An Evaluation of Rehabilitation in the Home: Client, carer and staff perspectives.

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List of abbreviations

Abbreviation	**Meaning**
ADL	Activities of daily living
AFRMVB	Australian Faculty of Rehabilitation Medicine, Victorian Branch
AHA	Allied health assistant
AMA	Australian Medical Association
APA	Australian Physiotherapy Association
BHS	Ballarat Health Services
BHS-QEC	Ballarat Health Services Queen Elizabeth Centre
CAOT	Canadian Association of Occupational Therapists
CCGS	Client-centred goal setting
COPM	Canadian Occupational Performance Measure
CRC	Community Rehabilitation Centre
CSI	Caregiver Strain Index
CSS	Client Satisfaction Survey
DH&CS	Department of Health and Community Services, Victoria
DHS	Department of Human Services, Victoria
DNHW	Department of Health and Welfare, Canada
FIM	Functional Independence Measure
GEM	Geriatric Evaluation and Management
GHQ	General Health Questionnaire
GP	General medical practitioner
HACC	Home and Community Care
HAH	Hospital at home
ICIDH	International Classification of Impairments, Disabilities and Handicaps
LOS	Length of stay
MA	Master of Arts
NOF	Neck of femur
OT	Occupational therapist
PT	Physiotherapist
QE	Queen Elizabeth Centre
RHP	Rehabilitation in the Home Program
SIP	Sickness Impact Profile
SP	Speech pathologist
THR	Total hip replacement
TKR	Total knee replacement
UR	Unique registration
WFOT	World Federation of Occupational Therapists
WHO	World Health Organisation

Declaration

This thesis contains no material that has been accepted for any other degree in any other university. To the best of my knowledge and belief, this thesis contains no material previously published or written by any other person, except where due reference is given in the text.

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Abstract

This study is a process evaluation of the Ballarat Health Services Rehabilitation in the Home Program (RHP). The research to date on home-based rehabilitation has found that it is generally as effective as hospital-based rehabilitation and that there is a potential for cost containment through reducing the client's length of stay in hospital. There has been little research to date, however, that focuses on the experiences of the direct participants. Both qualitative and quantitative methods are used in this study to evaluate the program from the point of view of the clients, carers and staff participating in the program.

The client centred model of rehabilitation on which the program is based promotes active client and family participation in the rehabilitation process. This model is part of the health care paradigm shift from the biomedical approach to a holistic approach which focuses on the client as a whole person interacting with his or her social, emotional and physical environment. Moreover, the model of practice provides a critical alternative to the biomedical model. The study design seeks to empower clients and their families by actively involving them in the evaluation of the RHP and in making recommendations for change.

This study draws from and builds on a critical theoretical approach and aspects of symbolic interactionism. Both theories inform the choice of methodology and the interpretation of the study findings.

The three groups surveyed in this study expressed different views on the RHP. Clients and carers seemed happy with the program particularly with the program staff and being able to be at home. They reported high levels of satisfaction with the program. Carers did not find that having the client at home increased their stress levels. In fact, for some, having the family member at home made life easier. Staff were more critical of the RHP as it increased their workload and decreased their professional control.

These findings have implications for the model of practice. There is a need to develop a model that includes the client and carer as active participants and operates in the client's own home. However, staff require adequate resources and appropriate education and training to feel comfortable with the degree of client control that client-centred rehabilitation practice entails. There are also broader implications for rehabilitation in Victoria. As there has been a rapid increase in the development of home-based rehabilitation in the three years since this study began, there is an opportunity for research to be undertaken into the social and financial impact on carers, client satisfaction and the further development of practice models. A critical approach is recommended as there is a danger that home-based rehabilitation will be developed for economic rather than humanitarian reasons.

Chapter One

Introduction

1.1 Introduction

Home-based rehabilitation is a relatively new concept in Victoria, Australia; the first program was established by the North-West Hospital at its Greenvale Campus in May, 1995 (Butler and Charlton, 1998). There are many unanswered questions about the effectiveness and cost of home-based rehabilitation and about the impact that it has on clients, carers and staff (Lafferty, 1996). This study presents an evaluation of a pilot Rehabilitation in the Home Program (RHP) that was established by Ballarat Health Services Queen Elizabeth Centre (BHS-QEC) in 1996. Ballarat is a regional city in Victoria, Australia, situated approximately 100 kilometres from Melbourne with a population of approximately 80,000.

This study was undertaken because the RHP was initially funded for only 12 months and it was necessary to evaluate the program in terms of its effectiveness and acceptability to clients to decide whether it should be continued. In addition, there was a strong culture of quality improvement at BHS-QEC (Bauer, 1996) which meant that every employee with program responsibilities was expected to engage in continuous quality improvement. Finally, after this study was well underway, the Department of Human Services, Victoria (DHS) requested BHS-QEC involvement in the Continuum of Care funding pilot that required evaluation of the clients' experience of home-based services.

The author of this study was employed in January, 1996 to establish the RHP and to conduct an evaluation of its effectiveness. As she had had only limited experience in program evaluation, she decided to undertake a Master of Arts (MA) in Sociology to assist her to develop the skills necessary to undertake the research. The research then became directed by the requirements of the MA as well as the demands of the workplace. As discussed in the final chapter, the author found the needs of the workplace and the university to be in conflict at times, so this thesis was written principally with the requirements of the degree rather than the workplace in mind.

In this chapter the economic, political and policy background and the philosophical context for the development of the RHP has been described, the need for and potential implications of evaluative research have been discussed, and the aims and objectives of this study have been outlined. The organisation of the thesis has been described and finally, the major terms used in this study have been defined.

1.2 Background

There has been a trend recently in many countries towards the development of community-based alternatives to hospital care. Whilst care in the community is not new, the development of acute, post-acute and rehabilitation services which replace hospital-based care is a relatively new phenomenon in health care. The main group to use these services are older people (Philp, 1996).

Philp (1996) identified a number of potential benefits from these types of services. First, older people feel empowered when decisions are made in their own homes. Further, this autonomy is more important to them than risk. Second, hospitals are not always beneficial for older people. There are risks of iatrogenic illness and exacerbation of confusional states. Third, home is an appropriate place for rehabilitation and there is a potential in home-based service delivery for the development of new models of multidisciplinary teamwork. Finally, savings arise from avoiding the hotel costs of hospital care, for example, catering and domestic services.

The RHP is an example of this type of service delivery. The RHP was established in the context of a world-wide trend towards home-based care which had been taken up in Australia in the 1990s with the development of hospital in the home (Clayton, 1995) and home-based rehabilitation initiatives (see Bairstow, Ashe, Heavens and Lithgo, 1997 for example). Although it has many potential benefits, there has been little research to date into the efficacy of this approach, particularly the impact it has on clients and carers

(Clayton, 1995; and Lafferty, 1996). This study aims to address the need for research into the experiences of participants by conducting an evaluation of the pilot home-based rehabilitation program at BHS-QEC, focusing on the perspectives of clients, carers and staff.

1.2.1 Political, economic and policy context

Since 1984, when the Commonwealth Government's Home and Community Care (HACC) program was initiated in Australia, there has been a shift in the provision of services for older people from institutional settings to home and community settings (Clayton, 1995; McCallum and Geiselhart, 1996; and Clutterbuck, 1997). At the same time, advances in technology and methods of care have meant that health care services that had previously been restricted to hospitals could now be provided in peoples' homes (Clayton, 1995; and McCallum and Geiselhart, 1996). In addition, an increasingly political aged care movement has demanded that older people should be able to remain in their own homes as long as possible (Clayton, 1995; and McCallum and Geiselhart, 1996).

Because of the need for cost containment in a rapidly growing aged population (Clutterbuck, 1997), there was increased emphasis on finding efficient ways to use limited resources, including effective coordination and integration of services (Metropolitan Hospitals' Planning Board Phase 2 Report, 1995; McCallum, Simons, Simons, Sadler and Wilson, 1995; McCallum and Geiselhart, 1996; and Clutterbuck, 1997). This was consistent with economic rationalism, the overall Federal and State Coalition Government philosophy that favors small government and a small public sector (Gleeson, 1996).

The contraction of nursing home services illustrates this trend towards community-based care together with a reduction in government expenditure. In 1985 Victoria had 53 nursing home beds per 1,000 persons aged 70 and over. In 1996 this had reduced to 45 (Clutterbuck, 1997). At an average cost per place per annum of $26,793 in 1996, this represented a considerable saving. Although there has been some concurrent increase in community and home-based care, the decrease in funding for nursing home beds has not been translated into an equal increase in funding for community services (Clutterbuck, 1997). As well as reducing nursing home beds, the Federal Coalition Government introduced the principle of "user pays" into nursing homes and HACC services. In July 1997, the Federal Coalition Government planned to reduce the cost to the state of nursing home care through the levying of accommodation bonds and resident contributions in nursing homes (Clutterbuck, 1997). It had also been suggested that a "user pays" system will soon be introduced into community-based aged care services that are HACC funded[1].

Moving hospital-based services into the home provides scope for reduction or containment of government spending in health care (Portnow, Kline, Daly, Peltier, Chin and Miller, 1991; and Philp, 1996). It has been predicted that, *"in a few years the number of hospitals will be halved as will patient's length of stay"* (Picone, 1993 in Clayton, 1995, p299). Although there are aspects of these policy directions that meet the demands of consumer groups, the author believes there is a danger of economic considerations taking precedence over humanitarian ones. Philp (1996, p196) *warned "community care could become community neglect".* It could be *"politically easier for hard-pressed funding bodies to close community rehabilitation teams than to close hospitals".* This, Philp argued, would push disabled older persons into nursing homes or force their families to care for them. Either way the patient and family would pay.

In 1996, when the RHP was established, there was no specific Victorian Government policy relating to home-based rehabilitation. The impetus for the development of these programs was probably a combination of their potential cost effectiveness compared with inpatient rehabilitation (Farnworth, Kenny and Shiel, 1994; and O'Cathain, 1994) and the Victorian Government's overall policy of providing more health services in the home (Health and Community Services Victoria, 1993).

In 1996, the most recent Victorian Government aged care policy document included the principles of customer focus, continuity of care, integrated and coordinated service

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[1] As of August 1998, all HACC funded services were required to collect a fee for service on a means-tested basis from their clients.

delivery and the maintenance of older people in their own homes for as long as possible (Health and Community Services Victoria, 1993). Alternative ways of providing acute care services were being explored to achieve greater efficiency as well as ways of improving customer focus and continuity of care (Clayton, 1995).

The RHP was established in a policy context that seemed to meet everyone's needs: the needs of consumers for a customer-focussed service that enabled them to be at home rather than in hospital; and the needs of funding bodies for a more economical way to provide healthcare. However, there was a potential for conflict should the government wish to contain the cost of health services.

1.2.2 Organisational context

The RHP was initiated as a result of a proposal submitted to the Ballarat Health Services Queen Elizabeth Centre's (BHS-QEC) main funding body, the then Department of Health and Community Services (DH&CS), now the Department of Human Services, Victoria (DHS). The proposal was prepared by the Manager of Rehabilitation Services at BHS-QEC. The background to the submission was that BHS-QEC had failed to meet its target of "bed days"[2] for the previous year. As BHS-QEC Rehabilitation Services were funded on the basis of bed days, this meant that a significant proportion of funding was to be lost (approximately $250,000). The DH&CS, through the Manager of the Aged Services Division, offered to continue to fund BHS-QEC Rehabilitation Services at the same level as the previous financial year if they would establish a home rehabilitation program.

During the course of this study, BHS-QEC was invited by DHS Aged Care Division to be included in the pilot of a funding model called the Continuum of Care Model. This model provided block, rather than bed-day funding, to the participating hospitals so that they could provide the service mix that was required by their rehabilitation and Geriatric Evaluation and Management (GEM) clients in the most appropriate setting. The aim of

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[2] Bed days refers to the number of days per year that the BHS-QEC's rehabilitation ward beds were occupied.

the pilot was to encourage continuity of care by *"a funding model which does not provide either incentives or disincentives for care in a particular setting or location, but allows clinicians, service providers and patients to select the most appropriate setting to meet the patient's needs"* (Calder, Robinson, Walker, Street and Dow, 1998, p6). For BHS-QEC, this did not mean any additional funding but it secured the same level of funding as 100% occupancy of bed days would have, without having to meet the bed day targets for the duration of the pilot. At BHS-QEC, the pilot was mainly conducted in Rehabilitation Services, rather than GEM. The RHP was the primary focus in evaluating the effectiveness of the funding model. Thus, the RHP was established with no additional funding. This meant that the resources to run the program had to come from within Rehabilitation Services' existing staffing profile and budget.

The issue of cost containment was ever present in the minds of the management and staff of the RHP. For example, because of economic considerations the length of stay (LOS) on the RHP had to be restricted to less than or equal to the LOS for someone with a similar condition in hospital. Although this was sometimes varied due to client need, restriction of LOS was always a team concern. As mentioned above, the RHP was intended to cost less than a hospital alternative, not more.

The BHS-QEC was an extended care facility that provided a range of services to older and disabled people living in Ballarat and the Grampians Region in Victoria. It was originally established as the Ballarat Benevolent and Visiting Society in 1857 (The Queen Elizabeth Geriatric Centre, 1982 Annual Report). Although it changed its name to the Queen Elizabeth Home in 1956, some people in the community still refer to it as "the benev". The "QE", as it is most commonly now called, has two hospital wards, one for rehabilitation and one for Geriatric Assessment and Management (GEM). Apart from these wards, on site there are nursing home and hostel facilities, a rehabilitation outpatient clinic and various medical clinics.

During the course of this study the QE merged with the Ballarat Base Hospital and Grampians Psychiatric Services to become Ballarat Health Services. The predominant model of practice at the QE was a biomedical one. The organisational structure consisted of a Medical Director, a Director of Nursing, a Manager of Rehabilitation Services and Financial and Human Resource Management. Because the Manager of Rehabilitation

Services was not a medical practitioner, all clinical staff were responsible through their discipline seniors to the Medical Director for their clinical practice, and were administratively accountable to the Manager of Rehabilitation Services. The author believes that this dual responsibility at times led to conflicts between staff. Further, since the merger in 1997, the biomedical dominance has become more pronounced. The Manager of Rehabilitation Services was not included initially in the new Executive Committee, which was made up of medical, nursing and management specialists.

It is interesting to note that in the 140-year history of the QE, this biomedical focus is of relatively recent origin. Prior to World War II, the Ballarat Benevolent Home functioned more as a charitable institution than a hospital. Further, the organisation originated as a home-based service. As the author of a report on its 125th birthday noted: *"Perhaps the most remarkable feature of this one and a quarter centuries has been the pendulum swing from home care only in 1857 to predominately institutional care until 1956 and then back in the direction of home care"* (The Queen Elizabeth Geriatric Centre Annual Report, 1982).

During the course of this study the BHS-QEC campus has undergone a major physical transformation. The nursing home patients were previously accommodated in a three-story building from which evacuation due to fire would have proven difficult. Furthermore, many residents were unable to go or even look outside. The new nursing home facilities are all single story and have been designed to enable privacy for the residents, to encourage family involvement and to promote outdoor and community access. The rehabilitation ward has also been rebuilt and will be integrated physically with the outpatient and community-based services to further enhance continuity of care. Thus, the environment within which this study was conducted was in a state of organisational and physical change, some of which enhanced the establishment of the RHP and some which exacerbated the existing conflicts.

1.2.3 Therapeutic and practical considerations

There were a number of considerations that were important in the development of home-based rehabilitation at BHS-QEC apart from the political and economic issues discussed above. The first was that the policy directions coincided with professional beliefs, particularly among occupational therapists (Head and Patterson, 1997) and physiotherapists (Meeds and Pryor, 1990), that the home was the best place to conduct rehabilitation. These have been outlined below and will be discussed in more detail in Section 2 of Chapter 3. The second was the move towards a client focus that seemed to sit better with home-based than hospital-based care. The third were practical considerations, such as travel, which were important for older people's access to health services. Finally, the impact upon carers of having someone at home who was in need of hospital-level rehabilitation was considered to be an important aspect of home-based rehabilitation.

The establishment of a home-based rehabilitation program at BHS-QEC was not just economically driven. The Manager of Rehabilitation Services had for some time believed that the home with family support was the best place for people to participate in rehabilitation once they could be safely discharged from hospital (Bauer, 1998). This belief was shared by many people in the rehabilitation field (McGrath and Davis, 1992; Philp, 1996; and Head and Patterson, 1997). Clients are happier and more motivated at home (Head and Patterson, 1997) and it is sensible to practice rehabilitation activities in the environment in which they are to be used (Meeds and Pryor, 1990) with the steps, shower or kitchen utensils that are familiar to the client.

The potential for client and family participation seems to be greater at home because moving services into the home increases the involvement of customers in their own health care (Clayton, 1995; and Philp, 1996). In hospital some clients are inclined to lose their identity and become more passive and compliant (Funnel, 1997). Meeds and Pryor (1990, p77) argued that *"the hospital environment tends to discourage independent thought or action in any patient, especially the elderly"*. In rehabilitation the full and active participation of the client, and family if possible, is vital for the successful resumption of life roles (Bauer, 1989). A program in the home and focussed on the client's own goals encourages their active participation in the rehabilitation process (Bauer, 1998; McGrath and Davis, 1992; and Gladman, Foster and Young, 1995).

Travel is often difficult for someone who requires rehabilitation due to a stroke or major surgery. Although clients do not have to travel far to the rehabilitation centre whilst in hospital at BHS-QEC, their relatives and friends have to travel to visit them and participate in their rehabilitation. This is often a real problem for elderly relatives (Forster and Young, 1990) which can be eliminated with home-based rehabilitation. However, travel may significantly impact upon the workloads of staff. Brent (1988, in Butler and Charlton, 1998) found that community physiotherapists spent a considerable amount (up to 8%) of their time on travel.

There are other practical advantages for clients and their carers with home-based rehabilitation. The home environment is very different from hospital. For example, hospitals have bathrooms already fitted with rails and other safety features but at home bathrooms are rarely equipped for people with disabilities. With rehabilitation at home the client is assisted to make the transition from the protected hospital environment to home. The home environment can be adapted, for example, in the bathroom, rails, a bath board and a hand-held shower may be installed. Community support services can be coordinated (Forster and Young, 1990) and the client can practise activities at home under the supervision of therapy staff to ensure their safety after discharge from hospital (Meeds and Pryor, 1990).

Already, there is considerable reliance on carers for the provision of health care and support to the elderly. In 1992, *"the estimated value of informal care provided by volunteers to frail and disabled adults in the household was $3.4 billion"* (Clutterbuck, 1997, p7). The move from hospital to home-based rehabilitation could potentially increase the burden of care experienced by carers. If the program truly replaces inpatient level rehabilitation, then the client will be sent home before he or she has reached a level of independence that was previously considered necessary for discharge. It is likely then that there will be increased reliance on the carer for help in activities of daily living and in rehabilitation tasks. This may also have benefits for carers in that they will be more aware of what the client is capable of and how to assist in their rehabilitation (Forster and Young, 1990) and they will not have to visit them in hospital.

1.3 Significance

This section discusses in broad terms the areas in which research needs to be undertaken and the potential significance of the findings.

1.3.1 Potential benefits of this study

The results of this study should provide an insight into the experiences of clients, carers and staff participating in a home-based rehabilitation program. Their reflections on issues of client focus, participation and control, on travel and on the benefits or otherwise of the home environment will help to determine whether home-based rehabilitation is a feasible mode of health service delivery. The results should also shed some light on the issue of carer strain and whether home-based rehabilitation is too much of a burden for carers.

Further, the study results will indicate those aspects of the model of practice that are perceived as important, positive or negative by the program participants. The findings will be significant in determining whether the RHP should continue to operate and how the model of practice should be adapted in the future. Other home-based rehabilitation programs will be able to use the findings to help them decide upon the model of practice they wish to adopt. A critique of this study's design and methodology should assist other home-based rehabilitation programs in designing their approaches to evaluation.

The author believes that evaluation of home-based rehabilitation from the perspective of the direct participants is very important because the combination of political, economic and social forces that have led to its development are very powerful. As discussed above, the shift from hospital to home-based services has been supported by government policy, the impact of economic constraints, consumer groups and professional beliefs about the best place for health service delivery. There is still little information about the impact of home-based care on the direct participants. This study will explore the perspectives of these groups in one home-based rehabilitation program. The findings of this study will contribute to the discussion and debate about the desirability of home-based care and whether this direction for health care services is a positive one for clients, carers and staff.

1.3.2 The need for evaluative research

Clayton (1995, p299), in her review of the studies published relating to Hospital in the Home and early discharge rehabilitation programs argued that:

> *without exception, the studies published have focused on experimental and/or quantitative aspects of morbidity and resource utilisation; in other words the focus has been on economics rather than customer satisfaction... be they (the customers) providers (health care workers) or users (patients and their carers).*

Clayton argued that other issues needed to be investigated, such as *"continuity of care, the needs of carers, health service integration and the perceived need for cultural changes (away from the conventional medical model) associated with the implementation of Hospital at Home services."*

Lafferty (1996), also undertook a review of the world-wide literature on home-based rehabilitation and concluded that further research into community based alternatives to hospital rehabilitation was required before a comprehensive shift of care into the community was undertaken. Lafferty argued that the areas that needed to be studied were the risk to the patients, the cost of these services, the models of care and the acceptability of the services to patients and carers.

The focus of this study was on the experience of the direct participants, the clients, carers and staff, and the model of practice of home-based rehabilitation. It has addressed some of the issues identified by Clayton (1995), namely customer satisfaction, the experience of carers and some of the cultural issues that emerge from changing the context of care. It also addressed some of Lafferty's (1996) areas of concern. These were evaluation of the model of care and the acceptability of the program to clients and carers. The aims and objectives of the study have been listed below.

1.4 Study goal, aims and objectives

The goal of this study was to conduct a client-focussed evaluation that included the perspectives of carers and staff of the pilot RHP.

1.4.1 Aims

The three aims of this study were to:

- Assess aspects of the effectiveness of the RHP, that is, client satisfaction, carer strain and achievement of the program aims relating to
    - choice
    - community reintegration
    - relevance of rehabilitation and
    - active participation;

- Explore the appropriateness of the model of practice used in the RHP from the points of view of clients, carers and staff; and to

- Adapt the model of practice according to the feedback from clients, carers and staff.

1.4.2 Objectives

In relation to the RHP, this study sought to:

- Measure client satisfaction with the program;

- Assess the effectiveness of the model of practice in relation to client, carer and staff perspectives about the extent to which they were given choices in the rehabilitation program; their active participation in the rehabilitation process; how the program helped to reintegrate clients into their families and communities; and the relevance of the home environment to rehabilitation.

- Identify those aspects of the model of practice that were perceived to be important and positive or negative to clients, carers and staff;
- Determine the effect of the RHP on carer strain;
- Compare client, carer and staff responses to the philosophy of practice; and
- Adapt the model of practice on the basis of feedback from clients and staff.

1.5 Format of the thesis

The thesis has eight chapters which have been briefly outlined below.

Chapter Two, the Literature Review, includes a review of the world-wide literature on home-based rehabilitation and identifies the gaps that this study attempts to address. This review was restricted to those programs that aimed to replace inpatient care with care in the home.

Chapter Three, Theoretical Framework, has been divided into two sections: the first includes a discussion of the major sociological theories which have informed this research and the second outlines the philosophy of rehabilitation that underpins the model of practice in the RHP.

Chapter Four, Program Description, describes the RHP and how the philosophy outlined in Chapter Three was put into practice.

Chapter Five, Methodology, outlines the methodology used in the study and includes a description of the measures, the method of application and analysis and the ethical considerations.

Chapter Six, Results, details the results of the study. Section One concentrates on the results derived from the clients; Section Two on the results of the Caregiver Strain Index (CSI) and the carers comments from the focus group; and Section Three on the experiences of staff.

Chapter Seven, a continuation of reporting of results and discussion, looks at the areas in which the perceptions of the clients, carers and staff concur and differ and the implications of the findings for the model of practice.

Finally, Chapter Eight, Conclusions and Recommendations, presents a brief summary of the findings and some recommendations for the RHP and home-based rehabilitation in general, and discusses the outcomes of this study and their implications for health-care policy in Victoria.

1.6 Definition of terms

1.6.1 Rehabilitation and community integration

The first term that requires definition is 'rehabilitation', a many faceted concept. The New Shorter Oxford English Dictionary (1993, p2531) defined it as, *"the action of restoring something to a previous (proper) condition or status"*. This definition included the concept of a previous status and makes explicit the assumption that this previous state was "proper" or right. Although some people still restrict rehabilitation to conditions where improvement is expected (Wade, 1992), this assumption is no longer commonly part of definitions of rehabilitation. For example, The Australian Faculty of Rehabilitation Medicine, Victorian Branch (AFRMVB) (1997, pV) defined rehabilitation as aiming to:

> *improve function and/or prevent deterioration of function to bring about the highest possible level of independence, physically, psychologically, socially and economically, to maximise quality of*

> *life and to minimise the long-term health care needs and community support needs of these people.*

Bauer (1996, p1)[3] defined rehabilitation as:

> *A continuous process, which ideally starting from the onset of illness or injury comprises all measures to:*
>
> - *prevent undue loss of physical, cognitive, psychological or social function;*
>
> - *assist convalescent clients recover full function and resume their normal way of life without undue delay;*
>
> - *help those for whom permanent disability is unavoidable regain the maximum possible independent function and to be reintegrated into the community adapting to their residual disability.*

In the above definitions there was no assumption of a valued previous state but rather one about the value of independence, the highest possible level of independence being the primary aim. This is a common assumption in rehabilitation. Many of the objective measures of rehabilitation, such as the Functional Independence Measure (FIM) (UDS, 1993) and measures of activities of daily living (ADL), such as the Barthel Index (Wade, 1992), measure the extent to which the person is independent of others before and after the rehabilitation process. Moreover these two latter definitions included re-integration or integration into the community as an essential aspect of rehabilitation and the concept of holism, that is, *"the treatment of the whole person rather than the physical symptoms alone"* (The New Shorter Oxford, 1993, p1248). Both holism and reintegration are important concepts in the definition of rehabilitation used in this study.

Although community reintegration is a term that is often used in rehabilitation, it is rarely defined. Bauer (1996, p1) describes the principle goal of rehabilitation as the *"functional reintegration of the disabled client into the usual living environment and community* *chosen by that person"*. For the purposes of this study, community reintegration has been defined as *the reintegration or integration of someone into their usual physical and social environment and includes the resumption of meaningful life roles, whether social, vocational or recreational.*

Wade (1992, p11) used the International Classification of Impairments, Disabilities and Handicaps (ICIDH) model (World Health Organisation (WHO), 1980), as a basis for his definition of rehabilitation. *"Rehabilitation is a problem-solving and educational process aimed at reducing the disability and handicap experienced by someone as a result of disease, always within the limitations imposed both by available resources and by the underlying disease."*

This definition introduced the idea of resource limitations impacting on the potential for rehabilitation. AFRMVB (1997, p2) also discussed the economic implications of rehabilitation and the aims of rehabilitation which were to:

> - *maximise independence and quality of life for people with a disabling medical condition, and maximise the likelihood that they will remain or become active and productive members of the community; and*
>
> - *minimise the long-term health care needs and community support needs of these people and so bring about considerable cost savings both in acute health care and in long-term social security, community care and supported accommodation.*

Economic considerations are not always made explicit in the way rehabilitation is defined. For example, when decisions have to be made about where limited resources are to be directed, the potential for improvement may become important. The author believes that it is more likely that the client who has obvious potential to improve will receive extensive rehabilitation than the client for whom improvement is unlikely or more difficult to assess. Further, a younger client who has the potential to make an economic

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[3] This definition was adapted from the Hospital and Allied Health Services Advisory Council, Glossary of Health Service Research Terms, 1997.

contribution to society, either in the work-place or through caring for children or elderly relatives, will be given more opportunity to demonstrate their potential for improvement, and therefore their suitability for rehabilitation, than an elderly person who relies on others for support.

AFRMVB (1997, p2) also included a description of the typical rehabilitation service as *"a coordinated program (provided) by a specialist team of health professionals"*.

Each of the above definitions contains important concepts that underpin the way in which rehabilitation has been understood in this study. None, however, make explicit the client-focussed approach to rehabilitation that is the aim of rehabilitation practice in the RHP. For this reason, the author has defined rehabilitation as, *coordinated, client-goal oriented interdisciplinary team interventions aimed at enabling a person to reintegrate into his or her usual community life and to realise his or her fullest physical, psychological, social and vocational potential in line with his or her preferences.* Therefore, this statement will be used to define rehabilitation throughout this thesis.

1.6.2 Continuity of care

Continuity of care is a term used frequently in this study. It refers to the integration of services provided to clients across a sequence or continuum of care and means that each service fits logically and seamlessly into the sequence of services required by the client. Continuity of care is characterised by well-developed communication systems and flexible funding arrangements. Continuity of personnel, that is, the same staff working with the client from one program to another, is also one way in which continuity of care is enhanced (Calder et al., 1998). The continuum of rehabilitation includes the provision of appropriate care from the acute medical or surgical phase where the primary aim is to prevent secondary disability; through the sub-acute or post-acute phase where the aim is to provide assessment of function and a goal oriented program which re-establishes the client in the community; to the work and recreational phase in which the client resumes all their life roles (ARFMVB, 1997). In this study, rehabilitation was confined mainly to the second and third phases outlined above (that is, those interventions that aim to re-establish the client in the community and resume their life roles), but continuity of care at all stages was one of the aims of the RHP.

1.7 Summary

Rehabilitation can be understood as a process that involves the intervention of a multi-disciplinary team in the life of a person who has undergone a traumatic event. It takes place within a complex service system, in a context of government, health service, professional and client interest groups in institutional and home settings. This study looked at one part of this system, a pilot home-based rehabilitation program, from the perspective of some of the people involved: the clients, carers and staff. As home-based health service delivery seemed to have considerable momentum in the late 1990s, this study is significant in informing the development of other programs and government policy in this country and elsewhere.

The next chapter reviews the literature on home-based rehabilitation summarising the current knowledge in the field and identifying research gaps.

Chapter Two

Literature Review

2.1 Introduction

This review encompasses three major areas that are pertinent to this study. These are: an overview of the world-wide literature on home-based rehabilitation programs since 1980; a critique of the research methodologies; and a discussion of the implications that the research to date has for this study.

The literature on home-based rehabilitation can be divided into three main groups (Lafferty, 1996). The first includes programs that have been established as an addition to an existing health service system. An example of this is a home-based rehabilitation program for patients recovering from acute myocardial infarction (Linden, 1995). The second group includes programs that replace hospital-based outpatient or community rehabilitation services with a home- based alternative (Young and Foster, 1992; Gladman and Lincoln, 1994; Gladman, Whynes and Lincoln, 1994; and Gladman et al, 1995). The third group includes programs that have been established as an alternative to hospital-based inpatient rehabilitation. In these programs clients are discharged early from hospital and participate in an intensive rehabilitation program provided in their own home. As the RHP fits into this latter category, this review will focus on the third group of studies.

2.2 History

The first home-based rehabilitation program in the literature reviewed here was established by the Department of Orthopaedic Surgery at the University Hospital of Lund, Sweden (Ceder, Thorngren and Wallden, 1980). In this program, hospital staff worked with the local community care centre staff who were involved in patient care pre-and post-admission to hospital for hip surgery. Key features of this program were coordination of care and discharge planning by a social worker and specialist physiotherapy treatment in the home. Even at this early stage in the development of home-based rehabilitation, the patients' goals, motivation and social situation were considered crucial to their successful rehabilitation at home (Ceder et al, 1980).

After the Swedish study there is a gap of ten years until the early 1990s when a large number of studies were published about home- based rehabilitation (Brown, 1990; Meeds and Pryor, 1990; Portnow et al., 1991; Möller, Goldie and Jonsson, 1992; Colbourne, 1993; Currie, Tierney, Closs and Fairtlough, 1994; Farnworth et al, 1994; O'Cathain, 1994; Widén Holmqvist, de Pedro Cuesta, Holm, and Kostulas (1995); Widén Holmqvist, de Pedro Cuesta, Möller, Holm, and Sidén., 1996; and Bairstow, Ashe, Heavens and Lithgo,1997).

The rapid development of these programs seemed to be due to the increasing demand for rehabilitation and the potential cost effectiveness of providing hospital care in the home, together with an awareness that it was possible and preferable to provide inpatient level rehabilitation in the home (Portnow et al, 1991; and Farnworth et al, 1994). A growing number of older people with neurological and orthopaedic conditions in the populations of the world has put increasing pressure on hospital-based rehabilitation programs (Portnow et al, 1991; Currie et al, 1994; Farnworth et al, 1994; and Widen Holmqvist et al, 1996). Hospital-based care has been associated with iatrogenic illnesses, that is, illnesses such as pressure sores that are associated with being in hospital (Portnow et al, 1991; and Philp, 1996). These factors, together with the generally positive findings of the research into home-based rehabilitation, outlined under 2.4.4 below, have meant that home-based care has been seen as a viable alternative to hospital-based care.

Four of the ten programs established at this time were developed in Australia (Brown, 1990; Colbourne, 1993; Farnworth et al 1994; and Bairstow et al, 1997). The other programs were developed in Sweden (Ceder et al, 1980; Möller et al, 1992; Widen Homqvist et al, 1995; and 1996), the United States of America (Portnow et al, 1991) and the United Kingdom (Meeds and Pryor, 1990; Currie et al, 1994; and O'Cathain, 1994).

2.3 Description of programs

This review considered 13 studies undertaken between 1980 and 1997: Ceder et al, 1980; Meeds and Pryor, 1990; Brown 1990; Portnow et al, 1991; Möller et al, 1992; Colbourne, 1993; Currie et al, 1994; O'Cathain, 1994; Farnworth et al, 1994; Widén Holmqvist et al, 1995; Widén Holmqvist et al, 1996; and Bairstow et al, 1997. The following section outlines and discusses the key features of the 11 programs described in these studies. The studies have been summarised in Appendix A.

2.3.1 Continuity of care

In seven of the programs reviewed there was continuity of care from hospital to home. This means that some or all of the same staff who treated the patient in hospital continued to work with the patient after discharge from hospital (Ceder et al, 1980; Brown, 1990; Meeds and Pryor, 1990; Colbourne, 1993; Farnworth et al, 1994; O'Cathain, 1994 and Widén Holmqvist et al, 1995 and 1996). There was a subgroup of five programs where continuity of care was maintained from before admission to the acute hospital until discharge from the home-based rehabilitation program (Ceder et al, 1980; Brown, 1990; Meeds and Pryor, 1990; Colbourne, 1993; and Farnworth et al, 1994).

2.3.2 Diagnostic groups and age

The ability to provide continuity of care was related to the diagnostic condition of the target population. In the studies mentioned above, where continuity was maintained from pre-admission to post-discharge, the programs were designed specifically for people who had suffered a fractured neck of femur. As the patient usually has some prior warning of the need for surgery with this condition, it is possible for the treating team to visit prior to hospitalisation to provide education and support to the patient and family and to commence discharge planning.

There was another group of studies that provided rehabilitation primarily to people who had suffered a stroke or other neurological condition (Widên Holmqvist et al, 1995 and 1996; and Bairstow et al, 1997). The Widen Holmqvist et al study (1995) identified continuity of care, in time and personnel, to be one of the most important factors in successful home rehabilitation.

The remaining studies involved people with a range of diagnostic conditions (Portnow et al, 1991; and Colbourne, 1993) or with orthopaedic conditions including fractured neck of femur (Ceder et al, 1980; Möller et al, 1992; Currie, et al, 1994; and O'Cathain, 1994). The diagnostic condition of the patients did not seem to impact on suitability for early discharge or on the results of the outcome measures.

Most of the programs reviewed were concerned with an older population. The mean age of patients ranged from 65.8 years (Bairstow et al, 1997) to 78.9 years (Brown, 1990).

2.3.3 Multi-disciplinary team

All of the studies reviewed adopted a cooperative, multi-disciplinary team approach to rehabilitation. Generally an occupational therapist visited the patient's home prior to discharge to ensure that the environment was safe, to advise on modifications and order equipment required (Brown, 1990; Meeds and Pryor, 1990; Portnow et al, 1991; Colbourne, 1993; and Bairstow et al, 1997). The physiotherapist would provide the bulk of the home therapy for orthopaedic patients (Ceder et al, 1980; Meeds and Pryor, 1990; and Colbourne, 1993) but speech therapists and other disciplines were involved more with neurological patients (Widên Holmqvist et al 1995; and 1996; and Bairstow et al, 1997). The programs differed in the extent to which nurses were involved, some providing daily nursing care (Meeds and Pryor, 1990; Portnow et al, 1991; Colbourne, 1993; and O'Cathain, 1994) and some providing no nursing care (Bairstow et al, 1997).

The rationale for the provision of nursing care was not explored in any of the studies. As nursing is a major component of hospital-based care, the provision of nursing in a home-based alternative is likely to be significant in determining whether early discharge is possible. It is argued here that the cost and need for nursing care in home-based rehabilitation could be usefully explored in future studies, however, these areas are beyond the scope of this study.

2.3.4 Care coordination

Care coordination or case management was often mentioned as an important aspect of the home rehabilitation programs (Ceder et al, 1980; Brown, 1990; Meeds and Pryor, 1990; Portnow et al, 1991; Colbourne, 1993; Widén Holmqvist et al, 1995; and Bairstow et al, 1997). The role of coordinator was taken up by a single discipline: the medical practitioner (Portnow et al, 1991), the physiotherapist (Meeds and Pryor, 1990), the social worker (Ceder et al, 1980), the program coordinator (Brown, 1990) or the most appropriate team member, (Colbourne, 1993; Widén Holmqvist et al, 1995; and Bairstow et al, 1997). The care coordinator's role in the these programs was similar and included the following tasks:

- to make the initial contact with the patient and family;
- to provide ongoing education and information to the client and family;
- to liaise between the team, the client, community services, medical practitioners and the hospital;
- to provide a coordination role in discharge planning and;
- to follow up the patient post discharge.

Apart from Portnow et al (1991), none of the studies reviewed explored the experience of the staff involved in the program. This study described the medical practitioner in the care coordination role, a designation that seemed to be generally accepted by the staff team. As the role of care coordinator was taken up by a range of different disciplines in the studies reviewed, it would be useful to explore their understanding and experiences of this role. Through the staff focus group conducted in this study, staff were given the opportunity to discuss care coordination and any other issues that were of significance to them in their work in the RHP.

2.3.5 Client goal setting

In most of the home-based rehabilitation programs the treatment was based on the client's own goals (Meeds and Pryor, 1990; Portnow et al, 1991; Widén Holmqvist et al, 1995; and Bairstow et al, 1997). This represents a shift away from the traditional approach to rehabilitation where the goals were set by the professional staff team. These team-generated goals were often based on those activities that the patient needed to be able to achieve in order to be safely discharged home, see McGrath and Davis (1992) for a critique of this approach. Client goal setting is seen as a fundamental part of the client-focussed approach to rehabilitation practised in the RHP and will be discussed in more detail in Chapter Four.

2.3.6 Approach to rehabilitation

Most of the studies failed to identify a theoretical framework on which to base both their approach to rehabilitation and the study design. The only framework identified was the "Stockholm Model". This Model included the following goals: *"1) increased freedom of choice for patients; 2) improved quality, continuity, accessibility and productivity of health services; and 3) improved influence by personnel"* (Widén Holmqvist et al, 1996, p9).

A functional approach to therapy, in which the therapy is organised around *"goal directed, functional behaviour rather than ... muscles and movement patterns"* (Widén Holmqvist et al, 1995, p44) was identified as the approach to therapy adopted in some of the home- based programs (Meeds and Pryor, 1990; Portnow et al, 1991; and Widén Holmqvist et al, 1995).

All studies reviewed identified the need for more efficient ways of delivering health care as the main reason for exploring home-based rehabilitation. This need for efficiency was seen as being due to the aging of the population and increasing demand for health care

(Meeds and Pryor, 1990; Portnow et al, 1991; Currie et al, 1994; and Widen Holmqvist et al, 1995).

The move from hospital-based to home-based service delivery and the features of the programs described seems to represent a move away from a traditional biomedical model of rehabilitation to a more holistic, team-based and client-centred model. However, this was not made explicit in the literature.

2.4 Methodologies and philosophical approaches

With the exception of the study by Portnow et al, 1991, all of the studies reviewed took an empiricist or positivist approach. They were interested in cause and effect, in this case, in identifying the factors inherent in the person and in the rehabilitation process that affected the outcome of rehabilitation. These outcomes were seen as standardised and measurable through objective testing (Neale and Liebert, 1986). In these studies, outcomes such as functional improvement and non-reliance on others were seen as the goals of rehabilitation, regardless of the individual goals of the client. This approach assumes that these measurable outcomes are universally applicable and valued.

The problem with a positivist approach in this context is that it is inconsistent with the approach to rehabilitation being explored here. The individual experiences of clients and their families that should be valued within a holistic, context-based, client-centred approach to home-based rehabilitation have not been systematically examined. Clients and staff have not had the opportunity to reflect on their experience and to identify what is important, beneficial or deleterious to them.

The studies reviewed can be divided into three groups according to the study purpose, that is, exploratory, descriptive or evaluative, with some incorporating more than one purpose. Appendix A depicts in detail the major features of each of the studies.

Most studies used standardised tests or surveys to determine the feasibility or impact of the rehabilitation program. There were few qualitative tools used and although patient satisfaction was measured, there was no exploration of the clients' or staff's interpretations or experiences of home-based rehabilitation. Surveys and structured interviews, utilising standardised assessment measures, were the most common methods chosen. Case studies were also used in the descriptive studies and in some of the exploratory studies in which small groups were examined in depth. The studies of Widen Holmqvist et al (1995 and 1996) are good examples of this approach.

Bairstow et al (1997), were unable to find an adequate standardised measure of rehabilitation outcomes and developed their own measure based on the clients' and staff's assessment of the client's achievement of rehabilitation goals. Unfortunately, the authors did not describe the tools used. However, the authors did allow clients to identify the goals of rehabilitation that were important to them and were therefore more subjectively valid.

It is argued here that the lack of qualitative methodologies in the studies reviewed means that there is insufficient opportunity for the home rehabilitation participants to identify and explore what is important to them. Given the shift away from reliance on professional staff and institutional care to increased self-reliance and reliance on family and community supports that home-based rehabilitation represents, the absence of qualitative research is seen as a weakness in the literature reviewed here.

2.4.1 Study purposes

One group of studies aimed to establish the feasibility of home rehabilitation with their patient population and to identify which patients could be targeted for early discharge and rehabilitation at home (Ceder et al, 1980; Möller et al, 1992; Currie et al, 1994; and Widén Holmqvist et al, 1995). Another group of studies sought to describe their home-based rehabilitation programs, (Meeds and Pryor, 1990; Portnow et al, 1991; and Colbourne, 1993) emphasising different aspects, such as the role of the physiotherapist (Meeds and Pryor, 1990). A third group conducted evaluations of existing home rehabilitation programs, using a before and after study design (Brown, 1990; Widén Holmqvist et al, 1996; and Bairstow et al, 1997) or a combined before and after design with a comparison group (Meeds and Pryor, 1990; Farnworth et al, 1994; and O'Cathain, 1994). The former aimed at establishing the effectiveness of home rehabilitation in terms of their stated aims, the latter to compare the effectiveness of home rehabilitation with hospital-based rehabilitation.

2.4.2 Study designs

The studies which aimed to establish the feasibility of home rehabilitation used an ex-post facto research design (Cohen and Manion, 1989) to identify the factors that were consistent with successful early discharge with community support. For example, Ceder et al (1980), studied 103 patients who were admitted consecutively to hospital having suffered a fractured hip. They then identified, retrospectively, the factors that impacted on the patients' successful discharge to home. The criteria for success were: discharge to home rather than an institution; return to pre-morbid functional ability; and non-reliance on community services.

The most comprehensive example of the descriptive approach was the study of Portnow et al (1991), written by the whole multi-disciplinary team. Each member of the team described his or her role, using client case studies as illustration. In this and the other descriptive studies, however, there was no systematic collection of information from staff or clients, but rather a discussion of the anecdotal experiences of the authors.

The studies that evaluated home-based rehabilitation used quasi-experimental research designs (Cohen and Manion, 1989). Some studies compared a group receiving home-based rehabilitation with a group receiving hospital-based rehabilitation. An example of this approach is the study by O'Cathain (1994), in which the responses of a home-based group were compared with the responses of a similar hospital-based group. This study utilised a patient satisfaction measure, the Nottingham Health Profile and readmission and mortality rates. The Nottingham Health Profile was administered on acceptance to the program and after discharge. This study was typical of this group, in that the two groups were selected for admission to home rehabilitation, rather than randomly assigned and the group that stayed in hospital did so because circumstances did not allow for their discharge home. In this case, lack of consent and unsuitability of the home environment were the factors that led to the hospital group remaining in hospital.

None of the comparative studies used a randomised control study design and it is argued here that this weakened the generalisability of their findings. A meta-analysis of the literature on workplace health promotion programs conducted by O'Donnell (1997) showed a relationship between the strength of the study design and the outcome conclusions. One hundred percent (100%) of non-experimental studies resulted in positive outcomes compared with only 25% of experimental studies. Whilst it is difficult to randomly assign patients into experimental and control groups for practical and ethical reasons, the failure to do so means there is less scope for making general conclusions about home-based rehabilitation from the research findings.

The other evaluations conducted longitudinal studies using functional measures to assess the impact of rehabilitation.

2.4.3 Study samples

There was a wide range of sample sizes and sampling strategies in the studies reviewed. The sample sizes ranged from the pilot studies of Widén Holmqvist et al (1995 and 1996) of 15 clients to the Bairstow et al (1997) study which included 282 clients over a 38 month period. The study by Ceder et al (1980) included 103 patients of whom 75 undertook their rehabilitation in the early discharge scheme. Meeds and Pryor (1990) compared groups of 68 (at home) with 48 (in hospital), Brown (1990) sampled 79 patients, O'Cathain (1994) compared groups of 76 (at home) with 34 (in hospital) and Farnworth et al (1994) compared 67 (at home) with 71 (in hospital).

The longitudinal studies were able to include all the patients who had accepted the offer of home-based rehabilitation. Whilst it would not be ethical to include people who do not wish to participate in home-based rehabilitation, including only the group who wished to participate may have resulted in selection bias. For example, the home rehabilitation group may be more motivated to get home and get on with their lives than the hospital-based group. This may have skewed the results towards a more positive outcome.

The studies in which two groups were compared were not able to use random selection. While this weakened the study design, as discussed above, the studies were strengthened by controlling for other factors that may have influenced the outcome. For example, in Meeds and Pryor (1990), the two groups were similar in age, mental function, mobility and living circumstances, but the hospital-based group did not have access to a nursing service at home.

2.4.4 Findings

The studies were generally positive in their assessment of home-based rehabilitation and there was a significant group of people for whom home-based rehabilitation was found to be suitable: 75% (Ceder et al, 1980) to 100% (Currie et al, 1994) of all patients post-orthopaedic trauma and 50% of all stroke patients (Widên Holmqvist et al, 1995). The main factor that influenced suitability of home-based rehabilitation was the availability of support at home (Meeds and Pryor, 1990; Möller et al, 1992; and Widên Holmqvist et al, 1995).

The studies that compared progress in a hospital-based rehabilitation program with progress at home concluded that home rehabilitation was as good or better in achieving functional improvement as hospital-based rehabilitation (Meeds and Pryor, 1990; O'Cathain, 1994; and Farnworth et al, 1994). Providing a comprehensive post-discharge rehabilitation program was generally found to reduce the patient's length of stay in hospital (Brown, 1990; Meeds and Pryor, 1990; O'Cathain, 1994; Farnworth et al, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997).

There were some tentative findings in relation to cost effectiveness, based on the reduction in length of stay, with most estimating some savings. However, caution in interpreting these results was advised as many costs, including the cost of carer's time, were not calculated (Farnworth et al, 1994; and O'Cathain, 1994). When patient and carer satisfaction were measured, the results were generally positive (Brown 1990; O'Cathain, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997). For example, Bairstow et al, (1997) found that 93% of patients and 92% of carers were satisfied with the service.

Portnow et al's (1990) descriptive study was also very positive in its analysis of home-based rehabilitation. A case example of an older woman who was the head of a large extended family was used to demonstrate how home-based rehabilitation had enabled her to resume the life roles that were important to her. This in turn had helped her to regain the confidence she needed to tackle some of her more difficult rehabilitation goals.

There were some adverse findings. Brown (1990) found that the reduced length of stay led to increased workloads for staff in the orthopaedic ward. Widên Holmqvist et al (1996) discovered that there was some increased burden on carers but that it was temporary and suited their preferences.

2.5 Critique and implications for this study

2.5.1 Limits of approach

Most of the literature took a quasi-experimental approach to assessing the effectiveness of home-based rehabilitation (Brown, 1990; Meeds and Pryor, 1990; O'Cathain, 1994; Farnworth et al, 1994; Widen Holmqvist et al, 1996; and Bairstow et al, 1997). Within this approach there were some weaknesses in study design, namely the failure of all the studies to use random sampling in selecting the experimental and control groups. Future studies that adopt this approach would be strengthened by increased rigour in the sample selection process. It is not the aim of this study, however, to demonstrate effectiveness, so this problem will not be addressed here.

The approach taken by these studies limited the findings to the outcomes of the chosen quantitative measures. This means that other issues, themes or interpretations were either not reported or reported as additional assertions by the study authors. A number of the studies included some additional observations, considered important when reviewing home-based rehabilitation, but not revealed via the formal study, for example, Meeds and Pryor (1990) and Currie et al (1994).

In developing a new approach to service delivery, it is important that the views of clients, carers and staff are heard and considered. These experimental approaches allow this to occur only through client, carer and staff responses to questions that have been set by the researchers and even this occurs in only three of the 12 studies reviewed.

2.5.2 Lack of theoretical framework

As mentioned previously, the studies reviewed did not explicitly identify a theoretical framework either for rehabilitation practice or for research into their practice. However, rehabilitation was carried out in the person's own home and was based on the client's goals and meaningful activities and life roles (Meeds and Pryor, 1990; Portnow et al, 1991; Widén Holmqvist et al, 1995; and Bairstow et al, 1997). This suggested a holistic approach in which the client should be considered in the context of his or her own environment.

Bairstow et al (1997) used the client's own goals to assess effectiveness, an approach that is more consistent with client-centred practice. Although this approach will not be covered in this study, it is the subject of another study currently being undertaken at BHS-QEC. The study will compare a group of clients receiving rehabilitation at home with a group receiving rehabilitation in hospital in terms of their self-assessed achievement of their rehabilitation goals.

2.5.3 Emphasis on cost containment

All the studies reviewed cited the need to contain the cost of health services as one rationale for establishing a home-based rehabilitation program. This has a number of implications for the model of practice used in home rehabilitation as well as for the focus of evaluation of these programs.

There is a need for a detailed economic appraisal to be undertaken to establish the real costs of providing home-based rehabilitation (Lafferty, 1996). This should include the costs to carers, for example, the time spent looking after the caree and the cost of any time lost from work or leisure activities; the increased demand on community services of early discharge from hospital, for example, increased use of home care and nursing services (Brooten, Brown, Hazard Munro, York, Cohen, Roncoli and Hollingsworth, 1988); and the costs to the client such as, power, food and medication that would be met by the hospital if the client was resident there for the full period of rehabilitation. Although there is an acknowledged need for such research, it is beyond the scope of this study.

The need to contain costs also has implications for the model of service delivery adopted by home rehabilitation. It may take a staff member longer to visit a client at home than to see the client who comes into the rehabilitation centre for treatment. It may also take longer to identify client-centred goals and adopt an interdisciplinary approach than it does to set the client's goals for them. Unless the cost of the client's time is taken into consideration, then these approaches will be seen as more expensive than the traditional approaches and therefore at risk of cost cutting measures. However, time may be saved in other ways. There is some evidence to show that adherence to the client's goals is more efficient (Law, Baptiste and Mills, 1995; and Bowen, 1996) and that client-centred goal-setting increases client motivation and compliance (McGrath and Davis, 1992; and McGrath, Marks and Davis, 1995).

2.5.4 Lafferty's review

Lafferty (1996), in his review of community-based alternatives to hospital rehabilitation services, argued for caution in shifting care from the hospital to the community. He asserted that there have been too few studies to date and that the nature of the services they evaluate vary considerably as do the study designs. The studies have not established a superior model of rehabilitation nor have they conducted a thorough economic appraisal. Lafferty (1996) was concerned that the risks to the patient had not been fully investigated nor had the acceptability of the services to the patients and carers. Furthermore, the sample sizes were too small and too limited in diagnostic groupings to draw any generalisable conclusions.

Lafferty (1996) included the studies by Farnworth et al (1994), O'Cathain (1994) and Portnow et al (1991) but did not include the other ten studies reviewed here. This study supports his conclusions about the diversity of study design, the lack of an economic appraisal and the need for more extensive evaluations of acceptability to clients and carers but does not support his other conclusions.

As can be seen from the comparison of the program features, there is considerable similarity between the approach to service provision among the programs that have been evaluated here. The results show that home-based rehabilitation is at least as effective, if not more so, than hospital-based rehabilitation, according to the measures used. These measures include measures of physical and mental functioning (Meeds and Pryor, 1990; Currie et al, 1994; Farnworth et al, 1994; O'Cathain 1994; and Widên Holmqvist et al, 1996) patient satisfaction (O'Cathain, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997) and limited evaluation of the experience of carers (Widên Holmqvist et al, 1996; and Bairstow et al, 1997). The follow up research did not indicate any increased risk to patients in terms of increased mortality or readmission to hospital.

The author agrees that the studies reviewed here did not comprehensively explore the experience of clients, carers or staff. Although measures of patient satisfaction were used in three of the studies (O'Cathain, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997), these did not explore the experience of participants.

Satisfaction surveys are structured to gain responses to questions that are set by the program evaluators (Lund, 1996); they do not generally give the respondents the opportunity to identify the issues that they see as important and to comment on them in their own words (Avis, Bond and Arthur, 1995). This is best done through participant observation and individual and group interviews (Makut and Morehouse, 1994).

Interviews were used in four of the studies reviewed (Currie et al, 1994; O'Cathain, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997) but these were structured interviews in which a quantitative measure, such as a measure of ability to perform activities of daily living (ADL), was administered by the interviewer. If the respondents were given the opportunity to comment, this was not reported in the literature.

2.6 Conclusion

The research into home-based rehabilitation found that it was an appropriate option for a significant percentage of rehabilitation candidates (Ceder et al, 1980; Currie et al, 1994; and Widên Holmqvist et al, 1995). Further, it was found to be at least as effective as hospital-based rehabilitation in achieving rehabilitation outcomes (Meeds and Pryor, 1990; O'Cathain, 1994; and Farnworth et al, 1994). Reduction in hospital LOS was achieved with home-based rehabilitation (Brown, 1990; Meeds and Pryor, 1990; O'Cathain, 1994; Farnworth et al, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997) and clients were generally satisfied with their care (Brown 1990; O'Cathain, 1994; Widên Holmqvist et al, 1996; and Bairstow et al, 1997). The two areas of concern identified in the literature were the impact of home-based rehabilitation on staff workloads (Brown, 1990) and carer strain (Widên Holmqvist et al, 1996).

This review has identified a number of areas that the author believes would benefit from further research, for example, the need for a full review of the cost of home-based rehabilitation. The views of clients and staff in relation to home-based rehabilitation, the author believes, have not been adequately researched. Further, the literature does not make explicit the philosophical approach to rehabilitation implicit in the program models described above. The methodology described in the literature is largely quantitative and it is argued here that qualitative methodologies are needed to adequately canvass the views of the program participants.

This study will not consider the impact of home-based rehabilitation on client's independence or ADL status as this has already been well covered by the literature. Instead, this study will address some of the gaps identified in this review by utilising qualitative methods to explore the experience of clients, carers and staff from their own perspective. The impact of the program on staff workloads and carer strain will be explored through focus groups and the use of the Caregiver Strain Index (CSI) (Robinson, 1983). The philosophical approach to rehabilitation practised in the RHP will be outlined and, from a critical theoretical perspective, extended into the evaluation of the program.

The theoretical framework of this study and the philosophical approach to rehabilitation practised in the RHP are the subject of the next chapter.

Chapter Three
Theoretical Framework

3.1 Introduction

In the first section of this chapter, the major sociological theories that inform the choice of methodologies for this study and the approach to rehabilitation taken in the RHP will be discussed. The second section will outline the philosophical approach to rehabilitation that is practised in the RHP.

3.2 Study framework

Applied social research, such as program evaluation, is often conducted without an explicit theoretical framework. This does not mean that the research is not influenced by the researcher's theoretical understanding of the world, but that this influence remains hidden (May, 1993). As the literature review illustrated, the research into home-based rehabilitation was generally positivist and atheoretical. The purpose of this section of the chapter is to make explicit the social theories that have influenced the author in the choice of methodology and in the interpretation of the findings of this evaluation.

The focus of this evaluation is the experiences of clients, carers and staff. It is their perspectives, interpretations and ideas that have been sought by the researcher in order to evaluate the effectiveness of the RHP and to recommend the changes that should be made. These experiences occur within and are influenced by a context of power relationships. For this reason, it is also important to focus on the context within which the program was established, in particular, the dominant biomedical tradition and the political context of economic rationalism that is partly behind the move from hospital to home-based health care.

It is argued here that it is necessary to draw on two major sociological approaches, symbolic interactionism (or an interpretive approach) and critical theory to illuminate the experiences and interpretations of the individual program participants and to understand the broader political and economic context in which these everyday experiences occur. This requires both a micro level approach that focuses on understanding *"the face-to-face interactions between people in everyday life"* and a macro level approach which is concerned with *"analysis of social systems or structures"* (May, 1993, p30). The interpretive approach provides a rationale for the focus of the evaluation and for the choice of qualitative methodologies in this study. Critical theory provides a framework for understanding the approach to rehabilitation practised in the RHP and the context of power relationships in which the study took place.

3.2.1 Critical theory as a framework for research

Critical theory is an umbrella term for a number of different social theories that have in common a *"questioning of the relationship between power and knowledge and how that relationship is evident in practice"* (Cheek, Shoebridge, Willis and Zadoroznyj, 1996, p162). Critical theory does not assume that there is a *"truth that we can reach as researchers by simply concentrating on techniques of social research"* (May, 1993, p27), but rather argues that our ways of knowing about the world are inseparable from relationships of power. Critical theory is concerned with exposing the power relationships that lie beneath the construction of truth or reality that is taken for granted. This leads to the empowerment of individuals through the exposure of alternative constructions of reality (Allen, 1985 and Fay, 1987).

In relation to the health care industry, critical theorists maintain that for too long, the majority of research has been technical rather than practical, and reductionist, that is, focussed on the aspects of the person that are observable and measurable, rather than interpretive (Carr and Kemmis, 1983 and Allen, 1985). Street (1992, in Cheek et al, 1996, p166) challenged nurses and other health workers to *"head for the swamps"* and engage in research that explores the subjective experience of clients rather than just those aspects of their behaviour that are able to be subject to objective scrutiny. This type of research, Street argued, will challenge the dominance of medical/scientific ways of knowing about health care.

Fraser (1989 in May, 1993, p27) described critical social theory based research as one which:

> *frames its research program and its conceptual framework with an eye to the aims and activities of those oppositional social forces with which it has a partisan, though not uncritical identification. The questions it asks... are informed by that identification and interest.*

For the above reasons, this study has attempted to move away from positivist, economic rationalist approaches to evaluation. It focuses instead on the experiences of the participants and analyses the political and economic forces relating to home-based rehabilitation. The *"oppositional forces"* with which the author identified are those such as client-centred practice and holism (outlined in Section 2 of this chapter) which challenge the dominant biomedical tradition in health care. To date, as illustrated in Chapter 2, there has been little assessment of the impact of the move of services from hospital to home on clients, carers and health care workers. Through exploration and exposure of the experiences of the direct participants, the way in which home-based rehabilitation is understood in the general community may be enriched. Further, exposure of the views of subordinate groups will offer alternative ways of knowing about home rehabilitation and the shift of health services that may challenge the dominant biomedical and economic rationalist paradigms. The primary aim of this study is not so much to analyse these relationships, although some analysis will be necessary, but to act in awareness of them. That is, to ensure that the way in which the results of this evaluation are interpreted accurately reflects the perspectives of the people directly involved, rather than just the powerful interests of the hospital, state, and the biomedical tradition.

3.2.2 Critical theory as a framework for alternative approaches to health care.

It is argued here that the emergence of alternative approaches to health care that emphasize the values of self-knowledge and client self-determination is partly due to the challenges posed to biomedical science by critical theorists. The RHP, although based within a traditional health service, has tried to implement a model of client-centred practice that is based on these values.

Until ten years ago, the biomedical model dominated the way in which health services were delivered in Australia (Willis, 1989). Although there have been some more recent challenges to this domination (Easthope, 1993; and Siahpush, 1998), the author believes that at BHS-QEC, the biomedical model is still dominant. This is even the case in rehabilitation, where an explicit client-focussed philosophy has been adopted. For example, the Client-Centred Goal Setting (CCGS) process described in Chapter Four sits alongside an alternative model often used in the inpatient program, in which client's goals are set by the therapists on the basis of their professional assessment of the client's functional ability. The team meetings, held every week to discuss client progress, are chaired by a medical practitioner. For staff, who work within the RHP, there is the potential for conflict between the client-focussed philosophy and practice of the program and the biomedical context in which it operates. This is especially true for staff who work in both the inpatient and home-based programs. This will be discussed further in Chapter Seven.

Critical theorists have challenged the biomedical claim to scientific and political neutrality, claiming that the dominance of the medical profession in the Australian health context is as much to do with political and social forces as with medical science. Willis (1989) argued that the medical profession achieved its position of power through class advantage gained in the early 19th century and subsequent political influence. He identified three ways in which the medical profession sustains its position of authority and dominance over other health professionals. First, he argued it is not subject to control or surveillance by other health professionals. Second, it has been able, through its political influence, to get the state to limit or exclude other health professionals, such as chiropractors and homeopaths, from its sphere of influence. Third, it has disproportionate administrative power over referrals to other health professionals, over access to sick leave and is over represented in senior management of health organisations.

Some of the medical scientific claims in relation to cure or eradication of illness have been questioned by critical theorists. For example, McKeown (1965 in Cheek et al, 1996) demonstrated that the eradication of some communicable diseases that medical science claimed was due to immunisation was in fact due to changes in dietary habits and living conditions in the general population.

As medical scientific knowledge is questioned and challenged, alternative health care paradigms are starting to gain credibility (Kenny and Adamson, 1992; and Condeluci, 1992). There is more emphasis on the knowledge the client or patient has about his or her body, on self-help, the ability of clients/patients to help themselves and each other, on a team approach and on community-based rather than hospital-based care (Condeluci, 1992; and Baum and Law, 1997). These postmodern values have contributed to the move from conventional to alternative health services (Easthope, 1993; and Siahpush, 1998). The way in which these philosophical concepts have influenced the development of the RHP has been discussed in the Section Two of this chapter.

3.2.3 Symbolic interactionism

As critical theory does not represent the everyday understandings that people have of their world (May, 1993), and because this study was very much concerned with the everyday experiences of people going through rehabilitation, it was also necessary to adopt a interpretive or symbolic interactionist approach in the evaluation. Symbolic interactionism is concerned with the meaning that individuals give to their actions, with human action, which includes intent and reflection, as opposed to human behaviour, that can be viewed as a stimulus response activity. The interpretive approach *"places a priority on searching for and interpreting what is happening and being done according to the participants in the social activities being studied. It recognises as crucial the meanings of social action to those who are acting "* (Wiseman, 1993, p105). Allen (1985, p60–61) defines interpretive science as *"...an analysis of social action that focuses on understanding the meaning, grounds, motivations, or reasons for human action rather than seeking the universal regularities demanded by empirical science."*

In this study, the experiences of the individual participants were considered to be vitally important, as it is at the individual level that the impact of structural changes to the health system is felt. Based on the ideas of symbolic interactionism or interpretive science, this evaluation focused on the individual meaning that the staff and clients participating in the program gave to their experience. The clients in the RHP were there because they had suffered a major health problem. This may have been a stroke, an amputation, a joint replacement or a chronic illness. These health problems were experienced by each individual in a unique way. Furthermore, the health problem could not be disassociated and treated separately from other areas in the person's life (Bauer, 1989). The evaluation of the program needs to provide an opportunity for each participant's unique experience to be heard and acted upon. An interpretive approach provides the scope for this to occur.

3.2.4 Limitations of symbolic interactionism

Symbolic interactionism has been criticised for failing to attend to the social structures that shape the meaning that individuals give to their experience. Hammersley (1992, p99-100) stated that *"... simply to describe people's behaviour as if it were the product of a freely expressed culture is systematically to misrepresent their behaviour."* This criticism is very pertinent to this study as the RHP was established within a political and economic context of fiscal restraint and a hospital with a tradition of biomedical model practice. These factors may influence the meaning that program participants give to their experience and the extent to which these meanings and interpretations can be freely expressed and acted upon. A critical approach to the interpretation of the findings has been taken in order to give credence to these factors.

The symbolic interactionist perspective, particularly the work of Goffman on deviance, has been used to argue for deinstitutionalisation and normalisation (Hudson, 1991; and Lloyd, 1992). Unfortunately, recent cuts to health care funding mean that deinstitutionalisation has not been supported by adequate community-based health services (Clutterbuck, 1997). Consequently, critical sociologists have questioned some of the work of the symbolic interactionists as providing an excuse for the state to relinquish responsibility for those for whom care should be provided and to shift the burden of care onto families, particularly women (Hudson, 1991; and Lloyd, 1992). The RHP could also be criticised for shifting the burden of care from hospital to home under the guise of providing a more contextually relevant, client-focussed service. Adopting a critical approach in the discussion of the findings cautions against allowing this to occur.

3.2.5 Qualitative research

The subjective world-view of symbolic interactionism lends itself to qualitative methods of inquiry (Willis, 1995), such as unstructured or semi-structured individual or group interviews. Qualitative research enables the researcher to focus on the perspectives of participants (Bogdan and KnappBiklen, 1992). Focus groups have been chosen as the qualitative method of evaluation in this study because they allow for exploration of the subjective meaning that the RHP participants attribute to their experience. A group rather than individual interview enables a range of views to be expressed and discussed. It is also hoped, as May (1993) argued, that in a group, clients and staff will be encouraged and supported by each other to raise issues that they may otherwise feel afraid to express. The use of a group method in this study is intended to challenge the existing power relationships by enabling the traditionally less powerful groups, that is, clients, carers and staff, to critique the program in which they have been a participant. In this way, critical theory as well as symbolic interactionism, has informed the evaluation method. Focus groups are also considered to be a good way to monitor the impact of a new or developing program (Murphy, Cockburn and Murphy, 1992).

The use of focus groups also allows for separate group interviews of clients and staff so that the similarities and differences in their perceptions can be explored. Staff, clients and carers may have different constructions of the same event. For example, the practice of client-centred goal-setting aims to give clients control over the direction, duration and intensity of the rehabilitation process. Clients may interpret this process as empowering or they may find it to be irrelevant, burdensome or staff directed. Bringing two groups, one of clients and one of staff, together to discuss their experiences provides the opportunity for these various interpretations to emerge.

3.2.6 Conclusion

This study will analyse the everyday understandings that people gave to their experiences on the RHP and the relationship between these experiences and the political and economic context in which these experiences occurred. Thus, both critical theory and symbolic interactionism have influenced the way in which this evaluation has been conducted and the way in which the results have been understood and acted upon. Both theories support the involvement of the program participants in the evaluation process and *"emphasize understanding and emancipation"* (Allen, 1985, p58). In the next section, the rehabilitation philosophy that has been put into practice in the RHP will be described.

3.3 The client-focussed approach to rehabilitation

3.3.1 Introduction

Client-focussed rehabilitation is the name given to the philosophy of rehabilitation practised at BHS-QEC Rehabilitation Services. It means that the client and carers are essential members of the rehabilitation planning team, participating in all major decisions about the client's care (Bauer, 1998).

The principles which underpin this philosophy are: a holistic view of the client in the context of his or her environment; a focus on handicap and the inclusion of the client (and family as appropriate) as active participants in the rehabilitation process.

The BHS-QEC Rehabilitation Service has developed this philosophical approach over a number of years. Although it has changed in response to new research and feedback from clients and staff, the description provided in this chapter underlies the practice model of the RHP, which is described in Chapter Four.

The approach is based on the work of Doreen Bauer, the Manager of Rehabilitation Services. It has also been drawn from the Guidelines for Client-centred Practice developed by the Canadian Association of Occupational Therapists (CAOT) (Law, Baptiste, Caswell, McColl, Polatajko and Pollock, 1994) and the client-centred goal planning interdisciplinary approach developed by the Rivermead rehabilitation team in Oxford, UK (McGrath and Davis, 1992; and McGrath et al, 1995).

3.3.2 A holistic approach

The holistic view of the individual has been defined as *"the view of the individual as a whole person whose parts cannot be considered in isolation of one another"* (McColl and Pranger, 1994, p253). Bauer (1989) stated that the individual is made up of a number of interconnected physical, intellectual, psychological and social systems. An impairment or disability in one system is likely to impact upon other aspects of the person. Furthermore, a disability that is manifest in one system may have its source in another. Thus, *"Clinical consideration of a client's neck or knee pathology in isolation from the many other aspects of the client's life may not assist the rehabilitation process at all"* (p31). Bauer argued that rehabilitation should be concerned with the whole person and that the traditional emphasis on pathology has tended to obscure *"the essence of rehabilitation, the person"* (p31).

The holistic view of the individual is one of the fundamental values of the Client-Centred Model (McColl and Pranger, 1994). In the Interdisciplinary Model, with its focus on handicap, it was suggested that the model *"should be capable of being comprehensive and of considering the whole person"* (McGrath and Davis, 1992, p234)'.

The holistic approach has been proposed as an alternative to the biomedical model with its traditional emphasis on pathology. This model is characterised by the diagnosis of a problem, which resides in the person, and the initiation of expert treatment designed to fix or heal the problem. The requisite knowledge and power reside with the expert professional, who is either a medical practitioner or under the supervision of a medical practitioner (Condeluci, 1992; and Nordholm, Adamson and Heard, 1994). As discussed in 3.2.2, the biomedical model of health-care has been subject to increasing criticism in recent years. For example, the WHO recommended that other approaches to health care should be considered by its member nations (WHO, 1986, in Nordholm et al, 1994).

3.3.3 Handicap focus

The WHO defined handicap as *"a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors for that individual)"* (WHO, 1980, p29). A handicap approach to rehabilitation takes into account the interaction between the patient's disability and the environment (Wade, 1992). It is concerned with a person's valued life roles, for example, being a worker, a friend, a care-giver or an important community member. It is consistent with the way in which clients see rehabilitation (McGrath and Davis, 1992).

The WHO ICIDH provides a useful framework in which to consider rehabilitation (Wade, 1992; and McGrath and Davis, 1992). The ICIDH defines and distinguishes between the concepts of impairment, disability and handicap.

Impairment is defined as, *"any loss or abnormality of psychological, physiological or anatomical structure" (WHO, 1980, p27). Disability is "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being"* (WHO, 1980, p28). Rehabilitation is usually focussed on disabilities. The impairment, for example, the hip-fracture or amputation is usually treated in the acute hospital setting with medical and surgical procedures.

Improvement in physical functioning may not lead to the resumption of activities and roles that are meaningful to the client (McGrath and Davis, 1992). Conversely, it is possible to modify handicaps without improving the functional ability of the client. They can be addressed by modifications to the environment. Modification of the role definition held by the individual client can also lead to a reduction in handicap as the client finds other ways to fulfil the role (WHO, 1980; Wade, 1992; and McGrath and Davis, 1992). For example, it may be possible for an individual to resume the roles of worker and breadwinner by adapting the work environment to accommodate the disability or by adapting the work to fit the capacities of the disabled person.

3.3.4 The importance of the environment

The environment was defined broadly by Bauer (1989) as encompassing the internal: physical, spiritual and mental aspects of the person; the physical space environment; the organisational environment including legal, cultural, religious and traditional aspects of the person's life; and the social environment. Bauer (1989) argued strongly for home-based rehabilitation: *"clients should learn skills in the environment in which those skills will be used. For most clients this will be in the home and in the community"* (p103). Bauer also argued that the traditional rehabilitation focus on the pathology of the person assumes that all the client's problems lie within their limitations or disabilities. The adaptation of the person's environment, as defined above, may lead to successful rehabilitation, as well as, or instead of, improvement in his or her physical functioning.

McGrath and Davis (1992, p229) linked the importance of the environment with the WHO ICIDH described above. *"On moving from one level of this scheme to the next a progression from the molecular to the molar level of description takes place, and the importance of the environment increases"*. They stated that: *"Constructing a suitable environment for the individual is as much part of rehabilitation as fitting the individual to the current environment"* (p231).

The CAOT model of occupational performance also emphasises the importance of the environment including: *"the individual's social, physical and cultural environment"* and *"active participation"* in the integration and execution of occupational performance (Townsend et al, 1990, p71). Head and Patterson (1997, p453) stated that *"therapists should evaluate performance in the environment in which their clients will be functioning"* rather than in a clinical setting. This has the advantage of allowing the therapist to identify barriers in that environment and to adapt it to the client's advantage. It gives therapists a greater understanding of the challenges faced by the client in that environment and the resourceful ways in which they can meet those challenges. The client may be seen differently at home. Without the anxiety and fatigue generated by a trip to the rehabilitation service, the client may be more active, confident and resourceful (Head and Patterson, 1997).

Haley, Coster, and Binda-Sundberg (1994) used the example of a disabled child trying to walk to illustrate the importance of the environment. The child's performance in the task depends on the physical environment, that is, the surface (carpet, linoleum, gravel or grass); the setting (home, school or community); and the social environment, for example, whether the child is participating in play or being asked to go to bed.

It has been found that there is a reduction in functional performance between a rehabilitation clinic and a home setting for adults with hemiplegia and rheumatoid arthritis (Haworth and Hollings, 1979; and Strub and Levine 1989 in Haley et al, 1994). A reduction in both objective and subjective assessments of quality of life for older people has also been found to occur in the first month after discharge from inpatient rehabilitation (Gething, Fethney and Blazely, 1998). Moreover, many patients with severe head injury, who have been treated in acute settings, have failed to successfully integrate into the community (Huber and Edelberg, 1993). Gething et al (1998, p191) argued that effective rehabilitation must *"include strategies to increase confidence in the home and in the community..."*. It is argued here that it is crucial in physical rehabilitation to ensure that assessment and treatment occur in the environment in which the assessed tasks are to be carried out.

Rehabilitation at home is focussed at the handicap end of the ICIDH scheme. By locating the rehabilitation in the client's home and community environment, the environmental barriers to role resumption are obvious immediately and often have to be modified before the client can return to that environment. The broader social, cultural and emotional aspects of the client's roles are also easier to identify and address within the client's own home.

3.3.5 Active participation

Client participation, empowerment and client self-determination are not new concepts in health service delivery. Carroll's (1980) examination of social work literature found descriptions of attempts at participatory programs in the United States of America as far back as the 1920s. In rehabilitation too, the participation of clients in decisions relating to their own health care is an important consideration. Bauer (1989) stated that the client and family should be actively involved in the rehabilitation process. *"Participation (in planning and decision making) helps to develop a commitment to achieving the desired outcomes"* (p63). This view is supported by Davidson (1991, p453, in Head and Patterson, 1997) who stated that *"providing clients with choices increases motivation, which, in turn, improves performance on a task"*.

During the past ten years, the CAOT together with the Department of Health and Welfare, Canada (DNHW), have developed guidelines for client-centred occupational therapy practice. The RHP used these guidelines to assist in the development of the program protocols. The way in which these guidelines have been put into practice in the RHP is described in Chapter Four.

3.3.6 Goal setting

One of the ways in which the client-focused philosophy is put into practice in the BHS-QEC Rehabilitation Service is through a process called Client-Centred Goal Setting (CCGS). This process was developed by a team of staff at BHS-QEC and was commenced on the inpatient rehabilitation ward two years prior to the development of the RHP. When the RHP was established, it was decided that, in line with the philosophy of client focussed rehabilitation, CCGS would be undertaken with every client. The process is described in Chapter Four.

Although CCGS developed independently of the Rivermead Interdisciplinary Approach (McGrath and Davis, 1992; and McGrath et al, 1995) it shares some of its features; both are goal driven and interdisciplinary approaches to rehabilitation. In the Interdisciplinary

Approach, rehabilitation is seen as a *"goal driven problem solving activity"* (McGrath and Davis, 1992, p225). The starting point of the interdisciplinary approach is the identification of aims based on the client's *"ability to assume valued roles"*. The *"impediments to role assumption are identified and these become objectives"* (McGrath and Davis, 1992, p233). The rehabilitation objectives were set in relation to the client's overall aims and required the cooperation and joint intervention of various disciplines. This approach was compared with the more widely used multi-disciplinary approach in which the client was allocated to different professionals for assessment and treatment according to the nature of the disability. This approach is illustrated in **Figure 1** below:

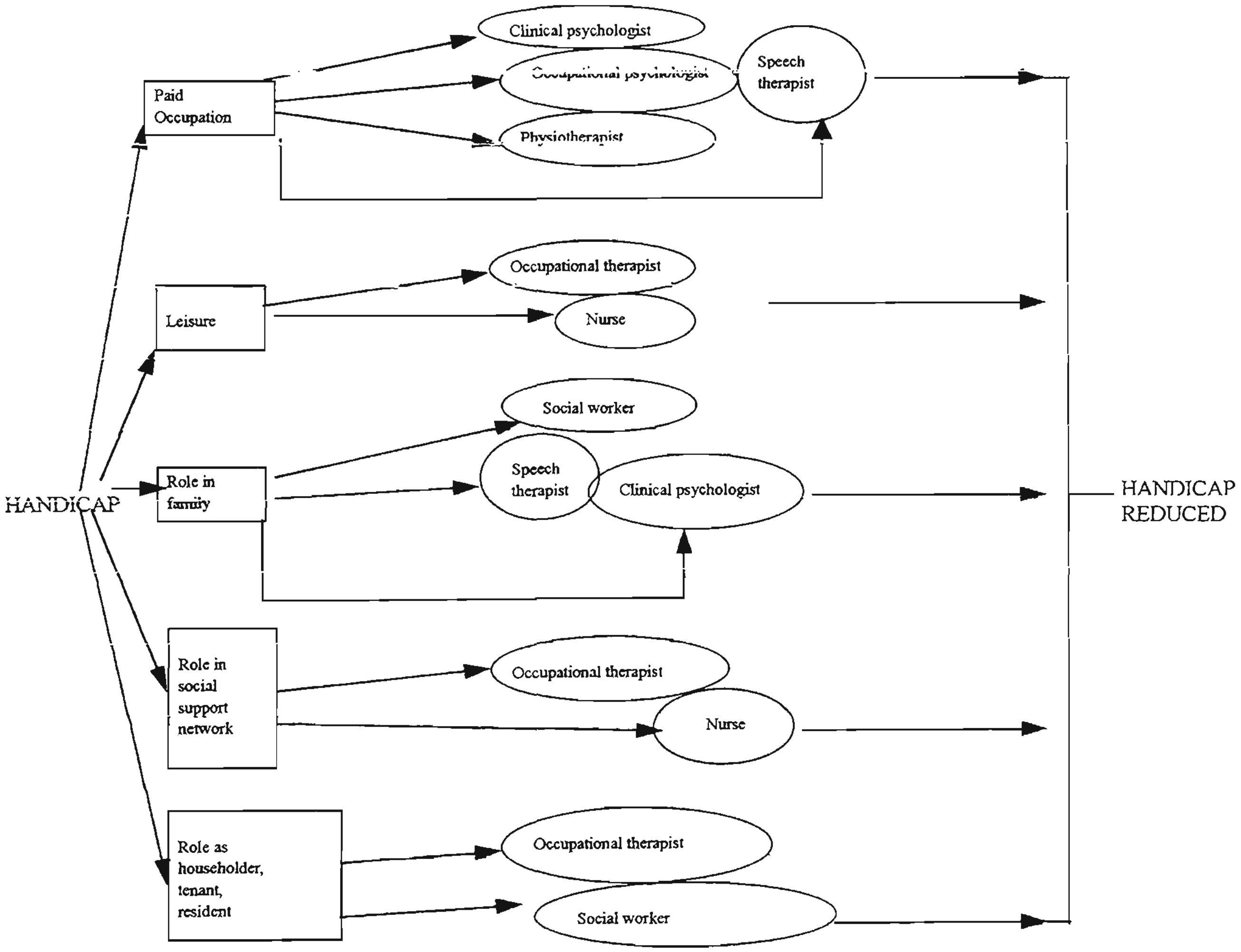

Figure 1 Interdisciplinary Model
(McGrath, and Davis, 1992, p233)

3.3.7 Client-focussed evaluation

Until recently, health service evaluation has been based on clinical tools derived from professional knowledge rather than consumer acceptance (Avis, Bond and Arthur, 1995). A client-centred approach that aims to reduce handicap can only be evaluated from the point of view of the client. As a handicap can only be measured by comparing expected with desired results (Wade, 1992) it is crucial to identify the expectations of the client in order to evaluate the outcome. Furthermore, clients are the best judge of whether their rehabilitation has enabled them to *"gain control over their own wellbeing"* which is one of the goals of a holistic approach to rehabilitation (Gething et al, 1998, p191).

One of the problems with a client-centred handicap approach to evaluating rehabilitation outcomes is that there are no validated and reliable handicap level measures that are easy to administer (Wade, 1992; and Bairstow et al, 1997). Despite this some of the studies discussed in Chapter Two did use handicap measures such as the Frenchay Activities Index (Widên Holmqvist et al, 1996) and the Nottingham Health Profile (O'Cathain, 1994). Bairstow et al (1997) used their own measure of client goal attainment to evaluate their rehabilitation outcomes. These client-centred handicap level approaches to evaluation need further development. Perhaps there is more scope for qualitative approaches in evaluating the success of these new approaches to health care.

Gething et al (1998) used objective and subjective measures of quality of life as well as functional measures to assess the effectiveness of hospital-based rehabilitation over the three month period following discharge. They found that the only functional measure that was related to quality of life was confidence in carrying out functional activities. The views of clients, therefore, need to be incorporated into the assessment of rehabilitation treatment outcomes in order to gain an accurate picture of the effectiveness of the rehabilitation process.

3.3.8 Conceptual framework for home-based rehabilitation

The major philosophical concepts that relate to rehabilitation in the home that are discussed above are summarised in **Figure 2** below. The client and family are central to the rehabilitation process and they are considered in the context of their social, cultural, physical, emotional and spiritual environment. Rehabilitation is focussed on the client's meaningful life roles that are an integral part of the home and community environment. The rehabilitation is based on the client's own goals and is undertaken by the client and family assisted by a team which functions in an interdisciplinary way.

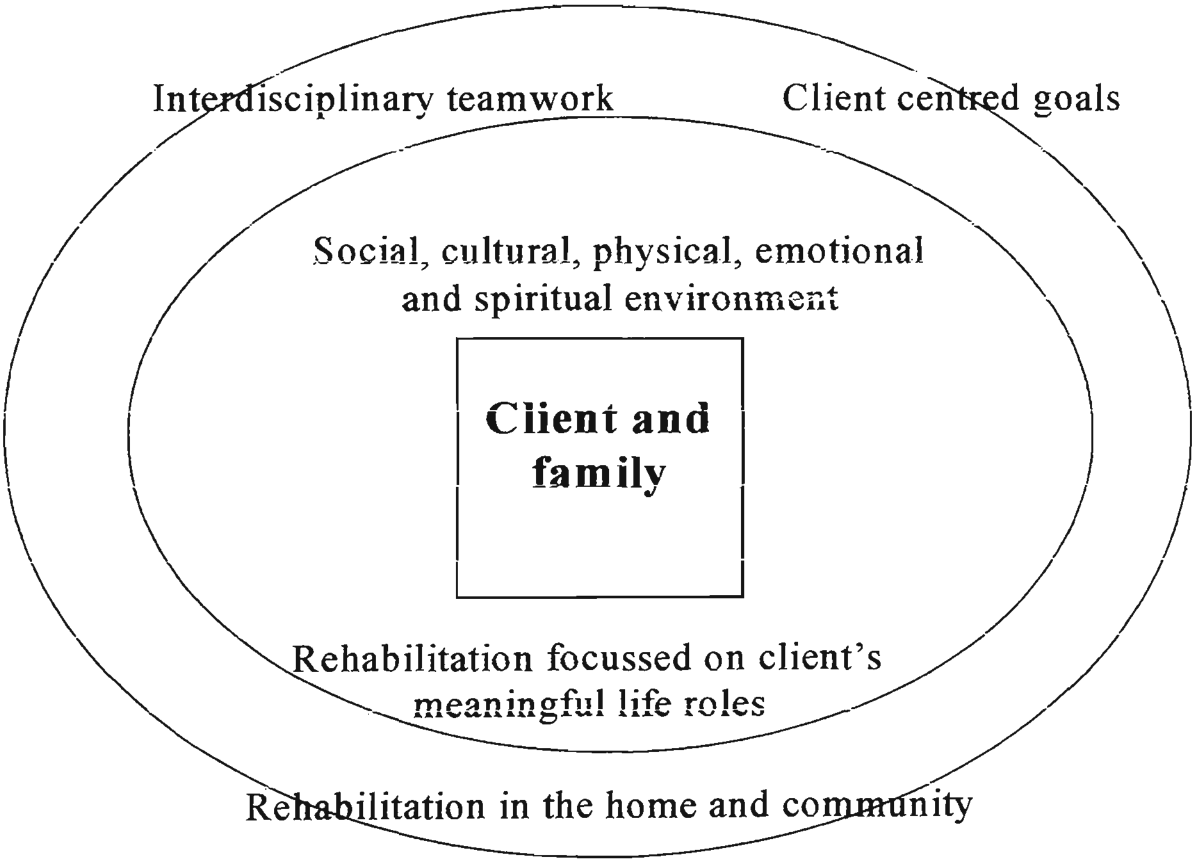

Figure 2 **A Conceptual Model of Home-Based Rehabilitation**

3.3.9 Critique of the home-based rehabilitation model

The philosophy of client focused rehabilitation with its focus on the micro level is consistent with the theory of symbolic interactionism. Importance is placed the life roles that are meaningful to the client (handicaps), goals are negotiated between staff and clients and the work of rehabilitation directed to the attainment of these goals.

This approach requires a paradigm shift from the more traditional biomedical model (Condeluci, 1992; and Baum and Law, 1997) and yet it operates within a broader context in which the biomedical model is still dominant (Övretveit 1985; Willis, 1989; and Nordholm and Adamson, 1992). Dixon (1997, p115) identified *"the challenges of operating inside an acute care delivery paradigm"* as a major task facing rehabilitation today.

These problems are compounded by difficulties in the measurement of client-defined handicap level objectives compared with the relative ease of measurement of disability and impairment. This reinforces further the biomedical model, which is more easily subjected to positivist, quantitative research methods. In evaluating this model in this context, a critical theoretical approach needs to be taken. Consideration should to be given to the power relationships that exist within the multi-disciplinary team and between professional staff and their clients. The philosophy of client participation is seen as empowering for clients but it is not known whether this empowerment really does occur and, if it does, how this impacts upon the existing power structures in the health service system.

Another problem with this approach is that there can be problems in getting professional staff to focus on client-identified goals (Nordholm et al, 1994; and McGrath and Davis, 1995). Carers and patients may also have different views about the important issues in health care (Jones and Lester, 1994). Despite evidence that clients and carers are better able to identify their own rehabilitation goals, even when they have cognitive impairments, there is still a belief among some health professionals that they know better (Pollock, 1993). This paternalistic belief *"that the professional, not the person, knows best"* was identified as a barrier to client autonomy by Abramson (1985, p391) in her discussion of the autonomy-paternalism dilemma in social work practice. The belief, that the client does not always know best, together with the dominance of the biomedical model, the imperative of cost containment and the problems in measuring the success of this type of approach, may impede the implementation of this model. These issues will be explored further in Chapter Seven.

This chapter has outlined and critiqued the philosophical approach that underpins the rehabilitation practised in the RHP. In the following chapter, the way in which this approach is put into practice will be described.

Chapter Four

Program Description

4.1 Introduction

The background to the establishment of the Ballarat Health Services' Rehabilitation in the Home Program (RHP) has been outlined in Chapter One. This chapter focuses on the aims, principles and practices of the RHP and the tasks related to a client's progress through the program are illustrated in **Figure Six** on page 66.

Although this chapter has been written as if the program is established and fixed, the description reflects a continuous process of program development. The RHP was established as a pilot and it is only through trial and error that some of the aspects of the program described here have been determined. One of the aims of this study is to further adapt the model of practice according to the feedback from clients and staff generated by this research. This will be reported in Chapter Eight.

4.2 Program aims

The RHP was established to give some clients a choice between going home for their rehabilitation or remaining in hospital. This was possible because it was expected that home-based rehabilitation would be at least as effective as hospital-based rehabilitation and would cost less. The aims of the program reflect these considerations. These are to:

1. Offer selected clients and their carers a choice between an inpatient and home-based rehabilitation program;

2. Facilitate clients' reintegration into the community after an inpatient stay;

3. Enhance the relevance and effectiveness of the rehabilitation process;

4. Ensure continuity of care; and

5. Encourage clients and their carers to participate actively in their own rehabilitation.

These aims have been taken from the program description (see Appendix B). The aim of finding a more cost-effective way of delivering rehabilitation services was reflected in the admission criterion relating to the estimated cost of the RHP which had to be less than the cost of a comparable inpatient program.

There are times when there could be some conflict between these aims. For example, a client may choose to come onto the program but the program may cost more than an equivalent inpatient program. The reality is that the choice is limited to refusal. That is, the program is only offered to those clients who meet the admission criteria, outlined below. However, a client may refuse the RHP and elect to be admitted for inpatient rehabilitation instead.

4.3 Program principles

The principles of the RHP are that:

1. The program will be client-centred, the client's wishes and requirements being paramount;

2. A holistic approach will be adopted with the client's rehabilitation needs being considered in the context of general health, and emotional and social needs;

3. Continuity of care will be maintained by BHS-QEC inpatient staff working with the client on transferral to the program so that disruption to the client's usual community support network is minimised; and

4. The privacy of the client and carers will be respected and all ethical principles usually related to confidentiality will be maintained.

4.3.1 Client-centred practice

In relation to occupational therapy, client-centred practice has been defined as:

> *an approach to providing occupational therapy which embraces a philosophy of respect for and partnership with, people receiving services. Client-centred practice recognises the autonomy of individuals, the need for client choice in making decisions about occupational needs, the strengths clients bring to a therapy encounter, the benefits of the client-therapist partnership and the need to ensure that services are accessible and fit the context in which a client lives* (Law et al 1995, p.253).

Table 1 **Client-Centred Practice in the RHP**

Client-Centred Concepts	**RHP Practice**
Autonomy/choice	Informed consent
Partnership and responsibility	Client/team goals
Enablement	Client/team goals, ongoing communication, negotiation, monitoring and review
Contextual congruence	Home/community based program
Accessibility and flexibility	Program in client's home and community
Respect for diversity	Program based on client goals, team goals negotiated with client

Law et al (1995), identify six concepts that they regard as central to client-centred practice. The RHP has tried to put these concepts into practice in its model of service delivery, illustrated in **Table One**, above.

RHP staff try to ensure that clients are in a position to exercise autonomy and choice by providing them with information and by assisting them to set the goals around which their rehabilitation will be based. Locating the program in clients' homes is also an attempt to give clients more control. A home and community based program should be easily accessible to clients and flexible enough to meet their diverse needs. Whether or not this client-centredness has been achieved will be one of the foci of this study.

4.4 Program parameters

4.4.1 Admission Criteria

The RHP is offered to clients who would otherwise have been offered inpatient rehabilitation but who live within a 20 minute radius of Ballarat by car and whose home environment and physical capacity do not pose a risk to their physical safety.

The admission criteria to the RHP are that:

- the client lives in the City of Ballarat;
- the client has been assessed as requiring active rehabilitation and has the potential to improve functional ability;
- the client is medically stable;
- the estimated costs of the RHP are less than those applying to inpatient care;
- the client's home environment has been assessed by an occupational therapist as being accessible and suitable for the client and carer(s) to implement or continue the rehabilitation program;
- all other safety considerations have been considered, for instance swallowing, transfers, lack of insight or impulsivity;

- the client's general medical practitioner (GP) has agreed to undertake the client's medical management, to participate in the rehabilitation process;
- the client and the carer(s) have had the option of a RHP explained fully and agreed to participate;
- environmental modifications and equipment, aids and appliances can be in place prior to the client's transfer to home; and
- all necessary community services can be in place on the client's transfer to home.

A total of ten clients may be admitted to the RHP at any one time.

4.4.2 Referral and Admission Process

To determine that the admission criteria have been met, a process of information exchange and assessment takes place. This process is illustrated in **Figure 3**.

First, a RHP staff member visits the client and family and explains the program and other options. Written information about the RHP is left with the client and if the client is ready to decide, an agreement form is signed.

The rehabilitation specialist medical practitioner visits the client and carries out an assessment to ensure that the client requires physical rehabilitation and is medically stable. The RHP occupational therapist conducts an assessment with the client by taking them home and observing how they manage the activities they need to carry out at home. The client may manage these activities independently or with the assistance of family or community supports. The occupational therapist determines whether the supports required are available and whether the RHP can fund their provision.

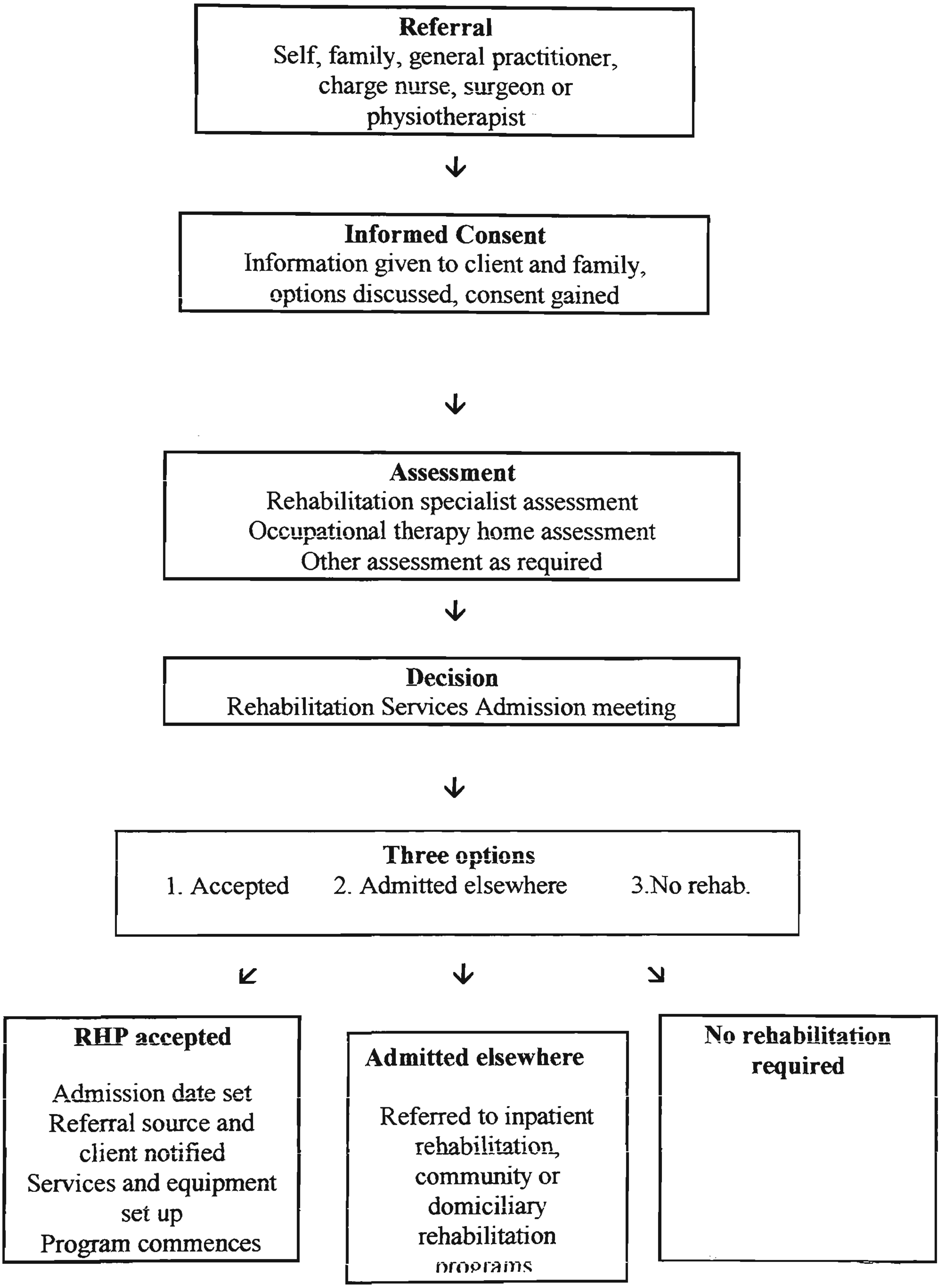

Figure 3 Referral and Assessment Process

The Rehabilitation Services Team makes a decision on the basis of the above information. If there is any doubt as to the suitability of the program for the client or if the client does not wish to participate, the referral is discussed at an admission meeting. This meeting may decide that other rehabilitation options are more suitable or no rehabilitation is required. If the referral is accepted, then the following steps are taken.

First, a care coordinator is allocated to organise the admission and communicate with the client, the therapy team, the client's family or carers and any other services involved in the client's program. Second, the client (and family) and the referral source are notified of the decision and an admission date is negotiated with them.

Third, community services, such as domestic help and delivered meals, are organised. Equipment such as rails, personal alarm system or access ramps, are installed. Arrangements are then made to transport the client home. It is RHP protocol to visit the client at home on the day of discharge. If the client and family prefer, a RHP staff member may transport the client home and ensure that he or she is set up comfortably.

Finally, the rehabilitation team is identified and an initial weekly program is negotiated with the client. The care coordinator uses the assessment information and some screening tools to identify which disciplines will be required to form part of the rehabilitation team. He or she approaches the stream leaders who allocate the appropriate staff to the client. A program of visiting times for each staff member is then negotiated between the staff and the client and a copy taken to the client at home.

4.5 RHP service delivery model

The service delivery model that has been adopted in the RHP is an adaptation of the model that was in place at BHS-QEC in the inpatient and community rehabilitation services. The RHP enabled the extension of this model into the client's home.

4.5.1 Continuum of care

At BHS-QEC, Rehabilitation Services have adopted a continuum of care approach. This refers to continuity of staff across the programs into which the client is admitted. This model is different to that used in many hospitals where staff are attached to a particular program, for example, the ward or the outpatient program, and the client is allocated a different staff team when they move from the ward to home (See **Figure 4**).

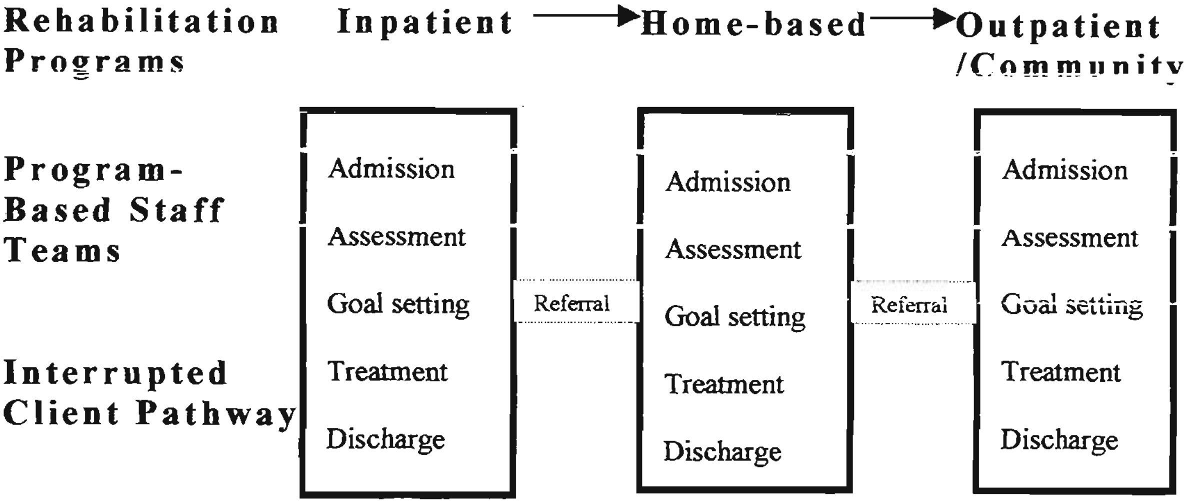

Figure 4 **Program-Based Structure**

With the BHS-QEC model, the client is admitted into either a General or Neurology Stream, each with a team of staff. This team continues to work with the client as he or she moves through the programs, for example, from inpatient to community rehabilitation. This structure reduces the need for referral processes and reassessment. It means that the staff develop expertise within a range of diagnostic conditions, either neurological or general, which includes orthopaedic, urology, oncology and general medical diagnoses. The client sets his or her rehabilitation goals at the beginning of rehabilitation and these can be monitored continuously as he or she moves through rehabilitation. The focus is more on the needs of the client than the organisation or the staff.

The RHP team consists of the full range of disciplines that are available to clients in the other rehabilitation programs. These include rehabilitation nurses, physiotherapists, occupational therapists, speech pathologists, psychologists, neuropsychologists, social workers, dietitians, allied health assistants and podiatrists.

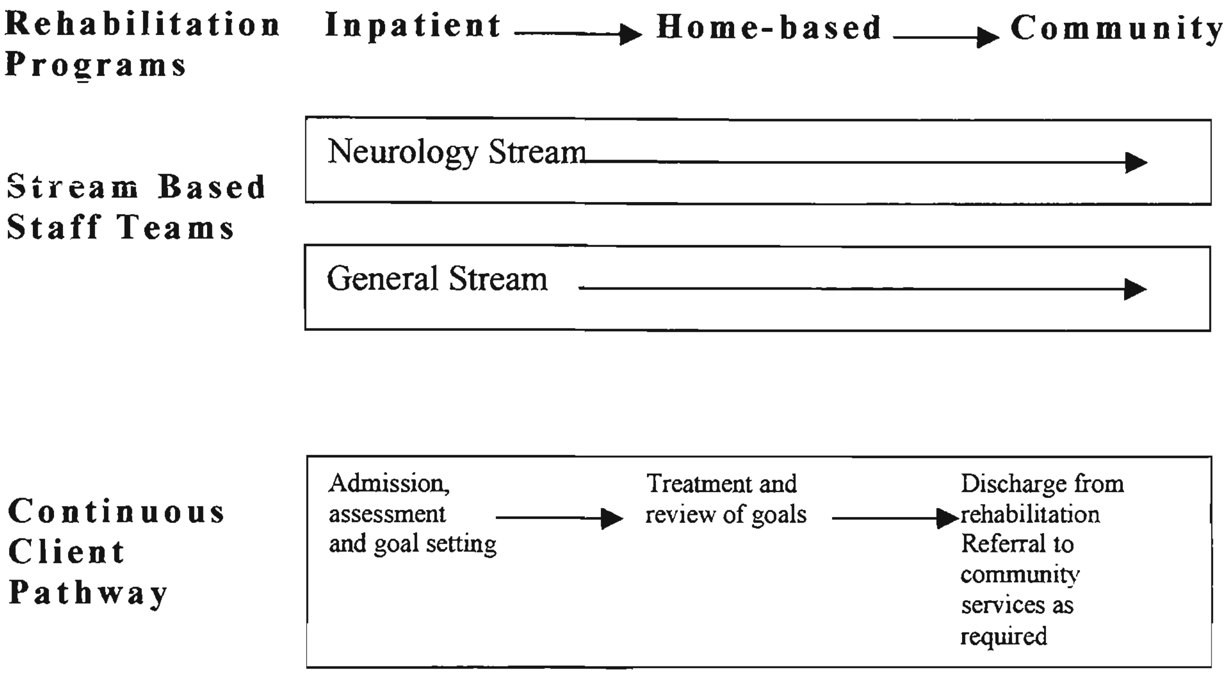

Figure 5 **Continuum (Stream Based) Model**

There are three staff members allocated specifically to the RHP: the coordinator who manages the program; an occupational therapist who conducts the home assessments prior to admission to rehabilitation services; and an allied health assistant who carries out day-to-day therapy tasks with clients under the supervision of the professionally trained staff.

For the service delivery model to be implemented fully, client-centred goals should be established as the focus of the client's rehabilitation and a care coordinator should be appointed to coordinate the client's pathway through rehabilitation. At BHS-QEC Rehabilitation Services, this occurs for clients who are admitted to the inpatient program and who have been identified as 'complex' clients, and for all clients admitted to the RHP.

4.5.2 Client-Centred Goal Setting

All clients admitted to the RHP are invited to participate in setting their own rehabilitation goals through a process called 'Client-centred Goal Setting' (CCGS). This process has been developed by a working party at BHS-QEC. The process involves the administration of the Reintegration to Normal Living Index (RNL) (Wood-Dauphinee, Opzoomer, Williams, Marchand and Spitzer, 1988) and an adaptation of the Canadian Occupational Performance Measure (COPM) (Law, Baptiste, Caswell, McColl, Polatajko and Pollock, 1994).

The first step in the CCGS process is an interview between the occupational therapist and the client, when a problem list is generated using the RNL. This list is then transformed collaboratively into a goal list. For example, if the problem identified is that the client is no longer able to go out into the community, this may then be transformed into the goal *"to be able to walk to the shops"*.

The occupational therapist then uses the COPM to work with the client to determine the following:

- the importance of the goal (Importance Measure);
- the extent to which the goal can be achieved at present (Performance Measure); and
- the extent to which the client is satisfied with his or her performance in relation to this goal (Satisfaction Measure).

These measures are rated on a scale of one to ten. In the *"walking to the shops"* example, the client may consider that this rates as ten for importance. However, the client rates his or herself as only able to achieve a one, able to walk to the front door, and rates satisfaction with this as zero, that is, not satisfied at all.

From the results of the COPM, and further discussion with the client, the goals are listed in priority order. For example: *"to walk to the shops, to be independent in dressing myself and to resume playing bridge"*.

The goal list that has been generated by the client, in conjunction with the occupational therapist, is circulated to the rest of the BHS-QEC rehabilitation team. They identify the steps that the client needs to achieve to accomplish the goal, in terms of their own discipline (therapy foci). In the example above, *"to walk to the shops"*, the physiotherapist may identify that the client needs to achieve independent outdoor mobility with a frame for 200 metres and that this will be the focus of physiotherapy treatment. Other team members may set team goals that they regard as important but that the client has not identified. For example, the nurse may set the goal of independent self-medication. Such goals are discussed and negotiated with the client.

These goals are allocated a time frame for attainment and the client's discharge from rehabilitation is discussed. Often discharge from the ward or the RHP may precede the achievement of the goals, but the continuum structure, discussed above, allows the client to continue to work towards these goals with the rehabilitation team until their final discharge from the Community Rehabilitation Centre (CRC). The identification of a discharge time frame and team goals occur at a team meeting attended by BHS-QEC Rehabilitation Services staff.

After discharge, the occupational therapist readministers the modified COPM to see if the performance and satisfaction levels have increased for the client (See Appendix C for an example of CCGS). The process of Client-centred Goal Setting described here is the same for 'complex' ward based clients and all RHP clients.

4.5.3 Care coordination

Although there is care coordination for some clients in the inpatient rehabilitation program, the following description applies to RHP care coordination only.

In a home-based program there is increased need for effective communication between all the members of the rehabilitation team. In hospital, the client is monitored daily by BHS-QEC nursing and medical staff. The staff all work within the hospital building. They see each other in the corridors and are able to catch up informally.

In a home-based alternative, staff work up to 20-minutes drive away from the hospital. The GP may provide the medical care and the District Nursing Service may provide the nursing care. The team usually includes community services, the GP and others not directly employed by BHS-QEC as well as the BHS-QEC team and the client and family. It is therefore necessary to ensure that regular formal communication is organised and the responsibility for this communication rests mainly with the care coordinator. He or she makes at least weekly contact with the client, organises the program for the week, and feeds back to the client and the GP information from the team discussions relating to the client's progress through rehabilitation. Finally, the coordinator feeds back information from the client to the team.

The other responsibilities of the care coordinator are to assess the client's need for community services and to manage the administrative tasks associated with the client's stay on the RHP. For clients coming directly from home or an acute hospital, the care coordinator also assesses the rehabilitation requirements, such as physiotherapy, speech therapy or podiatry, and allocates the team required. Either a social worker or an occupational therapist undertakes care coordination in the RHP. The allocation of a care coordinator is dependent on the referral source of the client. This is mainly for administrative efficiency but is occasionally varied if it does not suit the needs of the client.

4.5.4 Brokerage

As the RHP is provided as an alternative to hospital-based rehabilitation, the costs that would normally be associated with hospital care are borne by the program. These include any community services required by the client, for example, home care and meals on wheels; nursing and medical care; attendant care; medical tests and pharmaceutical requirements; transport; and a personal alarm system.

These services are provided to the client on the basis of the client's needs and are negotiated with the care coordinator. Where there are carers, some of their costs may be covered too, for example, delivered meals or transport. This may be done to relieve them of some household tasks so that they can care for the client or, in some cases, where the client is usually the one who undertakes these tasks but is not able to at the time. If the costs of these services are expected to exceed the cost of inpatient rehabilitation, the client would not be offered the option of RHP.

4.6 Client pathway

The tasks associated with the client's pathway through the RHP are illustrated in **Figure** 6 below:

Pre-admission → Admission → Program → Discharge → Follow-up

Assessment by rehabilitation specialist	RHP staff transport client home and ensure home is adequately equipped	Initial assessments by allocated team, eg, nursing physiotherapy, and dietitian	Need for ongoing services and equipment established and referrals made	Phone contact three months post discharge
Occupational therapy home visit	Screening for dietitian, speech pathology and podiatry needs	Client goals set	Referral to CRC if required	Client Satisfaction Survey posted to client
Meet with care coordinator	Team allocated	Team goals and foci set	Information about community services provided	----
Informed consent	First week program set	Weekly review and update to client and GP	----	----
Services and equipment	----	Treatment based on goals	----	----
GP, referral source notified	----	Team and family meetings	----	----

Figure 6 Rehabilitation in the Home Program Client Pathway

4.7 Summary

In this chapter, the way in which the client-centred approach to rehabilitation is put into practice in the RHP has been described. The question of whether this description fits with the experience of clients and staff of the program is the subject of this study. In the next chapter, the methodologies employed to conduct the evaluation of the RHP will be described.

Chapter Five
Methodology

5.1 Introduction

This chapter outlines the research methodology used in the evaluation of the RHP. The neasures have been described and critiqued, the ethical issues discussed and the pplication of the methodology outlined.

5.2 Theoretical framework

As discussed in Chapter Three, the methodologies used in this study have been derived from both critical theory and symbolic interactionism. In line with these theoretical pproaches, the views of the program participants, that is, clients, carers and staff have een sought. Although the RHP participants may not be aware of the relationships of ower that are impacting on their experiences, through a critical approach to the analysis f the findings, the author aims to bring uncover these influences. The recommendations an then be made with some awareness of their broader political, cultural and economic mplications.

n addition, through the distribution of the results of this study to BHS-QEC management nd staff, and the contribution of this study to the Continuum of Care Pilot the interests f the participants will become more widely known. This process could potentially ncover and challenge the existing power dynamics within the health system.

5.3 Study design

The study design included aspects of an impact evaluation and a process evaluation (Owen, 1993). An impact evaluation is used *"to assess the impact of a settled program"* and may include assessment of the extent of achievement of stated objectives, the attainment of outcome indicators or a compilation of intended and unintended outcomes (Owen, 1993, p24). A process evaluation is concerned with the practice and activities of a program. It may be used to *"make decisions about a program during its formation"* (formative evaluation) and/or *"to assist those responsible for delivering a program to improve their practice"* (Owen, 1993, p25). In this study, qualitative and quantitative measures have been used to explore the extent of achievement of the aims of the RHP from the point of view of the clients, carers and staff who participated in the program during its first year of operation from 1st March, 1996 to 28th February, 1997. The timing of the evaluation was chosen because the RHP was a pilot program, initially funded for one year, and it was necessary to demonstrate its effectiveness or otherwise by the end of this period so that a decision about its future could be made by the management of BHS. As the RHP was still in a formative stage during this period, the evaluation also aimed to improve the service delivery process in line with the feedback received from participants.

The foci of this evaluation were both program outcomes and delivery. A focus on program outcomes was important for accountability purposes and to make a decision about whether the RHP should continue. The way in which the program was delivered may have had an impact on these outcomes so it was necessary to focus on the process of service delivery during the evaluation and to make changes as required.

Data was collected using a Client Satisfaction Survey (CSS), two administrations of the Caregiver Strain Index (CSI) (Robinson, 1983), a staff survey and two focus groups, one involving clients and carers and one involving staff, were undertaken. **Table 2** illustrates the relationship between the tools chosen and the aims and objectives of the study.

Table 2 **Study Design**

Aims	Objectives	Methodology	Tools
1. Effectiveness	1.Client satisfaction	Quantitative	Client Satisfaction Survey (CSS)
	2. Carer strain	Quantitative	Carergiver Strain Index (CSI)
	3. Choice	Quantitative Qualitative	CSS Client focus group
	4. Active participation	Quantitative Qualitative Qualitative	CSS Client and staff focus groups Staff survey
	5. Reintegration	Quantitative Qualitative Qualitative	CSS Focus groups Staff survey
	6. Relevance	Quantitative Qualitative Qualitative	CSS Focus groups Staff survey
2. Appropriateness of model	7. Importance	Qualitative Qualitative	Staff survey Focus groups
	8. Satisfaction	Qualitative Qualitative	Staff survey Focus groups
	9. Comparison between staff and clients	Qualitative	Focus groups
3. Model development	10. Application of the results of above	Qualitative analysis of data	CSS Focus groups Staff survey

5.3.1 Triangulation

In this study, all three methods of triangulation were adopted. Clients, carers and staff provided three different sources of evidence, qualitative and quantitative methods were used and different researchers contributed to the conduct and analysis of the methodology. Triangulation refers to the use of multiple strategies for *"...mutual confirmation of data to ensure that all aspects of a phenomenon have been investigated"* (Knafl and Breitmayer, 1989, in Krefling, 1991, p219). Triangulation may involve the use of different sources of evidence, different methods and different researchers in a process of checking and verifying the findings (Miles and Huberman, 1984).

The use of both a satisfaction survey and a focus group with the RHP client group enabled the researcher to go beyond the questionnaire items and explore the issues raised by the respondents with a subgroup of clients. To minimise the possibility of researcher bias, the researcher invited colleagues to act as co-researchers on an aspect of the program. The researcher was present at the focus groups but they were both moderated by colleagues experienced in conducting focus groups. Colleagues were also involved in the analysis of focus group transcripts, in developing the CSS and in collating and analysing the quantitative data.

5.4 Description of measures

5.4.1 Client Satisfaction Survey

The Client Satisfaction Survey (CSS) was adapted from a survey already in use at the Queen Elizabeth Centre, as a follow up from inpatient rehabilitation. The questions relating to hospital care were deleted and some questions relating to the aims of the RHP were included. A copy of the CSS can be found in Appendix D.

The original survey was adapted from the survey used at the Royal Talbot Rehabilitation Hospital in Kew, Victoria. The adaptations for the RHP evaluation were made by the RHP Advisory Group, a group that consisted of staff from Rehabilitation Services (Medical Director, Director of Allied Health, Physiotherapy Clinical Leader, Social Work Clinical Leader, Charge Nurse of the Inpatient Rehabilitation Unit, General Stream Leader, RHP Coordinator, Occupational Therapist and other RHP and Rehabilitation Services staff attended as required). The Advisory Group had a strong research background with five members having completed post- graduate research. This meant that they had a good understanding of the ethical and methodological requirements of the RHP evaluation.

Although the survey had not been validated as a measure of client satisfaction, it was chosen for the purposes of this study because the original version had already been trialled in the inpatient program. It had generated a 66% response rate in that setting with a similar client group so it was assumed that the client population had found the survey to be readable and comprehensible. The survey method was chosen because satisfaction surveys enable access to a large group and are cheap and easy to administer (Avis et al, 1995 and Lund, 1996). The author acknowledges the need to develop reliable and valid measures of consumer satisfaction. This issue will not be addressed by this study, however, as it is currently the focus of another trial being conducted across three extended care facilities, including BHS-QEC.

There were a number of steps taken to improve the reliability of the CSS. Apart from the addition and deletion of questions, some questions were reversed to add to the reliability of the survey. The scale of strongly agree to strongly disagree was chosen to give balance to the responses, that is, each response has a balancing opposite response (Lund, 1996). A mail out method rather than face-to-face or telephone method was used as this has been found to bias the responses less in favour of the researcher (Lund, 1996).

Questionnaires are limited by the questions asked. Even though there is some scope for respondents to provide written comments, they tend mainly to answer the questions posed in the survey (Avis et al, 1995). Satisfaction surveys in particular have been criticised for not first identifying the expectations of health care consumers and then gauging the extent to which the service measures up to these expectations (Avis et al, 1994; and Lund, 1996). They also provide no opportunity for the researcher to clarify or explore the answers or comments given. These problems were addressed in this study by using a focus group as well as a satisfaction survey. This gave the researcher the benefit of in-depth discussion of the issues raised in the satisfaction survey with some of the program participants.

5.4.2 Staff Survey

The staff survey, provided in Appendix E, was developed by the author and the RHP Advisory Group to distinguish areas for discussion in the focus group. Staff were asked to consider the advantages and disadvantages for themselves and for clients and families participating in the RHP. They were also asked to identify any staff training needs they had in relation to their work in the RHP.

The staff survey was used only once as a qualitative tool to enable access to the views of a larger number of staff than could attend the focus group. It shared some of the advantages and disadvantages of the satisfaction survey discussed above. It was quick and easy to complete, it enabled access to a wider range of opinion than the focus group. However, it did not allow for in-depth discussion or clarification of the issues raised.

5.4.3 Caregiver Strain Index

The Caregiver Strain Index (CSI) is a 13 item scale that measures the extent to which the carer experiences sleep disturbance; inconvenience; confinement; family adjustments; physical strain; changes in personal plans; emotional adjustments; upsetting behaviour; the person being cared for seeming to be a different person; work adjustments; financial strain; and feelings of being completely overwhelmed. The CSI was developed by Robinson (1983) and has been validated for use as a screening instrument for detecting strain. A copy is provided in Appendix F. The author was interested in whether participation in the RHP increased or decreased over duration of the program. In order to compare the results of the first administration of the CSI with the second, the response type was changed from the original Yes/No to a 10 centimeter Likert Scale ranging from Always to Never. The CSI has not been validated for use as a Likert Scale.

This measure was chosen because it was simple to administer, it has been shown to be valid and reliable as a measure of caregiver strain and it could be adapted for use as a before and after measure. Furthermore, as with the CSS, staff at BHS-QEC were familiar with the instrument. This meant that there was minimal disruption to their usual work practices and no training required. These issues were important at the time because staff were being asked to change their work practices to incorporate the RHP, so any further disruption due to program evaluation had to be minimized.

There were a number of problems for staff associated with the use of this measure. It was found to be an excellent clinical tool for the social work staff as it helped them to focus interviews on areas of potential strain for carers and to guide their interventions accordingly. This meant, however, that they were reluctant to re-administer it for research purposes when there was no clinical benefit in doing so. They felt that it changed their relationship with the carer from second to third person, from *acting with* the carer to reduce any strain to *observing* the carer and his or her experience of strain (Discussion with BHS social workers, 1997). Consequently, there were 34 initial and only 11 second CSIs completed.

5.4.4 Focus Groups

A focus group is another name for a group interview or group discussion where the focus is on a particular topic of interest, usually a health problem or a response to a situation or issue (Hawe, Degeling and Hawe, 1990). Focus groups can be useful in the formative stages of program development (Murphy et al, 1992). They were used in this study to explore the responses of clients, carers and staff to their experience of the RHP. Focus groups were chosen as a research method for a number of reasons:

1. They gave participants the opportunity to identify the issues they wanted to discuss and express them in their own words.
2. They offered a way to clarify and gain a more in-depth understanding about the responses collected from the staff survey and the CSS.
3. They gave the program coordinator immediate feedback about problems with the RHP that could then be addressed in a timely manner.

4. The participants were able to support and encourage each other to raise problems and concerns they had about the RHP.

5. There were members of staff who were experienced in conducting focus groups available to assist the researcher.

The disadvantage of using focus groups in this study was the low attendance rate for the client focus group. Eight clients and three carers attended out of 41 invitations which were addressed to clients inviting the client and a carer or friend to attend. This meant that it was difficult to generalise from the group to the whole client population.

5.5 Population and sampling

Client Satisfaction Survey

There were 101 completed admissions to the RHP from March 1996 to March 1997. Eighty-four Client Satisfaction Surveys (CSS) were sent out during the evaluation period. Seventeen clients were not sent surveys: seven had died; four were in hospital when the survey was sent out; four had had more than one admission; and two clients were terminally ill.

Client Focus Group

The client focus group was conducted in December, 1996, nine months after the program commenced. There had been 49 admissions to the program to the end of November, 1996, and 41 of those clients were invited to attend with a family member. The other eight clients were not invited because five had died, one was in hospital, one was in a nursing home and one was terminally ill.

Staff Survey

All Rehabilitation Services staff who had worked in the RHP were asked to complete the Staff Survey. The continuum of care model, discussed in Chapter Four, meant that it was not known how many staff had worked in the RHP so surveys were distributed to all staff, with a request that they be completed by participating staff. Twenty-five responses were received out of 40 surveys distributed.

Staff Focus Group

For the staff focus group, identified discipline leaders were asked to nominate a representative of that discipline to attend the focus group. Nine of the ten disciplines invited to attend were represented and one discipline sent two representatives. There was no representation from the medical staff but there was representation from physiotherapy (2), occupational therapy (1), orthotics (1), nursing (1), social work (1), prosthetics (1), allied health assistant (1), dietetics (1) and speech pathology (1).

Caregiver Strain Index

The CSI was used in all cases where the client had a primary carer. The criteria for selection of a primary care were, a person who was living with the client for the duration of the RHP who was providing assistance to the client or whose presence in the home was necessary for the safety, security or wellbeing of the client. If there was more than one carer, the one who provided the most assistance to the client was selected. If the client lived alone or in a facility where a primary carer could not be identified (such as a hostel) then the CSI was not completed. All other carers were included in the carer sample.

Table 3 below illustrates the timing of the measures and the sampling strategies chosen.

Table 3 **Timelines and Sampling**

Measure	Sample	Timelines for inclusion	Administration
CSS	All clients	March 1996 – March 1997	Two weeks post discharge
CSI	All primary carers	July 1996 – February 1997	On admission and discharge
Staff survey	All participating staff	March 1996 – August 1996	August 1996
Client focus group	All clients with a friend or relative	March 1996 – November 1996	December 1996
Staff focus group	Discipline representatives	March 1996 – August 1996	September 1996

5.6 Ethical issues

Ethical approval for this study was granted by the Human Research Ethics Committee of the University of Ballarat at their meeting number 99/EM01 as shown in Appendix G. The Chief Executive Officer at BHS-QEC gave written approval for the data collected by the author in her evaluation of the RHP to be used to complete this study, a copy of which is provided in Appendix H. All ethical principles were followed in conducting this study as discussed below.

No information that identified respondents was collected on the CSS and identifying information about staff was deleted before the results were reported. As there was a collection period of 12 months, the completed surveys were kept in a locked filing cabinet in the RHP office until the time for analysis of the results. Prior to this the RHP manager screened the surveys in case any issues which required immediate action were raised.

The CSIs had the client's Unique Registration (UR) number written on them. This was done to enable the first measure to be matched with the second. Once completed by the social worker, these forms were placed in a locked filing cabinet in the RHP office. The researcher who collated and analysed these data had no other relationship to the respondents and could not identify them by looking at the form. There were no identifying data on the staff survey.

In the introduction at the commencement of the focus groups the need for the participants to keep confidential the information disclosed by others was explained and their cooperation requested. The interviews were audio-taped and the tapes were transcribed by a typist who understood the need to keep the information confidential. All identifying data were left out of the transcripts.

During the period of the study the results of the CSS, CSI, Staff Survey and the focus group transcripts, both hard and disk copies were kept in a locked filing cabinet in the RHP office. The computer disks containing the only copy of the transcripts as they were not saved on the hard drive. Following completion of the study the information will be stored in the BHS archive for a period of five years after which time it will be destroyed.

There was a possibility of distress to participants in the focus groups and to carers completing the CSI. This was addressed in the following ways. The focus groups were both conducted by qualified and experienced occupational therapists. Both of these moderators had over ten years experience in the rehabilitation field and had demonstrated group facilitation skills. The author and the moderator planned the steps that would be taken if anyone became upset during the group. If this did occur, the group process was to be interrupted or terminated while the distressed person was debriefed and if necessary, referred to counselling which was immediately available on the premises. This did not prove to be necessary.

The CSI was completed in an interview format with a qualified social worker. It was used as a clinical tool to identify those areas that were causing the carer distress so that assistance could be offered to resolve those issues. It was possible that it could raise subjects that were emotionally distressing to the carer. Its use as a research tool was secondary to this and it was not used in cases when the social worker felt that it was inappropriate for any reason including that it might cause distress above and beyond that usefully experienced in discussing these issues with a social worker.

As part of the consent to participate in the RHP, clients and carers agreed to data collected from them being used for research purposes. Each time a particular measure was used, its purpose was explained and the respondent was given a choice about whether or not to participate. In addition, it was explained that their participation in research did not have any influence upon their participation in the program. Copies of the consent form and the letter inviting clients and their carers to participate in a focus group are found in Appendices I and J.

Apart from strategies relating to participant distress outlined above, the Manager of Rehabilitation Services was kept informed of the responses received via the CSS, CSI, the staff survey and the focus groups. If anything had emerged that required immediate action, for example, allegations of abuse or neglect by staff, these would have been acted upon immediately. There were no such allegations.

5.7 Application and analysis

The following section outlines the way in which the methodologies were put into practice and the results analysed.

5.7.1 Client Satisfaction Survey

The CSS was sent to every RHP client at two weeks post-discharge from the program. A letter from the Manager, Rehabilitation Services, requesting their response was attached (See Appendix K). There was no identifying information on the questionnaire so the respondent's anonymity was assured. A stamped envelope addressed to the RHP Coordinator was enclosed.

The results of the CSS were collated by the Manager of Rehabilitation Services and then analysed by the researcher using the SPSS computer program. An overall satisfaction rate was calculated on each of the sixteen items. The items were allocated a numerical value, with strongly disagree rated as 1 and strongly agree rated as 5 (See **Figure 7**). The percentage frequency of answers rating either a 4 or 5 was calculated for each item, giving a percentage agreement or satisfaction rate. With the negatively worded questions the procedure was reversed and strongly disagree was rated a 5 and strongly agree rated as 1.

1	2	3	4	5
strongly disagree	disagree	neither agree nor disagree	agree	strongly agree

Figure 7 **Client Satisfaction Survey Response Scale**

5.7.2 Caregiver Strain Index

The CSI was administered by a social worker during an interview with the carer within two days of admission to the RHP and within two days of discharge. The carer was asked to rate each statement according to the extent to which their lives had been affected, from not at all to all the time (see **Figure 8**).

0……1……2……3……4……5……6……7……8……9……10

Not at all All the time

Figure 8 **Caregiver Strain Index Response Scale**

The results of the Carergiver Strain Indices were entered into an SPSS table and the difference between the first and second measures was calculated and tested for significance. Unfortunately, for the reasons discussed earlier, there were only 11 complete sets of data entered.

5.7.3 Staff Survey

The staff survey was placed in the pigeon-holes of all Rehabilitation Services staff who may have participated in the RHP. Forty copies of the survey were distributed. The survey included a brief explanation, a request that it be completed and returned to a box in the GS1 Writing Room.

As the survey questions were open-ended, the results were analysed according to the number of times a similar response was given, for example, the most frequently recorded response to the question asking staff to identify negative aspects of the RHP for themselves was transport or travel problems.

The results of the staff survey were used to provide a starting point for discussion at the staff focus group. The issues identified in the staff survey were validated by and explored further in the focus group.

5.7.4 Focus Groups

Discipline representatives were invited to attend the staff focus group. The process of selection and invitation is outlined in 5.5 above. A staff member who was employed as a researcher and did not have a clinical or supervisory role in relation to the staff who attended the group acted as the moderator. The prompts used were taken from the staff survey. Staff were asked to identify the positive and negative aspects of working in the RHP and to discuss any changes they would like to see made to the program. The group was held in a hospital meeting room and afternoon tea was provided. The group lasted for about one and a half hours and the conversation was audio-taped.

The focus group was transcribed and analysed according to the steps suggested by Murphy et al (1992). Firstly, the tapes were fully transcribed by a typist who omitted any personal references. The full transcript was read by three staff members: the researcher/program manager, an occupational therapist who had worked in the program and the senior social worker. The latter two were familiar with focus group research.

Major themes were identified by each of the analysts and comments relating to each of these themes were highlighted in different coloured markers. The researcher then cut and pasted the responses into the themes identified. Quotes were selected that substantiated the various points of view within each theme and subtheme. The results were written up under category headings according to the themes and subthemes identified, with quotes used to illustrate the findings. The cut and pasted results were then shown to the analysts and some of the participants for validation. The results section of this study includes a summary of the findings of the above.

The clients invited to attend the focus group were sent a letter of invitation. This was followed by a phone call to see of they had received the letter, to answer any questions and encourage their attendance.

Transport was provided if required and, although all participants made their own way there, some did accept the offer of a taxi home. The group was moderated by an experienced occupational therapist and attended by the researcher/program manager. The clients were asked what they had found to be the positive and negative aspects of the RHP and what areas they would like to see changed. The group lasted for about an hour and a half and morning tea was provided. The focus group was audio-taped, transcribed and analysed as for the staff focus group described above, with the exception of checking with participants.

In the following chapter, the results of these surveys and focus groups are outlined.

Chapter Six

Results

6.1 Introduction

This chapter has divided the results of this study into three sections, the first relating to client perspectives, the second to carer and the third to staff perspectives. In this chapter, client, carer and staff perspectives are discussed in relation to the research objectives outlined in Chapter One, using the results of the Client Satisfaction Survey (CSS), the Carer Strain Index (CSI) and the client and carer and staff focus groups.

6.2 Section One: Client Perspectives

6.2.1 Objective one: Overall satisfaction with the RHP

As mentioned in Chapter Five, client satisfaction was measured through a Client Satisfaction Survey that was sent to every client at two weeks post-discharge from the RHP. The CSS results provide an overall satisfaction rate and taken individually, some statements pertain directly to aspects of the model of practice used in the RHP, for example, informed choice.

Of the 84 surveys posted to clients, a total of 48 completed surveys were received, a response rate of 57%. The results are based on these 48 surveys, excluding the no response or missing cases.

The overall satisfaction rate was 84.9%. This is an average of the responses in the strongly agree or agree categories (or the strongly disagree or disagree categories for negatively worded statements) for the 16 items on the CSS. These results are illustrated in graph form in **Figure 9** below.

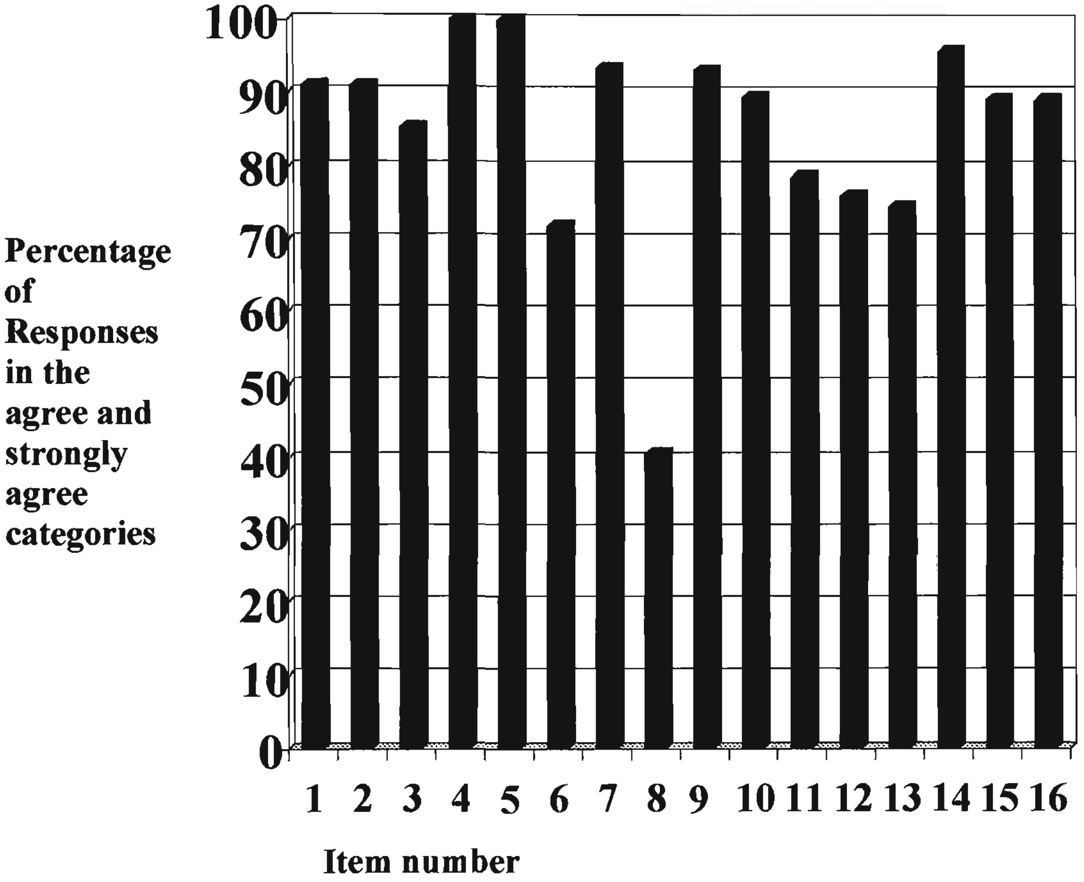

Figure 9 **Overall Satisfaction with the RHP**

There were 20 comments made on the 48 survey responses. They have been grouped as follows –

1. Happy with the RHP, the Queen Elizabeth Centre and or rehabilitation generally – 15.
2. Comments relating to the clients stay on the rehabilitation ward or the Base hospital – 3.
3. Could have done with more rehabilitation – 1.
4. Other – 1.

The RHP Advisory Group decided that a satisfaction rate of 75% or more was considered acceptable, that is, not requiring immediate action, as the RHP was still in a developmental stage at the time the survey was conducted. Items 1 (91.1%), 2 (91.1%), 3 (85.4%), 4 (100%), 5 (100%), 7 (93.4%), 9 (93.2), 10 (89.5%), 11 (78.6%), 12 (76.1%), 14 (95.7%), 15 (89.2%) and 16 (89.1%) fell into this category with an average satisfaction rate of 90.2%. The three items with less than 75% satisfaction were items 6, 8 and 13.

The three items with the lowest response were all negatively worded. However, statistical testing did not reveal a significant difference between the positively and negatively worded items.

Item 6 –"I have not received sufficient information about the causes and nature of my illness", recorded a satisfaction rate of 71.4%. See **Figure 10** below.

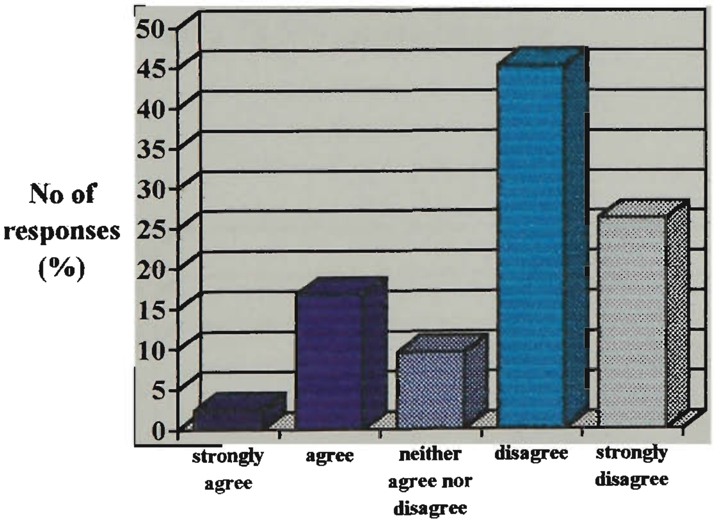

Figure 10 **Responses to Item 6, "I have not received sufficient information about the causes and nature of my illness".**

Item 8, "I have not made as much recovery as I would like since my illness" received a satisfaction rate of 40.5%. This was the lowest level of satisfaction recorded on the CSS as shown in **Figure 11**.

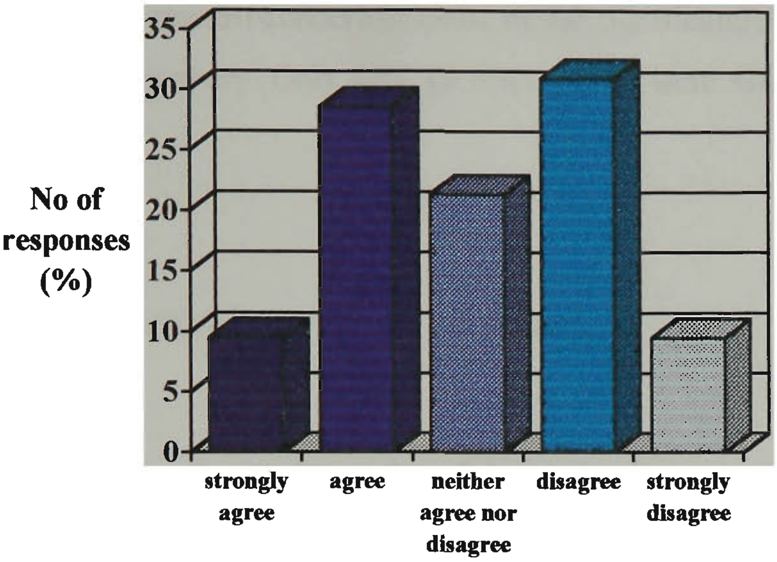

Figure 11 **Responses to Item 8, "I have not made as much recovery as I would like since my illness".**

Figure 12 below, relates to item 13, "I was not given sufficient information about the allowances and services I needed after the Rehabilitation in the Home Program withdrew" which recorded a 74.5% satisfaction rate.

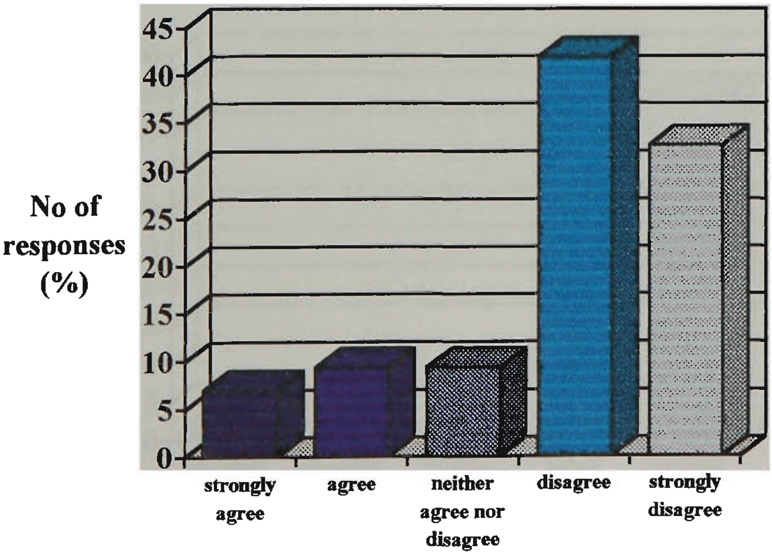

Figure 12 **Responses to item 13, "I was not given sufficient information about the allowances and services I needed after the Rehabilitation in the Home Program withdrew".**

Of these the item of greatest concern because of the significantly lower response rate was item 8, relating to recovery. Only 40% of respondents were satisfied with the extent of their recovery.

6.2.2 Objective two: Model of practice

This section examines the results of the CSS and the client focus group as they relate to the key elements of the model of practice used in the RHP.

6.2.2.1 Choice

The issue of choice was addressed by the CSS and in the client focus group. Item 2 of the CSS asked respondents to identify whether they agreed with the statement, "I felt I had a choice between having my rehabilitation at home and staying in hospital for rehabilitation". The majority of respondents (91.1%) agreed or strongly agreed with this statement (see **Figure 13** below).

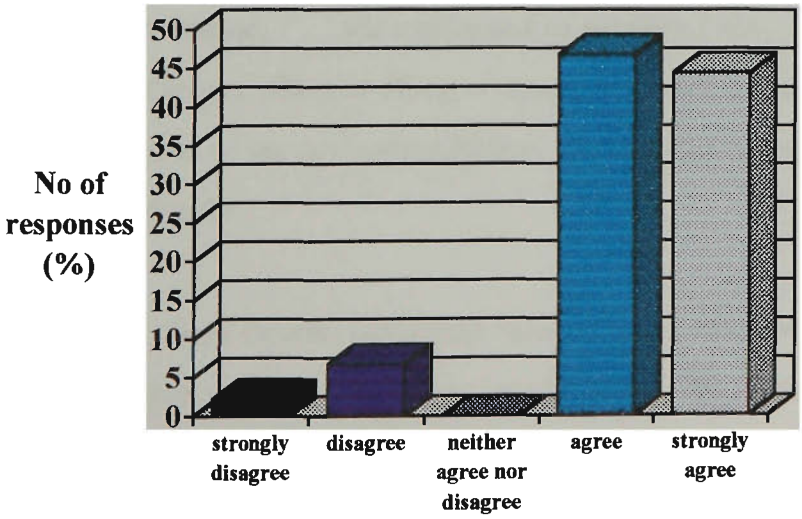

Figure13 Responses to item 2, "I felt I had a choice between having my rehabilitation at home and staying in hospital for rehabilitation".

Informed choice can only be made if the person has sufficient information to make a choice (Law et al, 1995). Item 3 of the CSS, "I received enough information about home rehabilitation to enable me to make a choice" addressed this issue directly. A majority (84.5%) of respondents agreed or strongly agreed with this statement (see **Figure 14** below).

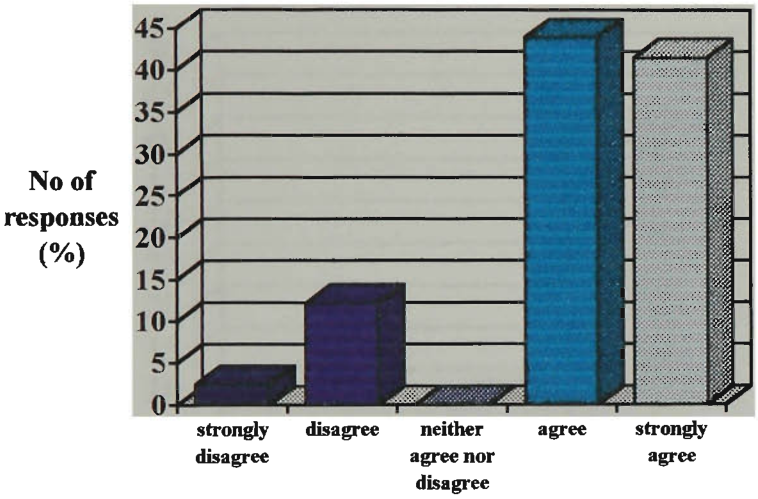

Figure 14 **Responses to item 3, "I received enough information about home rehabilitation to enable me to make a choice".**

In the client focus group informed choice was identified as one of the positive aspects of the RHP. One client stated, "*... she explained to me that I have three options: I could be transferred to the George Skerritt Wing, I could be a day patient but live at home or I could have them come to me at home which is the Rehabilitation in the Home Program. That's the one I opted for...* "

Although a further three clients identified information provision as a positive aspect of the RHP, there were several comments made about the lack of information in the community about the program. Six of the group participants identified the need to advertise the program as an issue: "*... let people know its available because I had no idea it was available to me, and there are so many people who don't know its available...* "

6.2.2.2 Active participation

Item 16 in the CSS was the only item to address participation in the rehabilitation program albeit indirectly, with the statement, "Rehabilitation at home helped me to get back into the things that are important to me". This statement recorded an agree or strongly agree response of 89.1% depicted in **Figure 15** below.

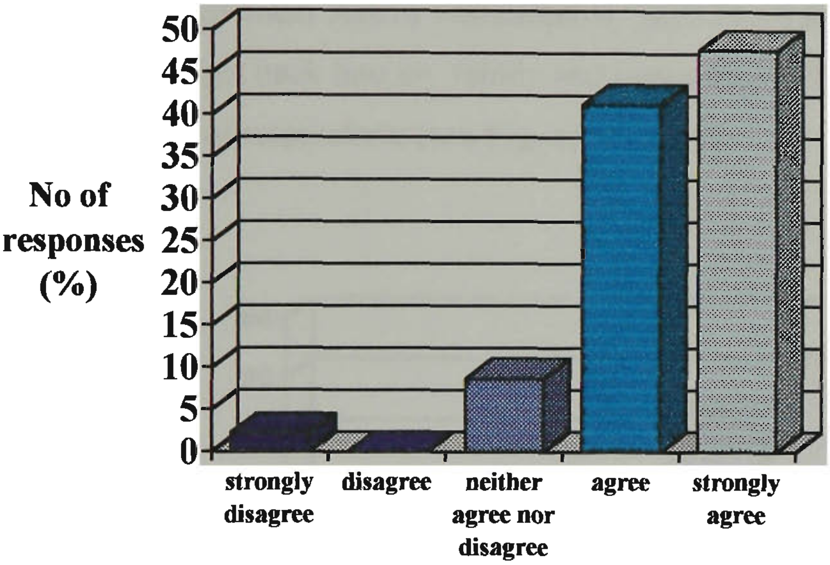

Figure 15 Responses to item 16, "Rehabilitation at home helped me to get back into the things that are important to me".

In the focus group, being able to participate actively was raised in a number of ways. Firstly, as discussed above, being given information and choice was seen as a positive aspect of the RHP, "... *one thing I found so good was all the books they lent me*... ". Secondly, three clients commented that they felt as if they were treated with respect by the staff, as a person, not a patient, *"I wasn't just brought in as a patient, I was welcomed"* and, *"When ... they respect you, you couldn't ask for more."* Thirdly, several clients stated that at home they felt more able to do things for themselves and that this increased their confidence, "... *if you're at home it gives you the chance to get up and do things for yourself*... " Fourthly, being involved in the pre-discharge preparation for home was seen as a good thing, "... *what I liked about it (was) they took me home first, had a look around to see what was necessary... it gave me a lot of confidence*... ". Finally, the focus group itself was used by the participants as an opportunity to share information and ideas with each other, information about pensions, recipes and equipment was sought and exchanged.

6.2.2.3 Community reintegration

The responses to Items 16 and 14 of the CSS relate to community reintegration. Item 16, 'Rehabilitation at home helped me to get back into things that are important to me' has been discussed above under Active Participation. Item 14, "I found that rehabilitation at home helped me to get back into my family and community life" was agreed or strongly agreed to by 95.7% of respondents (see **Figure 16** below).

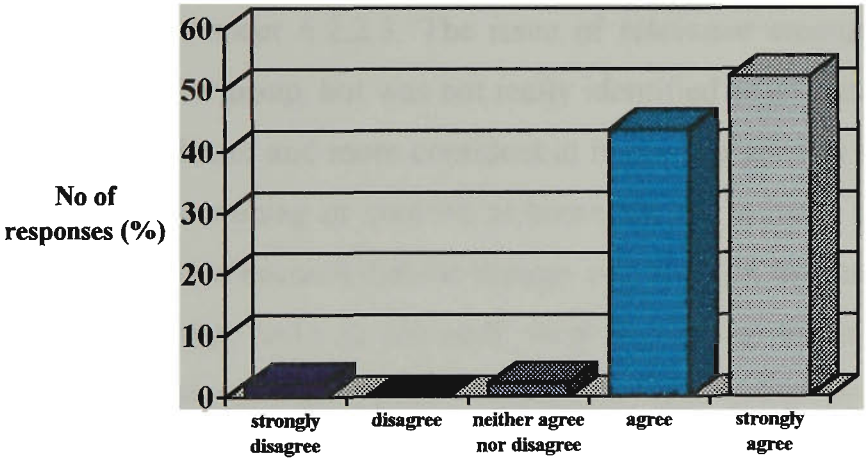

Figure 16 Responses to item 14, "I found that rehabilitation at home helped me to get back into family and community life".

Being able to be at home, in a familiar environment, amongst family and friends was one of the main positive themes to emerge out of the client and carer focus group. For one client, *"... the most important thing for me was being at home and being with what I know and being with the family... "*. Five of the eight client group participants identified being at home as a positive aspect of the RHP. One client said, *"... if you're at home it gives you a chance to get up and do things for yourself which really, when you think about it, is a good idea"*. Another identified being able to get out into the garden as a good thing, *"... I'm quite happy to get out and do a bit of work in the yard and that"*.

One carer said that having her husband at home where he could go everywhere with her reduced her feelings of stress and worry. In response to the question, *"... did you feel there was a burden on you with ... coming home from hospital ?"*, the carer replied, *"No, there wasn't because everywhere I went, even to the supermarket, he wanted to go too, so I wasn't stuck at home, in fact he was the one who wanted to go with me!"*.

6.2.2.4 Relevance

The only item on the CSS which relates to the relevance of the home environment for rehabilitation is Item 14, 'Rehabilitation at home helped me to get back into the things that were important to me.' This received an overall agreement rate of 89.1% and has been discussed above under 6.2.2.3. The issue of relevance emerged as an important theme in the staff focus group, but was not really identified as an issue for clients except in relation to feeling better and more confident at home in a general sense. Some clients talked about doing the ironing or cooking at home but not to make the point that being able to use their own iron ensured that the therapy was relevant to them. It is possible that the tasks seen as therapy tasks by the staff, were so relevant to the clients, that is, so much part of their everyday lives that they did not see them as therapy tasks.

6.2.3 Objectives three and four: Client perceptions of what is important, positive and negative.

In this section the main themes that emerged from the client focus group will be identified and discussed. The focus group transcripts were analysed by three different staff members and the emerging themes have been considered here in order of the amount of discussion devoted to them in the focus groups. An assumption has been made that the discussion centred around the themes that were most important to the participants. The first theme, the relationship with the staff was discussed the most, followed by carer issues and so on. Both positive and negative comments about the RHP have been included under the theme heading.

6.2.3.1 Relationship with staff

Generally the staff of the program, often referred to as *"the girls"* or *"those charming young ladies"*, were regarded very highly by the focus group participants. Most of the comments relating to the staff were very general, for example, *"... they were wonderful to me... "* or, *" I thought they were very good, they did everything they possibly could".* There were several comments about the attitude of staff. *"Yes, same attitude, you were just part of a family – not just a patient".*

Whilst the few comments about the therapy were generally positive, the fact of having someone there, someone to talk to, emerged much more strongly as a theme. *"... just someone to come and talk to you takes a lot of the stress and the strain... when you don't know what's happening, that's the worst, but when you've got someone to sit and talk to you, it alleviates it a bit".* Punctuality was also identified as a positive aspect of the RHP. *"... when they said they'd come at 10 in the morning they were there at 10, not... 1 o'clock – right".*

There were some comments which indicated that the clients felt that staff had less confidence in their ability than they should have had. One client felt that he should be able to drive after his stroke and that the staff member had underestimated his ability in this area. Another found the initial assessment left him feeling less confident. *"... in the beginning I didn't like it – it made me have even less confidence, thinking that 'Gee don't they think I can even lift a kettle up without putting it down... "*, but after a while, *"... it felt good that I could prove to them that I could do it!".*

6.2.3.2 Being able to be at home

Many clients expressed the view that being at home, in itself, was a positive thing. *"I felt that being at home and having the girls come to visit me was a very postive thing".* Being at home meant that clients could be in familiar surroundings, with their families. At home some clients felt more able to get up and do things for themselves and this increased their confidence. Being at home meant that they and their relatives did not have to travel to participate in therapy. *"... it saved the wife dragging in to see me all the time"*.

There was also a view expressed by some clients that after a while it could be a bit lonely and depressing at home, *"... a bit of depression starts creeping in in the second and third week... you don't have people coming and seeing you... "*.

Information emerged as a recurrent theme during the focus group. The issues were the lack of information in the general community about the RHP, the lack of information and knowledge clients had about their illness or injury prior to its onset and the usefulness of information received about the condition and about services available to them once they were admitted to the program.

6.2.3.3 Preparation for discharge to home and discharge from the RHP.

The discussion relating to preparation for discharge to home can be divided into two areas: personal preparation, which included information, expectations and choice, discussed above; and physical preparation, including equipment and services.

The focus group participants found the pre-discharge home visit useful in preparing them and increasing their confidence that they could manage at home: *"... getting in touch with the council home help people... "*, *"... (provision of) the adjustable high chair and the telephone with the loudspeaker ... "* and the fact that *"... all the services were available... "* were all mentioned as positive aspects of the RHP.

One client commented on the need for psychological preparation for discharge from hospital and how setting and deferring the discharge date can be very disconcerting: *"You are in here – you want to get out. Everyone is looking after you and you're going Friday, great... you psych yourself up. I'm leaving and shake hands with all your friends and then bang! No, you're not going – you get pretty down you know"*.

There seemed to be a gap in service provision between discharge from the RHP and follow-up. One client who had suffered an exacerbation in her athritis found that the withdrawal of the RHP coincided with being "weaned off" the strong medication. She did not know that there was any possibility of follow-up from or readmission to the program: "*... when the tablets started to wean off, the pain and everything came back again and I didn't know that I could ask for help, and it wasn't until quite a few weeks later that (the occupational therapist) rang and asked, 'How are you going?*" Once she did make contact with the program again she received the assistance she needed.

The comment above, under 6.2.3.2, about depression creeping in, also related to the time immediately after the withdrawal of the RHP.

6.2.3.4 Overcoming the handicaps

As mentioned above, under Active Participation, the focus group provided the opportunity for participants to exchange ideas about equipment and strategies that they had found to be effective. For example, someone suggested using a thick handled pen for writing Christmas cards and another asked for advice on recipes for one person. They also took the opportunity to discuss with each other the experience of the illness or injury that had led to them requiring rehabilitation in the first place. The experience was described as *"a shock", "a hard battle", "very frustrating"* and rehabilitation as *"the hardest work I've ever done!"*.

Generally, however, the participants had in some way been able to overcome the handicaps. They promoted the importance of motivation, *"If you want to do it, you can do it... "* and the importance of being able to do things that were previously or seemingly impossible. One participant was able to fix a jug, *"... it took me about ten times longer than it would have, but I did it, and you feel good when you have done it... and (being able to do it) is the greatest healer of the lot!"*.

Another participant had this advice to offer, *"Get up and go is my advice... I can mow lawns, I can climb fences, I can climb trees, I can do everything and I'm going on 80!"*.

6.2.4 Summary

In summary, the clients of the RHP seem generally satisfied with the program. They were less satisfied with their access to information about their illness and information about allowances and services on discharge from the program. The issue of information on discharge was identified as an area requiring improvement in the focus group discussion and in the results of the CSS. In the focus group people reported that once they had access to the health system they were given the information they needed about their illness and about the services available. However, this information was not readily available to them pre-admission and post-discharge from the health service.

An area identified as a problem in the CSS, but not in the focus group, was the extent to which clients were satisfied with their recovery. This item received the lowest satisfaction score, with only 40% of respondents disagreeing or strongly disagreeing with the negatively worded item. This result requires further investigation and discussion and will be addressed in Chapter 8.

The themes identified in the focus group indicate that clients regard most of the aspects of the model of practice as important to them. The provision of information, being involved in the preparation for and decision about discharge to home, being treated with respect by staff and being involved in their own recovery were all seen as important to the RHP clients and all are aspects of the model of practice used in the RHP. Some other related issues that were identified as being important to clients were the attitudes of the staff. This was reflected in the way clients felt they were treated, staff punctuality and the expectations clients felt that staff had of them.

The results of the CSS that related to aspects of the model of practice showed generally that the model had been successfully implemented in the RHP. Clients felt that they had been given a choice and given information to make a choice, once access to the health system had been gained. They identified a number of ways in which they were involved actively in the rehabilitation and they felt they were able to get back into their family and community life. There were few comments on the therapy itself, but the relationship with staff, being at home, self motivation and perserverance were identified as important in overcoming the challenges posed by the illness.

6.3 Section Two: Carer perspectives

6.3.1 Introduction

In this section the experience of carers who participated in the RHP are explored as they pertain to the study objectives. The results of the Caregiver Strain Index are analysed and a summary of the focus group transcript relating to carer issues is presented.

6.3.2 Objective five– Carer Strain

Caregiver strain was measured using the Caregiver Strain Index (Robinson, 1983). This was administered on admission to the RHP and on discharge in an interview between the carer and the social worker allocated to the client. There were 11 pairs of data collected and 19 additional initial indices completed. The results were recorded on a ten centimeter Likert scale on which 0 corresponded with 'Always' and 10 with 'Never'. For example, Item 1: "Sleep is disturbed (eg because ... is in and out of bed or wanders around at night)"

0____1____2____3____4____5____6____7____8____9____10

Always **Never**

T-tests for paired samples were conducted on each of the 11 items of the index. There were no significant differences found on any of the items between the first and second administration of the index. There was an overall trend for a slight increase in the results between the first and second administration of the test, which represented a slight decrease in caregiver strain. The mean score on second administration was greater than the first on eight of the eleven items in the index as shown in **Figure 17** below.

As the data are limited to only 11 pairs, it is not possible to draw any reliable conclusions. However, the data do not indicate that home-based rehabilitation increased the caregiver strain in this sample.

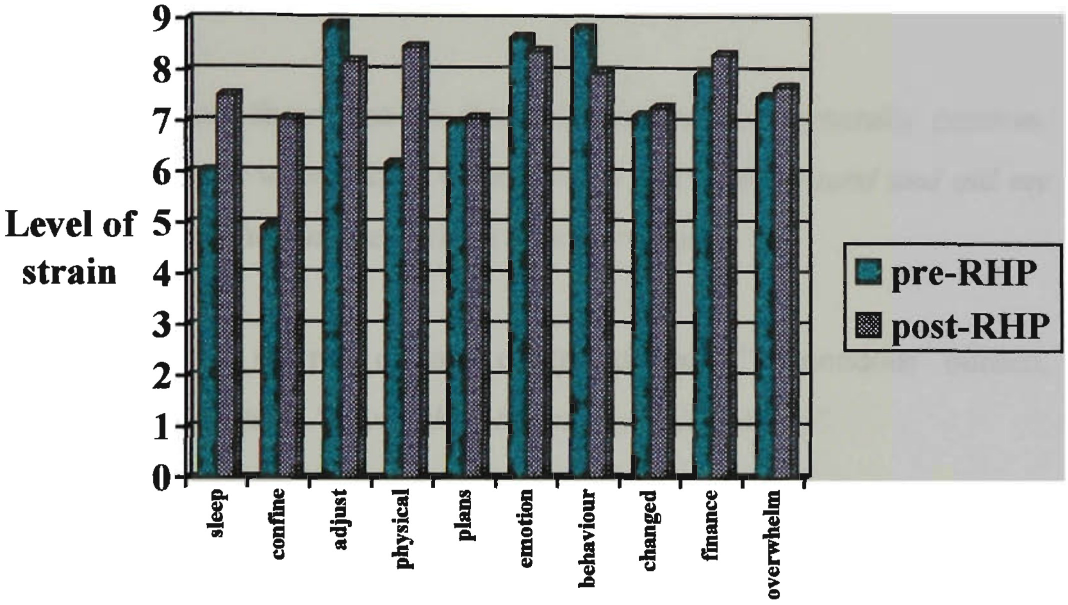

Figure 17 **Carer Strain Index Results**

6.3.3 Objectives three and four: Carer perceptions of what is important, positive and negative.

Carer issues were the second major theme raised in the focus group. Three of the 11 participants to attend this group were carers. Both positive and negative issues for carers were canvassed in the focus group. The role of carer is continuous. It does not stop and start when the client enters or leaves hospital or a program such as the RHP. For this reason, much of the dialogue relating to the caring role was general rather than specific to the time the client was on the RHP. The discussion below, however, has been largely restricted to the comments made about the carers' experiences of the RHP.

There was some ambivalence in the group as to whether there was more or less worry with the client at home, rather than in hospital. One carer saw being at home as less worrying in that she could watch over the client and keep up to date with what was happening. For another, the worry of caring at home was seen by the client as restricting her freedom, "... *when you're in hospital and they want to go somewhere, they can go, but when you're at home they're frightened to go in case something's going to happen*". Another carer felt that if her husband was in hospital she might have more free time.

When asked specifically about their time on the RHP, carers were generally positive. One said, "... *(if) anything went wrong, they were here... I just went around and did my washing and ironing... just left them alone... which was marvelous...* " .

One of the clients talking about the role of carer described it as a "tremendous" burden, but his carer did not agree. She said, "*...you do it because you love them*".

There were some comments relating to carer participation in the client's rehabilitation. For example, a client commenting on the progress he'd made, attributed it to his wife, "*... she pushed me into things, ____ is saying 'Do It'*".

For carers home rehabilitation meant not having to visit the client in hospital and not having to take them in for therapy appointments and this was regarded as a positive aspect of the RHP.

6.3.4 Summary

The results of the CSI did not indicate a trend for strain to increase for carers as a result of their participation in the RHP. Similarly, the focus group did not come to a conclusion about whether or not participation in the RHP had an impact on carer strain. The clients seemed to point to more problems for carers than the carers themselves did. The issues that were of concern to the clients and or carers in the group were; worry, restrictions on freedom, and travel.

6.4 Section Three: Staff Perspectives

6.4.1 Introduction

This section will outline the results of the staff survey and focus group. The aspects of the RHP that staff found to be positive and negative and the issues that staff working in the RHP considered important will be described. In Chapter 7, these results will be compared with the results of the previous two sections.

6.4.2 Objectives three and four: Staff perceptions of what is important, positive and negative.

There were two measures used to assess the responses of staff to the RHP. The issues that emerged from the survey were also discussed in the focus group so the two measures have been considered together and the results grouped under the theme headings. The staff survey asked respondents to indicate what they felt to be the advantages and drawbacks of working on the RHP, for clients and families; and for themselves. The focus group canvassed the positive and negative aspects of the program and the areas in which it could be improved.

6.4.2.1 Working with clients in their own homes

In the staff survey, the main benefit identified by staff, for both staff (25 comments) and clients (16 comments), was that of seeing the client in their own home. Staff found working in the client's own home to be more practical, more relevant, more conducive to realistic assessment and goal setting. This was also the main theme to emerge from the focus group.

For example, staff commented that:

> *...(it is) easier to identify their needs...;*
> *...it is better looking at (how they function in) their own shower than (in) the one in here...;* and,
> *...you often might talk about an aid or producing a strategy to compensate for a deficit, but if you are actually in their own home you will say, OK, what have you got here that we can use?...you use what is in the client's own environment and set up the strategies there....*

There were several comments in the focus group indicating that some staff felt that working with the client at home was more efficient because:

> *...you don't have to try and replicate it either, because you are there. If its getting up and down the steps they have problems with (they can practise) on that step not one that is two inches different....*

Ten survey respondents perceived clients as being happier and more relaxed at home. This was the second most mentioned benefit of the RHP for clients, as perceived by staff. It was also seen as a benefit to staff working on the RHP (three comments) as happier, more relaxed clients were seen to be more motivated to engage in therapy.

In the focus group clients were described as more relaxed in the RHP, but the conversation centered more around the benefits to the client of being more in control. Five staff were concerned that being at home would result in clients feeling worried or insecure because of the lack of supervision. This theme was also raised in the focus group with staff commenting that clients may feel more anxious and insecure at home and that being at home meant less opportunity for clients to have social contact with other clients.

6.4.2.2 Control over therapy

Working with clients in their own home was seen as more client-centred and as giving clients more control over the treatment process (21 comments). One staff member described working in the RHP as, "*...looking at what the individual needs that is different from every other individual...*" and another said:

> *...I find that they speak out more openly about what they want changed, often you will have reports on the ward where people say don't worry about it, more so because they don't feel that they can do anything about it. I find them more directive in the home, more directive about what they want, which I feel is attributed to having the power of feeling that they can ask for it....*

For some staff the perception of increased client control meant that the therapist had less control over the treatment process. This was the second most frequently mentioned drawback for staff who completed the survey, with ten comments, after travel time (discussed below). Sometimes this was related to the client refusing therapy because of other commitments; a feeling that in the client's home they lost their professional authority; or that the client treated the visit as social rather than therapeutic.

This issue was debated at some length in the focus group. Allowing the client to set the goals for therapy meant that some staff felt that they were compromising their professional standards. For example:

> *...even though the client is focussing on function and it may be more relevant to them...the perception is (that) we are trading the functional things for...quality, so in the end there is a bit of a feeling that we have not done our job well enough because the person is not doing it the way we would like them to do it, and that we think they might be able to do it....*

Staff felt that the client's goals often fell short of their own standards of quality treatment. They believed that, at times, clients could achieve more than they were aiming for and that in home rehabilitation, they would only accept the treatment they wanted. *"... they'll ask for what they want and bugger the rest... "*. Some therapists felt that this was also a disadvantage to RHP clients compared with inpatient rehabilitation clients who would get more therapy and therefore achieve a higher functional level.

6.4.2.3 Travel and other organisational issues

The third most mentioned theme in both the survey and the focus group was staff travelling time. Twelve respondents to the survey mentioned travel time as the main drawback of the RHP for staff. Not having to travel was identified as a major benefit of the program for clients and families in the staff survey (five comments).

As one staff member explained:

> *... if it's half an hour there and half an hour back ... even if it's just to the outskirts of Ballarat it can take 15 to 20 minutes. It's a huge chunk out of your day for the hour of therapy... normally you'd see two people in that time or three....*

There were a further 17 comments in the staff survey relating to organisational issues other than travel. Most of these (nine) related to drawbacks for staff working on the program. Staff felt that it took them more time to get their work done on the RHP (five staff), more time to see the patient at home and more time to liaise with the team, collect the patients folder and so on. As someone in the focus group said, *"It's also that the liaising takes longer, the report writing takes longer, the preparation, because you don't have everything at your fingertips like ... on the ward"*.

Issues of communication were also raised as a drawback for staff (four comments) who found it more difficult to have to rely on reports, rather than direct communication and to discuss the client in team meetings.

In the focus group similar issues were raised. Some staff felt that working in the client's own home was inefficient because there were more interruptions and because it was only possible to see one client at a time. Similarly, if the client becomes fatigued, *"...you don't have the option of OK, have a rest for 15 minutes, I'll go and do something else".*

These drawbacks were offset somewhat by some staff finding it easier to organise their work on the RHP (three comments) and that teamwork was better in the RHP (two comments). One staff member commented that the RHP was time effective for clients and this was mentioned again in the focus group. *"Having us come to them is easier".* Two staff members commented that there were more distractions for clients in their own home, which they saw as a drawback for the clients.

The third most frequently mentioned benefit of the program for staff (four comments) was that they enjoyed working on the RHP, they liked working in the community and the break from the ward. Two staff made the additional comment that they would like more RHP clients. For some staff, however, the conflict between the demands of working on the ward and on the RHP, was seen as a major drawback (three comments).

As described in Chapter Four, the RHP has a continuity of care model in which the therapists move from the ward to the community to ensure that the client retains the same staff member throughout the rehabilitation program. This continuity was seen as a benefit to clients (three comments) but as a problem for staff. In the focus group the difficulties this posed for staff were debated at some length. For example:

> *... there are peak times when everybody needs a shower, and often that is the time that the rehabilitation in the home program person has been allocated to have theirs... ;* and
> *... working in two places, in a ward and in the community and you have an interruption to your flow...you are putting everything down, hoping to stay on hold for a while; go out and come back and try to pick it up again.*

There were a number of other issues raised in the survey and focus group that relate to the way the program was set up. There were two comments about the geographical restrictions, suggesting that this was a drawback for clients not living within the program boundaries. There were some comments (two survey and one focus group) about the lack of equipment in the client's home and the difficulty of taking heavy equipment out into the community. The main suggestion for improving the program that evolved from both the survey and the focus group was to clarify the criteria for admission for the RHP as opposed to the Community Rehabilitation Program (CRP), suggesting that there was some confusion about the delineation between these programs.

6.4.2.4 Family involvement and carer strain

Staff perceived the potential for family involvement to be the second most beneficial aspect of the program for themselves (with four survey comments) and the third major benefit for clients (eight survey comments). This result was reinforced in the focus group where the ease of contact with and involvement of the client's family was raised.

Several staff in the focus group mentioned family involvement as a positive aspect of the program and another added that:

> *... from a social work point of view, just that the family like to be there, you don't have to make special arrangements for them to come in. You just get so much information about how they live, and who is important.*

Family involvement was also seen as beneficial to the therapy because the family could see the relevance of it and reinforce the need for it to the client.

Carer strain was also raised an issue for clients in both the survey and the focus group. Four staff identified this as a drawback of the RHP for clients and families in the survey and it was also raised on one occasion in the focus group. In the focus group the difficulty of talking to the client's family privately was discussed:

> *You really don't have much of an opportunity to just say, "Hi, how are you doing?" When they're walking out of a night or coming into visit on GS1 you can catch them very informally.*

6.4.2.5 Intrusion

The main drawback of the RHP for clients and families was seen by staff as having a number of people coming into their homes (ten survey comments). This was perceived as an invasion of privacy and as confusing for clients and their families. This view was further reinforced in the focus group with one staff member describing this as a loss of control for the client.

> *... like they have a lot of people coming into their home and... perhaps they haven't got a lot of control over that. I know there were some issues earlier on with some people who didn't want to be on the program anyway and removed themselves from the program through the invasion of privacy.*

6.4.2.6 Early discharge

Early discharge from hospital and improved follow up after discharge were seen as beneficial to both clients and staff (seven comments) in the staff survey but were not discussed explicitly in the focus group. Some of the dialogue about family involvement and increased efficiency outlined above, also relates to improvement in follow up post-discharge.

6.4.2.7 Education

Staff were asked to identify on the survey whether they required further information or education about home-based rehabilitation and if so, what areas they would like to have covered. Fifteen of the 23 respondents said they would like more information or education and the areas of interest were:

- General information about RHP/ Everything (3)
- Working with clients in their own homes (3)
- Information about the evaluation of the RHP including the results of this survey (2)
- Information about other similar programs (2)
- Transition from acute hospital to RHP (1)
- Client progress (1)
- Fractures, total hip and knee replacements (THR and TKR) (1).

6.4.3 Summary

The results of the staff-related measures indicate that staff perceived that working with the client in their own home was generally beneficial to clients. They seemed more relaxed, happier, more motivated and more in control. The increased participation of family was seen as a benefit for both staff and clients. For staff, however, working with the client at home was viewed as more problematic. Although there were some perceived benefits for assessment and therapy, there were numerous professional and practical drawbacks identified by staff. Professionally, some staff felt less in control over the therapy and sometimes torn between the demands of two programs leading to feelings that they were not doing their job properly. Practically, there were difficulties in finding the time to travel to the client, in communication with other staff and with equipment provision. Staff were also concerned about the lack of supervision for clients at home and the feelings of worry and aloneness that clients might experience. They were also concerned that clients perceived the RHP staff coming into the home as intrusive and that they were confused by the number of staff.

In the next chapter, these results will be compared with the results of the client and carer measures. The common themes will be identified and the areas in which clients, carers and staff differ in their perceptions of the RHP will be discussed.

Chapter Seven
Results and Discussion

7.1 Introduction

This chapter expands on and discusses the results outlined in the previous chapter. In the first section the areas in which clients, staff and carers had common perspectives will be considered. In the second section areas of difference will be reviewed and in the third section, the results will be considered in relation to the client-focussed philosophy of rehabilitation.

7.2 Shared perceptions

There were some areas where staff and clients concurred in their perceptions of the RHP. Both groups identified a number of benefits to the client in having the rehabilitation program based at home. The shared perceptions were that the client was more relaxed; that they could be among family and friends; and that they could do more for themselves, resulting in increased confidence and independence. This finding supported the conclusions of Meeds and Pryor (1990) and Portnow et al, (1991), that clients' confidence and independence was enhanced with home-based rehabilitation. The two groups also identified that being at home could mean increased isolation or loneliness at times. Foster and Young (1990) in their study of a community based alternative to day hospital also noted that clients and their carers may become depressed or isolated at home as visiting the hospital for treatment may be their one opportunity for a social outing. However, they point to the increasing availability of day centres as an alternative to day hospital or inpatient care. RHP clients too are offered the option of participating in day centres or attending the CRC for therapy if they prefer.

The potential for carers to experience increased strain was also identified as an issue by both groups, although the carers themselves were more ambivalent about this. Widen Holmqvist et al (1996) found that although there was some increased strain to carers in their study, it was temporary and suited their preferences. As noted in Chapter Eight, this issue requires further investigation before any firm conclusions can be drawn.

Improved preparation for discharge from hospital was identified by both clients and staff as a feature of the RHP. *"Within a day, I had everything that I needed, I had a high chair to sit on, I had a commode for the bedroom, I had a stool for the bathroom, I had a walking frame, I had everything."* For clients this involved the provision of information, equipment and services, and for staff it meant that they could follow through on therapy commenced in hospital. Gage, Cook and Fryday-Field (1997, p99), in their study of the transition from hospital to home from the perspective of patients, found that emotional preparation for discharge was very important to patients whereas staff were more concerned about physical preparation. For example *"being believed in"* by staff and *"feeling ready for transition"* emerged as important factors for patients in successful transition to home. The availability of rehabilitation services in the home was also found to be important as it *"enabled continued progress toward independence and was essential to the informants well-being."* Preparing the home environment to meet the needs of the client was also found to be an important aspect of the transition from hospital to home by Foster and Young, (1990) and Meeds and Pryor, (1990).

Preparation for discharge was an important issue with the RHP as the program was established in part to reduce the clients' LOS in the rehabilitation ward. In programs where LOS is reduced, discharge planning becomes even more crucial because clients are sent home before they are completely well and therefore require higher levels of support than if they stay in hospital until recovery is complete (Gage et al, 1997 and Funnell, 1997).

Most clients agreed that rehabilitation at home helped them to get back into things that were important to them (89.1%, Item 16, CSS). This perception was shared by staff. Although not all staff perceived this as positive, they believed that at home, the client had control over what they wanted to do and would therefore only engage in activities that were highly relevant to their own perception of their needs.

7.3 Different perceptions

There were a number of areas in which staff, carer and client perceptions of the RHP differed. In some cases the same themes were identified as important but they were experienced differently by the three groups. An American study which focused on the experiences of surgical patients also found differing perceptions between patients and health care providers about what was important in successful transition to community living (Gerteis, Edgeman-Levitan, Daley and Delbanco, 1993, in Gage et al, 1997).

7.3.1 Recovery and therapeutic effectiveness

The CSS revealed that only 40% of clients were satisfied with the extent of their recovery. For staff, the extent of the client's recovery was seen as an important issue and one that they believed reflected on their professional competence. It led to a *"feeling that we have not done our job well enough because the person is not doing it the way... we think they might be able to do it"*. Some staff in the focus group indicated that they felt that rehabilitation at home could result in lower functional outcomes for clients because they may receive less therapy due to practical constraints on staff: *"we were wondering if we were being as effective because we weren't giving the person as much...maybe (only) every second day"* or because they terminate the treatment before the time that the therapist thinks is optimal.

This issue of functional improvement was understandably an important one for staff as the tool used for ongoing evaluation of Rehabilitation Services at BHS is the Functional Independence Measure (FIM). The FIM is used in both the inpatient and home-based rehabilitation programs to measure the extent to which the client has reduced their dependence on others in seven areas of function (Uniform Data Set for Medical Rehabilitation (1993). Thus, for staff, the measure of their performance as therapists was seen in terms of the functional improvement of their clients.

Although the recovery item received a low satisfaction rate in the CSS, recovery or restoration of function did not emerge as an important issue for clients or carers in the focus group. The only focus group discussion that could be related to recovery focussed more on overcoming handicaps. Being able to do things that they had been previously unable to do was seen as important to clients and carers. The clients seemed delighted about these achievements and attributed them to their own perseverance or the prompting of carers, rather than the interventions of therapy staff. For example, one of the clients in the focus group described repairing a jug:

> *... it depends on ourselves a lot. If you are in no hurry to get better, well then you're not going to get better quick, but you've got to have a go at things, things you think you* ***can't*** *do. Like for instance this week, the electric jug was not working, we had another one, but I got out the one that was in bits and got it going, it's going beautiful...*

This supports the findings of Gage et al (1997, p98) that clients *"talked about success coming only through their personal determination to succeed"*.

The clients and carers expressed more concern about their interactions with staff, that is being treated with respect; staff punctuality; and feeling that they could talk to staff, than with their effectiveness as therapists. As mentioned above, clients did not attribute to staff their renewed ability to do things.

The things that staff identified primarily as the benefits of therapy at home for themselves and for the clients were: the ease and effectiveness of assessment; their ability to set realistic goals with the client; and the increased effectiveness of therapy when practised in the home context. For example:

> *I feel that they identify their needs more appropriately at home ... because you are sitting in their home environment and (they're) saying this is the problem for me and I can't do this.*

> and *...you use what is in the client's own environment and set up the strategies there and practice them there (which is more relevant for them).*

This perception by staff, that the home context enhanced the therapy process, has been reported in other studies (Meeds and Pryor, 1990 and Currie et al 1994). Head and Patterson (1997) described a case study in which observing the client in his own environment enabled the therapist to see how resourceful the client was. At home, the client already had in place numerous strategies for overcoming his handicaps, which had not been apparent in the hospital environment.

The perception that clients were happier and more relaxed was also identified by staff and was seen as an aid to the therapy process. For clients, being able to be at home and feeling happier and more relaxed seemed to be an outcome in itself. *"You're better off at home than what you are in hospital anyway, why be somewhere you don't know?"* Clients did not relate these feelings to improvements in therapeutic or rehabilitation outcomes.

7.3.2 Control

The issue of control over the therapy emerged as an important one for staff. There were a number of ways in which staff felt that they had lost control through working in the RHP. They felt that the program was more client-centred (than hospital-based rehabilitation) and that this meant that clients were making decisions about their participation in therapy that the staff did not always agree with. They felt that clients were more likely to have other commitments and interruptions at home that would interfere with their therapy. For example, *"people tend to drop in for a cuppa and all sots of things... So, there goes your hour."* Furthermore, clients were more likely to abandon the therapy altogether even though the therapists felt they could benefit from more. There seems to have been concerns here for staff about the clients' ability to determine for themselves what was best for them. For example, a staff member in the focus group said:

> *...you want what is best for them, like you have a sense of what is there for them even though that might not be what they want to see. I can certainly understand people wanting to strive for that, but what is best for them I guess is what they want for themselves.*

The staff seem be struggling with the view that as professionals they knew better what was in the best interests of their clients than the clients themselves did. As mentioned in Chapter 3, this has been found to be the case in other programs which have attempted to implement client-centred approaches to therapy (Pollock, 1993 and McGrath and Davis, 1995). Gage and Polatajko (1995, p116) suggested that *"paternalism is not necessarily excluded from the client-centred metaphor"* and argue for the term client-driven which puts the client clearly in the *"driver's seat"* with the final say about where they are going and how they are going to get there. The author believes that the RHP, too, needs to go further with the concept of client-centred practice in order to ensure staff acceptance of active client participation in all decisions affecting their rehabilitation. As noted in Chapter Eight, staff education about motivation and facilitation of client-driven decision making may be of benefit.

This paternalism on the part of staff may partly be due to the influence of the biomedical tradition which tends to be more authoritarian and less likely to give credence to the views of patients (Easthope, 1993). The conflict for staff between the philosophy of practice in the RHP and the biomedical tradition has been further outlined below.

Clients did not identify issues of control directly. One of the key issues for clients and carers that emerged in a number of different ways, in both the focus group and CSS results, was the provision of information. " *I didn't know anything about rehabilitation until I was in (a local hospital) and they said that they were going to send me and I didn't know anything about it, never heard of it before...* ".

Two of the three CSS items that received the lowest satisfaction rate related to the provision of information. They were: information about the causes and nature of my illness (71.4%); and information about allowances and services (74.5%). These findings were reinforced by the focus group discussion. Clients and carers felt that they had insufficient access to information about their medical conditions. They also felt that there was insufficient information in the general community about the RHP. After discharge from the program, they identified a gap in information provision about community services and follow-up care. For example, *"Once the tablets started to wean off, the pain and everything sort of came back again and I didn't know that I could ring again for help"*.

It is argued here that information can be understood in this context as a source of power and control for clients (Balnaves, 1993) because without it they had been unable to access the services they needed. From a critical theoretical perspective, the claiming of a body of knowledge as their exclusive province is one way in which professional disciplines compete for status and power (Kenny and Adamson, 1992). As discussed in Section Two of Chapter Three, the provision of information that enables clients to make informed decisions is an important element of client-centred practice (Law et al, 1995). Thus the failure to provide adequate information to clients, especially about the causes and nature of their illness may be an area in which there is conflict for staff between their professional understanding of their role and their desire to empower clients through the provision of information.

There was an apparent contradiction between these results and the results of Items Two and Three of the CSS pertaining to choice and information to make a choice that recorded satisfaction rates of 91.1% and 84.5% respectively. It seems to the author that once in the health service system access to information was ensured. Before and after clients gained access to the system, however, information access was poor.

7.3.3 De-professionalisation and the biomedical tradition

The de-professionalisation of the therapy staff in the RHP, that is, clients experiencing the therapists as friends rather than professionals, was seen as positive by clients. For some therapists, however, this de-professionalisation meant that they were no longer sure of their role and felt that they were not doing their job properly.

Most allied health professionals do not feel that they are regarded as professional equals by doctors or that doctors have an adequate understanding of their profession (Kenny and

Adamson, 1992). Further, it has been argued that attempts to professionalise allied health professions can create frustration in the workplace because the symbols of a profession, such as a code of ethics and a professional association, do not mean that allied health staff have achieved the status of the medical profession. Newly graduated allied health staff become disappointed when medical staff and patients fail to treat them as professionals (Brutven, 1985). Some disciplines, particularly nursing, do not feel that they have adequate professional autonomy or are able to contribute to decisions about patient care (Adamson and Harris, 1996). Allied health professions and nurses have attempted to emulate the activities of the medical profession in order to secure control over their own work and over their interactions with patients (Brutven, 1985; and Gardner and McCoppin, 1988). For example, in his analysis of his own experience as a patient in an orthopaedic ward, Hyndman (1985) describes the competition between doctors and nurses, and nurses and patients for patient care and control. It is argued here that allied health and nursing staff in the RHP were faced with the competing demands. These were the demand of trying to emulate medical model practices in order to gain control over, and professional recognition for, their work and that of working in a program that has a philosophy of practice that attempts to transfer control to the client and family. At the time of this study, this conflict had not been resolved.

It is further argued that the continuity of care approach, which meant that most staff were working in the hospital as well as the community setting, exacerbated this conflict. Nursing staff in community settings, have been found to be less dissatisfied with their professional standing and autonomy than their hospital-based counterparts (Adamson and Harris, 1996). Akroyd, Wilson, Painter and Figuers, (1994, in Adamson and Harris, 1996) found that there were differences in perceptions of professional issues between allied health professionals in hospitals and community settings. They suggested that organisational issues in the hospital setting impacted negatively on the perceptions of staff. One of the areas of dissatisfaction for staff in the RHP was having to work across two program areas. They commented that: *"you have that interruption to your flow... you know you are putting everything down, hoping (it will) stay on hold for an hour... go out and come back and try and pick it up again"*. This issue warrants further investigation but it is proposed here that this feeling of interrupted work flow could have been partly related to the difference in culture and work practices in a community-based, client-focussed program compared with a more medically-oriented hospital-based one.

7.3.4 Practical difficulties for staff

There were a number of practical issues that meant staff felt less in control in that they were less able to organise their work effectively. The most significant of these issues was travel. Staff found that having to travel to the client's home was a major disadvantage to them in working on the RHP. When this issue was explored in the focus group, it related mainly to a feeling that they were wasting their time and/or that they did not have the extra time allocated to RHP clients that they required: "*people perceive that it is time when they'd normally be treating somebody or they might be doing other admin. tasks or whatever, but they're just sitting in the car.*" They believed that their supervisors expected them to continue to see the same number of clients with a mix of RHP and hospital-based clients as they had when they worked solely within the hospital.

Other organisational issues for staff related to needing extra time to work with RHP clients. Staff needed extra time to communicate with each other, to write up reports and for preparation before the visit to the client's home. "*It is also that the liaising takes longer, the report writing takes longer, the preparation, because you don't have everything there at your fingertips like you do on the ward.*" Finally, as discussed above, some staff found that the requirement that they work across two program areas was adversely affecting their work practices.

The responses of staff to the question about their need for additional information and education about the RHP indicated that this too was an area of concern for them. Fifteen of the 23 respondents expressed an interest in further education about home-based rehabilitation. The four main areas they identified were: additional information about the RHP generally; working with clients in their own homes; results of the evaluation; and information about other similar programs. The delineation of the RHP and the CRC was also identified as an issue for staff.

For carers and clients, there was little dialogue relating to organisational issues. However, the few comments relating to travel and convenience were positive. Although having to travel posed a problem for staff, it was important to clients and carers not to have to travel. One carer said, *"Not having to drag myself in to see her was a positive thing."* In Gage et al (1997) study, the loss of the ability to drive was experienced as a major problem for patients and carers. This was also mentioned by clients and carers in the focus group. For example, for one carer who could not drive, the cost of taxis was a real problem. There seems to have been a transfer of inconvenience from clients to staff. Where clients or their carers would have had to travel for their therapy or to visit their relatives, staff were now required to do so. The issue for staff of having to spend more time with the individual client may also have contributed to the clients' feelings that their relationship with staff was better in the RHP.

7.4 Client-focussed rehabilitation

The RHP aimed to practice the philosophy of client-centred rehabilitation that was outlined in Chapter 3. The main elements of this approach are: the primacy of the client and family; a holistic approach; the home and community context; a handicap focus; and an interdisciplinary team approach. In this section, these elements will be discussed in relation to the results of the CSS, staff survey and focus groups.

Regarding the first element, the primacy of client and family, the focus group results seemed to support the RHP's successful implementation of most of the occupational therapy guidelines for client-centred practice (Law et al, 1995) (see Table 1, p47). Both clients and staff felt that clients had increased choice, that they were involved in decision making and took responsibility for their own participation in therapy. The staff comments about the inconvenience to them of working in the RHP and the few comments by clients and carers about these issues indicate that there has been a transfer of convenience from staff to clients, thereby increasing the accessibility and flexibility of the rehabilitation program for clients. Clients and staff both commented on the focus on each client as a unique individual in the RHP, indicating that there was respect for diversity.

The adoption of a holistic approach seemed to be supported by both staff and clients. Although there were very few comments that could be related to this, those that were expressed seemed to agree that it was a feature of the RHP. For example, the staff perception that each client was seen as unique and client perceptions of being seen as a person, not a patient, would seem to indicate that they experienced a holistic approach in the RHP.

The importance of the home and to a lesser extent, the community context, was identified by both staff and clients for different reasons. As discussed above, staff found the home and community context enhanced the therapy process. Clients, on the other hand, just enjoyed being at home, with their family and among things that were familiar to them.

Staff found that in the home they were more able to concentrate on handicap level tasks than in the ward. They felt that this was largely due to the different levels of disability of home-based compared with ward-based clients. For example, *"with neuro patients, you might spend a lot of time with transfers in the early stages when people out in the home don't have that difficulty"*. They also commented that at home clients were more inclined to practice their therapy *"homework"* because *"they're not even homework tasks, because it is a functional activity... they have to do it there (at home)"*.

Clients identified things that were meaningful to them in resuming their life roles as achievements. Mowing lawns, sending out Christmas cards and fixing a jug were some of the tasks that clients had been able to resume after their illness or injury. They did not identify disability or impairment level achievements, such as, limb weaknesses or cognitive problems, but the meaningful life activities that had been rendered difficult by the impact of the illness or injury. Batavia (1992, p157) writing as a consumer of rehabilitation services, argued that *"participants...focus primarily on the handicap level of ICIDH typology"* and that enhanced functional status is not as important to consumers of health care services as the ability to live in their communities, *"even if it requires the substantial assistance of other people"*.

Some of the important aspects of the RHP were not raised in the focus groups nor identified specifically in the surveys. An example of this was the client-centred goal setting process. This process was the primary tool for ensuring client-focus and an interdisciplinary approach in the implementation of the therapy. Clients did not mention at all that they had set goals or worked to achieve goals set with a therapist. However, the accounts of the therapy staff indicated that clients were only prepared to engage in therapy that was related to things that they saw as important. This may have been an outcome of the goal setting process.

Staff in the RHP did not yet seem to have wholly adopted an interdisciplinary approach to conducting the therapy. This issue was discussed in the focus group as an area that staff felt could be improved. Staff suggested that expanding the role of the allied health assistant (AHA), who had an interdisciplinary role, was one way in which the program could be improved:

> *I can see perhaps having an AHA as a core team member on the program is going to be an advantage... so instead of having speech four times a week.. using the AHA 3 or 4 days of the week and speech path only once a week ... " and "Perhaps they will go out and they might do physio and OT and it is a daily program, that one person can do because they are trained to do multi-therapy.*

For example, instead of each of the therapists going to visit the client at home, it was suggested that the AHA could combine therapy tasks in a number of discipline areas around an activity that was meaningful to the client and that he or she had identified as a goal. The AHA has had training in speech, physical therapy and occupational therapy tasks. An example of this might be, going shopping. This activity may involve physical challenges, such as walking; speech and cognitive tasks, such as making a list and requesting items from the shop assistant; and community access by car or public transport.

7.5 Summary

There seems to be a difference emerging from the focus groups results between the values of staff and clients. Clients valued; being at home, being treated with respect by professional staff, being treated as an individual, *"as a person, not a patient"*; and being given information and choice. Siahpush (1998) found that the emergence of a new value system, in which consumers of medical services are demanding choice, control and individual attention was more likely to predict attitudes towards alternative medicine than dissatisfaction with health outcomes. This finding is supported by the results of this study. In the RHP, clients were more concerned about their interaction with staff and issues of choice and information, than with health outcomes.

Staff, on the other hand, valued the assistance to the assessment and therapy process that the home context could provide. Staff were also concerned about the impact that working in the RHP was having on things that were of professional importance to them. These included decisions about the content and duration of the therapy, the improvement in clients' functional ability and control over their own work practices. The implications of these results for the program evaluation, the approach to practice and future research will be discussed in the next chapter.

Chapter Eight

Conclusions and Recommendations

8.1 Introduction

This chapter includes a summary of the major findings of this study, the recommendations flowing from these findings and a discussion of the broader implications of these findings. There have been some additional outcomes that have resulted from this study that will be outlined. The chapter concludes with some of the author's personal reflections on the process of conducting this research.

8.2 Major findings

The major findings of this study were that: clients and carers were generally satisfied with the RHP; there was no indication of increased carer strain; staff differed in their perceptions of what they felt was important, positive and negative, about the RHP compared with clients and carers; and, all RHP participants felt that it was of benefit to the clients to undertake their rehabilitation at home.

8.2.1 Client satisfaction

If the client-centred approach adopted in the RHP was successfully practised during the study period, then a high level of client satisfaction was to be expected. Clients in the RHP indicated that this approach had been adopted and that they valued this approach in practice. Issues such as the provision of information, being given a choice, being treated with respect and active participation emerged as important to clients, all of which were key elements of the client-centred approach.

8.2.2 Carer strain

The non-emergence of carer strain as an issue in the results of this study is an important finding, but one which should be treated with caution due to the small sample of carer participants (34 responses to initial survey). Carers are vital participants in any form of home-based care. The support they can provide is often highly valued by the client and highly valuable in terms of the savings it represents in professional staff time. Although the absence of increased carer strain is a favourable finding in this study, as it was based on only 11 pairs of CSIs, it should not be applied to carers in general or even to all carers participating in the RHP.

8.2.3 Different perceptions

The emergence of such distinctly different perceptions from clients and staff was an unexpected finding. The model of practice, successfully implemented was expected to result in high levels of client satisfaction. However, the finding that there were different and sometimes competing outcomes for staff was not expected. Although there were some areas in which the views of staff and clients concurred, there were more in which their views differed. Issues of control, therapuetic effectiveness, efficient work practices and the professional role of staff were seen differently by clients and staff.

8.2.4 Benefits of home-based rehabilitation

The one area which all RHP participants agreed on was the benefit to the client of having their rehabilitation at home. As discussed in Chapter Seven, staff and clients had different perceptions about why the home context was of benefit to clients. Clients felt it was of benefit to them to be with their family and in a familiar environment mainly for social and emotional reasons and staff felt that it was of benefit for professional reasons. For staff, seeing the client in their home environment enhanced the staff member's capacity to conduct a realistic assessment and to establish an appropriate treatment program.

8.3 Recommendations

8.3.1 Information and education

Recommendation 1: **That information about the RHP be distributed widely in the general community.**

As discussed in Chapter Seven, the focus group revealed that clients and carers were concerned about their access to information prior to, and after, their involvement with the RHP. This meant that people in the general community did not know the RHP was available and were not able to approach the program for assistance directly.

The lack of direct accessibility was partly due to the nature of the program. As it is a rehabilitation program, the RHP is usually required by people who have had a illness or injury severe enough to warrant acute hospital treatment, so referral to the program from acute hospital is the most common way to access the program. It was also partly due to the fact that as a new program, the RHP was not widely known in the general community. This issue needs to be addressed to improve client access to the program.

Recommendation 2: **That the RHP team should provide clients and their carers with more information about the causes and nature of their illnesses.**

This recommendation is made to address the two areas that recorded the lowest satisfaction rates in the CSS. The item related to satisfaction with recovery recorded the lowest satisfaction rate in the CSS. Given the high satisfaction rates on most other items, satisfaction with recovery did not seem to be linked to satisfaction with the rehabilitation services received. The second area to record a low satisfaction rate, however, was provision of information about the causes and nature of clients' illlnesses and this lack of information may have been related to satisfaction with recovery. Better information about the client's medical condition may lead to the client having more realistic expectations about recovery and therefore higher levels of satisfaction. This information should be provided by the RHP team, which includes the client's medical practitioner and the specialist in rehabilitation medicine at BHS.

Recommendation 3: That a discharge information package be developed and given to all clients on discharge from the RHP.

One of the findings of this study was that clients felt that they had been given insufficient information about the services that were available to them after discharge from the RHP. It is recommended that every client be given a package of information about services available to them. This includes those services provided as a follow-up from the RHP as well as information about general community support services.

Recommendation 4: That staff be consulted and offered education about the approach to practice adopted in the RHP.

This recommendation is made to address the difficulties that staff experienced with the RHP model of practice. Most of the findings that related to the model of practice were consistent with the problems identified in the critique of the model in Chapter Three and were discussed in Chapter Seven. First, there was a conflict between client-focussed practice and the biomedical dominance of health care. Second, staff had problems in accepting the transfer of control that client-focussed practice entailed and third, the focus on cost containment meant that the Rehabilitation Service was not able to employ additional staff to develop the RHP.

As the clients and carers were happy with the model of practice and particularly happy with their relationships with the RHP staff, the author believes that it is important to inform staff of these findings and to provide further education about client-focussed practice in rehabilitation.

8.3.2 Carer strain

Recommendation 5: **That further research be undertaken to explore the impact that home-based hospital type programs have on carers.**

The findings of this study relating to carer strain are inconclusive. However, this study and the related literature shows that there is a need for further research into the impact of home-based care on carers. As discussed in Chapter One, there is already considerable reliance on carers in the care of elderly and disabled people. Community care often means family care. Problems for carers may include increased worry and restricted freedom as discussed in Chapter Six, or inability to manage the patient due to the seriousness of their illness and loss of time from work (Brooten et al, 1988). It may be that shifting the burden of care from paid carers employed by hospitals to unpaid carers in the home will result in a reduction in the cost of these services to the state. The cost to carers and clients, however, should also be calculated if a realistic appraisal of the financial impact of these changes is to be made.

8.3.3 Organisational changes

Recommendation 6: **That a nursing position and an allied health assistant (AHA) position be allocated to the RHP.**

Working across two programs was identified as a problem for nursing staff. It was also difficult for them to maintain continuity of care due to rostering restrictions. There did not seem to be much benefit to clients in nursing staff working across two program areas and there was some loss of efficiency and job satisfaction for nursing staff with this model. It is therfore recommended that a nursing position be allocated to the RHP.

One of the original intentions of the RHP was to expand the role of the AHA so that he or she could work with the client over an extended period of the day on home-based tasks that were meaningful to the client. The staff focus group illustrated that therapy staff were still working in a more fragmented way, with each therapist visiting the client at home and conducting discipline based therapy. One of the recommendations from the focus group was that the AHA be used to combine therapy activities around a single functional task to enhance the therapy process and to achieve more efficient work practices within the rehabilitation team. The allocation of an AHA to work exclusively on the RHP would facilitate this change.

Recommendation 7: **That RHP staff have their workloads reduced to reflect the additional time taken for travel and preparation in order to visit RHP clients.**

Although there may be some efficiencies achieved through working with the client at home, staff found that the time taken in travel, additional preparation and being able to see only one client at a time meant that RHP clients took up more of their time than inpatient rehabilitation clients. For this reason it is recommended that this be taken into account when staff workloads are allocated. This may prove difficult to achieve because, as previously discussed, there were no additional staff employed with the introduction of the RHP, yet the same number of inpatient level clients were admitted.[6]

8.3.4 Further evaluation for the RHP

Recommendation 8: **That a focus group for carers be conducted.**

Apart from the Caregiver Strain Index, the only source of feedback from carers was through the client focus group which carers were invited to attend with the client. In order to find out more about the carers experience of the RHP, it is recommended that a

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[6] Six months after the introduction of the RHP, the inpatient rehabilitation program reduced its bed numbers from 30 to 20. The ten beds that were closed were transferred to the RHP. In effect, this meant that the same number of staff were required to see the same number of patients, however, ten clients were now based at home.

focus group be conducted specifically for carers. This would contribute to the ongoing evaluation and quality improvement of the RHP.

Recommendation 9: **That client satisfaction in the RHP be monitored through the distribution of a revised client satisfaction survey.**

In order to assess the impact of the changes that have been recommended in the RHP, further surveying of client satisfaction is recommended. Additionally, some changes should be made to the CSS to address some of the problems associated with its use.

Some respondents wrote a comment on each of the items on the suvey in addition to marking the response which matched their opinion. The format of the CSS did not encourage these comments, so it is recommended that the new survey have a space for comments after each item as well as at the end of the survey.

Second, it was not known whether the CSS was completed by the client or by someone else on their behalf. It was felt that this would be useful information to record as it would enable any differences in the perceptions of clients and carers to be identified. Third, there was no statement relating to the experience of carers. This is also recommended for inclusion in the new survey.

Finally, some, but not all, of the disciplines working in the RHP were identified for specific feedback in the CSS. The other disciplines involved wanted to know whether clients were satisfied with their interventions, so the inclusion of questions relating to the other key disciplines involved in the RHP is recommended.

8.3.5 Research into home-based rehabilitation in Victoria

Recommendation 10: **That a reliable and valid survey be developed to monitor client satisfaction in home-based rehabilitation programs in Victoria.**

In the course of this study and in other work undertaken by the author, no reliable and valid measure of client and carer satisfaction for home-based rehabilitation has been found. It is therefore recommended that the development of such a tool be one of the areas of attention for research into home-based rehabilitation in Victoria.

Recommendation 11: **That a comprehensive study be undertaken of the cost of home–based compared with hospital-based rehabilitation that includes the costs to carers and clients.**

In the course of this study, the author was unable to find any comprehensive costing of home-based rehabilitation compared with hospital-based rehabilitation. In making such a comparison, it would be important to include the cost to carers, including loss of income and the cost of carers time if paid staff were employed in the caring role as these potentially hidden costs could skew the findings in favour of home-based rehabilitation.

8.3.6 The future of the RHP

Recommendation 12: **That the RHP continue to be offered to ~~clients~~ as an alternative to hospital-based rehabilitation.**

The author believes that the RHP should continue to be offered to clients as an alternative to hospital-based rehabilitation. All groups involved in this study, albeit a small carer sample, identified benfits to the client in undertaking his or her rehabilitation at home. It is important however, that clients and their carers be given a choice to come into hospital for their rehabilitation if they prefer. Choice is a fundamental principle of a client-focussed model and this study does not claim that home-based rehabilitation is the best option for all clients and their carers.

8.4 Outcomes

8.4.1 Program improvements

There have been various changes made to the RHP as a result of this study. First information provision for clients has been improved. Clients are now given better information prior to their admission to the program and a discharge package of information on discharge. The care coordinators have a checklist to ensure that clients have a follow-up appointment if required at the CRC and that they know who to contact should they require further assistance.

The RHP team has also taken some steps to improve the information availability in the general community about the RHP. Education sessions have been offered to all community-based agencies and a newspaper article has been published. A display on the RHP has been prepared for showing at all appropriate functions, for example, arthritis week and carers' week.

The RHP team has expanded to include a full-time AHA and a rehabilitation nurse. This has relieved the pressure on therapy staff to some extent as these staff are available for daily monitoring of the client which means the therapists can restrict their visits to weekly or twice-weekly assessment and treatment sessions.

The continuous development and use of a satisfaction survey ensures that practices are constantly adapted to meet the needs of clients. Information provision is an area that requires continuous monitoring and review. For example, the recent influx of clients who had suffered from a stroke indicated that there was a need for more information on the causes and effects of stroke. The role of the care coordinator is also constantly monitored for its impact on clients, carers and staff.

Education sessions for existing staff have been conducted which included the results of this evaluation and discussion about the different skills and approaches needed when working with clients in their own homes. In addition the Director of Allied Health at BHS conducted some sessions with staff to enable them to discuss any problems they had with the RHP and other aspects of their work. This meant that the staff were involved in recommending changes to their workloads and work practices to improve their job satisfaction. Some of the changes that have been made as a result of these discussions are: the allocation of a specific discipline representative to attend the RHP team meetings and planning sessions; the purchase of mobile phones for staff working on the RHP; consideration to be given to the additional work required in the RHP in the allocation of clients; and relocation of the RHP medical records to suit the preferences of staff.

8.4.2 Community Based Rehabilitation Group

In 1997, the author and a colleague from BECC initiated the formation of a group made up of people working in home-based rehabilitation programs in Victoria. This group, called the Community Based Rehabilitation Group has membership from 15 (in November, 1998) home-based rehabilitation programs. The group meets quarterly to discuss the different program models, client-centred goal setting, evaluation and other issues of common interest.

This group has provided the opportunity for discussion and evaluation of the different models of practice adopted by the various programs. It has also provided a forum for the exchange of ideas, for example, a session on the CCGS process used in the RHP was conducted at the November, 1998 meeting. There is scope for the development of new practices that can be adopted by all programs, for example, clinical pathways and the development of research tools for home-based rehabilitation, such as the satisfaction survey discussed above.

8.4.3 Outcome of the Continuum of Care Project

The publication of the findings of this study relating to client satisfaction in the Continuum of Care Funding Model Report (1998) meant that this study has had a direct impact upon Victorian Government policy development. The Report (Calder et al, 1998, p5) found that the alternative funding model could provide improved outcomes for patients without compromising client satisfaction. It also provided support for the further development of *"funding models which support the full sequence of patient care recognising that patient care is best provided by an integrated service system providing genuine options for patients and their carers".*

If the above means that there will be greater flexibility in the way aged care services are funded in the future, then it is to be welcomed. If, however, it is used as support for shifting care into the home as a way to contain and reduce government spending in aged care, then this is of real concern. The RHP was established without any increased funds but until the end of the pilot period, the existing funding had been maintained. This was no longer the case in 1998/99. There has been considerable debate between the HCS staff involved in the pilot project and the HCS staff in the regional office about the current (1998/99) and future funding for extended care services based at the QE. As the author understands it, the regional office is still providing funding on the basis of bed days while the pilot project staff (based at the central Melbourne office) and the three participating health services believed that the Continuum Model had been adopted. For BHS in 1998/99, this meant that a reduction in funding was sustained, resulting in less service provision in Rehabilitation Services overall.

It is important that a critical approach is taken in the analysis of the implementation of government policy in this area. If the need for fiscal constraint is accepted as an unchallengable fact of life, then ways must be found of increasing efficiency, that is, of providing the same level of service with less resources, or as with the RHP, increased services with the same resources. There is an underlying assumption here of existing inefficiency and waste. As the author does not support this assumption, then it is argued here that funding cuts should result in cuts in service provision. If this does not occur then there is a risk of exploitation of staff, through them managing the unfunded portion of their workload by working longer hours for which they are not paid, or exploitation of clients and carers, as discussed above.

8.4.4 Research into allied health staff's attitudes to client-centred practice.

As a result of the focus group findings in this study, the author and two of her colleagues at BHS became interested in the extent to which allied health staff believe in the principles of client-centred practice. The author and a colleague conducted some research into the attitudes of occupational therapists in public employment in Victoria towards client-centred practice. The results, presented at the World Federation of Occupational Therapists (WFOT) Conference in Motreal, Canada in May, 1998 (Peart and Dow, 1998), challenged the perception that occupational therapists had fully embraced the principles of client-centred practice. A similar study conducted with Victorian physiotherapists was presented at the Australian Physiotherapy Association (APA) Fifth International Congress held in Hobart, Tasmania in March, 1998 (Hubbard and Dow, 1998). Although there was no significant differences between the two disciplines, physiotherapists did score slightly lower than occupational therapists on most of the statements about client-centred practice. The results of these two surveys supported the results of this study, for example, that none of the physiotherapists surveyed strongly agreed that the client knows best what is best for them.

8.5 Conclusions

8.5.1 The future of home-based rehabilitation in Victoria

This study has positive implications for the RHP and for home-based rehabilitation in general. The findings that clients are generally satisfied with the program and that all groups identified being at home as the most important aspect of the program in the focus group discussions indicated that home-based rehabilitation was well regarded by the RHP participants.

The future of home-based rehabilitation in Victoria seems assured. As illustrated by this study, the Continuum of Care Funding Model Report (1998) and by Butler and Charlton's evaluation of the Kingston Centre Program (1998), clients and carers in Victoria are generally satisfied with this type of care. There is now a strong network for mutual support, education and research for people working in the area. There is a need for a critical approach to be taken, however, because of the potential for a reduction or containment of Government funding through the expansion of these types of services. It is important that client and carer choice is maintained and their satisfaction monitored to ensure that they are not adversely affected by this shift in service provision from hospital to home.

8.5.2 Models of home-based rehabilitation

Apart from the BHS program, only two other home-based rehabilitation programs have a continuum of care model, BECC and the program based in Wodonga. The other 13 programs all maintain a separate team. Although continuity of staff across the inpatient and home-based programs was not specifically discussed by clients or carers, the author believes that it has some benefits for clients. As the focus group and survey indicated, however, it presents some problems for staff. There is a need for further research into the best way to deliver home-based rehabilitation.

The Community Based Rehabilitation Group will be able to conduct research into the effectiveness and client and staff acceptability of the different models that have been adopted within the group. This research will be informed by this study and by other research currently being conducted in to home-based rehabilitation in Victoria. This will enable the identification of best practice guidelines for home-based rehabilitation in Victoria and will inform the development of new programs.

8.5.3 Implications for the biomedical model

The location of a rehabilitation program in the client's own home has been shown to have implications for staff in terms of their ability to exercise professional control over the therapeutic process. If home-based care is to be the direction of healthcare into the future, then this may mean a fundamental challenge to the culture of professionalism that has to date been an important aspect of the biomedical approach to health care.

If there continues to be a consumer push towards health services that encourage the client's active participation, that are holistic and focus on prevention rather than cure (Siahpush, 1998), then in order to be successful as a medical or allied health professional a client-focussed approach will be required. One way in which the medical profession has already been dealing with the challenges posed to it through the popularity of alternative approaches has been to adopt aspects of this practice (Easthope, 1993). Instead of allied health professionals adopting aspects of the biomedical model in order to achieve professional status, the biomedical model may have to adopt a client-centred, holistic approach in order to maintain its position of power and influence within the health system.

Another problem for the medical profession is the conflict between *" the AMA, who seek more funding for orthodox medicine and the Treasury, who seek to limit funding"* (Easthope, 1993, p289). It is in the interests of Treasury to limit funding by promoting more cost effective health services and by arguing for preventative medicine (Easthope, 1993). Thus the state, a traditional supporter of the medical approach to health-care (Willis, 1989) now, for economic reasons, supports an approach which challenges that model.

8.5.4 Staff perceptions about client-centred practice

The findings of this study indicated that staff at times felt they should be able to decide what was in the best interests of their clients which the researcher believed was in conflict with the clients' fundamental right to self-determination. It seemed that there was a conflict here for staff between rehabilitation outcomes and client satisfaction. Some staff felt that in focussing on client satisfaction, there was a reduction in the rehabilitation outcomes that they would achieve.

Early analysis of FIM results indicate that there was less of an increase in FIM scores from admission to discharge for clients in the RHP compared with the inpatient program (Hubbard, 1998). This may be due to the differences in the client groups rather than the rehabilitation process, but it does support the perceptions of the staff. The author believes, however, that this is more of a philosophical issue than a scientific one.

Hallahan (1995, p3) described the fine line that health professionals must sometimes tread between empowerment and abandonment; and protection and paternalism, in working with disadvantaged clients. She argued that in acting as advocates for their clients, workers should keep in mind the insights of both the empowerment perspective and the protective response, always acting *"to facilitate and lead and not to determine" without "neglecting a real need for protection"*. The view of some of the RHP staff was that in allowing the client to determine the scope and duration of their therapy, they were neglecting their responsibility to the client to help them to attain the best possible rehabilitation outcomes. Abramson (1985, p387) identifies this as one of the most common and perplexing dilemmas in social work practice, that is *"respecting and upholding (the ethical principle of) client self-determination while doing good for a client whose conception of what is good for him or her differs from the social worker's conception"*. Belief in client self-determination is one of the fundamental principles of social work practice (Abramson, 1985). It is also an ethical principle for physiotherapy including the right to *"Choose to cease treatment and accept a level of disability even if further physiotherapy may improve their situation"* (APA, 1990).

So what is the role of the therapist who promotes client-centred practice? Some of the therapists in this study clearly felt that their traditional role of assessment and treatment based on the results of that assessment was threatened by increased client autonomy. Sumsion (1993), in her review of the impact of the Guidelines for Client-Centred Practice on Occupational Therapy, argued that facilitation of the clients' identification of their problems takes more skill than making those decisions for them. She argued that the role of the client-centred therapist is to motivate clients to meet their potential and to facilitate decision making by the client through the provision of information and other resources. This, she argues, is not a way of abandoning the client but rather a way to accept responsibility for *"ensuring that the client understands all the information that is being presented and has all that is needed to make a decision"* (Sumsion, 1993, p8). The findings of this study related to information provision would suggest that this is an area in which client-centred practice could be improved in the RHP. At the same time, staff education about client-centred practices such as: facilitating client decision making; motivating the client; and provision of information in a way that is accessible to the client, would provide some direction to therapy staff about their role in the RHP.

8.5.5 Competing perceptions

The symbolic interactionist framework used in this study encouraged the exploration of the individual perceptions of the study participants. This was achieved through the use of focus groups. Although there was some congruence in the perceptions of people within each group, for example, the staff survey results were reinforced by the staff focus group discussion, there were considerable differences in the perceptions between the groups.

The author believes that this was a particularly useful approach to take because it enabled the underlying conflicts and competing interests that were impacting upon the process of program development to come to the surface. This, in turn made it possible to discuss strategies with staff to address these problems. It also meant that further research into staff attitudes and beliefs was initiated.

These conflicts and competing interests need also to be understood as reflecting the underlying power relationships that are part of a medical model institution. Critical theory provides a framework for analysis of this context. However, this analysis does not necessarily lead to strategies to address these conflicts. It seems to the author that it is easier to address the belief system of staff through education and feedback, than to change the dominant power structures that exist within the health service system.

Some critical theorists emphasize the importance of enlightenment in empowering people and freeing them from the constraints of existing power relationships (Fay, 1987, Allen, 1985). Allen (1985) uses the example of psychoanalysis to illustrate the power of bringing to consciousness different interpretations of reality in a health context. The aim of psychoanalysis is for the client to move beyond requiring the help of the analyst for self-understanding and to use *"self-reflection to seize the power and dissolve their own resistance"* (p63). It is argued here that through participating in this evaluation, staff felt empowered to criticise the model of practice and to express their perceptions about the impact of the RHP on their own work practices. The author believes that a system, such as the health service system, in which one group has dominance and power over all other groups will always result in underlying tensions. This study has succeeded in bringing these out for analysis and discussion and has addressed some of the struggles for power between staff and clients. This, however, did not address the overriding inequalities within the system.

8.5.6 Critique of Methodology

When examined from a critical perspective, the use of a focus group to explore the experience of clients and carers in the RHP had some limitations. The focus group was used to explore how practices intended to be client-centred and empowering were experienced by the program participants. This feedback was intended to direct the changes that should be made, giving clients, carers and staff greater control over the operation of the program. The extent to which this approach was successful was dependent on the underlying power relationships. A common criticism of symbolic interactionism is that it focuses on individual meaning at the expense of a critical examination of the forces that shape those meanings (Cheek et al, 1996). Participants in the focus group may have felt constrained to make only positive comments as they may have feared repercussions from the hospital. BHS has power over health services that they may need in the future and therefore they may want to maintain good relations with the service.

In future research conducted at BHS, this constraining influence of the hospital could be minimised through conducting the interviews at a separate venue and using people who are not direct hospital employees as moderators.

A further problem with the focus group method used here was the inclusion of the author who was also the program manager in the group and as the primary interpreter of the findings. This may have influenced the responses of the participants and led to a positive bias in the interpretation of the results.

The failure to conduct a separate group for carers, the limited sample of carers to participate in the study and the lack of reliability and validity of the CSS were also methodological problems in this study that have been discussed elsewhere.

8.6 Personal reflections

As this section focuses on the personal reflections of the author it is written in the first person. There are three areas on which I would like comment on my experiences in the process of conducting this research. The first is that it has been a fantastic learning experience. I have gone from being someone who tunes out in the staff meeting when the conversation turns to outcome measurement or evaluation, to being one of five staff members to run the session on client satisfaction and other outcome measures at a recent weekend retreat. I have also written and co-authored three conference papers and one workshop which were in part based on the findings of this study (Dow, 1997, Hubbard and Dow, 1998 and Peart and Dow, 1998). The second reflection relates to the complexity of roles that I share with many part-time post graduate students and the third to the influence of theory on this study. The latter two areas have been discussed below.

8.6.1 Researcher/ProgramManager/ Student/Wife/Mother/Self

This project has been characterised by the juggling of all the above roles. A few years ago, when I had two part-time jobs, a toddler and a baby on the way, one of the jobs was teaching undergraduate welfare students. At the end of year party I was given the "Juggler's Award" and a set of juggling balls with family, work, and university written on them. In the course of this research, I have often felt the need of a few more juggling balls.

All the above roles influenced the way in which this research was conducted. The more personal roles meant that it was difficult to find the time to study and write and so the project has been completed in fits and starts. The role of student researcher meant that the evaluation had to be more scholarly and rigorous than the workplace required. This, I think, was an advantage and improved the quality and applicability of the research to other rehabilitation facilities.

The duality of roles most pertinent to this study were that of researcher/program manager. Being employed in the agency in which the study was conducted had both advantages and disadvantages. The advantages were that I had immediate access to: the RHP participants; two skilled focus group moderators; people with experience in research who were able to assist; a library with two very helpful librarians; and many people with expertise and interest in the field of research. A major disadvantage was that as the program manager, I could not always be certain of my objectivity. It was in my own interests for the program to be seen as successful and to be given ongoing funding.

Although the results of this research were considered worthwhile by management and staff, and the recommendations were implemented, it was the program's throughput that was most important in determining its continued existence. In the end, the program was successful in attracting referrals and in providing a service to clients so its existence was assured, regardless of my interpretation of the study findings.

A second disadvantage was that it was at times difficult to know who the research was for, myself, as a student of research, the employer, who required the results of the evaluation or the university, which required a certain standard of scholarship. These latter two were a source of conflict for me. Taking a critical perspective, particularly one that included a critique of the biomedical approach and called for caution in the implementation of government policy, put me in a difficult position. Although a student of sociology, I am also an employee of an organisation in which the biomedical model is dominant and my wages are paid through the channeling of government funding into the RHP program budget.

The findings and recommendations of this study relating to the RHP have already been documented and acted upon. This thesis has taken several years longer than would have been acceptable for program evaluation and improvement purposes. In the end, this has meant that, although the impetus for conducting the research was the need for program evaluation (employee driven), the theoretical analysis has been able to be separated out and only included in the (student driven) thesis itself.

8.6.2 Theory

The process of conducting and writing up this research has taught me a lot about the major social theories, albeit with some reluctance. I really just wanted to do a practical piece of research that would indicate where changes needed to be made to the RHP. Initially, I didn't see the need for a theoretical framework. However, as Chapter 3 illustrates, I now believe that the work and the research into it was theoretically driven, however unconsciously this occurred. In fact one of the ways I believe this project could be improved would be to raise my theoretical consciousness at an earlier stage. This would enable me to be more critical of the taken for granted power structures in my workplace and the ways in which they have influenced this research.

A critical approach has revealed that the influence of the biomedical tradition is still strong and influences the way in which allied health staff perceive their roles. This is a very difficult issue for me to address as I am part of the system in which this is the case. The above recommendations address the attitudes of the staff but not the context that creates and perpetuates these attitudes. This, I believe is the real problem that should be addressed. I can only hope that, as discussed above, recent challenges to the biomedical approach may in the end mean that alternative approaches are accepted, if not because they are philosophically embraced, then because they are successful in terms of client acceptance and cost savings.

APPENDIX A

Literature Review Table

Author/s	Date	Approach	Research Purpose	Research Design	Method	Sample	Findings	Critique
Ceder, Thorngren & Walldén	1980	Empiricist	To identify prognostic factors for early discharge and rehabilitation at home.	Longitudinal study Survey research	103 patients given surgical procedures, early mobilisation, early rehabilitation, continued at home. Survey conducted pre surgery, and at 2w, 5w, 4m and 12m post surgery. Pre- and post-op testing for ADL and ambulation.	103 consecutive patients with hip fracture, >50 years of age, divided into 3 groups according to the existence of other medical condition and whether this was expected to affect rehabilitation outcomes.	General medical condition and age were the most important factors. Social factors, such as living with some one, also important. Ability to manage ADL and early ambulation also significant. 76/101 surviving patients returned directly home. At 12 m 78/91 surviving patients at home.	No control group. Measurement of success was determined by researchers rather than participants. Acknowledged importance of carers. No qualitative analysis of the experience of clients, carers or staff. Assertion that being at home is better was not tested.
Brown	1990	Empiricist	To describe and evaluate the Post Acute Rehabilitation Service (PORS).	Case study of program. Evaluation uses an ex post facto research design	Analysis of hospital records.	Hospital records of 1990 compared with 1989 (prior to the program's establishment).	Reduced average LOS for patients with hip fracture. Increased number of operations. Increased productivity. Increased workload for staff. Tentative cost effectiveness claims	Rich and detailed description of a service. No evaluation of the impact on staff from their perspective. No evaluation of the impact on patients. Assertion that home is better for both physical and psychological reasons not tested.
Meeds and Pryor	1990	Empiricist	To describe and evaluate the Peterborough Hip Fracture Scheme emphasising the role of the community physiotherapist.	Quasi-experimental Non random controlled study Two groups of patients with the same medical	Pre- and post-rehabilitation surveys looking at the speed and degree of recovery of pre-injury independence and residence as measured by ADL score, residence, level of	224 consecutive patients, 68 selected as suitable for Hospital at Home (HAH), 48 used for comparison. Two groups similar in	Results statistically significant at 6 weeks, ie, more HAH patients had recovered pre-injury residence and level of support.	Statistical test not stated. Sample is not random. Description of the other benefits to patients, increased confidence, independence, cooperation

				condition offered two types of rehabilitation, one at home and one in hospital.	support, mental function and mobility.	age, mental function, mobility and living circumstances. HAH group had access to home nursing, control group did not.	LOS was reduced including HAH stay. Less nursing care was required for HAH group.	and relevance of home environment was not collaborated by patients or staff.
Portnow, Kline, Daly, Peltier, Chin and Miller	1991	Interpretive	To describe the roles of multi disciplinary team in a home rehabilitation setting.	Descriptive case studies from the perspective of the staff.	Descriptive based on staff's experience.	Case study of one team's approach, using case examples to illustrate the client's experience from the point of view of the staff.	This team finds their model of service delivery to be meaningful for themselves and their clients. Each staff member has a clearly defined role which is understood by all the team members. They suggest that multi-disciplinary home based rehabilitation could solve some of the problems associated with hospitalisation of the elderly, ie, physical, psychological and monetary costs.	No direct accounts from clients or measurement of the clients' experience. Rich description of the model practised by the authors.
Möller, Goldie and Jonsson	1992	Empiricist	To explore the feasibility of reducing hospital stays of patients with a total hip replacement (THR) by providing rehabilitation in the home.	Pilot study in two parts using small numbers of case studies.	Part one based on analysis of hospital records. Staff noted type and length of all care given to the patients during their hospital stay compared with a hypothetical home-based program. Part two consisted of interviews and analysis of hospital records to determine the medical and social factors which influenced the pattern of care, LOS and type of facility to which patients were discharged.	Part 1-12 patients Part 2- 18 patients Selection process not specified.	Limited time spent on rehabilitation in hospital. Services provided in hospital were similar to those provided through home-care services. Significant potential cost savings. Availability of family support more significant in allowing for early discharge than factors such as age and medical condition.	Finding on age and medical condition conflicts with Ceder above but social factors finding supported. Small sample in preparation for a bigger randomised control study. Home rehabilitation only hypothetical. No exploration of the concerns or issues subjective to patients, carers or staff.

Colbourne	1993	Empiricist	To describe the Early Discharge Program for Orthopaedic and Surgical Service at St George Hospital.	Case study of a program	Description from the point of view of the author, drawing on hospital and program records.	One program.	Detailed description of a program, the change process and some of the outcomes.	No direct account of the experience of the staff and patients.
O'Cathain	1994	Empiricist	To explore usage, patient satisfaction, acceptability and health outcomes in a HAH scheme for patients with fractured neck of femur (NOF).	Non random comparison study, comparing a group who received all their care in hospital with a group who were discharged early with community based follow up.	Survey and standardised tests conducted on acceptance to HAH or comparison group via an interview, repeated after discharge with patient satisfaction survey.	76-HAH 34-comparison group of 432 admissions for fractured NOF. The comparison group met all the criteria for HAH but had not consented or their home was not suitable.	18% of hospital admissions for fractured NOF were found to be appropriate for home based care. Tentative findings of cost reduction. Reduction of hospital LOS. Overall LOS same. Both groups satisfied with care. Nottingham Health Profile - 5/6 dimensions same, emotional health higher for HAH. Mortality same. Readmission not significant statistically but seemed higher for HAH.	Not randomly selected. Actual costs not assessed. Satisfaction measures used. Staff, clients and carers were not given the opportunity to describe their experiences in their own words. No analysis of staff satisfaction.
Farnworth, Kenny and Shiell	1994	Empiricist	To examine the costs and effects of early discharge of patients with a fractured hip.	Before and after study design, comparing a group who remained in hospital with a group who went home early and received follow up care there.	Survey data collected from hospital records, the patients and/or their general practitioner. General information, information on surgery and outcomes (mortality, complications and changes in living arrangements up to one year post discharge) was collected. Hospital group ex-post-facto design.	67 in program group, selected from consecutive patients during the first 6months of 1990. 71 in control group selected from consecutive patients admitted in the first 6months of 1989 (prior to the establishment of the home program).	Reduction in LOS. Either improved or no change to health outcomes. Home program cost effective.	Not random selection. LOS may be reducing for other reasons. Cost effectiveness claim questionable. No measure of patient satisfaction. No analysis of patient, staff or carer experience.

Currie, Tierney, Closs and Fairtlough	1994	Empiricist	To obtain the information required for setting up a scheme of early supported discharge for elderly trauma patients.	Descriptive survey.	100 patients studied in detail, prospectively. Information obtained from records, staff and patients via structured proforma interview on up to six occasions. Basic demographic data collected for 182/200 remaining patients.	300 consecutive patients over 70, every third patient studied in detail.	Characteristics of the group - frail, often living alone, well supported by community services and informal carers. 45% were discharged directly home after 8.3 days. Individual clinical predictions of discharge were not very reliable. Discharges to destinations other than home were associated with age, poorer functional capacity and poor morale. Recommended early rehabilitation, improvements in pain control and post-discharge support.	Findings related to discharge factors support Moller, Goldie and Jonson above. No investigation of the experience of clients, carers or staff. Successful outcomes specified by researchers.
Widén Holmqvist, de Pedro-Cuesta, Holm & Kostulas	1995	Empiricist	To identify the characteristics and feasibility of rehabilitation at home for acute stroke patients in south-west Stockholm.	Pilot study. In-depth study of 15 patients admitted to the home rehabilitation program.	Structured interviews using assessment tools conducted at 3, 6 and 12 m after stroke.	15/16 patients offered home rehabilitation. between Feb 1991 and April 1992 agreed to participate in the study. Sample selected by age and degree of dysfunction.	Estimated that 25% of all stroke patients in hospital for >one week are suitable for rehabilitation at home. Frail stroke patients did not benefit more from day hospital treatment than treatment at home. Personality traits affect adherence to structured training between sessions. Up to 50% of all stroke patients suitable for rehabilitation at home .	Sample not randomly selected. Small urban sample. Subjective health and other subjective measures mean that there is some data from the perspective of the clients, however all data collection methods are structured so patients and carers not able to express what is important to them, Only study in which carer perspectives sought.
Widén Homqvist, de Pedro-Cuesta, Möller, Holm and	1996	Empiricist	To describe the health economic implications and organisational issues	Pilot study as above.	Measured patient satisfaction and subjective health via a patient satisfaction survey,	15 patients as above	Patients satisfied. Cost effective compared with hospital	No direct assessment of the experience of staff. Use of satisfaction survey

Sidén			of rehabilitation at home.		competed once post discharge. Other measures taken 3, 6 and 12m after the stroke. Estimated time required from carers and the cost of this time was calculated. Sickness Impact Profile (SIP) was administered to spouses 3 and 12m after stroke and spouses were asked if any changes were consequent to the care-giving of the stroke patient. Cost analysis included the cost of informal care (not including lost production), hospital and outpatient care, medication, technical aids, home adaptation, transport and home help .		based care. Carer SIP at 3m slightly higher than the average. Two organisational problems identified were incorporating speech therapist into the home program and establishing cooperation with therapists in primary care.	and structured interviews with spouses means that their perspective has been considered. It is not clear how the conclusions regarding carer burden and organisational problems were reached.
Bairstow, Ashe, Heavens and Lithgo	1997	Empiricist	To describe and evaluate a home based rehabilitation service.	Evaluated in terms of the stated objectives, before and after design, same group.	Surveys including, satisfaction survey and General Health Questionnaire (GHQ), interview with patient and care-giver and analysis of patient records relating to goal achievement.	All patients who had received the service over a 38 month period, 282 subjects in total.	90% of goals attained. 93% of patient responses and 92% of carer responses indicating satisfaction. 61% of carers and 62% of patients maintained or improved scores on GHQ from admission to discharge. Reduction in LOS overall. Patients and carers commented on feelings of loss of control in a hospital setting.	Does give patients and carers the opportunity to comment on their experience through comments on survey and in structured interview. No staff perspectives. Goal attainment measure gives patients the opportunity to identify that measure by which 'success' should be judged - unique to this study.

APPENDIX B

THE QUEEN ELIZABETH CENTRE, BALLARAT

REHABILITATION SERVICES

THE QE REHABILITATION IN THE HOME PROGRAM

MISSION

The Queen Elizabeth Centre, Ballarat is committed to contributing to a society in which elderly and disabled persons are able to enjoy the lifestyle of their choice with dignity and maximal independence.

Rehabilitation Services fulfils the Centre's mission through goal directed programs designed to facilitate the restoration of disabled clients to their chosen lifestyle, as well as conducting health education and disability prevention programs which promote and maintain healthy living. Rehabilitation Services are available to clients and their carers throughout the Grampians Region, either directly or through collaboration with other health agencies.

The *QE Rehabilitation in the Home Program* (RHP) has been developed to allow selected clients, with carer support, undertake all or part of their rehabilitation in their own home, using that familiar environment to enhance the rehabilitation process.

AIMS

1. To offer selected clients and their carers a choice between an inpatient and a home-based rehabilitation program.

2. To facilitate the client's re-integration into the community after an inpatient stay.

3. To enhance the relevance and effectiveness of the rehabilitation process.

4. To ensure continuity of care.

5. To encourage clients and their carers to participate actively in their own rehabilitation.

PRINCIPLES

1. The program will be client centred, the client's wishes and requirements being paramount.

2. A holistic approach will be adopted, the client's rehabilitation needs being considered in the context of general health, emotional and social needs.

3. Continuity of care will be maintained, the QE inpatient staff continuing to work with the client on transferring to the program and disruption to the client's usual community support network will be minimised.

4. The privacy of the client and carers will be respected and all usual ethical principles related to confidentiality will be maintained.

TARGET GROUP

Initially, the program will be available only to people living in the Municipality of Ballarat who are in need of active rehabilitation following an illness, injury, surgery or deterioration in circumstances relating to their home care. Generally, clients will be adults.

Clients may be offered the program when they are being discharged from an acute hospital, during an inpatient rehabilitation stay or following a home assessment.

STAFFING

1. The RHP will provide comprehensive rehabilitation services tailored to meet the specific needs of the clients, using a care coordination (case management) model.

   Key disciplines:

   * rehabilitation medicine specialist
   * social work
   * rehabilitation nursing
   * occupational therapy
   * physiotherapy

   Other disciplines available:

   * dietetics
   * orthotics
   * pharmacy
   * podiatry
   * prosthetics
   * psychology and neuropsychology
   * recreation
   * speech pathology

   As far as possible, the staff who work with the client during a QE inpatient rehabilitation stay will continue to work with the client during the RHP.

2. The client's general medical practitioner (GP) will need to be a member of the rehabilitation team, willing to provide medical care in the client's home as well as participating in team conferences. Appropriate compensation will be negotiated with the GP to facilitate this involvement.

3. Where required, appropriate community care agencies will also be involved in the program, especially any that may have been caring for the client previously.

PROCESS

1. Clients may be referred to the RHP from an acute hospital, the QE inpatient rehabilitation service or directly from the community.

2. The initial assessment to determine compliance with admission criteria 1 -3 will be undertaken by the specialist in rehabilitation medicine.

3. Potential clients may then be on-referred to the RHP Coordinator directly or via the Admissions Meeting.

4. If there is a place available in the RHP, the assessment will be completed by the RHP staff and a team decision will be made to proceed further. The referral source and the client will be notified and given reasons if the RHP is not considered appropriate.

5. If the client accepts the offer of RHP a care coordinator will be appointed. In the case of a client being admitted to inpatient care with the view to being transferred to RHP in the future, the care coordinator will be appointed on admission to facilitate an ongoing relationship, thus smoothing the later transition to the RHP.

6. On admission to the RHP the care coordinator will arrange a team conference, inviting the participation of the client and carer(s), the GP, community agency representatives, as appropriate, and the QE RHP team. The purpose of this first meeting will be to develop a rehabilitation plan, including discharge plans, based on the client's goals. The therapy programs required may be undertaken at home or on site in the Peter Heinz Centre.

6\. Copies of the goals and plans will be made available to the client, carer(s), GP and other agencies as appropriate.

7\. The implementation of the plan will be monitored by the care co-ordinator and discussed at scheduled team conferences.

8\. The client will be discharged from the RHP when the discharge criteria have been met.

9\. A client follow-up and evaluation process will occur after discharge.

ADMISSION CRITERIA

1. The client lives in the City of Ballarat.

2. The client has been assessed as requiring active rehabilitation and has the potential to improve functional ability.

3. The client is medically stable.

4. The estimated costs of the RHP are less than those applying to inpatient care.

5. The client's home environment has been assessed by an occupational therapist as being accessible and suitable for the client and carer(s) to implement or continue the rehabilitation program.

6. All other safety considerations have been considered, for instance swallowing, transfers, lack of insight, or impulsivity.

7. The client's GP has agreed to undertake the client's medical management, to participate in the rehabilitation process, and the compensation process arranged.

8. The client and the carer(s) have had the option of a RHP explained fully and agreed to participate.

9. Environmental modifications and equipment, aids and appliances can be in place prior to the client's transfer to home.

10. All necessary community services can be in place on the client's transfer to home.

DISCHARGE CRITERIA

1. The client may be discharged when RHP team is satisfied that:

    - the client's goals have been met or

    - client improvement has plateaued and it is likely that the initial goals will not be met at this time, or

    - remaining goals can be met through other avenues without adversely effecting the wellbeing of the client, or

    - circumstances have changed and discharge, including discharge to alternative care is appropriate.

2. Ongoing services required by the client can be in place when the team withdraws.

CLINICAL DIRECTION

The specialist physician in rehabilitation medicine will provide clinical direction to the RHP, working closely with the client's GP to ensure appropriate medical management.

PROGRAM OBJECTIVES

The following client focussed objectives are typical of those which will apply to clients undertaking RHP.

1. Increase self-care skills
2. Increase communication skills
3. Increase mobility skills
4. Increase psychosocial adjustment
5. Minimize preventable medical complications
6. Increase cognitive function
7. Increase domestic and community skills
8. Maximise bowel and bladder function
9. Minimise accidents in the home
10. Increase productive use of leisure time
11. Ensure adequate nutrition
12. Maximise satisfaction with services
13. Progressively reduce level of service as the client improves
14. Minimise costs

PROGRAM EVALUATION MEASURES

The primary method of calculating program effectiveness will be the Functional Independence Measure (FIM) with more sensitive measures being used by specific disciplines.

1. Average gain in FIM self-care
2. Average gain in FIM mobility
3. Average gain in FIM communication
4. Average gain in FIM psychosocial adjustment
5. Average gain in cognitive function

6. Bowel and bladder status
7. Measurement of gains in domestic skills
8. Measurement of gains in community skills
9. Measurement of gains in use of leisure time
10. Evaluation of program interruptions, complications
11. Measurement of carer(s) satisfaction
12. Measurement of client satisfaction.

OTHER PROGRAM EVALUATION MEASURES

1. Geographical descriptors such as travel distance, time
2. Average age and breakdown by age groups
3. Gender distribution
4. Ethnic distribution
5. Percent who understand and speak English
6. Marital status
7. Referral source
8. General medical practitioner
9. Discharge destination
10. Living arrangements on admission, discharge and follow-up
11. Vocational status (category and effort) pre-admission, on discharge and follow-up
12. Follow-up method
13. Follow-up services
14. Follow-up therapy
15. Average time from onset to admission
16. Principal diagnoses - distribution by ICD 9 Code

17. Secondary diagnoses - distribution by ICD 9 Code

18. Impairment - distribution by Impairment Code

11. Length of stay

12. Time and cost of service, total and by discipline

The Queen Elizabeth Centre, Ballarat
Rehabilitation Services
February, 1996

APPENDIX C

CLIENT GOALS

The Queen Elizabeth Centre, Ballarat

Unit Record No: ....

Surname: “Clare”

Given Names: ....

D.O.B. ..../........../..........

SEX. ....

CLIENT GOAL	THERAPY FOCUS	AIM DATE	RESPONS.	DATE ACHIEVED
1 Increase memory	Use diary reliably as prompt	1.4	SP/OT	22.5
	Retain sentence level Auditory information 100%	1.9.96	SP	
2 Basic meal preparation	Prepare simple meal independently and safely	1.9	OT	22.5
3 To do the washing	Organise and complete washing.	1.6	OT	22.5
	Facilitate environment to complete washing on ward	13.3		13.3
4 Gardening (to resume)	Independent uneven surfaces	13.3	PT/OT	6.3
	1 flight stairs	20.3	PT/OT	6.3
5 To resume horse care (ie grooming, preparation)	Aware safety considerations	1.9	OT	22.5
	Use diary reliably as prompt	1.9	SP/OT	
6 To resume sewing	Complete short structured tasks, eg hems and buttons with prompt	30.3	OT	26.3
7 Assist with caring for children	Retain sentence level information planning	1.9	SP	
	Orientation and awareness of time, person and place to 100%	1.6	SP/OT	22.5
8 To return to driving	Cognitively able to complete driving assessment	1.3	OT	22.5
	Concentration on tasks to 1 hour	1.7	SP/OT	3.4
	Geographical orientation	1.7	OT/SP/PT/AHA	16.4
	Speed of processing to normal	1.9	SP/OT	
	Refer for driving assessment	Aug 96	OT	

APPENDIX D

SATISFACTION SURVEY

Please read each statement and mark on the line the answer which is nearest your view. There are no right or wrong answers. It is your opinion we are interested in. Please answer every question.

Things were well prepared for my home (ie aids such as rails or wheelchairs had been organised if necessary).

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I felt I had a choice between having my rehabilitation at home and staying in hospital for rehabilitation

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I received enough information about home rehabilitation to enable me to make a choice

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I have been treated with kindness and respect by the staff in the QE Rehabilitation in the Home Program

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I felt able to talk to the staff about any problems I might have had

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I have not received sufficient information about the causes and nature of my illness

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I have had all the medical attention I need whilst on the Rehabilitation in the Home Program

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I have not made as much recovery as I would like since my illness

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I was satisfied with the type of care the nurses have given me

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I was satisfied with the type of treatment the therapists have given me (eg physiotherapy, speech therapy, occupational therapy)

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I felt uncomfortable about too many people coming into my home

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I have not had enough therapy (eg physiotherapy, speech therapy, occupational therapy).

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I was not given sufficient information about the allowances and services I needed after the Rehabilitation in the Home Program withdrew (eg Home Care, district nurse, Meals on Wheels)

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I found that rehabilitation at home helped me to settle back into my family and community life

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I now get all the support I need from services such as Meals on Wheels, Home Help, District Nursing etc.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

Rehabilitation at home helped me get back into the things that are important to me.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

PLEASE TAKE THE OPPORTUNITY TO ADD YOUR OWN COMMENTS ON YOUR REHABILITATION PROGRAM.

THANK YOU

Please place in the enclosed envelope. No stamp is required

APPENDIX E

REHABILITATION IN THE HOME PROGRAM

The Rehabilitation in the Home Program has now been going for six months, and it is time to review its progress. As someone who has worked on the program, you will have ideas about how its going; those areas that are working well and areas that need to be changed.

WOULD YOU PLEASE COMPLETE THIS QUESTIONNAIRE AND RETURN IT TO THE RHP OFFICE IN JBG BY 4TH SEPTEMBER? THERE WILL BE A PRIZE FOR THE FIRST 25 COMPLETED.

---

1 **Number of clients you have worked with on the RHP** ☐

2 **What have been the main benefits to you of working on the RHP ?**

3 **What have been the main drawbacks for you in working on the RHP ?**

4 **What do you think are the main benefits of the RHP to clients and families ?**

5 **What do you think are the main drawbacks of the RHP for the client/family ?**

6 **Would you like more information/education about the RHP and/or working with clients/families in their own homes ?**

Yes ☐ **No** ☐

Which topics would interest you ?

Is there anything else you would like to add ? Please comment

APPENDIX F

A CAREGIVER STRAIN INDEX

R: . . . . RELATIONSHIP TO CLIENT: . . . . DATE: . . . .

am going to read a list of things which other people have found to be difficult when helping someone who ıs an illness'

ease indicate on the line how much the statement reflects your situation. A sample of question is given first demonstrate the scale used:-

have toast for breakfast Always ______________________________ *Never*

eep is disturbed (eg because.......is in and out of bed or wanders around at night)

lways______________________________ Never

is confining (eg helping restricts free time, or cannot go visiting)

ways ______________________________ Never

ıere have been family adjustments (eg because helping has disrupted routine: there has been no privacy)

ways ______________________________ Never

is a physical strain (eg because of lifting in and out of a chair: effort or concentration is required)

ways ______________________________ Never

here have been changes in personal plans (eg had to turn down a job: could not go on vacation/holiday)

ways ______________________________ Never

here have been emotional adjustments (eg because of severe argument)

ways______________________________ Never

ıme behaviour is upsetting (eg. because of incontinence: .... has trouble remembering things; or .... :cuses people of taking things).

lways ______________________________ Never

is upsetting to find ..... has changed so much from his/her former self(eg he/she is a different person than ɛ/she used to be.)

lways ______________________________ Never

here have been work adjustments (eg. because of having to take time off)

lways ______________________________ Never

is a financial strain

lways ______________________________ Never

eeling completely overwhelmed (eg because of worry about.......... concerns about how you will manage).

ways ______________________________ Never

Phai\carcind

APPENDIX G

Human Research Ethics Committee

Outcome of Meeting No *99/EM01* *Held on* *Thursday, February 04, 1999*

Ethics clearance for the recently submitted application is as follows:

Project No	**353**
Project Type	RP - Category B: Research Project
Title	An evaluation of rehabilitation in the home, client, carer and staff perspectives
Principal Researcher(s)	J McDonald
Associate Researcher(s)	B Dow
School	Behavioural & Social Sciences & Humanities

HREC Decision	**Approved**
HREC Comment	**A thoroughly documented application. Although some data has been collected prior to approval, the Executive Committee considers that all participants were aware that their contribution might be used in similar research.**
Project Start	3/1/99
Project End	3/31/99

Yours Sincerely

S. A. Boyle

SALLY BOYLE
Executive Officer
Human Research Ethics Committee

APPENDIX H

Executive Officer
x 577 Ballarat Victoria 3353

BallaratHealthServices

4 February 1998

Ms Briony Dow
Program Manger
Rehabilitation in the Home
Ballarat Health Services
PO Box 199
Ballarat Vic 3350

Dear Briony

I am writing in response to your letter of 19.12.97 and our further discussion today.

I understand that you are enrolled in an MA in Sociology at the University of Ballarat, and that you wish to submit a thesis based on your evaluation of the Rehabilitation in the Home Program.

You have my permission, as requested, to use the data you collected in the course of your employment at Ballarat Health Services to complete and submit your MA thesis.

Yours sincerely

Allan Hughes
Chief Executive Officer

Base Hospital
Drummond Street North, Ballarat Vic
Telephone 03 5320 4000
Facsimile 03 5320 4022

Queen Elizabeth Centre
102 Ascot Street South, Ballarat Vic
Telephone 61 3 5320 3700
Facsimile 61 3 5320 3860

Grampians Psychiatric Services
Sturt Street, Ballarat Vic
Telephone 03 5320 4501
Facsimile 03 5320 4835

All correspondence to be addressed to
Chief Executive Officer
PO Box 577 Ballarat Victoria 3353

APPENDIX I

BALLARAT **HEALTH** SERVICES
Queen Elizabeth Centre

Ballarat**Health**Services
QUEEN ELIZABETH CENTRE

The Rehabilitation in the Home Program (RHP)

AGREEMENT

Client's Name --

U.R. No --

Address --

Telephone No --

Carer to be involved in program ? Yes/No

Name --

Relationship to Client --

Address --

Telephone No --

I/WE --

1. Confirm that the RHP has been explained to me/us.

2. Agree to co-operate with the treatment plan as developed by me/us and the RHP treatment team.

3. Accept that the RHP will be discontinued when the team and I/we are satisfied that I/we can manage at home independently of the program.

4. Agree to data collected from this program being used for research and program evaluation purposes, on condition that I/we cannot be personally identified.

5. Understand that I/we can withdraw consent to any component of the RHP without jeopardising my/our overall involvement with the program.

Client's Signature --

Date --

Carer's Signature --

Date --

Base Hospital
Drummond Street North, Ballarat Vic
Telephone 03 5320 4000
Facsim[redacted]

Queen Elizabeth Centre
102 Ascot Street South, Ballarat Vic
Telephone 61 3 5320 3700
Facsimile 61 3 5320 3860

Grampians Psychiatric Services
Sturt Street, Ballarat Vic
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APPENDIX J

Telephone: (053) 203 700
Facsimile: (053) 203 860

All correspondence to be addressed to
CHIEF EXECUTIVE

THE QUEEN ELIZABETH
CENTRE BALLARAT

25th November, 1996

Dear

We are working on evaluating and improving the Rehabilitation in the Home Program and we need the help of former clients. While we try to do our best, we are not in a position to judge the quality of our service or to know what it is like to be on the receiving end. No one knows about our service better than people like you and your family, who have experienced it. While we hope that you will not need our services again, your comments will help us to improve our service for others.

One of the most useful ways of gathering information is through a small group discussion, often called a focus group, where invited clients discuss ideas with one or two staff. We will be running a focus group to discuss the Rehabilitation in the Home Program on Wednesday, 11th December and would like you to attend. The discussion session will last approximately one hour and a member of your family or a friend will be most welcome to join you.

People attending the group will :

- meet other clients who have used the Rehabilitation in the Home Program (no more than 10 in a group)
- contribute their views on the Rehabilitation in the Home Program, both positive and negative
- assist us to evaluate and improve the Rehabilitation in the Home Program

We can help you with transport if needed.

The group will be on Wednesday 11th December 1996, at 10am at the Queen Elizabeth Centre, Ballarat, Ascot Street, Ballarat in the Janet Biddlecombe Ground Sunroom.

A sample list of questions which the group will discuss is attached so you will be able to begin thinking about your participation, if you are willing to join us.

Cheryl Wheybrow will telephone you next week to learn if you would like to participate in the group. If you would like to know more about it, please phone me on 203727.

We do hope that you will become involved in this project, an essential ingredient in the development of the Rehabilitation in the Home Program.

Yours Sincerely,

Briony Dow
Rehabilitation in the Home Program Co-ordinator

The Queen Elizabeth Centre, Ballarat
P.O. Box 199, Ballarat, Victoria, Australia, 3353
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PPENDIX K

EHABILITATION
ACSIMILE NO: 03 53203 800
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March, 1997

Title» «CHRISTIAN_NAME» «SURNAME»
ADDRESS_1»
ADDRESS_2»
State» «POST_CODE»

ear «Title» «SURNAME»

we are to provide the best quality rehabilitation service, we really need your help. No one knows etter than you what standard of service we are providing.

e realise that there is always room for improvement, so we would be very pleased if you would omplete the attached questionnaire as honestly as you can, and return it to us in the reply paid nvelope provided.

ou do not need to put you name on the questionnaire.

anagers will act on the information you provide to improve the service for the future.

ours sincerely

er Helen D Manning

oreen Bauer
anager, Rehabilitation Services
nc

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