or not employed were quite isolated. They rarely left the confines of the immediate environment and thus had no access to a setting where friendships could naturally develop. Isolation has been seen as a major factor in the oppression of disabled people (Sutherland, 1981), and lack of social contacts

outside of the home has also been recognised as a major factor in the aetiology of depression (Thompson and Haran, 1983). Davies (1982) has also stated that "one of the greatest disadvantages which lack of mobility brings is the very limited opportunity to meet others" (p69). In this study there was a definite lack of opportunities for the subjects to meet new people and in particular, to spend time with the able bodied. Friendship and social contact would seem a priority need to be addressed.

Several participants stressed the importance of friendship with other disabled people. This emphasis was perhaps high because of the involvement of so many of the subjects within the groups of the occupational therapy project in Mitchells Plain, which provided opportunities for interaction with other persons who were disabled.

The value and need for peer support has also frequently been mentioned in the literature. Saxton (1983) has reported that the intervention of a disabled peer can significantly accelerate transition towards independent living for disabled people. Peer counselling has been viewed as an important part of I.L. programs (Lifchez and Winslow, 1979; Cole, 1983) and in the United States is most often offered at centres for independent living. The way in which it is used was found to be similar to the potential benefits mentioned in this study - support through shared experiences and the ability to empathise; assistance through role modeling and information about use of known resources.

A finding was the value respondents found in comparing themselves with other disabled people. If a peer was able to participate in tasks which the individual was not, they were encouraged to try harder to achieve the same level of functioning. Interestingly, the converse also applied. When a subject noted that he/she was able to do more than a peer, they commented then on feeling not that disabled. Thus the comparison assisted in a positive appraisal of their situations. Whether valid or not, it decreased the person's sense of disability. It also seemed suggestive of a competitive trait within the participants.

The value of peer support is clear. It would seem beneficial then to link disabled people with each other. This is presently done on a formal basis in South Africa, through D.P.S.A. (Disabled People of South Africa). On a more informal basis, newly disabled people could perhaps be placed in contact with others who have

similar physical problems and who have been disabled for a longer period of time. On a one to one level, the individual would then benefit from the experiences of his/her peer. The majority of the participants verbalised their desire to pass on and share their knowledge with others. What appears lacking is for therapists to recognise this as an important component for rehabilitation, and to incorporate peer role models into therapy. By doing so, and thus allowing disabled individuals to work in collaboration and find their own solutions to presenting obstacles, therapists would be contributing to the empowering process of people with disabilities.

It must be noted that not all participants were in favour of peer counselling. Promoting friendship among disabled people has been viewed as stigmatising and marginalising (Brooks, 1984; Spencer, 1991). Only one participant stated that she would specifically seek out and befriend a disabled person; in general the subjects' orientation was to the mainstream of society and not to a subculture of disability. Friendship with non-disabled people has been found to be equally important for the self concept (Magill-Evans and Restall, 1991), there being value in the sharing of varied life experiences. Perhaps it is the role of the therapist to make all possible strategies which could potentially promote independence known to the disabled individual (in this instance, placing disabled people in contact with one another), and the task of the disabled person to decide whether he/she wishes to act thereon.

An interdependence with neighbours would have seemed a natural form of assistance and support for the respondents in this study, particularly because the houses in Mitchells Plain are within close proximity to one another. However there was a general reluctance to do so. This was firstly related to the high incidence of socially deviant behavior evident in the community - drug and alcohol abuse, with which respondents did not wish to align themselves. Neighbours often appeared not to be the type of people they would choose to socialise with, regardless of the presence of their disabilities. Secondly, there was little to legitimise relying on them for help, as participants did not know how to reciprocate. Payment was difficult as subjects were mostly indigent. If it were possible to assist disabled people in identifying their assets and what they could offer in place of money for help received, then they would perhaps feel more comfortable in making these requests.

In the literature disabled people have often been disparaging towards professionals. It has been expressed that they feel left out of decision making processes and that insufficient knowledge is shared with them (Bury, 1985). While frequently critical, participants in this study were less disparaging of a role for the professional. Individual experiences were more in keeping with what Williams (1987) has said; namely that the health professional can be a potential resource which the disabled person can choose to utilise in order to enhance independence.

Several participants mentioned specific people who had been helpful to them. There seemed to be several reasons why these relationships between respondents and professionals had been beneficial while others were not. Respondents focused on their attributes and abilities as a strategy for adapting to their disability and remaining positive. Some professionals appeared to do the same during the hospital period. Feelings of self worth would be fostered in such a setting and this could account for memories of favourable relationships. The converse would also be true: treatment that focused too heavily on the physical deficit and resultant difficulties could cause a lowering of self confidence and lead to less favourable impressions of the worth of therapy. This is supported in previous qualitative research (Kibele, 1989). The need to strike a balance between focusing on the individual's strengths and problems is a principle of occupational therapy (Rogers, 1982); the results of the study suggest that in reality the latter is over emphasized and the former too often not incorporated or ignored.

Professionals could also make a valuable contribution to the individual's sense of autonomy through working towards short term, achievable goals. This was again a strategy employed with some participants by professionals to assist in adaptation to disability. In this way expectations would be graded, resulting in repeated experiences of success and ultimately then an increased sense of personal causation. Rogers (1982) has also highlighted that it is primarily through the attainment of short term goals that individuals are helped to sustain interest in a task. The disabled person can experience satisfaction when mastering a desired level of performance, and this also builds motivation.

Two opposing viewpoints were found in the literature on the importance of completing physical tasks in determining independence. Some researchers, such as Jones and Summerville (1983) or Shipham (1988) placed a large emphasis on being able to complete tasks by oneself. In contrast studies have suggested that for some disabled people it is not always worth the effort, time and energy which must be spent on caring for themselves in order to be self reliant (Rogers, 1982; Yerxa and Baum, 1986; Kibele, 1989).

Participants in this study tended to support the latter view. They were willing, in some instances, to receive help as this allowed them to concentrate on more fulfilling tasks, such as work or social activities. They therefore chose to receive assistance without in any way feeling compromised. This lent support to a definition of independence which focuses on leading a self determined lifestyle, not in any way reduced by physical dependence on others or environmental aids (Jagoe and Du Toit, 1983; Rock, 1988).

Frequently a focus of O.T. and a measurement of rehabilitation success is on increasing the individual's functioning in A.D.L. tasks. However in the light of the present findings this would seem incomplete as it may cause neglect of broader aspects of the person's life. There is also agreement in the literature that an emphasis on acute restorative care is no longer in keeping with the long term needs of disabled people (DeJong, 1979; Acton, 1982; Fuhrer et al., 1990). The apparent discrepancy in views between disabled people and professionals on where the focus in rehabilitation should lie is questioned. One explanation for this may have been given by the results of a case controlled study conducted by Stensmen (1985), in which severely mobility disabled persons, in need of daily assistance, assessed the quality of their lives. A conclusion reached by the study was that the disabled individual's decreased physical function is often less important than the image of the same loss in the mind of the non disabled individual. This leads one to query who it is that values self reliance: the disabled individual, or the rehabilitation professional.

Williams (1983) has viewed self reliance as a myth. He stated that people are dependent in different ways, and that there is a play-off between dependence in some areas and independence in others. He therefore preferred to use the term autonomy, which suggested the importance of choice while recognising that choices occur in contexts which are a source of power and which are both

enabling and constraining. This was reflected in the examination of when participants sought assistance. There was no subject who chose to receive help with all tasks, or with none at all; the balance was influenced by their present circumstances. For example, subjects who were vehemently self reliant appeared prepared to accept assistance when time was limited, or in situations where they felt they otherwise would not be able to take part.

It might be expected that people with physical disabilities would perceive dependence on others as a lack of control over their lives. This was not true for the subjects in general. It was clear that when attempts to help themselves resulted in continual struggling and frustration, participants viewed this as counterproductive. A qualitative study carried out by Kibele (1989) with adults with cerebral palsy also pointed to this. The respondents recalled repeated feelings of failure as a consequence of being unable, despite years of trying, to meet goals such as walking or feeding without help. Participants in this study were clear: unless there was an obvious increase in function, they preferred to receive assistance rather than to struggle on their own. Therefore the reality of being disabled appeared to be that it was not always desirable to do tasks for themselves. Speed and quality of performance were frequently more important to respondents than active participation.

It would seem then that more energy is often required to deal with the disability itself than is available to do other tasks. When physical or emotional endurance is limited, perhaps energies are best channelled into higher priority pursuits. Therapists should guard against thinking that because the disabled individual can complete a task, he/she should. Rather, when attempting to build functional competence, it would be worthwhile to respect the individual's autonomy in deciding what these higher pursuits are. Practise and repetition of tasks leading to improved skill could potentially facilitate participation in an activity; however it should be remembered that choosing to get help is also an option for the individual.

There were times when participants chose not to receive assistance. In some instances respondents started helping themselves because of a need for privacy. They also attempted tasks in situations where they felt feelings of powerlessness. Subjects described this as having to wait on others for help, not being able to control the quality of the task undertaken, and internal feelings of being seen as

a burden. There were thus two components essential for maintaining a degree of control which were lacking; namely when and how tasks were completed. Williams (1987) in a study with arthritis sufferers found that the experience of dependency on others gave rise to more fear and loathing than almost any other aspect of living with arthritis.

Participants maintained an autonomous position when, knowing that they could manage a task if they really had to or if they persevered when struggling, they chose to have help. Assistance in these circumstances was viewed as practical and helpful, rather than constraining. Initially when unable to help themselves, receiving assistance made respondents feel like a burden on others. They were thus reluctant to ask for help and would either persevere themselves, or gave up. However, once they had been able to test themselves, and could participate if they really wanted to, they were able to ask for help. It would seem then, that participants were comfortable in asking for assistance when they had a sense of personal autonomy.

A key to the apparent disparity between situations where participants felt comfortable in being assisted with tasks and situations where they did not, may well be interpersonal relationship factors, between the giver and the receiver. The disabled person requesting help needs to be able to articulate his/her needs and preferences. In this study participants pointed out the importance of monitoring their own communication, such as how they phrased requests and to whom they directed these. By being aware of how they made demands on other people for assistance, and modifying their requests appropriately, participants were thus able to maintain some degree of control. In a study by Nosek, Parker and Larsen (1987) focusing on individuals with severe musculo-skeletal impairments it was found that persons with high levels of independence were able to solicit assistance with the daily tasks as needed.

When an individual was severely physically limited, the need to verbalise his/her needs was important, as this was frequently the only way in which to participate in an activity. Thus, being able to direct others was paramount to autonomy. The growth of autonomy for people with disabilities has also been viewed as being ultimately connected with learning to be the recipients of help (Rogers, 1982). However it may be that not all participants in this study were able to

direct the assistance given. It has been documented by Jagoe and Du Toit (1983) that the ability to ask for and receive help is an important skill for independent living and that it cannot be assumed that all disabled people will naturally have these abilities. Occupational therapy services could therefore be extended from working towards self reliance on daily living skills to, for the more severely disabled individual, the ability to direct these skills. Important components would be to assist the individual to take control and to initiate action, choosing the helper, and concisely communicating his/her needs. This approach has been successfully utilised in American independent living skills training programmes (Neistadt and Marques, 1984) and is in keeping with the principle that the consumer directs the provision of his/her care.

In addition to the disabled person feeling comfortable in articulating his/her needs, the caregiver must also allow this. An article which reported on the setting up of a home in the community for four severely disabled persons stressed that the degree to which the individuals were able to direct their own care and develop their preferred lifestyle was dependent on the staff's willingness to respond to his/her direction (Brown and Ringma, 1989). It is thus possible that where participants in the present study felt powerless and unhappy in receiving care, this was due at least in some way to the reactions of the helper concerned. Further research would need to confirm this.

Another way in which participants were able to maintain control in receiving help was through the changing of the nature of their role in a situation. This strategy for tackling the disability directly rather than struggling to overcome it, has previously been documented by Williams (1987). In his study with rheumatoid arthritis sufferers he quoted examples of housewives who maintained the role of primary food preparer by deciding on what should be cooked and how this was to be done, while the actual physical preparation was carried out by a helper. Changing the nature of one's role is thus a workable solution that allows disabled people to engage in activities that are meaningful to them, despite any physical limitations.

One of the ways participants were able to legitimise the receiving of care was if they were able to reciprocate and offer something in return. In these instances there was a constant interplay between dependence, independence and

interdependence. There was again strong agreement with the literature, which confirmed reciprocity as a way to legitimise help being received. One author (Borsay, 1990) went so far as to state that only reciprocity legitimises the acceptance of care and allows the recipient to keep an autonomous position.

In some instances a few participants were able to set up a supportive network to provide assistance as needed which reduced the necessity to rely heavily on specific people. They also had far greater choice over whom they requested to help, and with what task. This was a strategy frequently cited in the literature which allowed severely disabled people to live independently (Frank, 1984; Kibele, 1989).

Gloag (1985) has observed that obtaining adequate personal care is the biggest problem facing many severely disabled people, especially those wanting to live on their own. In this study all the participants were living with family members onto whom the burden of care in all instances fell predominantly. The literature confirms that it is often the family who play the major role in caring for the individual. A trend has developed that emphasises the family as carers and supporters as a move towards de-institutionalisation of disabled people continues (United Nations, 1986). Relying on family members for help can however place heavy financial and social burdens on them. Personal care attendants (P.C.A.'s), assistants who were paid to provide help in carrying out self care tasks, were conceptualised to reduce the acknowledged excessive dependency on family members.

The use of P.C.A.'s was not seen in this study, predominantly as such services (both training and employment) are not well established in Cape Town and financial limitations remain a major constraint, with no money allocated for the hiring thereof. This is in contrast to trends in America and Britain where independent living centres have been geared specifically towards attendant care referral, and a grant can be obtained to cover the expenses of hiring the helper. It is also possible that the idea of a paid care attendant was not known to the participants, and thus no alternative was thought possible other than relying on family members.

The use of assistive devices to promote the functional ability of physically disabled persons is a major component of occupational therapy treatment. In this study few participants made use thereof. Primarily, financial limitations hindered the buying of technologically advanced equipment (eg computerised devices, hoists). In addition however where an assistive device had been given early on in treatment, participants appeared most often to ask for assistance rather than continue to utilise the device, or they chose to struggle without it. Several reasons for this were apparent.

It has been stated in the literature that reactions to equipment and devices are frequently personal (Lifchez and Winslow, 1979). A solution that works well for one individual may not necessarily be acceptable to, and suit the needs of, the next disabled person. This also emerged from the present study. No two participants with similar medical diagnoses and residual impairments made use of the same approaches to function. This was because of differences in life experiences, and in the context in which they lived (eg, whether people were available to provide assistance, tasks performed in a day, roles held). This suggested that there can be no standard approach to individuals with a specific disability. When a disabled person is struggling to complete a task, it would seem necessary to consider the whole person and to examine the context in which he/she lives before deciding how best he/she should do the task and what, if any, device would be beneficial. In addition, it was noted that where participants had been involved in designing or choosing assistive devices, they were more likely to use them. For carry over of treatment into the home then, disabled people need to play a more active role. Involving them in decision making would thus ensure feelings of self direction and autonomy from early on in the rehabilitation process.

There appeared to be a certain stigma attached to using an assistive device obviously designed for a disabled person. Participants felt that when utilising such devices they appeared, and were perceived to be far more disabled than they actually were. This was echoed in the literature where it was commented that dependence upon devices could result in people with disabilities feeling like failures and devalued members of society (Finkelstein, 1980). The increased use of commercial products, already adopted by many participants, would seem a viable solution. This implies a need for occupational therapists to explore in depth the potential value and adaptability of commercially available items as devices to assist in function. A possible stumbling block may well be the cost

involved in buying such products for individuals with poor socio-economic circumstances.

The primary reason given by participants for not using the devices given to them was because in their opinions these performed inadequately, were cumbersome, and caused the individual to struggle unduly with tasks. Participants also appeared to expect an immediate increase in functional ability when given an assistive device which they most often did not see. Few therefore continued to utilise the device beyond the unfamiliar, awkward phase. However, it would appear to not be enough just to be able to perform the task. All activities of daily living need to be practised until they are perfected, sequenced and routinised in a manner that sustains the habits of function. It is possible that the therapist providing a device should thus focus more on assisting the individual to practise tasks with the aid so as to become skilled in the use thereof.

Overall, subjects were so negative about the use of assistive devices that one must question the effectiveness of them. Given the time involved in the making of assistive devices, the cost, and time spent in teaching usage during therapy, this is of major concern. However, a limitation of this study was that it did not explore where the actual problem primarily lay - with the devices themselves, or with the procedure whereby they were given to the participants. No confirmatory or disconfirmatory information was available from the literature. A larger, quantitative study is needed to explore the universality of the participants' experiences. It would also be of value to examine the procedure by which devices are supplied, the education of disabled people in the use thereof and any follow up which is given.

The area where participants perceived themselves to have the least control was in the realm of community integration. Most respondents felt powerless to change their social circumstances, find work or make interactions with others occur as desired. It is questionable however how different this is from any resident of Mitchells Plain, regardless of disability, because the area is in general home to an impoverished community. In this context it is perhaps ill founded to discuss independence for disabled people.

It is self evident that for choice to be a reality, there must to be a variety to choose from. Therefore until attention is directed towards promoting structures

and providing opportunities for the Mitchells Plain community autonomy will remain largely a myth. In addition the society would need to be orientated towards incorporating the needs of persons with disabilities to afford them greater control over their circumstances.

Notwithstanding the above, it was possible to explore what participants were doing within their present circumstances which led potentially to increased independence.

The social setting of the study influenced the participants' potential for independence considerably. The majority of the participants were disadvantaged in many ways - there were high incidents of poverty, unemployment and social isolation. Thus although their residential area was no doubt considerably different to that of subjects in other studies, the results reflected similar issues related to Q.O.L. which have been recognised internationally (W.H.O., 1981) and noted in other South African studies (Disler et al., 1986; Cock, 1988a).

An environmental barrier for people with disabilities frequently mentioned in the literature is accessibility to buildings and public places (Winslow and Lifchez, 1979; DeJong, 1981). However participants in this study did not find this a major obstacle. For them, the availability of suitable transport was a greater limiting factor. The majority of the participants verbalised wanting to go out more, but being limited by transport, they saw this as out of their control. Therefore the desire was there, but the means not. They saw no alternative but to remain at home and make the most of the situation. Perhaps if they had been able to go out more, the question of environmental access would have been more significant.

A concern to the respondents from Mitchells Plain was a need for safety. It was the subjects' perceptions that their residential areas were to varying degrees unsafe (they spoke about the presence of gangs, acts of violence, presence of drug and alcohol abuse). This affected the time they spent outside of the home - when, where and with whom they went and modes of transport. From this theme then the importance of examining the specific cultural constraints of the setting which influence the disabled person's activity participation was clear. In order to

understand the choices made by the individual an understanding of the environment from whence they came would be essential.

The presence of social services in a given community is of benefit to its members. When available and apparent they have been found to be a positive predictor of independent living (DeJong, 1982; Jones and Summerville, 1983). The occupational therapy community project in Mitchells Plain had an obvious positive influence on the lives of the respondents involved therein, providing both work and social opportunities. The church was a second important resource, providing support and social contact. Participants could not list further potential supportive services in their residential area and it is not known whether others do in fact exist. In a study carried out with spinal cord injured persons in Soweto, low usage of community resources was thought to be due, at least partly, to a lack of knowledge thereof (Cock, 1988a). Respondents were generally poorly informed about other resources; namely sources of practical and financial assistance (eg organisations which sponsor buying of equipment), which lends support for Cock's findings.

As knowledge has been equated with power (Hadingham, 1987), clearly it would benefit the disabled individual to be aware of all possible avenues to which he/she could go when in need of help. This would also, in keeping with primary health care principles (W.H.O., 1981), promote greater community responsibility in the life of people with disabilities, and decrease the need for professional involvement.

Studies have shown that disabled people frequently have restricted opportunities and limited choice in vocational activities (Kuh et al., 1988; Granger, 1985). In the 1984/1985 Cape Town based study by Disler et al. (1986) almost all the subjects saw the unavailability of suitable work as the greatest deterrent to obtaining employment. Unemployment in general is a problem in Mitchells Plain, compounding the difficulties facing the respondents in this study. Participants who were working had been able to do so via two routes. Firstly, due to the scarcity of work available for the respondents to chose from, they were not able to be proactive. Rather, opportunities were created for them; it was then up to the individual to decide whether or not to act thereupon. Most subjects had thus found a job through personal contacts. This highlighted the

importance of networking and making one's needs known to all those who can potentially be of help. The assumption underlying this approach to problem solving would be that the greater the number of people aware of a need, the greater the likelihood that someone could be of assistance. Thus respondents made use of all possible contacts and increased the potential for their needs to be met.

Secondly, working from home seemed to be a viable alternative to formal employment in the open labour market. This solution has already gained much momentum, as noted by Rendall (1988) who stated that in South Africa specifically informal sector activity has escalated as a major source of income for those unable to find work. In this study a group setting appeared to work best, as members provided support, motivated each other and were able to provide physical assistance if needed. Perhaps occupational therapists with expertise in work rehabilitation could play a role in investigating and assisting in the establishment of home based work projects. As employment is a problem facing the community at large, these groups could possibly be co-operative ventures between people with varying skills and disabilities and the able-bodied. In this way members could assist one another (physically and intellectually) while working towards common goals. Subjects in the present study felt that work had the potential to decrease the gap between being disabled and the able bodied; because of their composition these groups could thus also be beneficial in promoting the community integration of the disabled members.

The potential benefits of meaningful leisure time pursuits have been documented in the literature. These include the use of activity to improve physical functioning, the potential for increased social contact and the fostering of a positive self concept through personal talents and developing talents (Valliant et al., 1985; Cotton, 1987; Jackson, 1989). In this study, although some participants did partake in them, no emerging theme developed out of the use of leisure time. The primary reason for this may well be found on examination of the respondents' premorbid lifestyles. They described having focused on work rather than leisure, and remembered having had little free time. DeJong (1981) in his concept of productivity recognised the importance of all contributions the individual makes to community life and would thus argue that work and leisure could be equated. This was not supported by the study. In the economic reality of Mitchells Plain, a largely indigent community, employment

and the generation of an income would seem by necessity to be more of a priority than time spent focusing on hobbies or interests. Work was thus a far greater need.

It is also possible that participants who had not previously been active in leisure time pursuits and who after their injuries found themselves suddenly faced with an abundance of free time, were not sure how to make use thereof. In the light of their compromised physical functioning, they could have been unsure of what tasks they were capable of doing. It was noted that the subjects knew of few resources (such as clubs or societies) which they could join, but practical problems (ie transport, money) could also have been contributing factors.

A finding in this study which is a matter for concern was that few participants felt that the rehabilitation process had played a role in enhancing the potential for independence. In previous research, such as a study by Susset et al. (1979), rehabilitation input has appeared to be one of a number of inter-related variables influencing disability outcomes. This was despite the fact that the type and extent of services received varied amongst the subjects, and had often been incomplete (77% of the sample had received physiotherapy and 46% O.T. services. Social services and psychological input had been rare). The study found that psychosocial indices were significantly higher ($p < 0.007$) when some rehabilitation had been undertaken.

A possible reason for the differences in the two studies was that the work done by Susset et al. was a one year retrospective study, whereas in this project length of disability varied considerably, spanning up to 11 years post injury. It is feasible that for the respondents, as time past, other factors became more pertinent than the early rehabilitation they had received.

Another possible reason is that participants placed little focus on the hospital period, and gave more attention to their experiences within the community. Jagoe and Du Toit (1983) have stated that this is where the real implications of the disability become known. However, no subjects had received services within their home environment. It was a finding of this study that it was not always possible for the respondent to plan ahead, anticipate problems and devise suitable solutions. Only once within the situations did their needs often become paramount. If rehabilitation services therefore are going to have a meaningful

effect on the individual's autonomy, they must be available when and where they are needed most - this appears to be within the disabled person's living environment.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

6.1.1 Achievement of study objectives

6.1.2 Factors influencing independence

6.2 Recommendations

6.2.1 Future research

6.2.2 Implications for O.T. student training

6.2.3 Implications for practise

CHAPTER SIX

6.1 CONCLUSIONS

This study focused on the life experiences of ten participants who were physically disabled in order to identify factors which influence the freedom of disabled people to make choices that will enable them to live independently.

Independence emerged as a dynamic process. It was not a static state which once achieved constituted success. Rather, behavior was the result of achieving a daily balance between three major influences, namely individual characteristics, psycho-social functioning and environmental factors. Independence was thus not determined purely by physical ability but by the relationship between the disabled person and the context in which he/she lived. A key distinction between individual and social factors however is that while it is up to the disabled person to determine how he/she responds to situations and to change this if desired, it requires collective and political action to remove environmental restraints.

The severity of the individual's physical limitations did not seem paramount in determining his/her level of independence. Rather, psychological factors such as the respondents' subjective view of themselves and coping mechanisms played a more fundamental role in influencing their participation in tasks.

6.1.1 Achievement of Study Objectives

The objectives of the study (see section 1.2, p6) related to the respondents' perceptions of control, and the opportunities afforded to them for decision making and choice within their lives.

It was found that feelings of control varied amongst the participants. They were not always able to obtain what was important to them. This seemed to relate primarily to the individuals' self esteem and their present life circumstances. The area over which the subjects felt they had the least control was in achieving active participation in the community.

Perceptions of power were fostered firstly through the personal experience of overcoming an obstacle and secondly feelings of success. A consequence of positive experiences and opportunities that came their way was that participants developed increased hope and optimism that good things would happen to them in the future, and that they would be able to obtain what was important to them. They were then more willing to try to make events happen as a result of their own actions. In contrast those who cited few positive experiences after their injuries seemed to resign themselves to their existing situations and expected less for the future.

The social environment provided an emotional climate conducive to the perception of control and a positive view of the self. This was through the support and encouragement provided by others which acted as external motivation for the subjects. Participants who were accepted by others for being themselves also tended to view themselves more favorably.

Opportunities for participation in activities were frequently created by others, particularly when subjects were self doubting and could not imagine how they could manage a task. Respondents' greatest sense of autonomy then was in deciding how to respond to the situations in which they found themselves, and in particular directing their interactions with others. However this did vary among respondents depending on the situational constraints placed on them. Of paramount importance was the freedom afforded to the individual by his/her main caregivers and support systems (in this study, primarily the role of family members). Equally of value were the restricting influences of their greater living environment (Mitchells Plain) where high incidents of poverty, unemployment and social isolation were common. Within this context, with little variety to choose from, freedom of choice was severely limited.

Choices made were culturally and socially bound. In the community of Mitchells Plain a need for safety governed when and how the participants left the confines of their immediate home environments.

Self reliance did not seem an important value to the participants. The subjects appeared to be living within a community which placed higher value on co-operation, affection and interdependence amongst its members. It was thus only

when participation was valued above speed or quality of performance that they made continual attempts to help themselves.

The receiving of assistance promoted independence when participants were freed from time and energy consuming activities (eg self care) to concentrate on tasks considered to be more fulfilling (eg work). This allowed them to take part in activities which otherwise were felt to be beyond their reach.

An interdependence with others and thus the reciprocation thereof, legitimised the receiving of help. The presence of a number of potential caregivers was seen to minimize the assistance provided from a single person, and this prevented feelings of being a burden on others. A sense of privacy was also then maintained when the subjects limited the people on whom they relied for help and for what task.

In most instances participants chose not to utilise assistive devices to aid function but preferred to struggle without a device, or to ask other people for assistance when needed. Respondents were more willing to make use of a device if they had negotiated some control over the attainment thereof. This was through having been involved in the making of the aid, or if it had been altered in some way for their specific needs, and through the purchasing of a commercially available item.

6.1.2 Factors influencing Independence

The results of the study have been documented as themes and discussed in the preceding chapters. What follows is a summary of the main findings. In accordance with the first aim of the study (see section 1.3, p6) several factors which heighten the disabled person's potential for achieving independence were identified. These factors were derived from the themes which emerged from the study. They were considered to be the fundamental influences affecting the participants' autonomy.

The reader is again reminded that looking only at single or obvious variables belies the complexity of human behavior. In reality factors were interrelated and the relative strength of each was specific to the individual.

The most important factors identified included the following:

- * Examination of the participants' **premorbid personalities, lifestyles and experiences** provided insights into what tasks they were motivated to partake in, and determined how they responded to external influences.
- * **Motivation** was influenced by the desire to complete **age appropriate life tasks**.
- * **Individual values and preferences** governed choices made in activity participation, not function alone.
- * **A combination of personality characteristics** were noted to enhance the potential for independence. These included:
 - perceiving change or problems as a challenge
 - a willingness to take risks
 - an ability to persevere during difficult situations
 - an ability to problem solve and devise solutions to potential barriers
 - a competitive spirit
 - a sense of humor
 - outgoing and confident
 - assertiveness, particularly in directing the provision of care and dealing with prejudice
- * **A re-organisation of values, lifestyles and perceptions of themselves** appeared crucial in the process of adjustment to disability.
- * The **cognitive appraisal** of their present circumstances assisted subjects to view their situation more favourably and to reduce their pre-occupation with the disability. This was accomplished in the following ways:
 - a focus on strengths and abilities
 - the setting and achievement of short term goals
 - a focus on future plans
 - a search to find meaning for the cause of their disablement

- * **A positive self concept** enhanced the potential for respondents to take chances or face challenges.
- * **Employment** influenced the individual's self concept favourably. Within the study setting (Mitchells Plain) the informal sector, in the form of home-based work groups, seemed a viable alternative to work in the open labour market.
- * **Necessity** (when others were not readily available to be of assistance) prompted the first voluntary attempts at helping themselves.
- * **Situational changes**, either through an alteration in social circumstances or by the involvement of other people, created opportunities for participation in activities thought to be beyond their abilities.
- * **The ability to be able to rise to the demands of the situation** in which respondents found themselves promoted independence.
- * **Positive experiences** motivated subjects to repeat their behavior and led to increased hope for the future.
- * **Ongoing adaptation** was evident as respondents, with time, found out about new ideas or worked out new solutions to presenting problems.
- * **The development of a routine**, which could be executed automatically, assisted participants in planning their time effectively and decreased stress.
- * **Participation in meaningful occupations** such as work or social events reduced pre-occupation with disability.
- * **The activities conducted by family members** with whom the participant lived influenced the potential for independence in several ways:
 - the availability of family members to provide assistance

- facilitated community (rather than institutional) living
 - the household routine exposed the individual to a specific range of tasks and the opportunity to participate therein
- * **Contact with other disabled people** was a positive factor influencing independence for the following reasons:
 - the sharing of experiences provided support
 - peers acted as role models and resource people
 - through the comparison of progress subjects gained a sense of their own achievement
 - * **Community services** that were available and accessible enhanced the potential for independence.
 - * **Religious beliefs** emerged as sources of motivation for the participants. The Church was an important community resource.
 - * **Belonging to a community group** held the following main benefits:
 - subjects were able to spend more time outside of the home
 - this gave them access to potential support systems other than family members.
 - * **Networking** was used as a way of problem solving and increasing knowledge of available resources.

There was strong agreement between these findings and the literature reviewed. As stated earlier (p 153) the present study placed the factors into a South African context. Perhaps one fundamental difference between this and other work published from the perspective of disabled people, was the considerable importance of psychological adjustment to disability which was found in this study to be a crucial influence on autonomy. The ability of disabled people to cognitively appraise their situation; re-organise their values, lifestyles and perceptions of themselves; and the importance of the self concept emerged as essential factors which were given more recognition for their role in influencing independence than in previous studies.

Another major difference was the emphasis placed on the family. In the present study they appeared to be afforded a far greater emphasis than they have been

given in other research emanating from Britain or America. This may well be due to the economic differences between the settings. Within the study context of Mitchells Plain opportunities for living with a disability on one's own, the hiring of a care attendant, the use of sophisticated and expensive equipment, and the availability of work or social activities appeared to be limited. In these instances then, family members may have by default become paramount in the participants' desire for greater independence.

6.2 RECOMMENDATIONS

The study documented the experiences of a few people; its value was as a sensitizing device which suggested what were important factors influencing independence and gave direction for future exploration of the same topic. It also recognised the contribution that disabled people from their own personal experiences could make in identifying these influences and thus gave them a voice to do so.

In research which relies on qualitative methods there is always the question of how representative the chosen respondents are for the problem under review. It must be remembered that the emphasis throughout the study was on obtaining data of the best quality and of making as full use of the context as possible. It is not possible, with any degree of certainty, to generalise these results to the disabled population in South Africa at large. This would first necessitate a focus on the similarities or differences in the study contexts. Environmental variables (eg community resources, family structures, socio-economic circumstances) were found to be crucial influences on the individual and thus the potential for independence for people with disabilities could vary considerably depending on the enabling or constraining influences of their social circumstances. Perhaps the closest match would be with other disabled people living in Mitchells Plain and the surrounding areas.

However notwithstanding this, the study's weightiness was thought to be shown by the similarities in experiences amongst the participants, and with the literature. In addition the results were met with much enthusiasm and little

criticism from the disabled people with whom they were discussed. It is in this light that the following recommendations were made.

6.2.1 Future Research

In qualitative research, when the problem under discussion necessitates the recollection of early experiences (eg in this study participants were required to give a detailed history from the time they were initially injured up until the present day), it was felt that the use of reminiscences as an additional method of data collection could be a powerful adjunct to direct interviewing and observation. This could be in verbal or written form; the participant being invited to speak around a specific topic.

Research which used a combination of qualitative and quantitative methods would ensure findings of more substantial reliability and generalisability. This would also yield a breadth and depth of data that neither method could obtain in isolation. Following on from the factors found to influence independence in the present study then, and to meet the second study aim (see section 1.3, p6), several hypotheses were put forward for further testing:

- * The presence of a physical disability engenders changes in the self concept, notwithstanding its severity.
- * The ability to take risks is related to the self concept. Disabled people are less likely to initiate change when self doubting. A positive self image promotes the potential for taking up challenges.
- * Disabled people meet the expectations that a situation places on them. When these are high, they rise to the ensuing challenge and when low, they gradually resign themselves to the presenting circumstances.
- * The vulnerability experienced by the sudden onset of disability affects the individual's sense of personal causation.
- * The experience of success provides an increased sense of personal causation. Therefore the disabled person's motivation (and likelihood of

participating in a task) would at the very least be enhanced through the experience of success.

- * The disabled person's unit of self-support is the individual and his/her immediate caregivers.
- * The disabled individual can be viewed as a function of his/her social relations.
- * Disabled people are able to receive help without feeling compromised once they have a sense of personal autonomy.
- * Disabled people are more likely to value therapy if they are active participants therein.
- * Work has the potential to decrease differences between people with disabilities and the able bodied.

In addition to the above, areas needing further research also became evident. No specific hypotheses were formulated because the present study gave broad direction only. Some topics which need further exploration follow.

Within the context of the study participants were disparaging about the use of assistive devices. In occupational therapy emphasis is placed on adaptation to function and the use of these devices in the execution of A.D.L. tasks (Trombly, 1983). Further research is thus necessary to explore the universality of the findings and to identify the benefits of, and the potential problems in, supplying disabled people with assistive devices.

The influences of the family, particularly a spouse or parent, were found integral to the respondents' functioning and activity participation. Their involvement appeared to be so substantial and crucial that the disabled person and his/her immediate caregivers were viewed as one unit. A qualitative study, focusing then on the caregivers' perspective, would seem paramount. Specifically this could deal with the influence of the presence of a disability on the functioning of the family; how the spouses, siblings and parents viewed their roles; and the specific needs of these caregivers.

Another area for exploration would be the passage of time between discharge from hospital and the first voluntary attempts by disabled people to do tasks, as well as the first desires to spend more time outside of the home. Questions to answer would be why they began to help themselves or wanted to leave the home, what activities they first participated in and how they managed to do this. The present study suggested that disabled people are able to rise to the expectations placed on them. Further research would need to confirm this. If disproved, a study could examine under what circumstances disabled people left to their own devices do cope, and when the experience is too overwhelming.

6.2.2 Implications for Training of O.T. Students

Occupational therapy students are given training in the use of adaptive techniques and equipment to assist in the completion of A.D.L. tasks. A finding of the study was that respondents were more likely to make use of commercially available products than assistive devices specifically designed for disabled people. When students are taught about assistive devices then, at least one lecture could be devoted to examining the potential of commercial items, and their adaptive capabilities, to aid function.

Qualitative research methods, because of their powerfulness as a sensitizing device for work of an exploratory nature, could be well adapted and used for teaching purposes. When students are taught of the problems facing people with disabling conditions and the possible treatment thereof, valuable insights could be gained by spending time with individuals who have these limitations. For example, by spending a day in the homes of people who were blind, students could observe first hand how they managed to carry out their activities of daily living. Teaching would then be done by the individuals who arguably have the most knowledge and insight to do so and this would potentially be a far more dynamic learning situation than in the classroom. The use of videos (of disabled people in their home environments, and in which they spoke about their experiences following illness or injury) could also be effectively utilised as

teaching devices if direct visits into the field were thought to be too time consuming and costly.

6.2.3 Implications for Practise

It should be kept in mind that much of what follows is not new to occupational therapy, but rather re-affirms the value thereof. However, the findings of the study suggest that in reality very often its basic principles are not adhered to. The challenge facing O.T. readers then is to critically examine their present methods of practise and to once again, if necessary, align these with the underlying philosophies of the profession. Readers from other disciplines could perhaps see what strategies they could utilise in their treatment to enhance the potential for independence of people with disabilities.

Before rehabilitation begins time taken to get to know the individual (eg premorbid personality and lifestyle, home circumstances) would be beneficial in establishing strengths on which to build. Information about the person's needs and priorities would also give clues as to potential motivating factors.

There was also evidence in this study which suggested the need to integrate treatment with the developmental stage of the disabled person. Younger individuals may focus on opportunities for socialisation and the execution of self care tasks without help because of concerns with body image. With increasing age a shift towards greater emphasis on work and family responsibilities may become apparent.

It is paramount to examine the specific cultural constraints which are a reality for the disabled individual as these influence when, how and in what tasks they choose to participate.

Although specific disabling conditions may result in similar problems for all those affected, it was clear that the participants differed in their responses to the resulting limitations. Therefore there can be no prescribed formula for

treatment; therapists should strive towards an individualised approach to each patient's unique needs rather than remaining bound by stereotypical models (eg providing every stroke patient who has a hemiplegia and poor balance with a bath board).

Rehabilitation focusing solely on the performance of physical tasks and the use of adaptations which promote A.D.L. functioning would seem unrealistic as this would provide a limited view of the individual. Perhaps the most important issue in treatment is not to negate physical ability, but to include as many other components (such as psychological and social functioning) as possible that will facilitate greater independence for the individual.

More time could therefore be spent in treatment on developing or strengthening individual coping skills (eg assertiveness, problem solving skills) as these determine for the most part how disabled people respond to the circumstances in which they find themselves. In addition attention could be given to values clarification and the identification of priority needs and goals. In this way disabled people would be assisted in the re-organisation of the perceptions of themselves, which was found to be a necessary step towards adaptation to disability.

An area over which the participants felt they (potentially) had the most control was in relationships. It cannot be assumed that all disabled people will have good interpersonal skills and therapy time could be focused on the ability of disabled people to ask for and receive help, refuse assistance when this is not desired and deal with prejudices as they arise.

Confidence in their abilities was needed for participants to be willing to actively negotiate situations and to take advantage of opportunities that came their way. A focus given to the individual's strengths rather than limitations would promote a more positive appraisal of the self. This implies a re-orientation of thinking from treatment designed to compensate for losses to a greater emphasis on enhancing residual function and capabilities.

The setting of short term, attainable goals in therapy which are shared with the disabled person would provide opportunities for the achievement of success. This in turn would foster feelings of control and optimism for the future.

It was noted that in some instances participants took years to adapt to their disability or to find solutions to presenting problems. Trained therapists, along with other support networks, could perhaps speed up this process. It was also clear that making their needs known to as many people as possible in the hope of obtaining a solution to the problem was a strategy employed by some respondents. All professionals thus have a role to play in the provision or creation of opportunities which the disabled person can choose to utilise in order to enhance their independence.

In particular, disabled people should be informed of all existing resources from which they can obtain assistance, including financial help. When these services are available within the individual's living environment, the autonomy of the community as a whole would be enhanced and reliance on professionals minimised. The role of professionals and other people may be to inform disabled people of all possible resources, and the role of the individual to choose to which he/she wishes to be affiliated.

An important finding of the study was that it was frequently through necessity that the participants began to help themselves. Professionals could perhaps facilitate the start to this process by creating opportunities within the treatment setting whereby the individual was left to his/her own devices and was thereby forced to attempt a task. A precaution to be taken in therapy would also be to guard against overprotecting the disabled person and preventing the taking of risks (a factor which appeared crucial for the development of autonomy).

The study confirmed the appropriateness of the value in O.T. placed on purposeful activity. Participation in work, leisure and social activities would potentially provide opportunities for success and self acceptance, both factors found important for fostering feelings of control. However a disturbing finding of the study was the widespread lack of involvement in the community amongst

the participants. This necessitates the rapid creation of work and social opportunities for disabled people, and the means to participate therein.

Professionals in the community, and specialists in vocational rehabilitation, are in key positions to facilitate the development of the worker role for disabled people. One way to accomplish this within the present economic constraints of South Africa would be the setting up of home-based production units in the informal sector. Ideally these would be small group settings, the contact with others providing both encouragement for the individual to persevere under difficult conditions and a much needed opportunity for socialisation.

There is perhaps also a role for O.T.'s to assist disabled people in making as full use of their free time as possible. Activities which were income generating, no matter how limited in scope, could contribute to feelings of power for indigent disabled people who are thereby able to contribute to the household income as a direct result of their own efforts.

It was noted that ideas to overcome obstacles frequently become apparent only once in the situation. It cannot thus be guaranteed that there will be carry over of learning from the hospital treatment center into the home environment. In order to achieve the above, the professional person should be available when and where the individual's needs become most apparent. This would seem to be through longterm contact with disabled people within their own communities, as demonstrated by the occupational therapy project active in Mitchells Plain.

The unit of self help was considered to be the respondents and their immediate caregivers. It is possible that disabled people are too often treated in isolation; the influence of their main support systems on function would seem to be so substantial that these people should clearly be active participants in the rehabilitation process. It is thus important to prepare the main caregivers so that they know what to expect and how to best deal with the specific needs of the disabled family member. This would include giving attention to the psychological as well as physical care of the individual. Carry over of treatment into the home would then be promoted.

Value was placed on peer role models. Their contribution to rehabilitation should be recognised by professionally trained therapists. A peer counsellor could be available as a team member to be utilised should the newly disabled person choose to do so.

The Church emerged as an important community resource. For disabled people with religious affiliations a religious leader (and the corresponding organisation) could be brought into the rehabilitation process while the individual is in hospital, and in this way be beneficial in providing stability, ongoing assistance and support for the person when he/she negotiates the transition into the community. Volunteers who visited individuals at home could also play a valuable supportive function, decreasing feelings of isolation. Hospital based therapists, when linking disabled people to community services, should thus also consider the Church as a viable option.

If disabled people are to value their own participation (or the use of assistive devices) in basic self care tasks above receiving help, then more practise in treatment would seem necessary to build skill and endurance, and to make the performance thereof more routine. However it should be borne in mind that receiving help is also always an option available to the individual which he/she can choose to utilise and still be seen therefore as autonomous.

It was noted in the study that when respondents had been given choice in treatment about what to participate in (eg verbalising their priorities, giving ideas for designing adaptive equipment), they were more motivated (to carry this out or make use of the device). Perhaps then, starting at a student level, the inclusion of the individual's priorities when planning O.T. treatment could be taught as a fundamental principle guiding the rehabilitation process. In this way a focus in intervention would be developed which is directed by the disabled person's self-perceived needs.

Most importantly, the results of the study pointed to the need for an integrated approach to disability which gives attention to the individual as well as the social context in which he/she lives. Occupational therapy from its conception has striven to take an holistic approach to treatment by examining the physical, psychological and social needs of the individual. A team approach to all

rehabilitation would ultimately be the most beneficial, whereby various professionals could contribute their expertise leading to the formulation of a comprehensive treatment programme. In accordance with the preceding paragraph, people with disabilities would be the key players in this team.

This study has highlighted important factors influencing independence for disabled people. By examining what they are doing to manage their lives and listening to their perspectives, valuable insights into the reality of life as a disabled person have been gained. To adapt to the disability, positively appraise the situation and to strive towards greater autonomy in spite of numerous presenting obstacles is no easy accomplishment. Perhaps overriding all other factors is the tremendous amount of perseverance and determination needed on the part of the individual. As one participant was told in response to the various situations in which he placed himself:

"You've got more guts than brains".

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APPENDICES

- A: Preparing the subjects for the fieldwork:
Information shared with participants**
- B: Personal details sheet**
- C: Interview guide**
- D: Mitchells Plain**

**APPENDIX A: PREPARING THE SUBJECTS FOR THE FIELDWORK:
INFORMATION SHARED WITH PARTICIPANTS**

1. Where to be held:

- most likely within disabled person's home
- any venue convenient to the participant

2. With whom:

- disabled person who meets sample criteria
- include family if possible

3. Who am I:

- O.T., master's student at U.C.T.
- doing a project, studying disabled people to:
 - * understand what it is like to be disabled
 - * look at what allows the disabled person to be independent
 - * plan further O.T. services to help other disabled people

4. What do I want:

- to spend time observing and talking to disabled people
- 6-8 people who live in Mitchells Plain

5. What do I require from the disabled person (and family):

- to spend time with the individual, observing all the routine everyday events (self-care, work, social activities and leisure). To be where ever that person is and to accompany where ever he/she goes
- to be present for interactions with family and friends eg mealtimes, visiting neighbours, going to church
- all different times of the day; not evenings or night. Also weekends. 1-3x weekly. Times can be jointly agreed upon.

APPENDIX B: PERSONAL DETAILS SHEET

NAME: _____ **AGE:** _____

ADDRESS: _____ **TEL.NO.:** _____

PHYSICAL DISABILITY: _____

DATE OF ONSET: _____

FAMILY: _____

LIVING ARRANGEMENTS: _____

EDUCATION: _____

FURTHER TRAINING: _____

WORK HISTORY: _____

PRESENT OCCUPATION: _____

INCOME: _____

PERSONAL INTERESTS: _____

COMMUNITY PARTICIPATION: _____

APPENDIX C: INTERVIEW GUIDE

1 DISABILITY HISTORY:

- [probe: - changes in lifestyle over time
- changes in function, activity patterns, social relations, attitudes over time
 - what brought about changes?
 - what helped them to cope
 - solutions found to problems, obstacles]

Q: Looking back, from the time you were first injured, returned home, up until now, how has your life changed since you became disabled?

Q: Looking back, tell me how things were when you first returned home:

- has your physical condition changed at all since you were first disabled?
- when you first came home, what could you do for yourself; with what did you need help? And now?
- what were your feelings when you first came home, newly disabled? And now?

Q: Have any good things happened to you since you became disabled? Tell me about them. How did they come about?

- have there been times when you have felt really good about yourself and about your life? What let you/helped you to feel that way?
- have there been times when you have not felt good - particularly sad, upset or negative about yourself and your life? What helps you on those occasions?

Q: Is there anything you have found particularly helpful in learning to live each day with a disability?

2 FUNCTION:

2.1 Use of Time:

Let's talk about how you spend your time:

Q: Tell me about your daily routine.

Q: Where, and doing what, do you spend most of your time? (by choice?)
 - what do you like to do most with your time? (probe why)

Q: What (activities) give you the most enjoyment? (why)
 - are some activities more important to you than others? (which and why)

2.2 Physical Functioning and Personal Care Tasks:

Q: When you first came home from hospital: were you able to use what you learnt in the hospital and apply it in your home life?
 (what used, what did not - why and how)
 (what helped, what hindered)

Q: Do you use the physical ability you have to the maximum?

Personal care:

Q: Are you limited in any way in the type or amount of personal care tasks you can perform?
 - Tell me how you manage (eating, dressing, washing, bladder and bowel care)
 - What helps you to carry out these tasks? (assistance, technology, assistive devices)
 - What limits? (physical, structural, feelings re: unable, unwilling)

if receive assistance:

probe: - from whom, why
 - how feel re: asking for and accepting help
 - is it possible to maintain a degree of privacy?

Mobility:

Q: Tell me about your mobility: (in home, transfers, going out, stairs)
 - are you limited in any way by where you can go:
 - in your home
 - and to leave your home

3 PARTICIPATION IN THE COMMUNITY:

[probe: - sources of information
 - relative importance of various tasks; why
 - any choices involved in execution of daily tasks

- what helps them carry out tasks
- when problems arise: conflict and coping strategies]

3.1 Work:

- Q: - Did you work before you became disabled? Describe job
- Have you worked since becoming disabled? Describe all jobs held
 - Tell me about your present work/studying: what does it involve and how do you manage?
- (how organised, why took part, why stopped, where, when and payment, aspirations for the future)

3.2 Housework:

- Q: How has your disability affected the way household chores are managed in the place where you live ? (shopping for groceries/clothes; washing, cleaning and ironing tasks; preparing meals; outdoor tasks such as gardening)
- (who does what and why - different from before?)
- (participant's contribution; how manages)

3.3 Leisure:

- Q: How has your disability affected the way you spend your time when you are not working/doing household tasks?
- tell me about what you do in your spare/free time?
- (what enjoy doing, any future aspirations - different from before; where, when and how carry out tasks)

3.4 Community Involvement:

- Q: Do you belong to, or have any contact with, any voluntary groups, clubs or organisations (including religion)?
- (why and how joined; importance and meaning to them)

4 SOCIAL ENVIRONMENT:

Lets talk about the important people in your life.

- Q: Have there been certain/any people in your life who have helped you in any way since you have been disabled?
- [probe: - with whom; and how help/hinder

- what they mean to the participant; how NB
- how they have behaved (eg interaction, frequency, reaction to disability)]

Q: Has your disability affected the way people relate to you?

- do people treat you the same as everyone else or differently?

Q: How does your disability affect the contact you have with other people?

(amount of contact, nature thereof, who contacts who)

- How do you feel about the amount of company you have?

4.1 Family life:

Q: Tell me about your family life:

- altered at all since your injury?
- has your disability affected the way they relate to or treat you?
- have your intimate IPRs been affected or altered at all?

[probe: family spend time together, do things together; space and privacy; IPRs pre and post disability; sexual relations]

4.2 Friends:

[probe: - friends, peer group, neighbours

- IPRs pre and post disability: reaction to disability, things do together, old and new friends
- IPRs with members of the opposite sex]

Q: Are there any specific people in your life with whom you feel at ease with and can talk with about what is on your mind?

Q: Have you made any new friends in the last few years, since you became disabled? (who, how met, things do together)

Q: Are you well enough acquainted with families in the neighbourhood that you visit each other in your homes?

5 STRUCTURAL ENVIRONMENT:

5.1 Living Arrangements:

- [probe - set up, structure
 - adaptations to the home
 - presence of others
 - surrounding environment
 - why chose to live here]

Q: With whom are you living?

- how long have you lived here in Mitchells Plain?
- what was important to you in deciding to live here?

Q: Tell me about your home: is there anything special or different about it which helps you

- 1) manage without help or
- 2) do what you want to do?

- since you have become disabled, has the house been altered in any way?

5.2 Physical Environment:

[probe - do they go out; where to; same places as before?

- what has presented as specific obstacles; how overcome
- public attitudes, accessibility
- knowledge, attitudes and use of resources]

Q: Are you able to go where ever you want to? If not, why not

- are you able to leave your home
- tell me about the places you go to

Q: What form of transport do you use most often? (why, how manage, who provides)

Q: Has there been anything about living here in Mitchells Plain that has helped you to

- 1) manage without help or
- 2) do what you want to do?

5.3 Economic Environment:

Q: Has your disability affected your financial situation/money matters?

- where gets money to live on; who handles finances

5.4 Health Services

Q: What services have you used in the past for any medical/health complaint?

- who has visited, or continues to visit you at home to render a social or health service?

[probe: - type of services receive; where; payment

- medical precautions; medication]

Q: Have any health personnel helped you in any way at any stage to manage on your own without help or do what you want to do?

6 FEELINGS AND ADAPTATION:

6.1 Feelings:

Q: How has your disability influenced/affected the way you feel about yourself?

- does having a disability make you feel different about yourself; different from before you were disabled?
- Do you feel you are the same person even though you get older each year?

Q: Do you view yourself as a "disabled" person?

Q: How satisfied do you feel with your life? Why? What helps you to feel that way?

- are there things in your life that you would like to change? And leave the same?

6.2 Adaptation:

Q: Do you look forward to anything special each day?

- are there any reasons why you look forward to the day ahead when you wake up?
- are you impatient to get out of bed?
- when getting on with your life, what frustrates you, what holds you back?

Q: What strengths do you have, inside yourself, that help you to do what you want to?

Q: Have any experiences from before you were disabled helped you to do what you want to, or to manage tasks on your own without help ?

Q: Has your disability had any purpose, or positive meaning in your life?

7 FUTURE:

Q: Is there anything really special you would like to see happen or would like to do in the future?

[probe: - what is NB to participants to achieve or obtain and anything they daydream of
- think it is possible to achieve? why and how]

Q: Have your plans/dreams/goals in any way been influenced by your disability?

[probe - why; in what way
- see possibilities for intimate IPRs, marriage, work]

Q: Do you have any specific concerns or worries about the future?

(why, think it is possible to overcome? why and how)

8 GENERAL - CLOSING:

Q: From your own personal experiences would you give any advice to a disabled person, in a similar position as yours, that you think would help them to do what they wanted to ?

[probe: - when faced with new situations, coping strategies
- when problems arise, conflict and coping strategies]

Q: Is there anything you would like to see happen in the future for disabled people?

Q: As we finish, would you like to make any last comments about life as a disabled person and independent living?

APPENDIX D: MITCHELLS PLAIN

Mitchells Plain is a large, densely populated dormitory town on the Cape Flats, 25 kilometres from the Center of Cape Town. The area was established in 1974 in an attempt to alleviate housing shortages and to allow home ownership amongst the so-called "coloured" community. Originally 40 000 houses were planned to be built in ten years for 250 000 people. Today the population is conservatively estimated at 500 000.

The houses are traditionally three bedroomed, on small plots, and situated close together. There is some variation between the residential areas, which are separated by wide boulevards. For example, Lentegour, Eastridge and Tafelsig are lower socioeconomic, high density regions whereas Westridge and Woodlands are more middle class, lower density areas. The town is built on sand dunes, with very little natural vegetation left. This is evident in the sandy open spaces found amongst the houses. Originally designated as public parks, these places are now mostly barren and scattered with litter.

From early on in Mitchells Plain's growth, community facilities were also planned. Examples include community halls, clinics, schools, sportsfields and libraries which can be found in each of the areas. A large shopping complex, the Town Center, was completed in October 1980 and in October 1991 a second complex was opened. The Town Center, railway station, Day Hospital and small business area are all in close proximity to one another.

Job availability in the area is generally low, and many people commute long distances to work. The informal sector appears to be growing, for example the selling of sweets and other food items or clothing from the home to neighbours. However, unemployment is high and there are related problems such as gang violence, alcohol and drug abuse within the community.

Modes of public transport include the train, bus or taxi. Services are frequently run, the main terminuses being situated at the Town Center shopping complex. Bus and taxi routes include all the main boulevards. The majority of the train stations do not have subways; the train line is crossed via an overhead walkway with stairs on either side.

Public health services comprise a day hospital (with one physiotherapist), six clinics, and Lentegeur Psychiatric Hospital. Community health sisters undertake home visits in the area. A private hospital is situated at the Town Center and there are also numerous general practitioners within the shopping complex itself.

The community occupational therapy project (together with O.T. students from the University of the Western Cape) which is active in the area was started in 1987. This offers a range of services, including a domiciliary home visit service to disabled people of all ages, weekly social groups and a weekly sports group. Presently it also co-ordinates two woodwork home industry groups within the region, which subcontract from a local factory. Disabled people themselves are encouraged to partake in the planning and running of the project.

The findings of this study should be understood within the South African political context. The policy of apartheid, which existed in the country for decades and which was only recently abolished in 1991, resulted in grossly inferior facilities being available for all persons not classified as white. This can be said of the facilities available to the participants living within Mitchells Plain; they reside in a potentially disadvantaged community.

ADDENDUM

The following comments have been made in response to the examiners' reports. The author has sought to address issues raised by one examiner in particular which have appeared to warrant further clarification.

The examiner remarked that the thesis confirmed findings of other studies and thereby allowed them to be applied to local communities. It was stated that: "Additional factors that influence the adjustment to disability and the development of independence in these communities were identified".

The author had also noted that there was strong agreement between the literature and the present study, thereby placing the factors into a South African context (see p 152 and p 184). However where the author's work differed most from previous studies was the importance placed on the psychological implications to physical disability. Additional factors found to influence the achievement of autonomy related to the personal adjustments individuals needed to make in order for independence to be promoted (see section 4.4, pp 68-97). These factors were not dependent on, or determined to any great extent by, the community in which he/she lived. Rather, individual characteristics (eg personality traits, motivation, coping mechanisms) fundamentally influenced how the person responded to external (environmental) influences. These additional factors could therefore be understood to be universally applicable and potential influences of independence for disabled people.

Another point raised by the same examiner was the positive attitude which was apparent among the study participants. It was queried whether this was different to other studies, and whether living in a community like Mitchells Plain was "an advantage for disabled people".

There would seem to be two main factors which assist in making Mitchells Plain appear as an advantageous living environment for disabled people. The presence of the occupational therapy project in the area provided work and a social outlet for many of the study participants. Such services are not well established in other communities. Perhaps in this respect disabled people in Mitchells Plain are better off than others who do not have such easy access to similar projects. Family members who are available to provide support or assistance as and when needed could also be seen as an advantage.

Other disabled people, living in areas where it is less common for family members to live together or in the near vicinity, would not be able to call upon this resource. The participants seemed to view the role which their families fulfilled in fostering independence positively. However, this has been questioned by the author. It was felt that the subjects, through lack of access to other resources, were forced to rely on relatives for help and in this way their autonomy was denied. It is possible that if other options such as hiring an attendant had been available some participants would have chosen not to be assisted by their families.

The author wishes to emphasise that in an environment in which unemployment is high and there are few work opportunities, where most disabled people receive disability grants and are thus potentially indigent, where lack of suitable public transport hinders social outings, and where social isolation is common (see section 4.7, pp 131-143), there can be little advantage for disabled people. Rather, the participants' attitude which was perceived as positive was thought firstly to reflect the purpose of the research. This focused on enhancing independence and not constraining influences or problems experienced. Furthermore the positive attitude which was apparent may have been due to the need felt by subjects to make the most of their existing situation. As discussed in the study (see pp 157-158) it suggests that the individuals were adjusting to their circumstances, and perhaps accomodating to it by expecting less from the environment. This view is supported by literature where other studies have found high levels of satisfaction amongst disabled people despite low levels of social integration (Green et al., 1984; Decker and Schultz, 1985; Yerxa and Baum, 1986). Existing theories have also explained the concept of learned helplessness whereby individuals resign themselves to their situations in order to cope as best they can (Kirchman, 1986).