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**AN EVALUATION OF THE IMPACT OF THE  
“MAISS” NEEDS ASSESSMENT CONCEPT IN INFLUENCING  
THE EMPOWERMENT OF PEOPLE WITH DISABILITIES**

**A Thesis presented in partial  
Fulfilment of the requirements**

**For the Degree  
Of Master of Philosophy  
In Rehabilitation at  
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## Abstract

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MAISS, (Managed Access to Integrated Support Services) as defined within Midland Health's service requirement definition, will be the single means of access to all support services for people with disabilities living within the Midland Health region. It must, therefore be considered, if not as the single most significant service purchased for people with disabilities then as one of the major disability service initiatives to have developed from the 1992 health reforms.

For people with disabilities, the manner in which the MAISS services are delivered, the level of skill of the people delivering the services, and the subsequent availability of flexible, responsive service provision, will be the test of the Governments ability to achieve stated health reform outcomes. These outcomes were clearly articulated by people with disabilities themselves within the Self Help and Empowerment document, developed from the Consensus Development Conferences of the Core Services Committee.

This research took the form of an evaluation of the impact which MAISS has had on the expressed feelings of self help and empowerment for one group of significant services users. The MAISS concept as delivered by one of three contracted providers, is examined to determine whether or not MAISS services are perceived by people with disabilities as having resulted in an enhancement of their perceived empowerment or mastery over the decisions which impact upon their lives. Judgments are made on the extent to which the MAISS concept and its implementation is seen to be supporting the enablement of people with disabilities. The research identifies those aspects of service delivery which most significantly contribute to expressed feelings of empowerment.

Investigation was undertaken through the development of a structured questionnaire. This questionnaire was used as the single means of data collection. The questionnaire was developed from a conceptual framework based upon the New Zealand Standards for Needs Assessment developed and promoted by the Ministry of Health.

The key recommendations made within this study relate to the need for assessment services to utilize assessment practices which foster the integrity and internal validity of the assessment process. The study also recommends that there needs to be a greater sharing of knowledge and accuracy of information in interactions between providers and consumers of services. Finally the research notes the need for continued investigation into the concept and implementation of services as defined within MAISS as such services continue to act as the major gatekeeper for people with disabilities seeking access to essential support services.

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## Chapter One - Introduction:

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A major change has occurred in the philosophy underlying the provision of services to persons with a disability over the last two decades. This change has come about as the result of the independent living movement, a social/political movement revolving around the rights of persons with disabilities (Lindsay, 1995). This movement was similar to and fashioned after the civil rights movement of the 1960's and 1970's and the woman's rights movement of the 1970's and 1980's.

The independent living movement advocated a change in the view of disability itself, its causes and solutions (De Jong, 1979). Fundamental to this change was the emergence of the concept of empowerment as the desired outcome of disability policy and service.

### 1.1 Empowerment Literature:

The use of the term empowerment as an enabling construct seems to have had its origins in psychological theories of power (Dempsy 1994). From a practical point of view, however, empowerment had its roots in the civil rights movement in the United States in the 1960's and 1970's. Although the term empowerment is now commonly used by the general public, any theoretical analysis of the concept has only occurred since the 1960's and 1970's. Efforts to measure empowerment in any quantitative sense have been limited and this limited empirical analysis along with the fact that empowerment can be both a product and a process, both of which can take different forms depending on the characteristics of the settings and the participants, has resulted in the concept being slow to establish credibility amongst researchers (Zimmerman, Israel, Schulz & Checkoway, 1992).

Kieffer (1984) described those conditions found to be necessary if empowerment was to occur. Using indepth interviews with 15 individuals who had emerged as leaders in community organisations, Kieffer concluded that the emergence of empowerment required a personal attitude or sense of self that is strong enough to promote active social involvement; sufficient knowledge to understand and critically analyse the social environment in which one lives; and an ability to plan and acquire the resources necessary to achieve one's goals and an ability to act.

A paper presented by Rappaport in this same year (1984) expressed the view that "empowerment was easy to define in its absence; powerlessness, real or imagined; learned helplessness; alienation; loss of a sense of control over one's own life" (p.3). Suggesting, however, that it is more difficult to define in a positive sense because it appears to take on different forms in different people and contexts. In this work Rappaport defined empowerment as a process. The mechanism by which people, organisations and communities gain mastery over their lives. He expresses the view that a predominant feature of empowerment is the notion that people are seen as already being competent or having the capacity to become competent in order to meet their own needs. The failure of someone to display competence was not due to intrinsic deficiencies on the part of that person. Rather it was due to the failure of the social system to create opportunities for individual competence to be displayed.

One of the early comprehensive efforts to measure the concept of empowerment was undertaken by Zimmerman and Rappaport (1988). This study sought to determine the relationship between citizen participation, perceived control and psychological empowerment. The authors identified 11 scales selected from published literature which assessed different aspects of personality, cognition and motivation; factors which the authors believed to be indicative of empowerment. The research consisted of three studies which examined the relationship between empowerment and participation.

Study one was designed to identify four types of citizens and their respective levels of psychological empowerment. The sample for this study consisted of 392 randomly selected students enrolled in an introductory psychology course. The participants were divided into two groups. Data was collected using a structured questionnaire, with different delivery processes used for each group. Each questionnaire contained one personally relevant and one community relevant scenario. Half of the participants being presented with the community relevant scenario first, half receiving the personally relevant scenario. Students rated the undesirability of each scenario on a six point Likert scale. The results tested for expected group differences on the personality, cognitive and motivational measures as a functions of one's reported willingness to participate in personally and community relevant activities.

The second study was an attempt to replicate the findings of the first study using naturalistic behaviours rather than hypothetical scenarios. Respondents in study two were the same as those in study one. Study three was a replication of study two using members of community voluntary organisations as the sample. The results of the three studies supported the notion that psychological empowerment is a multivariant concept which involves a connection between a sense of personal competence, a desire for involvement and a willingness to take action.

Zimmerman, Israel, Schulz and Checkoway (1992), studied the relationship between citizen participation and perceived control. This study identified that while empowerment theory is widely written about there is a limited amount of specific, empirical research which has been undertaken into empowerment theory. These researchers drew upon the literature which was available and used their study as a means of both replicating previous studies and further developing a theory of empowerment. The study was undertaken using a large randomly selected urban and suburban community sample of 911 people over the age of 18 living in the Detroit,

Michigan area. Data was collected using face to face interviews and sought to find answers to three major questions: (a) whether measures of perceived control combine together to form a single theoretical dimension; (b) whether those individuals who are involved in community organisations and activities score higher on the interpersonal component of empowerment than people who are less involved, and (c) whether there are observed differences in psychological empowerment between white and African American people.

The Zimmerman, Israel, Schulz and Checkoway ( 1992) study advanced the notion that empowerment consists of two major perspective's. Firstly as a relational construct, where empowerment is seen as the perceived control or power that an individual or an organisation has over others. This perspective of empowerment is based upon the assumption that those who have power are more likely to be in a position of achieving their own desired objectives than those who lack power.

Conversely those who lack power are more likely to experience obstacles to attaining their desired objectives, and even to have those objectives thwarted by those who hold the power. As a consequence empowerment becomes a process by which those who hold power have the capacity to share power with those who do not.

The second perspective is that of empowerment as a motivational construct. From this perspective power and control are seen in terms of belief states that are internal to individuals. Power is referred to in terms of an individuals ability to cope with the events, situations or people they are likely to encounter in their everyday lives. Such a sense of power is referred to in terms of a need for self determination or self efficacy. From this perspective empowering is seen as enabling. It is related to raising the individuals convictions in their own ability to exert influence over the decisions and events of daily life.

The Zimmerman, Israel, Schulz and Checkoway (1992) study drew heavily on an analysis of the literature undertaken by Conger and Kanungo (1988). This analysis focused upon the concept of empowerment as a principle of management. Through this work Conger and Kanungo sought to provide an analysis of the construct of empowerment by integrating the diverse approaches found in both management and psychological literature. In their analysis these authors identify certain antecedent conditions of powerlessness and define a range of management practices and process designed to empower employees. Their analysis promoted the notion that empowerment can be viewed as existing on two contractual levels, as relational construct and as a motivational construct. Conger and Kanungo suggest that where empowerment is perceived as primarily a relational concept then it is used to define the perceived power and control that one individual or system has over another. When empowerment is considered in relational terms it becomes the process whereby those who possess power share power with those who are subordinate.

When empowerment is viewed as a motivational construct then the individual believes that they have power when they can adequately cope with the events, situations and people which impact upon their daily lives. From a motivational construct empowerment implies the heightening of motivation through the development of a strong sense of personal efficacy.

In seeking to identify new strategies to deal with emerging social problems, Dodd and Gutierrez (1990) express the belief that existing models of social work practice neglect the pivotal role that power plays in the creation and resolution of social problems. Using established literature these authors identify what they describe as first, second and third levels of empowerment. The first levels identify empowerment as a personal construct and focus on the ways in which individuals develop personal power. The second, or interpersonal level stressed the development of specific skills

which can lead to increased influence. The third level theories of empowerment center on political action and social change. Dodd and Gutierrez (1990) suggest that if we are to create communities and individuals with the ability to change negative social situations and to prevent the recurrence of social problems then it is necessary to unify these three levels of empowerment.

Gutierrez and Ortega (1991) sought to expand upon the understanding of empowerment as a multifaceted concept in their empirical study of how group interaction can affect the personal and political levels of empowerment. This research, entitled 'Developing Methods to Empower Latinos: The Importance of Groups', developed three measures to assess different aspects of empowerment amongst people from Latin America. Two of their measures focused on political empowerment, commitment and activism, with the third measure focused on personal empowerment defined as the ability to engage in change strategies.

Participants in this study were a random sample of Latin American undergraduate students attending a large midwestern university. Seventy-three people participated in the study. Fifty participants were assigned to one of two kinds of group discussions. One group was developed to arouse subject's feelings of ethnic identification and the other to arouse critical consciousness. Twenty-three participants made up a control group which did not attend group sessions but completed the dependent measures individually. The results of this study provided further validity of a model for empowerment which consists of a number of interdependent levels, suggesting that where group interaction focuses upon mutual support, acceptance and understanding people find it easier to accept a positive image of themselves and of their social group.

Koren, DeChillo and Friesen (1992) provided further support for the notion of empowerment as a multifaceted construct in the design of their instrument developed to

measure empowerment in families whose members have disabilities. This study, "Measuring Empowerment in Families Whose Children Have Emotional Disabilities: A Brief Questionnaire," describes the development of a questionnaire for assessing empowerment in families whose children have emotional disabilities. The study outlines the questionnaires conceptual basis, describes its development and analyses its reliability and validity based on 440 responses of family members. The conceptual framework for this questionnaire consists of two dimensions, the level of empowerment and the way that empowerment is expressed. The results of this study indicate that expressions of empowerment are to be found in an individual's attitudes, knowledge and behaviour. Attitudes include the individual's perspective of their ability to cope, knowledge involves the awareness of the choices and options a person may have and behaviour deals with the actions taken by the individual to exercise control over circumstances and situations. These expressions of empowerment are found to exist at three major levels. In relating these levels to the context of human services Koren, DeChillo and Friesen (1992) like Zimmerman Israel, Schulz and Checkoway (1992) described empowerment as existing at the level of the family or the person's immediate environment, the level at which the individual interacts with the service system and at the level of the wider community. Where empowerment exists at the personal level it is concerned with the individual's feelings of personal power and effectiveness. At the interpersonal level, it is concerned with the individual's ability to influence others and at the political level is concerned with social action and social change.

These studies which have lead to an understanding of empowerment as a multifaceted concept had their origins in Solomon's (1976) studies into powerlessness. Solomon described three sources of powerlessness which exist across three levels.

- (1) Negative self evaluations which are the attitudes expressed by oppressed people,
- (2) negative experiences, or the interactions between oppressed people and the system and

(3) the impact of the larger environmental systems which act to block effective action by powerless people.

Another dimension of empowerment is explored by Staples (1990) into the ways in which empowerment is expressed, through his small scale research, "Powerful Ideas About Empowerment". Drawing on examples from the literature and using a single participant case study, Staples asserts that "empowerment requires practical knowledge, solid information real competencies, concrete skills, material resources, genuine opportunities and tangible results" (p38).

In a study reviewing the relationships which develop between service providers and service receivers, Cochran, (1990) identified that mutual respect between the two parties was the critical component within the empowerment process. This study promoted the need for people who were disadvantaged by the way in which society and social service systems were structured to be given opportunities to take a primary role in the development of strategies by which they might gain increased control over the resources necessary to enable their needs to be met.

Cochran (1990) used a case study approach to determine how personal networks are developed and how such networks contribute to the process of empowerment. Cochran sought to determine whether there were community level interventions that could enhance the supportive aspects of personal networks available to parents and other family members. This case study was undertaken using 160 families who were participating in the Family Matters programme in Cornell. Each of the families had a three-year-old child and were drawn from 10 different urban neighbourhoods. Two processes were used to involve families in activities related to their children. A home visit approach aimed at individual families and a cluster building approach aimed at linking together all the Family Matters families in a given neighbourhood.

Two general questions guided the analysis of network related impact. First, has participation in the programme altered social supports? If yes, then are those network changes reflected in parents' attitudes, parent child activities, or child performance in school? The results of this research indicate that healthy, productive communities are most likely to develop when parents are supported to help themselves, are connected through social ties and when public policy ensures access to adequate and sufficient education, employment and humane housing conditions.

A review of the literature by Parsons, (1991) suggests that it is consistent in agreeing that the process of empowerment is initiated by interaction with others through which support, mutual assistance and respect for one's experiences and knowledge is received.

Although research with a focus on the concept of empowerment remains limited, the available literature is broad based in that empowerment has been studied in areas as diverse as organisational management and family dynamics. The literature is consistent in defining empowerment as a complex and multifaceted construct which is both relational and motivational. Empowerment appears to be a process which is dependent upon a level of personal competence and knowledge, a relationship with a wider environment and a desire and ability to take action.

## **1.2 Empowerment**

Empowerment is the central concept in this research. Empowerment extends the concept of 'to empower,' which is defined as " to give power or authority to, or to enable or to permit " (The World Book Dictionary, 1970), to include both a psychological sense of personal control or influence and a concern with actual social influence, political power and human rights (Rappoport, 1987). Empowerment has been variously described as both a process and a state; as both an individual and a

collective characteristic; as an attitude, a perception, ability, knowledge and action, and as a phenomenon that can be expressed in a range of circumstances and environments (Koren, De Chillo & Friesen, 1992).

There are a number of themes which have been experienced as being central to the concept of empowerment. These themes include (a) the reduction of powerlessness (Solomon, 1976), (b) the gaining, developing, seizing, enabling or giving of power (Staples, 1990), (c) the ability to influence the people, organisations and environments affecting one's life (Vanderslice, 1984), and (d) attaining control over one's life and participation in the life of the community (Rappaport, 1981; Rappaport, Swift & Hess, 1984; Zimmerman & Rappaport, 1988).

These themes, however, lack the full essence of this concept when used in relation to human services. Within this context, the most accepted definition of empowerment is that of 'a process by which individuals gain mastery and control over their lives, and a critical understanding of the environment in which they live' (Zimmerman, et al: 1992: Zimmerman 1990). From this perspective, empowerment means to enable and implies a raising of the individual's level of belief in their own effectiveness. A further feature of this notion of empowerment is that people with disabilities are seen as being competent. That the failure of someone to demonstrate competence is not due to personal deficiencies as much as it is due to the failure of the system to create opportunities for competence to be displayed. Thus, to foster empowerment requires the development of an environment that supports the individual with a disability to exercise their rights, to gain control and demonstrate competence.

Empowerment exists as both a personal and institutional construct and is found to operate at three distinct levels; (a) the interpersonal, (b) the interactional and (c) the behavioural (Gutierrez & Ortega, 1991; Koran, De Chillo & Friesen, 1992). At the interpersonal level, empowerment is related to the person's immediate environment, the

self and their immediate situation at home. This level defines how people think about their capacity to influence those social and political systems which are of importance to them. This perception of one's personal power may refer to beliefs about one's own capacity to influence others and to have an impact upon the prevalent social and political structures (Zimmerman & Rappaport, 1988).

The interactional components of empowerment relate to the service system, that is those professionals and agencies that provide services. It is concerned with those transactions which occur between the individual and the service system which enable the individual to successfully exercise mastery over or within such systems. The primary factor in this level of empowerment is the ability to actively work with the system to attain the services that are required to meet personal needs. This component connects the perceptions one holds about oneself, or the interpersonal component, with what one does to exert influence, or the behavioural component. Finally, the behavioural component consists of those specific actions one takes to exercise influence at that level where the broader community is concerned with or influences the life of the person.

The notion of empowerment, therefore, includes the elements of (1) personal control, or what the person feels and believes; (2) a sense of competence, a critical awareness of the socio-political environment, or what the person knows and can do; and (3) an active participation within the community, or what the person actually does.

These states of empowerment are not necessarily constant. Rather, they appear to change over time in response to new experiences, new conditions or evolving circumstances. For people with disabilities to experience empowerment as an outcome of service interventions then, such interventions would need to be structured and delivered in a manner which ensured that individuals were provided with genuine opportunities to participate in and gain mastery over decisions that affect their lives.

Consequently, empowerment will look different in its manifest content for different people, organisations and settings.

Empowerment is increasingly seen as a central goal of efforts to improve services for people with disabilities (National Advisory Committee on Core Health and Disability Support Services, 1993). Virtually all human service organisations that serve people with disabilities have adopted this concept to some degree. Thus it is beginning to emerge as a common value within disability service provision. The concept is playing an increasingly important role in shaping services for people with disabilities, and is often a stated service goal. Empowerment, however, is often poorly specified and the effectiveness of interventions designed to empower are largely untested. To date, disability services do not have a good record in attaining goals of empowerment (Dempsey, 1994; Corbett & Ralph, 1994; Law, 1994).

That the notion of empowerment has assumed primacy within human service delivery has been largely influenced by the growth of movements and assemblies of people with disabilities. These assemblies with their emphasis on self help and self reliance (Moxley, Raider & Cohen, 1989) and on strengths rather than deficits (Poertner & Ronnau 1992) have resulted in a recognition that services can be delivered in ways that either promote or inhibit self efficacy (Dunst & Paget, 1991).

The emergence of disabled people and disability issues as a social and political force stemmed, as with most other social movements, from a long history of oppression. Within this disability rights movement, people with disabilities are increasingly involved in a serious challenge to the prevailing system which is dominated by the medical profession and its precepts. Within this challenge, they are endeavouring to provide alternative definitions of, and understandings and insights into, the concept of disability. This has led to a rejection of a medical, sickness framework for the delivery of disability services and a promotion of an alternative social and political model.

Members of this movement refuse to accept the deficit and dependency role which has historically shaped disability policies and practices. Their approach is based upon the belief that the concept of disability is not fixed and absolute, but can be, and indeed has been, defined in a variety of different ways throughout history (Oliver, 1989). It is this understanding of disability as relative rather than absolute, social rather than physical, made rather than inherent, that has led to the view of disability as a social construct (Albrecht & Levy, 1981).

### **1.3 Disability as a Social Construction**

It has been a central criticism by many people with disabilities that the explanations of disability put forward by non disabled professionals have their focus on the body as the principle cause of disablement. They reject any construct which defines people with disabilities solely in terms of their physical, sensory, intellectual or psychological impairments. Rather, they embrace a social construct of disability which defines disability as arising from the institutional, environmental and social discrimination leveled against individuals who do not fit prescribed norms. These social explanations developed by people with disabilities themselves question the prevailing concept of normality and open a discourse on the influence of the social environment on the construct of disablement (Ballard, 1994, 1997; Barton, 1992,1994; Munford & Sullivan, 1997; Sullivan, 1991).

In seeking to construct an alternative to the medical model of disability, people with disabilities have linked their own experiences to those of other oppressed peoples (Abberly, 1993; Crow, 1992; Morris, 1993; Sutherland, 1981). They have sought a change to their own oppression by challenging the notion that disability is an inevitable outcome or consequence of impairment (Chadwick, 1994). People with disabilities disputed the notion that an impaired body is the principle source of disablement

(Finkelstein, 1993). Such a notion, they contended, concentrates on the individuals body rather than on the social context in which activities and roles are performed. As such it is heavily dependent upon a concept of normality. This position does not in any way deny the physical impairment, nor its impact on the individual. It does however, deny that the impairment itself is the cause of disability. Suggesting instead that disability is not fixed, that it has a cause and a remedy and should be seen as

‘the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers’ (Finkelstein & French 1993; p.28).

In short, the subjective knowledge of people with disabilities themselves has led to the construct of a socio-political model of disability. This model defines disability as the product of the limits imposed on people by society through organisational structures and social policies ( Barnes, 1991). This social theory provides a position from which the attitudes which create and maintain oppressive structures can be challenged (Morris,1996; Sullivan, 1996).

When disability is characterised in this manner the locus of responsibility shifts from the individual disabled person onto those social and environmental structures that discriminate. As a consequence, it becomes clear that the marginalisation of people with disabilities is not an inevitable outcome of their impairment. Rather, it is something which has been created by society and can be changed by society. The social model of disability has come to be used not only to explain how people become disabled but also to show how such disablement could be changed.

While the removal of disabling barriers would reduce disability, impairment would remain without the oppression of disability. This position does not deny that at

times impairment may be so debilitating that the wider environment becomes irrelevant. What it does is acknowledge that disability and impairment can operate independently of each other. Impairment may remain consistent, but disability is dependent upon different environments. Environments can be changed by both individual action and socio-political pressure (De Jong, 1979). One way to ensure that these changes come about is to ensure that the systems designed to serve persons with disabilities adopt empowerment as a primary outcome.

#### **1.4 Historical Perspective:**

New Zealand as a colony was influenced significantly in both its social and political structures by Britain. The history of attitudes towards people with disabilities in this country had its origins in the British system. Many of the past and present negative attitudes towards people with disabilities began with the poor laws of England. British institutions largely set the patterns leading to people with disabilities being perceived as dependent, a burden upon a charitable society and to be pitied. These attitudes along with the absence of any social policy were dominant in New Zealand during the 19th century. What social responses there were for people with disabilities came from churches or other charitable organisations. Throughout the rest of this century the problems which people with disabilities presented to a young and developing nation were not seen in isolation, but were dealt with as part of a group of larger social problems affecting the poor (Angus, 1987).

The first substantive piece of legislation which acknowledged people with disabilities as a distinct group in New Zealand society was the Disabled Soldiers Civil Re-establishment Act of 1930. The purpose of this act was to assist disabled soldiers from World War I to obtain suitable employment and rehabilitate themselves back into

civilian life. This was followed by the establishment of the National Rehabilitation Board and Council in 1941.

The establishment of this board led to an acknowledgment of the need to provide education, housing, training and financial assistance for men disabled as a result of the war. These benefits, only available to ex-service men initially, were extended to civilians with disabilities in 1954. In 1960, in an attempt to make better provision for people with disabilities to obtain work, the Disabled Persons Community Welfare Act was passed. These various pieces of legislation pertaining to people with disabilities were fragmented and ad hoc responses to prevailing social issues. In an attempt to remedy this situation and to coordinate legislation impacting upon people with disabilities, the Disabled Persons Community Welfare Act of 1975 was enacted. This Act contained a mix of provisions focused on both medical and social constructs of disability. For the first time, disability was seen as being more than an individual problem. The structure of society was seen as contributing to individual problems and the responsibility for alleviating those problems was placed on society and its governmental structures.

The marked shift in thinking evident within this legislation was largely influenced by coordinating councils for the disabled. These councils were established in the four major cities in 1975. They were formed for the purpose of making submissions to the Act. These councils marked the beginning of the formal organisation of disabled persons in New Zealand. On completion of the task for which they were established these councils, rather than disbanding, formed together to constitute the New Zealand Council for the Disabled. This Council was legally incorporated in 1978 (Munro, undated).

The 1980's was a decade of activism for disabled persons in New Zealand and around the world. The United Nations declared 1981 to be the 'International Year of

Disabled Persons'. By focusing international attention on the issues impacting upon the lives of people with disabilities, disabled people in New Zealand became aware that the events and conditions they were experiencing in their lives were also common experiences of many others. Awareness was also raised of their collective ability to influence governments. This developing self advocacy movement was highly critical of the medical model of disability (Newsome, 1987). Along with the medical model, the dependence upon charity to fund essential services, and the subsequent ethos of pity were, and continue to be, challenged.

The political empowerment engendered from involvement with the United Nations initiatives led, in 1981, to a petition being presented to the New Zealand Parliament on behalf of people with disabilities in this country. This petition requested that the Government adopt legislative policies to achieve specific objectives to further the United Nations Declaration on the Rights of Disabled Persons. This declaration contained three main objectives; (1) to improve services to persons with disabilities; (2) to increase accessibility to all public places, and (3) to enhance the power, control and authority experienced by persons with disabilities. This later objective was to be accomplished by appointing disabled persons as members of all statutory bodies, boards, corporations and commissions in New Zealand. This was extended to include the demand that a Minister of the Crown be appointed as a Minister for the Disabled.

Two overwhelming themes emerged from the International Year of Disabled Persons. These were (1) that people with disabilities wanted the rights to have a say in their own affairs, and (2) they needed the means to have that say implemented in legislation and policy. From this period, the notions of empowerment, participation and independence began to be called for in both legislation and service delivery. These principles demanded a move beyond a purely medical, treatment approach. They forced an acknowledgment of people with disabilities as an oppressed social group with

little power to influence the decisions that affect their lives. Service providers were challenged to recognise that people with disabilities live in 'multidimensional environments' (Moore, 1995). Without consideration of all aspects of these environments, services were unlikely to succeed in obtaining the outcomes desired by people with disabilities themselves.

The dramatic restructuring of the Welfare State experienced in this country in the 1990's had a significant impact on the experience of disability as it did with numerous other aspects of life in New Zealand. Services for people with disabilities were shifted from the Ministry of Social Welfare to the Ministry of Health. This occurred despite stiff opposition from people with disabilities and their representative groups. The resulting policy shift, now known as the New Deal, is currently the framework under which services are provided for persons with disabilities in this country. Ironically, these policies specifically recognise empowerment as a desirable outcome of disability support services (Self Help and Empowerment; People with Disabilities Challenging Power and Promoting Change, 1993; Disability Services; Client Orientation, 1993 ; Disability Service Priorities, 1993).

### **1.5 Empowerment and the New Deal:**

In 1992, the Government published a "Blue Paper" entitled "Support for Independence" as a consultation and discussion document. This paper proposed the transfer of responsibility and funding of all disability support services from the Ministry of Social Welfare to the Ministry of Health. The discussion and debate which was to follow was preempted by the government's final statement on the funding and delivery of health and disability services published later that year. That document was entitled 'Support for People with Disabilities: A New Deal' (The New Deal, 1992). The focus of this document was to report on the outcome of extensive government consultation on

the incorporation of disability support services into the wider health arena. In this document, the government announced its intent to place all disability support services under the responsibility of the Ministry of Health creating a single funding source for these services and give responsibility to the Regional Health Authorities (RHA's) which were to become the single purchaser of such services. In addition, this document specifically acknowledged that both (a) the current assessment processes had in many instances been a negative experiences for people with disabilities, and (b) that present arrangements for access to services were confused and inefficient. In doing so, it specifically stated that assessment was the key to the government being in a position to identify disability support service needs and the range of necessary service options for meeting those needs. From the position taken within this publication, assessment of need and the subsequent coordinated management of services were likely to become the principle features of government policy which would drive the newly developing purchasing strategies of the RHA's.

Acknowledgment was also given by the New Deal to the universal support expressed in submissions that people with disabilities themselves were to have more input into decisions about disability support services in general, and to have greater involvement in decisions about how their needs might be met specifically. From The New Deal, clear directives were given to policy makers that the framework on which the reformed disability support services would develop must consist of three distinct policy areas: (a) needs assessment, (b) service co-ordination, and (c) service provision.

### **1.6 New Zealand Framework for Service Delivery**

In August of 1994, the Ministry of Health produced the New Zealand Framework for Service Delivery (MOH, 1994). Within this document, needs assessment and service co-ordination are given a priority within the framework of

service delivery. These aspects of service delivery are acknowledged as the principle factors affecting access to all other services for people with disabilities. The Framework document refers to the principal policy documents of 'Standards for Needs Assessment for People with Disabilities' and the 'Regional Health Authority Guidelines for Service Coordination', as companion documents to this framework. Indeed, needs assessment and service co-ordination are identified as two of the four major services for development and represent the principle areas of strategic development which were to be pursued by the Regional Health Authorities. According to this document, this new framework "has been designed to be driven by the needs of people with disabilities (MOH, 1994, p.11).

### **1.7 Standards for Needs Assessment for People with Disabilities.**

The major policy document which has been produced to guide the development of disability services through the reform period is the 'Standards for Needs Assessment for People with Disabilities'. There are eight standards: (1) entry to be easy, (2) written policies and procedures, (3) the assessment process will be culturally safe, (4) people oriented process, (5) the appropriate people will be involved in the assessment process, (6) information will be provided to the person being assessed, (7) collection, storage and transfer of information will be carried out in a secure, confidential manner, and (8) the outcomes of assessment will be an accurate identification of individual needs. These standards are governed by principles which reflect the goals defined within the New Zealand Framework. They emphasize both individual empowerment in decision making and respect for the knowledge and experience of the person being assessed within a safe, flexible and responsive process (MOH, 1994). The emphasis throughout these standards is on the implementation of a process which enhances the involvement of the person with a disability. The assessor role is one of skilled facilitator in a process

which will enable the support needs of the person to be accurately identified.

In this same year, the 'National Standards for Needs Assessment' and a supporting document identifying the 'Rights and Responsibilities' of people accessing assessment services was published by the Ministry of Health. The priority given to needs assessment and service coordination within the reform process was driven to a large degree by the work of the National Advisory Committee on Core Health and Disability Support Services. In January of 1993, this advisory committee produced the document 'Disability Support Service Priorities' matching services to needs. This document emphasized that assessment and who carried out assessment would be key factors influencing the quality of the match between an individual's need for services and the services delivered.

A significant feature of this report is the weight it gives to the concept of disability as a social construct. Subsequent to the publication of this report, the core services committee hosted four consensus conferences. These conferences were attended and influenced predominantly by people with disabilities themselves. They were intended to advise the Ministry of Health on policy and the design and delivery of disability support services.

During 1993, two further National Advisory Committee on Core Health and Disability Support Services documents developed from the consensus conferences were produced. These were 'Disability Services: Client Orientation,' and 'Self Help and Empowerment; People with Disabilities Challenging Power; Promoting Change'. These documents placed emphasis upon the principles by which disability support services should be purchased and provided. They identified the outcomes which services delivered by such principles should aim to achieve. In having been given an opportunity of having their voices heard, people with disabilities seized this chance to redefine and reconstruct the position of disabled people within New Zealand from a

position dominated by medical and professional interests towards a view of disability as a social construct.

These publications, influenced primarily by people with disabilities themselves, and their support organisations, gave a clear direction to the Regional Health Authorities as purchasing bodies. They articulated the priority which people with disabilities were giving to assessment and coordination as major issues within the delivery of services. In addition, these documents identified the principles and processes which should govern the definition of any such services. The most recent National Advisory Committee on Core Health and Disability Support Services document advising on disability support services is 'He Anga Whakamana A Framework for the Delivery of Disability Support Services for Maori'. While this document does not place the same emphasis upon assessment and coordination, it does provide significant guidance as to who Maori consider to be the most appropriate people to undertake needs assessment, and what process should govern such assessments for Maori.

In response to the issues highlighted within these health reform documents, Midland Health began a consultation process in 1993, through a document "We are Listening". Through this process, Midland Health identified its approach to addressing the need for improved assessment and coordination of services for people with disabilities. This approach acknowledged assessment as the key to matching individual needs to available services, with Midland Health working with existing providers to trial and evaluate various types of assessment and service coordination (Statement of Intent, 1994/95). In the subsequent "Have your Say" documents of 1994/95, 1995/96 and 1996/97, Midland has continued to clarify the purchasing process which would be taken. The 1996/97 document identified the goal of developing and improving access to support services through Managed Access to Integrated Support Services (MAISS)

which is a comprehensive approach to needs assessment and service coordination. A full definition of the MAISS services is contained within the 'Request for Proposal, Midland Health: MAISS'. This document clearly specifies the principles which must be demonstrated in the delivery of these services. Included as one of the guiding principles is the stipulation that the provider define how they will uphold the principles of maximising the self determination and empowerment of the individual with a disability.

### **1.8 MAISS and this Study**

MAISS, as defined within Midland Health's service requirement definition, will be the single means of access to all support services for people with disabilities living in the Midland Health region, and is the focus of this study. The manner in which MAISS is delivered will have a major and long term impact upon the lives and aspirations of people with disabilities in this region. It will effectively stand as a gate keeper to all disability support services and will have responsibility for the management of those funds available for the purchase of all services assessed as being required.

For people with disabilities themselves, the manner in which the MAISS services are delivered, the level of skill of the people delivering the services, and the subsequent availability of flexible, responsive service provision, will be the test of the Government's ability to achieve the health reform outcomes so clearly articulated by people with disabilities themselves within the documents developed from the Consensus Development Conferences of the Core Services Committee.

There are a number of principles of good practice which support individual empowerment identified in the 'New Zealand Framework for Service Delivery'; the 'Needs Assessment Standards'; and the 'MAISS Service Requirement Definition' which will be investigated in this study as a means of determining how well this system

addresses the issue of empowerment on a practical, individual bases within its needs assessment protocol.

For an assessment service to foster empowerment, according to these protocols the service itself must (1) be flexible, easy to access and responsive to the population and community it serves, (2) be conducted by qualified and knowledgeable staff, (3) be delivered in a timely manner and within a clear set of standards, (4) have a well developed process for making complaints and responding to them in a positive way, (5) provide quality information to foster accurate expectations on the part of the recipients. (6) respect, recognise and respond appropriately to cultural differences, and (7) meet the purpose for which it is designed (i.e., accurately identify one's needs to ensure that appropriate services are provided). People using such a service should at all times feel, (a) free from discrimination, coercion and harassment, (b) that they had an influence on the process, (c) confident in the process, and (d) satisfied with the manner in which the service was delivered. Finally, they should feel that their needs had been accurately identified and the appropriate services made available.

### **1.9 Aims of the Study**

This study will seek to assess the effectiveness of MAISS (Midland Health, 1996) in fostering a sense of empowerment in people with disabilities receiving these services. The services delivered by one of the two MAISS pilot initiatives will be evaluated. This evaluation will determine the degree to which the principles of good practice for fostering empowerment are adhered to within the process, and will identify the extent to which such adherence affects the recipients sense of personal empowerment. A number of hypotheses relating adherence of these principles to the sense of empowerment and satisfaction will be tested. The effects of a number of personal and demographic variables will also be investigated.

## Chapter Two - Methods

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### 2.1 MAISS Service Provider

The MAISS services were contracted to two Crown Health Enterprises within the Midland Health region, Health Waikato and East Bay Health, as pilot initiatives. The pilot operated by Disability Support Link, a division of Health Waikato is the initiative selected for investigation by this study. The Health Waikato pilot was selected because of the larger population base and geographic area served.

The Health Waikato pilot operates from the Thames Valley/ Coromandel district in the north, through the greater Waikato, into the King Country in the South, (refer Appendix.6). This is a population of 215,160 (Midland Health, 1997) based upon the 1995 census and represents 30% of the total population of the Midland Health region. Within this geographic area there are potentially 58,211 people with disabilities significant enough to impact upon their capacity to undertake the tasks necessary for daily living ( NZCCS, 1997).

### 2.2 Questionnaire Development:

The development of the Empowerment Questionnaire began with the formation of a conceptual framework to serve as a guide for writing questions. This conceptual framework was based on the 'Standards for Needs Assessments for People With Disabilities', developed and promoted by the Ministry of Health. The standards were considered as the most appropriate document to inform the questionnaire framework as they were specifically designed to reflect the policies for service delivery identified within the New Zealand Framework and Core Services Committee documents. In turn the Request for Proposal for MAISS sites the standards as minimum requirements for

the implementation of an assessment service of acceptable quality.

These standards identified eight critical components of best practice which must be present if needs assessments are to be effective in meeting the objectives set within the 'New Zealand Framework for Disability Support Services'. These best practice components are: (1) entry processes; entry standards require the provider to make available sufficient information to enable people to know about the service, how it is contacted, what the purpose of the assessment is, who is eligible to use the service, and the rights and responsibilities of any person using the service, (2) quality and consistency of service; the service provider must develop policies and procedures to ensure a minimum level of quality and consistency in the way in which needs assessment services are to be managed and administered, (3) cultural safety; must be recognised as a minimum requirement, this requires that there be a focus on the ability of the assessment provider to provide a service which would recognise and respect the values of different cultural groups, particularly Maori, (4) and (5) are delivery standards, which emphasize that needs assessment is to be a process of empowerment with the person being assessed playing an active role throughout the assessment process, (6) relates to the provision of information, it emphasizes that any information gained during the assessment belongs to the person being assessed, and as such all documentation generated within the process should be provided to them, (7) is an administrative standard which prescribes minimum acceptable practice for the collection, storage and transfer of information, and standard (8) emphasizes the need for the outcomes from any assessment process to be an accurate reflection of identified needs.

From these eight standards, six outcome objectives were identified. These outcome objectives formed the headings on which the conceptual framework for the questionnaire was developed. (See appendix 2). These six outcome objectives focus

upon, (1) the accessibility and responsiveness of the service, (2) the confidence which can be placed in the knowledge and wisdom of the system, (3) the standards and procedures which govern the behaviour of the system, (4) the ability of the individual to influence the system safely, (5) the shared understanding of both parties and the respect accorded, and (6) the level to which the service actually achieves what it was designed to achieve. From these outcome objectives, a series of rationale were formed. Broad based topic areas were then developed which began the process of identifying the type of question which would be most likely to engender a response which was reflective of the rationale (a full copy of the questionnaire and the conceptual frameworks from which it was developed are included as appendices 1 & 2 of this study).

In developing a context within which this large pool of broadly based questions could be reduced to a meaningful set of questions, reference was made to two major studies, Zimmerman, Israel, Schultz and Checkoway, 1992, and Koren, De Chillo and Friesen, 1992. Both studies sought to develop a measure for empowerment, and both recognised the multifaceted nature of the empowerment. These studies promoted the theory that empowerment was dependent upon the complex interaction of interpersonal skills, interactional relationships and behavioural outcomes.

Using the empowerment theory as promoted by Zimmerman, Israel, Schultz and Checkoway and Koren, De Chillo and Friesen, and following standard scale construction techniques (Carmines & Zeller, 1979; Dawis, 1987; De Vellis, 1991.), two to seven items for each outcome were selected from the large pool of potential questions. These items were selected on the basis of clarity, simplicity and relevance. This selection process was determined by the need to view empowerment as primarily being expressed in three ways: (1), through attitudes and competencies, or what the person feels and believes, (2) through knowledge and information, or what the person knows and understands they can potentially do, and (3) through behaviour, or what

actually happens and the eventual results or outcome of the process. The way in which empowerment is expressed is in turn influenced by the level at which the individual experiences empowerment. Empowerment may be experienced (1) at the level of the self and one's immediate environment, (2) at the level of the service system, or the professionals and organisations which directly impact upon the self, and (3) at the level of the greater community (Koren, DeChillo & Friesen 1992).

At the interpersonal level the questionnaire seeks to identify the attitudes and competencies an individual might have which would enable them to use available information to influence the process of assessment and to exercise some personal control over the outcome. Questions are developed around the person's perception of their ability to make decisions and exercise choice within the assessment process. These questions seek to identify the relationship between perceived empowerment and the ability to make decisions and to exercise control and influence over what happens in one's life.

Information regarding the relationship between the service system and the individual, and the extent to which this relationship impacts upon empowerment at the interactional level is sought through questions relating to: (1) the knowledge and information available to the person: (2) the common expectations of the person and the assessor, and (3) the level to which the person felt respected, valued and personally safe. Questions focusing upon the interpersonal and interactional level relate to the process of assessment and the potential impact of the process on perceived empowerment. Questions relating to whether or not the person believes the services they received as a result of the assessment process reflected their needs and expectations are used to identify the impact which the outcome rather than the process may have on perceived empowerment.

From this analysis of the content of the needs assessment standards, and on an

understanding of the multifaceted nature of empowerment, the specific questions to be included in the questionnaire were identified. (See appendix 2)

The questionnaire that resulted from this process consisted of an anchor question which asks the respondent to indicate whether or not the MAISS process overall had contributed to their sense of empowerment as an individual. The body of the questionnaire is composed of 33 questions which could be seen to have an impact on peoples expressed feelings of empowerment. The 33 questions were grouped into eight major themes consistent with the standards for needs assessment. Questions one to seven focus upon the persons ability to easily access the service, the timeliness of the service and whether or not a complaint was made. Questions eight and nine focus on the adequacy of the information received about the process. Questions 10 to 15 seek information on the regard which people were accorded during the assessment and their perceived ability to influence the process. Questions 16 to 18 have a focus on the credibility and competency of the person conducting the assessment. Questions 19 to 21 pursue issues relating to the cultural sensitivity of the process. Questions 22 to 24, the accuracy of the assessment, questions 25 to 28 the persons ability to influence the outcome of the assessment, and questions 29 to 33 ask the person to respond to the extent to which they believe that the outcome of the assessment would make a positive improvement in their quality of life. In addition to the questions which formed the body of the questionnaire, there were ten questions seeking a range of demographic information.

A small pilot study was conducted with four members of the Multiple Sclerosis Society Committee and staff. The purpose of this study was to receive feedback on how easy it would be for people to understand the questions and to make the appropriate responses. As a result of this small trial some of the structure and wording of the questionnaire changed. Also some additional questions relating to demographic

data were included on the suggestion of the Society members.

### **2.3 Ethical considerations:**

Ethical approval for this study was sought and granted from both the Midland Health and Waikato Ethics committees, (see appendix 3 for copies of the proposal submitted to the ethics committees, and other general correspondence with these committees). Consideration was given to the principles of the Code of Ethical Conduct for Research and Teaching involving Human Subjects. The ethical requirements considered by this study are: (1) the informed consent of subjects, (2) confidentiality of information, (3) truthfulness, and (4) social sensitivity.

On completion, a full copy of the research will be made available to the Multiple Sclerosis Society, with an abstract prepared for publication in their regular newsletter.

### **2.4 Sampling and Data Collection**

The sample for this study was drawn from the 123 people with Multiple Sclerosis who are members of the Waikato branch of the Multiple Sclerosis Society (see appendix 5). This population was selected as it enabled the study to focus upon the needs and experience of a homogeneous group of people from within the same geographic boundaries as the Health Waikato needs assessment service. Furthermore, there is reason to believe that people with multiple sclerosis are significant users of both needs assessment and of ongoing support services (Community Living, 1997) .

Members of the Waikato Multiple Sclerosis Society were invited to participate in the study through an introductory letter which identified the aims and purpose of the research project. The letter also explained how the information was to be used and the means by which information from the project would be provided to those people who participated in the study, as well as to the Multiple Sclerosis Society to which they all

belong. All contact with the sample group was by mail and controlled by the Multiple Sclerosis Society, with all 126 subjects receiving a copy of both the introductory letter and the questionnaire (see Appendix 4). Participants self selected into the study. They did so following receipt of information describing (a) the purpose of the research, (b) who would be involved, (c) how the research would be conducted, (d) how information from the study would be disseminated, and (e) the potential uses of the results. This information was provided in a general way through the Multiple Sclerosis Society newsletter, and directly to each person within the subject group through an introductory letter. The confidentiality of participants was ensured by (a) making no request for personal identification on the questionnaires, and (b) by having all information distributed by the Multiple Sclerosis Society.

A structured questionnaire was used in this study. The subjects were asked to complete the questionnaire and return it in a return stamped addressed envelope provided for that purpose. Three weeks following the original mailing a follow-up letter was sent. This letter thanked those people who had completed the questionnaire and asked for those who had not to take the opportunity of doing so. A second copy of the questionnaire was included with the follow up letter, as was another stamped addressed envelope.

A further follow up was undertaken two months later. The approach used for this second follow up was for the Multiple Sclerosis Society social workers to directly target people who had undergone an assessment during that two month period, leaving a questionnaire for them to complete, with a return envelope. In all 38 people returned completed questionnaires, a response rate of 31%, of this 38 only 20 (52%) had undergone a recent needs assessment. This study will focus on those 20 people who had been assessed through the MAISS assessment process.

From the sample group of 20 people who had been assessed, eighteen were

female, with two male. Their ages ranged between 30 and 67 years, with an average age of 53 years. The majority of the sample group identified themselves as New Zealand European (16), with one man identifying as a South African European and two women identifying as Maori.

There was considerable variation in the length of time the respective participants had required support as a result of their disability. Two had begun requiring support within the 12 months prior to this study, with eight people having been in need of support for more than five years. The average length of time for which support had been required across the total sample was three years. The intensity of the support which was required again differed considerably amongst the sample group. Seven of the 20 people in the sample reported that they needed less than one hour of support a week, with three people reporting a need for support in excess of 20 hours per week. The average amount of support which was reported as being required was four hours per week.

All of the people in the sample lived in their own homes, with 13 of these people sharing their homes with other family members. Five of the respondents lived on their own, the remaining two people, both women, lived with others who were not family members. Seventeen of the respondents lived either within Hamilton city (10) or in one of the larger towns in the district (7). Three people identified themselves as rural dwellers.

The majority of the respondents (14) lived in circumstances where they no longer had responsibility for the care of dependents, although six people did report that providing for the care of others was a regular feature of their daily lives.

There would appear to be a gender bias with respect to who had and who had not been assessed. This will be analysed using a Chi Square with Steven's exact test for small cell size to determine if the observed proportion of males was indeed significantly

different than that expected.

## 2.5 Analysis:

The information from the questionnaire was analysed to determine (1) the number of people who reported that they felt empowered as a result of the assessment process; and (2) to determine which responses were most significantly correlated with expressed feelings of empowerment. The degree of relevance for all responses was determined using the Pearson Product Moment Correlation Coefficient. A level of significance of .01 was set with no correction for repeated tests due to the clearly exploratory nature of the research.

The Pearson Product Moment coefficient was used to determine the extent to which responses correlated with expressed feelings of empowerment.

## Chapter Three - Results:

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Of the 20 people in the sample who had completed a MAISS assessment, nine expressed that overall the assessment process had either had some positive influence, or had greatly contributed to their feelings of empowerment, or mastery over the decisions which impact upon their daily lives.

Ten demographic variables were analysed to determine the extent to which differences within such factors may influence people's perceived feelings of empowerment. These factors were (1) gender, (2) age, (3) ethnicity, (4) type of dwelling, (5) geographic location, (6) status of caregiver, (7) living arrangements, (8) amount of support required, (9) length of time support had been required, and (10) whether the person was responsible for the care of others. None of these demographic variables were found to be significantly correlated with an overall perception of empowerment.

Of the remaining 33 responses which made up the body of the questionnaire, nine were found to be significantly correlated to an overall perception of empowerment beyond the .01 level. These responses related to the level at which the person felt they were able to influence the outcome of the assessment, whether or not they were treated respectfully, whether or not decisions made about services to be received were consistent with the assessment, and whether or not the services to be received as a result of the assessment were seen as likely to make a positive difference in their daily lives. Specifically these responses are: (1) the decisions made about the services I should receive were consistent with those identified in the assessment,  $r=.885$ . (2) The services I have received correspond to those recommended by the assessment,  $r=.805$ . (3) My opinions and desires were reflected in the findings of the needs assessment;  $r=.724$ . (4)

Overall I was pleased with the way the needs assessment was conducted,  $r=.670$ . (5) I was able to influence the needs assessment processes to a degree that I felt that I had control over the process,  $r=.612$ . (6) Overall I feel the services I am receiving are sufficient to maintain an acceptable quality of life,  $r=.603$ . (7) I was treated with courtesy and respect during the needs assessment process.  $r=.596$ . (8) My opinions and desires were considered and respected as part of the needs assessment process,  $r=.584$ , and (9) I believe my needs were accurately and appropriately identified,  $r=.569$ .

Two of these responses, (1) the decisions made about the services I should receive were consistent with those identified in the assessment and (2) the services I have received correspond to those recommended by the assessment, are both highly correlated with an overall perception of empowerment and are very closely related to each other (see table I).

**Table I: Factors Influencing Empowerment**

<b>Factors Influencing Empowerment</b>	<b>R</b>	<b>P</b>
(6.3) The decisions made about the services I should receive were consistent with those identified in the assessment	.885	0.01
(8.1) The services I have received correspond to those recommended by the assessment	.805	0.01
(3.5) My opinions and desires were reflected in the findings of the needs assessment	.724	0.01
(4.3) Overall, I was pleased with the way the needs assessment was conducted	.670	0.01
(3.6) I was able to influence the needs assessment processes to a degree that I felt that I had control over the process	.612	0.01
(8.3) Overall I feel the services I am receiving are sufficient to maintain an acceptable quality of life	.608	0.01
(3.1) I was treated with courtesy and respect during the needs assessment process	.596	0.01
(3.2) My opinions and desires were considered and respected as part of the needs assessment process	.584	0.01
(6.1) I believe my needs were accurately and appropriately identified	.569	0.01

When correlation's are calculated for an overall perception of empowerment and the response 'the decisions made about the services I should receive were consistent with those identified in the assessment', controlling for the response, 'the services I have received correspond to those recommended by the assessment, the result is a positive  $r$  of .6344  $p = .004$ . When this same calculation is run for an overall perception of empowerment and the response 'the services I have received correspond to those recommended by the assessment' controlling for 'the decisions made about the services I should receive were consistent with those identified in the assessment' a correlation of .1784,  $p = .466$  is found. This result indicates that it is the response, 'the decisions made about the services I should receive were consistent with those identified in the assessment' which is the response most positively related to an overall perception of empowerment. The critical nature of this response is re-enforced by an analysis of variance. Almost all of the variance in peoples expression of perceived empowerment (78.33%) is explained by knowing this one response. When this response is controlled for none of the remaining eight responses which are identified as having a positive correlation with empowerment are found to be significant (see table II).

**Table II: Factors accounting for variation in perceived feelings of empowerment**

<b>Factors Influencing Empowerment</b>	<b>Variance</b>
Services received were consistent with those recommended	78.33%
Services received corresponded with those recommended	64.80%
Opinions were reflected in the assessment findings	52.4%
Overall was pleased with the assessment	44.89%
Was able to influence the assessment process	37.45%
Services were sufficient to meet needs	36.36%
I was treated with courtesy and respect	35.52%
My opinions and desires were considered	34.10%
I believe my needs were accurately identified	32.37%

As indicated in Table I, being pleased with the way in which the needs assessment was conducted was one of the factors which was found to have a positive relationship with perceived empowerment. These results indicate however that satisfaction with the process accounted for less than 45% of the variance associated with feelings of empowerment. Further analysis of the information gained from the questionnaire was undertaken in an attempt to better understand the relationship between the concepts of satisfaction with a process and perceived empowerment. This analysis sought to determine whether those factors which contributed to peoples expressed satisfaction with the assessment process correlated with those factors related to expressed feelings of empowerment.

Of the twenty people who had completed a MAISS assessment, twelve expressed overall satisfaction with the assessment process. Thirteen of the thirty three possible responses were found to be significantly correlated with expressed satisfaction to a level of .001 or greater. Included within these 13 responses were all nine of those responses which had been found to have a significant correlation to expressed feelings of empowerment (see Table III).

**Table III: Factors related to satisfaction with the assessment process:**

<b>Factors Related to Satisfaction with the Assessment process</b>	<b>R</b>	<b>P</b>
I was able to influence the needs assessment process to a degree that I felt I had control over the process (3.4)	.890	≥.001
My opinions and desires were reflected in the findings of the needs assessment (3.5)	.870	≥.001
The person conducting the needs assessment appeared to understand my needs and those of my family or caregivers (4.2)	.825	≥.001
Overall I was pleased with the findings of the needs assessment (6.2)	.788	≥.001
My opinions and desires were reflected in the findings of the needs assessment (3.4)	.766	.001
I was treated with courtesy and respect during the needs assessment process (3.1)	.735	.001
The decisions made about the services I should receive were consistent with those identified in the assessment (6.3)	.713	.001
I was given the opportunity to choose the support services I felt I most needed (7.3)	.699	.001
I believe my needs were accurately and appropriately identified (6.1)	.698	.001
Overall I was pleased with the recommendations for service following the needs assessment (7.2)	.667	.001
Overall I feel the services I am receiving are sufficient to maintain an acceptable quality of life (8.3)	.641	.001
I was involved as an important part of the needs assessment process and not simply the object of assessment (3.3)	.578	.001
The services I have received correspond to those recommended by the assessment (8.1)	.570	.001

Those factors which accounted for the variation in responses to expressed satisfaction with the assessment process were however found to be different from those related to perceived empowerment. The responses ‘I was able to influence the needs assessment process to a degree that I felt I had control over the process’, and ‘My opinions and desires were reflected in the findings of the needs assessment’ were found to account for 79% and 75% of this variance respectively.

A potential bias in the sample in respect of a gender difference between those respondents who had been assessed and those who had not was identified using a Chi square. Of those who had been assessed 18 were female and 2 male, with 11 male and 7 female subjects being in the group who had not been assessed. The observed

proportion was significantly different than that expected (chi square =  $P = 0.00162$ ).

Analysis of other demographic variables between those men who had been assessed and those who had not indicated that those who had not been assessed had equally as high as, or in some instances higher levels of support need, than those who had been assessed. A majority of all men in both groups identifying that they were dependent upon family members to provide all of their support needs.

## Chapter four - Discussion

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The results of this research are consistent with the Empowerment Theory proposed in the literature by Zimmerman, Israel, Schultz and Checkoway, 1992, Gutierrez and Ortega (1991) and Koren, DeChillo and Friesen (1992). This study lends support to the ideas expressed in the literature which contented that empowerment is a multi faceted construct which requires that the individual experience mastery at the interpersonal, interactional and behavioural levels.

Factors related to expressed feelings of empowerment were found to be drawn from all the three levels of the empowerment as identified within the literature. (1) The interpersonal level, where the attitudes and competencies of both the individual being assessed and the individual assessor are the primary focus. (2) The interactional level, or the point where the individual and the service system interact through the sharing of knowledge and information, and (3) the behavioural level, where the long term enduring impact of the assessment is likely to be experienced. This study would suggest that assessment providers are most likely to influence feelings of empowerment where there is an emphasis on the interactional level. Empowerment at this level appears to involve the service user and the assessor interacting in a way which gives integrity to the outcome of the assessment process.

Findings of this research indicate that aspects of all levels of the empowerment matrix do have a combined influence on the persons expressed feelings of empowerment with the interactional level being the most significant.

The primary purpose of this research was to determine how effective MAISS needs assessment services are in fostering a sense of empowerment in people with disabilities who use such services. The results of this research indicating that around 45% of those people who had been assessed found the experience to have had either

some positive influence, or to have greatly contributed to their feelings of empowerment, or mastery over the decisions which impact upon their daily lives. . It would appear from this study that it is the internal validity of the assessment process which is most significantly related to people's expressed feelings of empowerment.

Such feelings of empowerment appear to be most evident when people believe that the service system has acted with integrity, or where there is a fit between the information provided during the assessment process and the outcomes which are delivered from that process. For MAISS to positively influence the empowerment of people with disabilities, then, it would seem to be essential that the ongoing services provided as a result of the assessment are consistent with those that were identified as being required during the assessment process. Positive engagement with the service system through the sharing of knowledge and accurate interpretation of information were found to be the over riding factors influencing expressions of perceived empowerment. These factors were found to be even more significant in fostering empowerment than whether or not the services received were seen as being sufficient to maintain an acceptable quality of life.

MAISS as a major assessment system then, is clearly able to have a positive impact upon people's perceived empowerment. This assessment process, it would appear, will only be successful in fostering empowerment when the outcomes from the assessment are consistent with the expectations of the person being assessed. These expectations appear to be best met when the person believes that the process of assessment has accurately recorded and reflected a true identification of their needs.

With the need for the MAISS providers to manage budgets, a potential risk to the internal validity of the service is introduced. This research suggests that the introduction of such risk to internal validity directly threatens the capacity of the assessment process to engender empowerment within those people using the service. If

the promotion of individual empowerment is to be retained as an outcome of MAISS service system involvement, and if it must be maintained alongside of the need for the MAISS provider to control access to services through budget management, then some essential tensions will need to be addressed. For empowerment to be maintained it will be critically important that the needs assessment process does not become a process of resource allocation in the first instance, with the assessment of need becoming a secondary consideration.

Inevitable tensions must be created when a single provider is responsible for both the identification of need and for the managing of limited resource. This tension of itself does not need to detract from the promotion of empowerment amongst service users. Rather, this study would suggest that providing the service system clearly and honestly identifies need, and is prepared to expose the reality of the gap between demand and supply, then a person's feelings of empowerment, mastery and influence within the system would remain intact.

This study would also suggest that it is the integrity of the service rather than the type of service provider which makes the difference as to whether or not people experience feelings of empowerment. The provision of MAISS services through large medical service provider organisations such as Health Waikato need not necessarily result in negative outcomes for people with disabilities using the service. These medical model providers can foster empowerment providing they are able to ensure that those people conducting the assessment are consistently able to recognise the knowledge base of the person being assessed, and to effectively integrate this knowledge into an assessment outcome which is truly reflective of need. As this study had a focus on one MAISS provider only, that provider being a large hospital provider, it is not possible to determine whether those aspects of service which lead to empowerment would be more or less evident in smaller, community, disability focused

provider organisations.

Although the composition of question responses which lead to empowerment were found to be similar to those which influence client satisfaction, the relative importance of the responses differed for the two concepts. This difference in relative importance suggests that the concepts of empowerment and satisfaction relate to different aspects of the assessment process. The majority (8) of responses for both concepts are found to exist within the interactional level of the empowerment matrix. Those responses with the most significant influence on expressed satisfaction with the process came from the interpersonal level, or the level related to attitudes and competencies, rather than the interactional level as was the case with expressed feelings of empowerment. This would suggest that client satisfaction is associated with the process of service delivery, while empowerment is associated with the internal validity of the service, or the relationship between process and outcome.

This raises some questions with respect to client satisfaction surveys and what it might be that such surveys actually measure. Satisfaction with services appears to be more a reflection of the way in which people perceive they were treated by individuals from within the system. Satisfaction would appear to be a concept related to the attitudes and competencies of individual employees in their relationship with individual clients. Expressions of high client satisfaction would appear to be related to high levels of compliance with service standards, as service standards are able to prescribe in some detail what actions should be undertaken for an appropriate quality of service to be delivered.

Empowerment on the other hand appears to be more related to a meaningful sharing of information and knowledge between the system and the client. With such an exchange of knowledge being reflected in the service outcome and thereby giving validity to the assessment process. Client satisfaction surveys then may tell us more

about the individuals employed within service systems and the level to which such systems comply with standards and guidelines, than they do about the effectiveness of the service which has been provided. It would appear that where assessment providers adhere most closely to principles of best practice such as those identified within the 'Needs Assessment Standards' service users will be more likely to report satisfaction with the service provided. Where assessment providers reflect the service users own knowledge and experience to provide a true assessment of need then positive feelings of empowerment are more likely to be expressed.

The results of this study endorse the quality of the Needs Assessment Standards which have been developed by the Ministry of Health. The first seven of these standards provide a guideline as to those service inputs which will be required for a high quality assessment process to be delivered. Adherence to these standards would be likely to result in high levels of satisfaction amongst the client group being assessed. For the service to actively promote empowerment then it would seem that a concentration on the eighth standard, 'the outcome of the assessment will be an accurate identification of individual need', would provide an excellent starting point. If providers of MAISS services place a high priority on compliance with all of these standards, and are rigorous in their implementation it is likely that the service which is provided will be a positive and effective one for everybody involved.

The results of this study indicate that a significantly higher number of women have been assessed for support than men. The gender imbalance between those people who had been assessed and those who had not was significant enough to suggest that further research into this situation may be warranted. Although the two men who had been assessed did require high levels of support, that is over 20 hours per week, this was not an uncommon level of support identified as being required by those men who had not had their needs assessed.

Even in the two instances where men had had their support needs assessed, one continued to receive his entire support from a family member with the other dependent upon a family member for at least part of his support. For those men who had not been assessed, their support requirements were provided for almost entirely by family members. In those instances where men reported they did require care or did not have a caregiver all lived with family members.

This gender bias seems to suggest that men with disabilities may be more likely than women in the same circumstances to be dependent upon the natural unpaid supports of the family to provide care. This care is often at very high levels provided over extended periods of time.

Even in those circumstances where formal assessment systems such as MAISS have identified that high support need levels exist, the resultant provision of this support is largely a responsibility of the family. The likelihood that these family members acting as long term, informal caregivers are women is very high. From these results it would appear there could be a tendency for the MAISS process, in its gatekeeping role, to be using the existence of natural family supports as a means of reducing access to formal support services and thereby managing budget expenditure.

Recent policy changes within Work and Income New Zealand which target those people who are acting as informal care givers of adults with a disability must call into question the sustained viability of such strategies. These policy changes identify that the provision of informal care giving on its own does not make a parent or spouse of a person with disability automatically eligible for an invalids or domestic purposes benefit. Indeed, this policy explicitly states that such care givers must be registered as job seekers and be actively looking for paid work outside of the home. The impact of this policy change has the potential to negatively affect both the caregiver and the person with a disability. It is likely to be instrumental in furthering the inequities

experienced by woman care givers, and by those families who depend upon these woman to provide full time, unpaid care. As a result a gatekeeping process dependent upon informal caregivers operating as the principal or only providers of care is unlikely to be able to be sustained. An unplanned and therefore unexpected increase in demand on health funded, formal caregiving services within the disability sector is likely to result.

#### **4.1 Limitations:**

In entering into any discussion, or seeking to reach any conclusions from this study, some significant limitations must first be acknowledged. The major limitation is the sample size. Although 38 questionnaires were returned, only those 20 representing people who had undergone an assessment could be used as the sample group for this research. If this percentage is reflective of the situation in the community, and only 50% of people eligible for assessment have indeed been assessed, then the 20 people who have undergone an assessment would represent 33% of those people in the total sample population who had undergone an assessment. Nevertheless this sample size is too small for the results to have any predictive validity and any conclusions reached must be interpreted cautiously and would require replication for them to be substantiated.

In addition, the questionnaire developed for this study was exploratory and would need to be validated on a much larger sample before it could be said to represent an accurate measure of empowerment.

#### **4.2 Further Research Opportunities:**

Due to its size and nature, this research has been limited in investigating all of the possible consequences of the introduction of the MAISS needs assessment process on the lives of people with disabilities. It focused on the participation of a small group

of consumers from one MAISS service provider area. There has been no attempt to generalise the stated findings above and beyond this context.

The key emphasis for the researcher was to identify whether or not needs assessment services developed from policy which emphasized the need for the consumer to exercise control over the assessment process was indeed able to be implemented in practice, the rhetoric of the policy. This has, to a limited extent been achieved, however it does not denote that further research is not necessary, indeed, one of the key findings of this research is that further research is required. Future research could broaden the parameters of this thesis by replication with a larger sample population within those areas where MAISS is the model for the delivery of needs assessment services. This would serve to better establish the validity of the questionnaire as a tool for measuring perceived empowerment within human service delivery. Further research using the components of the empowerment matrix would also help to determine how the respective cells of this matrix contribute to empowerment. Whether empowerment exists only as a complex multifaceted composite of all components within the matrix, or whether the very nature of empowerment means that the three measures combine together to form a single discriminate function which determines empowerment.

Undertaking empowerment research within models of needs assessment other than the MAISS model, and with MAISS providers other than hospital based medical models, would serve to determine the strengths and weaknesses of the various models of needs assessment with respect to their impact on the perceived empowerment of service users. The opportunity for a comparison of expressed feelings of empowerment between people receiving services from hospital, medical MAISS providers, and those receiving services from community, disability focused providers would also serve to determine whether or not people with disabilities are indeed better able to be

empowered when services are provided outside of a sickness or medical paradigm.

Another avenue for further research is an examination of the gender bias which became apparent in the course of this research. Research is required to take this observation further and to look more closely at (1) the extent to which the ongoing support needs of men with disabilities are being acknowledged within assessment systems, (2) the extent to which men with disabilities are perceived as requiring support over and above that which would ordinarily be provided by one family member in support of another, and (3) a comparison between the perceived support needs of women and men with disabilities who live with a spouse. Included as part of further research in this area, consideration needs to be given to the extent to which MAISS or MAISS type assessment services are leading to increased expectations that the provision of support for adults with a disability will be provided by family members. The impact such caregiving may have on both the caregiver and the family unit also warrants further investigation.

Two additional areas for further research which would assist in increasing our understanding of the role of service providers in enhancing the empowerment of people using their services would be in the areas of (1) client satisfaction, examining those aspects of service which lead service users to express satisfaction, and (2) the impact of budget holding on the behaviour of needs assessors.

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# Appendix: One

## Questionnaire:

### EMPOWERMENT QUESTIONNAIRE

I am  Male  Female

I am \_\_\_ years old

I identify myself as being  NZ Maori  Pacific Islander

NZ European  European

Asian  Other \_\_\_\_\_

I have required support as a result of my disability for

12 months or less  1-3 years  3-5 years  more than 5 years

As a result of my disability I require

No support  1-2 hours  2-5 hours  5-10 hours  10-20 hours

More than 20 hours of support per week.

I live  Alone  With family  With others

I live in  A house  Hospital  A nursing home

I live in  A city  A town  A village  The country

I have a  Caregiver who is part of my family

Caregiver who is not part of my family

No caregiver

I have responsibilities for the care of dependant family members.  Yes  No

I have undergone a MAISS needs Assessment in the last

0-3 months  4-6 months  7-9 months  9-12 months  13-15 months

The assessment found I needed: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

The services recommended included: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

OFFICE  
USE  
ONLY

1. At that assessment, were you given the opportunity to

1.1 Select the person or agency to conduct the assessment?

- Yes       No

1.2 Have an advocate or support person present?

- Yes       No

I found that the service

1.3 Was easy to contact

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

1.4 Responded to your referral in a timely manner

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

1.5 I was given information on how to lodge an appeal or make a complaint ?

- Yes       No

1.6 I did make a complaint or appeal about the assessment, or about the services received?

- Yes       No

1.7 I feel the complaint or appeal I made was well received and appropriately responded to?

- Yes       No

If you responded no or disagree to any question 1 to 7 above please explain.

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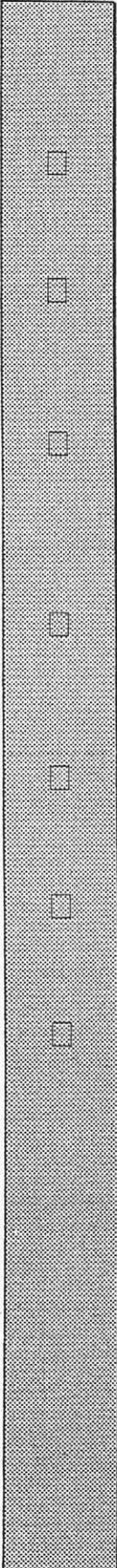
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Please respond to the following statements by checking the most appropriate box

2. At my MAISS needs Assessment I felt that

2.1 I recieved ample information about the needs assessment process prior to it being conducted

- |                          |                          |                            |                          |                          |
|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> |
| Strongly agree           | Agree                    | Neither agree nor disagree | Disagree                 | Strongly disagree        |

2.2 The information I recieved about the assessment process was accurate and prepared me for the actual experience of needs assessment

- |                          |                          |                            |                          |                          |
|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> |
| Strongly agree           | Agree                    | Neither agree nor disagree | Disagree                 | Strongly disagree        |

If you disagree strongly disagree with statements 1 or 2 above, please explain

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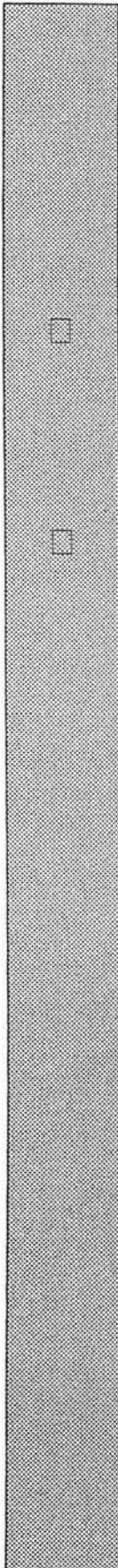
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3.1 I was treated with courtesy and respect during the needs assessment process

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

3.2 My opinions and desires were considered and respected as part of the needs assessment process

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

3.3 I was involved as an important part of the needs assessment process and not simply the object of assessment

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

3.4 I was given the opportunity to identify the services I felt were most important to me

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

3.5 My opinions and desires were reflected in the findings of the needs assessment

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

If you disagree or strongly disagree with any of the statements, 3 to 8 above, please explain

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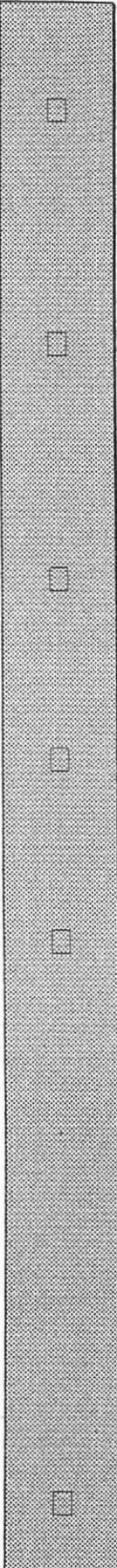
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3.6 I was able to influence the needs assessment process to a degree that I felt I had control over the process

- Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree



4.1 The information I received during the needs assessment process enabled me to understand how decisions about my needs were being made

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

4.2 The person conducting the needs assessment appeared to understand my needs and those of my family or caregiver(s)

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

4.3 Overall, I was pleased with the way the needs assessment was conducted

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

If you disagree or strongly disagree with any statement in 4.1 to 4.3 above, please explain

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5.1 I felt that my cultural background was understood and respected by the assessor

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

5.2 I was able to decide who I wanted to attend my assessment

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

5.3 I was able to decide where I wanted my assessment to take place

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

6.1 I believe my needs were accurately and appropriately identified

Strongly agree       Agree       Neither agree nor disagree       Disagree       Strongly disagree

6.2 Overall I was pleased with the findings of the needs assessment

Strongly agree       Agree       Neither agree nor disagree       Disagree       Strongly disagree

6.3 The decisions made about the services I should received were consistent with those identified in the assessment.

Strongly agree       Agree       Neither agree nor disagree       Disagree       Strongly disagree

If you disagree or strongly disagree with any statement in 6.1 to 6.3 above, please explain

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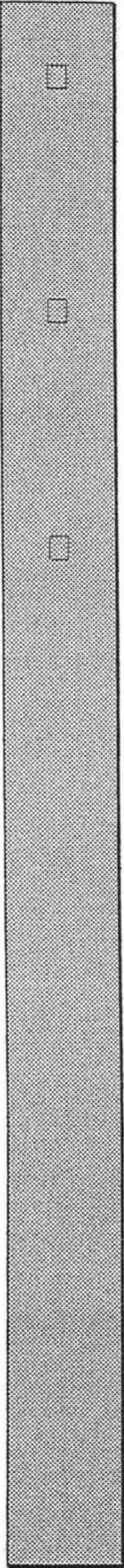
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7.1. Following the assessment I was given a full copy of the assesment and the recommendations for services, for my own records.

Yes       No

7.2 Overall, I was pleased with the recommendations for service following the needs assessment

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

If you disagree or strongly disagree please explain

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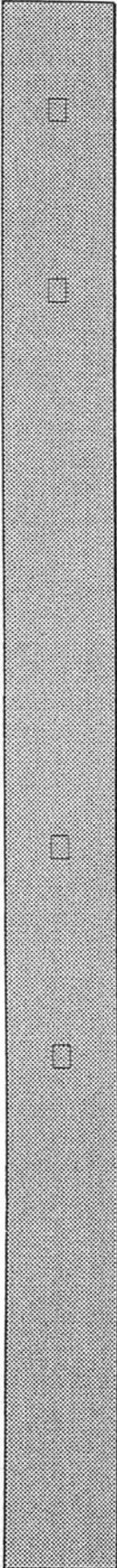
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7.3 I was given the opportunity to choose the support services I felt I most needed

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

7.4 I was given the opportunity to select the provider (i.e. the organisation or individual who will provide) of my services

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree



8.1 The services I have received correspond to those recommended by the assessment

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

8.2 I believe the services I am now receiving will enable me to increase or maintain my involvement within the community

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

8.3 Overall I feel the services I am receiving are sufficient to maintain an acceptable quality of life

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

8.4 I am confident that the services I am receiving now will be maintained in the future

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

8.5 Overall I feel that the MAISS process has contributed to my empowerment as an individual.

\*Note: Empowerment is defined as having mastery over the decisions which impact on your own life.

Strongly agree     Agree     Neither agree nor disagree     Disagree     Strongly disagree

If you disagree strongly please explain.

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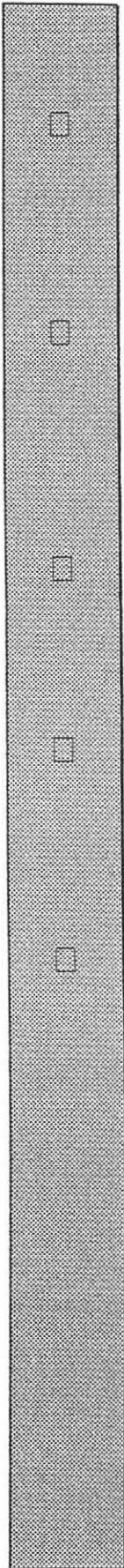
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## Appendix: Two

### Conceptual Frameworks

#### A) Questionnaire Development:

**Outcome Objective:** A partnership between consumers and service providers in the design and presentation of services.

Question Topic Area	Rationale
<p><b>Expectations:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* What did the person expect the MAISS process to be like:</li> <li>* Did the process meet their expectations</li> </ul>	<p>In a partnership, partners should have common expectations, developed from sound information and prior consultation about the process.</p>
<p><b>Personal Safety:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* Was the person treated with respect</li> <li>* Was the person treated with dignity</li> <li>* Was the assessor appropriately skilled</li> </ul>	<p>Within a partnership model services would not be professionally dominated. The position of both partners would be respected and valued. In an empowerment model, the position of the client would be paramount. The framework itself indicates services are to be "driven by the client."</p>
<p><b>Information:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* Was full information provided</li> <li>* Was the person kept informed throughout the process</li> <li>* Was the information provided easily understood.</li> </ul>	<p>A partnership can not exist unless both partners have access to full, clear information. The needs assessment standards require that the person be fully informed at all stages of the process.</p>
<p><b>Involvement:</b></p> <ul style="list-style-type: none"> <li>* A scale to measure the persons overall feeling of involvement in the process.</li> </ul>	<p>In an equal partnership, or a partnership where the person with a disability has the balance of power, they would perceive the process as one in which they were involved and influential.</p>

**Outcome Objective:** As users/consumers of services we should be responsible for evaluating the quality and appropriateness of services:

Question Topic Area	Rationale
<p><b>Complaints:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* The persons feeling of their right to complain</li> <li>* Their knowledge of the complaints process</li> <li>* Response to any complaints made</li> </ul>	<p>In any evaluation of the quality of a service a person must have the right to complain, and to expect a positive outcome from any such complaint.</p>
<p><b>Access:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* Was the service accessible to the individual</li> </ul>	<p>If a service is not accessible to the person using it, it is not likely to be considered to be of quality.</p>
<p><b>Timeliness:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* How long did the person have to wait to get an assessment</li> <li>* How long did the person have to wait to get services following an assessment</li> </ul>	<p>Timeliness is a major quality indicator. Is included in the SRD and the Needs assessment standards.</p>
<p><b>Self determination:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* Did the person feel they were free from discrimination: coercion: harassment: etc.</li> </ul>	<p>Quality, from the position of empowering the person with a disability, would place the power of decision making and self determination with them, with all decisions being of benefit to that person.</p>
<p><b>Satisfaction:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* A scale to measure the overall satisfaction with the assessment process</li> <li>* A scale to measure the overall satisfaction with the services received.</li> </ul>	<p>If the person feels they are satisfied with the process and outcome of the service, then it is likely that they would find the quality to be satisfactory and for the process to be enabling.</p>
<p><b>Support:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* A scale to measure the level to which the person feels they are adequately supported</li> <li>* A scale to measure the confidence the person has in the support they are getting continuing to be maintained.</li> </ul>	<p>The ultimate measure of quality in a disability support service is that the person receiving the services feels appropriately supported, and confident that this support is reliable and consistent.</p>

**Outcome Measure:** The right to make individual choices about services we need, where we want to live, who we live with and how we live our lives.

Question Topic Area	Rationale
<p><b>Empowerment:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* A scale to measure the persons perception of their ability to make decisions and exercise choice in their own lives.</li> <li>* A scale to measure the persons perception of their ability to make decisions and exercise choice within the assessment/coordination process.</li> <li>* A scale to measure the person's perception of their ability to make decisions and exercise choice over the services provided.</li> </ul>	<p>If empowerment is defined as the ability to make decisions over the important issues in ones life, then a person should feel they have control over, or significant influence within the process of accessing essential services.</p>
<p><b>Choices:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* Were people given a choice in the services offered</li> <li>* Were people able to prioritise their own service needs</li> <li>* Were people given a choice in the assessor, or assessing agency used.</li> <li>* Were people given a choice of having a support person or advocate present</li> </ul>	<p>If people with disabilities are to have the right to make individual choices about the services received, then this would represent the major choices available within the MAISS process.</p>
<p><b>Decisions:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* How were service decisions made/what factors influenced the final decisions</li> </ul>	<p>The need to determine the extent of any outside influence which may have affected final decisions.</p>

**Outcome Measure:** Services that reflect the social model of design and delivery not the medical model.

Question Topic Area	Rationale
<p><b>Skills:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* The assessors ability to demonstrate knowledge of disability issues</li>   <li>* A scale to measure the clients overall impression of the assessors knowledge/skill</li> </ul>	<p>If the assessor is working from a social model they should demonstrate an understanding of those issues associated with empowerment: inclusion and rehabilitation, in the identification of needs.</p> <p>If people with disabilities had been involved in the core training of the assessors, then it is likely that they would be more comfortable with the level of skill and knowledge.</p>

**Outcome Measure:** The right to identify our own needs. ie self assessment and control of the identification and assessment process.

Question Topic Area	Rationale
<p><b>Accuracy:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* The persons perception of the accuracy and appropriateness of the assessment recommendations</li> </ul>	<p>If the person was enabled to identify their own needs, then they would be likely to see the assessment recommendations as accurate.</p>
<p><b>Holistic:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* Did the assessment cover all areas of the persons life.</li> </ul>	<p>If the person is able to identify their own needs then it is more likely that social, emotional, educational, etc. needs would be identified</p>
<p><b>Confidence:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* A scale to measure the level of confidence the person has in themselves.</li> <li>* A scale to measure the level of confidence the person has in the MAISS process.</li> </ul>	<p>If the person has been given the control of the process, and the right to make their own decisions about the services they need, they should have a sense of confidence both in themselves and in the process.</p>
<p><b>Involvement:</b> (questions to be based around)</p> <ul style="list-style-type: none"> <li>* What role did the person have in determining their own needs</li> <li>* Does the person know about and have full access to the range of services they feel they need.</li> </ul>	<p>If the person is able to identify their own needs then they would have played an active part in determining their needs, and would feel well informed about available service options.</p>

**Outcome Measure:** Being fully integrated into the community of our own choosing.

Question Topic Area	Rationale
<p><b>Inclusion:</b> (questions to be based around) Any changes in social interaction or community participation.</p>	<p>If the person is fully integrated into the community appropriate support processes should enable them to maintain a satisfactory level of involvement</p>
<p><b>Quality of Life: Self Esteem:</b> (questions to be based around) * A scale to measure the degree to which the person has a positive outlook on life.</p>	<p>If the person is treated with respect; given influence over the decisions which significantly impact upon their lives, and are fully integrated into the community, they would be likely to have a positive outlook on life.</p>
<p><b>Isolation:</b> (questions to be based around) A scale to measure the persons sense of isolation</p>	<p>A person who is fully integrated into their community would not be feeling overwhelmingly isolated.</p>

### B) Framework for Empowerment Scale.

	Self/immediate Environment	Service System	Community Participation
<b>Attitudes / Competencies</b>	<ul style="list-style-type: none"> <li>* I was given the opportunity to identify the services I felt were most important.</li> <li>* My opinions and desires were reflected in the findings.</li> <li>* I was able to influence the process to the degree that I felt that I had control.</li> <li>* I felt my cultural background was understood and respected.</li> </ul>	<ul style="list-style-type: none"> <li>* I feel the complaint I made was well received and appropriately responded to</li> <li>*I was treated with courtesy and respect.</li> <li>* My opinions and desires were considered and respected.</li> <li>* I was involved as an important part of the process.</li> <li>*The person doing the needs assessment appeared to understand my needs and the needs of my family.</li> <li>* I believe my needs were accurately and appropriately identified</li> <li>*I was given a full copy of the assessment and the recommendations</li> </ul>	
<b>Knowledge / Information</b>	<ul style="list-style-type: none"> <li>* I was able to have an advocate or support person present</li> <li>* The information I received enabled me to understand how decisions were being made.</li> </ul>	<ul style="list-style-type: none"> <li>* I found the service was easy to contact</li> <li>I was given information on how to lodge an appeal or make a complaint</li> <li>* I received ample information about the needs assessment</li> <li>* The information I received was accurate and prepared me well</li> <li>* The decisions made about the service I should receive were consistent with those identified.</li> </ul>	
<b>Behaviour / Outcomes</b>	<ul style="list-style-type: none"> <li>* I was able to decide who I wanted to attend my assessment.</li> <li>* I was able to decide where I wanted my assessment to take place.</li> <li>* I was pleased with the recommendations for services.</li> <li>* I was given the opportunity to choose the services I needed most.</li> <li>* I was given the opportunity to select the provider of my services.</li> </ul>	<ul style="list-style-type: none"> <li>* I was able to select the person or agency to conduct the assessment:</li> <li>* I found the service responded to me in a timely manner</li> <li>* I did make a complaint</li> <li>* The services I received corresponded to those recommended.</li> <li>* I am confident the services I am receiving now will be maintained.</li> <li>* I feel the MAISS process has contributed to my empowerment as an individual.</li> </ul>	<ul style="list-style-type: none"> <li>* I believe the services I am receiving now will enable me to increase or maintain my involvement with the community.</li> <li>* I feel the services I am receiving are sufficient to maintain an acceptable quality of life.</li> </ul>

## Appendix: Three

### Ethical Approval

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Pyes Pa  
R.D. 3  
TAURANGA  
20/11/96

Chris Mules  
C.E.O  
Midland Health  
P.O. Box 1031  
HAMILTON

Dear Chris,

I have recently submitted a research proposal to Massey University as a thesis paper for a M. Phil. (Rehab). This proposal has been accepted by Massey in principle. However, as the research topic is an evaluation of the implementation of the MAISS initiative, I believe it would be most appropriate for me to formally seek the support of Midland Health prior to enrolling for 1997.

I have taken the liberty of some discussion with Alec Sinclair with regards the proposal, and have requested that it be submitted to Midland Health's Ethics Committee in the early new year.

As you would be aware, I fully endorse the MAISS concept, and believe it to be the single most important development from the health reforms for people with disabilities. If people with disabilities are to benefit as they should from MAISS, it is critical that the initiative be successfully implemented.

I believe this research will have benefit to Midland. For it to be most effective, support from Midland in an advisory capacity would be of great value.

I would appreciate your giving consideration to this proposal, and am asking, if you would give Midland Health's endorsement to my undertaking the project during this coming year.

Thank you for this consideration

Yours sincerely



Midland Regional Health Authority  
P.O. Box 1031, Hamilton, New Zealand,  
2nd Floor, BDO House, 18 London Street,  
Telephone: 0-7-834 4500 Fax: 0-7-834 3355

13 December 1996

Lorna Sullivan  
Pyes Pa  
RD 3  
TAURANGA

Dear Lorna

Thank you for your letter dated 20 November concerning your research proposal on the evaluation of the implementation of MAISS submitted to Massey University. My apologies for the delay in responding.

I have discussed your proposal with Katrina and we believe it is a good idea and are therefore pleased to endorse the project. In giving this endorsement it is understood that Midland Health will not be committed in any way other than in an advisory capacity during this process.

Christmas wishes to you and your family and I wish you well for 1997.

Kind regards.

Yours sincerely

A handwritten signature in black ink, appearing to read "Chris Mules".

Chris Mules  
CHIEF EXECUTIVE

Pyes Pa  
R.D. 3  
TAURANGA  
28.12.96

Dr Alec Sinclair  
Midland Health  
P.O. Box 1031  
HAMILTON

Dear Dr. Sinclair

I am again seeking the approval of the Midland Ethics Committee to proceed with a research project in completion of a M.Phil Soc.Sc.

Approval was previously given to my undertaking a systematic evaluation of the implementation of the MAISS pilot provided through Health Waikato.

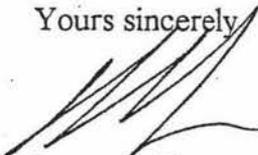
Subsequent correspondence with Health Waikato, however, indicates their reluctance to take part in such a process. As clearly, it is not my intent to in any way cause stress or conflict in undertaking this research, I respect the position taken by the CHE and have therefore restructured the research proposal. This has resulted in the following changes being made to the original proposal.

This research will now consider the impact the MAISS service, as delivered by Health Waikato, has had on fostering the empowerment of the people using the service. The target group for the research will now be people with multiple sclerosis living in the Health Waikato region. Initial dialogue has been undertaken with the Waikato Multiple Sclerosis Society. The society has expressed their willingness to participate in the project.

I have attached a brief description of the redefined proposal; a copy of the letter from Health Waikato expressing their concerns with the original proposal, and a copy of my reply to them

I would greatly appreciate a review, by the Midland Ethics Committee of this current proposal.

Yours sincerely



Lorna Sullivan

## *1. Research Questions*

This research will take the form of ;

- 1) A systemic analysis of the MAISS concept in relation to its ability to address the expressed goals of the New Zealand Framework for Service Delivery
- 2) An evaluation of the impact which MAISS has had on the feelings of self help and empowerment of a group of significant service users.

The research will seek to assess the MAISS concept, and evaluate the processes by which this concept is being implemented through:

- \* identification of critical components of the service, as determined by Midland Health within their request for proposal.
- \* Comparison of these critical components with the expressed goals of the New Zealand Framework for Service Delivery.
- \* identification, from the perspective of people using the service, of how these critical components have been implemented
- \* Identification of whether or not the MAISS services are perceived by people with disabilities as having resulted in enhanced quality of service provision, in relation to the desired outcomes expressed in the Self Help and Empowerment document.

Judgements will be made on the extent to which the MAISS concept is able to attain the expressed objectives of the Governments reforms as they impact upon people with disabilities, and to evaluate the extent to which MAISS is supporting the enablement of people with disabilities. The aim of the evaluation being to identify programme strengths and weaknesses so as to enhance the effectiveness of the service ongoing.

People with Multiple Sclerosis, living in the Health Waikato service area, who have used MAISS services, will form the sample population for this study.

### 3. *Significance of the Project*

MAISS, as defined within Midland Health's service requirement definition, will be the single means of access to all support services for people with disabilities, living in the Midland Health region. It must, therefore, be considered, if not as the single most significant service purchased for people with disabilities, as one of the major service initiatives to have developed from the 1992 health reforms.

The anticipated volume of people using the service in the first twelve months is in excess of 13,000. The current expenditure on services provided in support of this population \$93.87M. (Request for Proposal, Midland Health, MAISS. 1996)

Clearly, then, the manner in which MAISS is delivered will not only have a major and long term impact upon the lives and aspirations of people with disabilities in this region, it will also be the principle mechanism through which a significant proportion of publicly funded services will be accessed.

MAISS, as it will effectively stand as a gate keeper to all disability support services, will also be influential in identifying service duplications and service gaps. These will, in turn, impact upon policy, treasury decisions, workforce development and employment in this professional sector.

As MAISS is the only needs assessment, service coordination model currently operating with a budget management responsibility, the success of these pilot initiatives will influence whether or not Midland Health proceeds along the planned path towards full budget holding, and the buying and selling of service risk. It will also, undoubtedly influence the decision of the three other Regional Health Authorities who are currently not seeking to pursue such a comprehensive, or courageous model.

For people with disabilities themselves, the manner in which the MAISS services are delivered, the level of skill of the people delivering the services, and the subsequent availability of flexible, responsive service provision, will be the test of the Governments ability to achieve the health reform outcomes so clearly articulated by people with disabilities themselves within the Self Help and Empowerment document, developed from the Consensus Development Conferences of the Core Services Committee.

People with disabilities have repeatedly voiced their concerns that with disability services becoming incorporated under a health purchase and delivery framework, the medical model, a model, which negatively views disability as a personal tragedy, characterised by sickness, dependency and therapy, will inevitably overpower their expressed aspirations for social adjustment and change. Should MAISS, particularly a MAISS delivered through a CHE model, be unable to encompass the fundamental principles of empowerment and inclusion, not only will the health reforms have failed to live up to their rhetoric, the personal, social and political aspirations of people with disabilities will have been betrayed.

### ***Abstract of Research***

Midland Health has developed a comprehensive approach to the development and purchase of needs assessment and service coordination for people with disabilities, under the age of 65 years in the Midland region. This process, known as MAISS, (Managed Access to Integrated Support Services) has been developed as the principle means by which Midland Health will seek to meet the requirements of health reform policy for people with disabilities. MAISS will be the single point of access to all health funded disability support services and will therefore have a major influence on whether or not the health reforms achieve the outcomes, as identified by people with disabilities themselves, through the National Advisory Committee on Core Health and Disability Services. This research will undertake a systematic evaluation of both, the development of the MAISS concept in relation to the expressed goals of the New Zealand Framework for Service Delivery (DSS 1994), and the influence which MAISS has had on the self help and empowerment of people with Multiple Sclerosis, receiving services from the MAISS pilot provided from Health Waikato. Judgements will be made on the extent to which Midland Health has met its objectives in relation to the Governments intentions for the reform of Disability Support Services, and the extent to which the service has resulted in the desired outcomes for people with disabilities.

### ***2. Specific Aims of the Project***

The specific aims of this research project will be to:

- 1) assess the MAISS proposal established by Midland Regional Health Authority in relation to its ability to address the goals expressed within the New Zealand Framework for Service Delivery.
- 2) To evaluate the effectiveness of MAISS, as delivered by one of the two MAISS pilot initiatives in achieving the outcomes defined within the Self Help and Empowerment document. This evaluation will focus upon the critical principles and processes of service delivery, as defined by Midland Health, to determine the extent to which the MAISS services are resulting in an increased feeling of empowerment by those people using the service.

Judgements will be made on the extent to which Midland Health has met its objectives in relation to the Governments intentions for the reform of Disability Support Services, as defined within the framework, and the extent to which MAISS is supporting the empowerment of people with disabilities. The specific purpose being to identify the relative strengths and weaknesses of the model of delivery, so as to provide information able to be used to enhance the effectiveness and acceptability of the programme, ongoing.



a division of the Transitional Health Authority

2nd Floor  
18 London Street  
PO Box 1031  
Hamilton  
New Zealand  
Telephone 07 834 4500  
Facsimile 07 834 3355

10 September 1997

Lorna Sullivan  
Pyes Pa  
RD 3  
**TAURANGA**

Dear Lorna

Your letter dated 28 December 1996 (an obvious mistake!) arrived just too late for our local ethics committee meeting.

I suggest, since your target group live in the Waikato that you send this to the Waikato Ethics Committee; they will deal with it quickly, I'm sure.

The Secretary is Dianne Lawson  
PO Box 322  
Hamilton

Good luck and kind regards.

Yours sincerely

Alec Sinclair  
**ADVISOR**  
**HEALTH & DISABILITY SUPPORT SERVICE**

**WAIKATO ETHICS COMMITTEE**

16 October 1997

Ms L Sullivan  
Pyes Pa  
RD 3  
TAURANGA

Dear Ms Sullivan

**AN EVALUATION OF THE IMPACT OF THE "MAISS" PILOT INITIATIVE, OPERATING FROM HEALTH WAIKATO, IN INFLUENCING THE EMPOWERMENT OF PEOPLE WITH MULTIPLE SCLEROSIS**  
(Our ref: 73/97/480)

This proposal was considered by the Committee at its meeting on 15 October 1997 and a number of concerns were raised, as follows:

- a) The appropriateness of a questionnaire as a tool for accessing the required information was queried.
- b) The questionnaire should be validated.
- c) Provision should be made for those who agree etc. to comment in the questionnaire.
- d) The number of people involved in the study is not stated.
- e) A copy of the covering letter should be submitted.
- f) It should be made clear in the write-up of the results that only a specific group was targetted.

The Committee decided that as the outcome of your research may have implications on future health delivery policy, more work should be done on the design of the study. It was suggested that you consult with your supervisor and resubmit your proposal to us.

Yours sincerely



Rosemary J De Luca  
Chairperson

Pyes Pa  
R.D. 3  
TAURANGA  
2.10.97

Dianne Lawson  
Waikato Ethics Committee  
P.O. Box 322  
HAMILTON

Dear Dianne.

Thank you for your telephone call of 1.10.97. I trust the following information will provide you with the information you require.

Dialogue has occurred with the Waikato Multiple Sclerosis Society as to their willingness to participate in the project.

This was followed up with an article in their newsletter for August, telling members what the project was about, and asking them to give consideration to participating.

All research questions will be asked by way of a questionnaire (draft attached). A covering letter will accompany the questionnaire which tells people the purpose of the research, how the information collected will be used, how confidentiality will be maintained, and what feedback they can expect from their participation. This questionnaire will be sent to members of the Society, by the Society itself. The researcher will not know the names of the people who have received the questionnaire. Completed questionnaires will be returned directly to the researcher. All responses will be anonymous and confidential. All costs associated with the distribution and collection of questionnaires will be met by the researcher.

People will self select into the project. That is the questionnaires will be sent out, and only those people who choose to complete them will be included as part of the study.

In discussion with the Multiple Sclerosis Society an agreement has been reached regarding how information will be given back to both the Society and the individuals who have participated.

A copy of the results and relevant aspects of the discussion will be sent to each person who received a questionnaire.

A summary of the project, including results and conclusion will be published in the Societies news letter.

A full copy of the research paper will be given to the Society on completion of the project.

Should further information be required, I will be most happy to make this available.

Thank you for your consideration

Yours sincerely

A handwritten signature in black ink, consisting of several overlapping, sweeping lines that form a stylized, somewhat abstract shape. The signature is positioned above the printed name 'Lorna Sullivan'.

Lorna Sullivan

**WAIKATO ETHICS COMMITTEE**

26 November 1997

Ms L Sullivan  
Pyes Pa  
R D 3  
TAURANGA

Dear Ms Sullivan

**AN EVALUATION OF THE IMPACT OF THE "MAISS" PILOT INITIATIVE, OPERATING FROM HEALTH WAIKATO, IN INFLUENCING THE EMPOWERMENT OF PEOPLE WITH MULTIPLE SCLEROSIS**  
(Our ref: 73/97/480)

Thank you for your letter of 4 November 1997 responding to the concerns raised by this Committee. Your proposal was considered further by the Committee at its meeting on 19 November and given ethical approval.

Ethical approval is conditional upon the Committee receiving a final report at the completion of the study, and a copy of any publication. Please notify us of any adverse reactions or if the study is abandoned or the protocol changed in any way.

Best wishes for the success of your study.

Yours sincerely



Diane Lawson  
Secretary

## Appendix: Four

### Letters to Participants

---

Pyes Pa  
R.D. 3  
Tauranga

Dear Member of Waikato Multiple Sclerosis Society

Please accept my very sincere thanks for giving consideration to completing the attached questionnaire.

The questionnaire is part of a thesis research project. The project is looking at the effect that the (MAISS) needs assessment service is having on the general sense of well being and empowerment of people with disabilities.

With the support of your society, people with multiple sclerosis in the Waikato branch of the society will be the target group for this research. As you can see therefore, your participation is most important.

This is one of the first pieces of research to examine the impact the health reforms are having on the lives of people with disabilities. As such it will be a valuable resource for the Multiple Sclerosis Society, the Disabled Peoples Assembly and other disability support networks. Midland Health has also expressed an interest in receiving a copy of the research which, with your assistance through completing the questionnaire, will be available to them to help inform their decisions when the current Waikato needs assessment contract becomes available early in 1998.

Dr Tom Miller, Research Director for the Multiple Sclerosis Society, expresses his very real thanks for the support you have given to him over recent times. The results of Dr Millers research are now available, and you will find them summarised in your latest newsletter.

Your participation in this project is entirely voluntary, and all information provided is confidential and can not in any way be traced to its source. All people who have received a questionnaire will also receive a summary of the results of the project. A summary of results and conclusions will be published in your local Multiple Sclerosis newsletter, hopefully in February of 1998. A full copy of the research will be made available to the Waikato Multiple Sclerosis Society.

In light of the importance of the information being requested, please take the time to complete the questionnaire, and return it, in the enclosed envelope by **November 15.**

Thank you again for your time

Lorna Sullivan

Pyes Pa  
R.D. 3  
TAURANGA

1.11.97

Dear Member, Multiple Sclerosis Society

I am writing to thank those of you who have most generously given of your time to complete the recent questionnaire relating to needs assessment. I am very appreciative of the information which you have provided, and wish to thank people who have returned the questionnaire even though they had not had an assessment.

There are however, still a number of questionnaires which have not been returned. I would like to take this opportunity to remind you to please complete the form if you have not already done so. The more people who respond, the more valuable the information will be.

Another copy of the questionnaire is attached in case you may have mislaid your original copy.

Thank you again for your support in this matter

Yours Sincerely

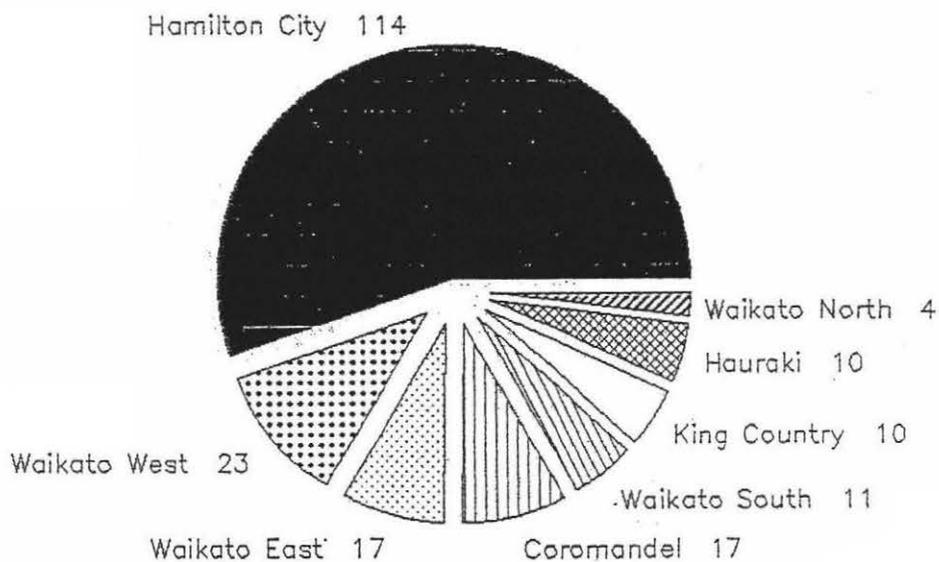
Lorna Sullivan.

## Appendix Five

### Membership Data for Waikato Multiple Sclerosis Society

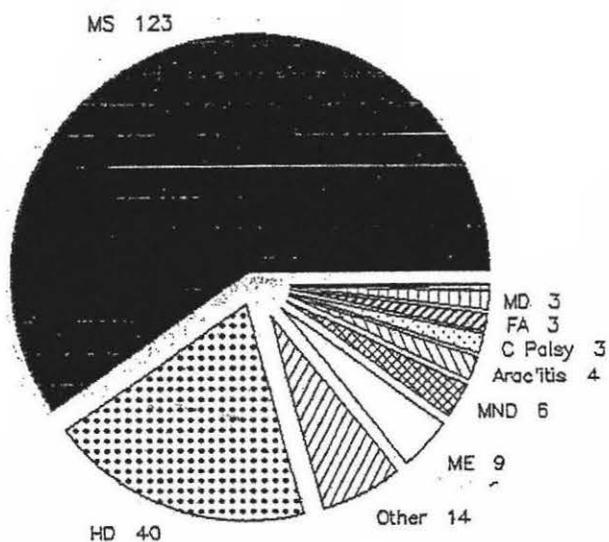
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Waikato Multiple Sclerosis Society  
Distribution of Clients



Total Clients 206 (12-4-97)

Waikato Multiple Sclerosis Society  
Diagnosis Comparison



Waikato Multiple Sclerosis Society  
Distribution of Disabled According to Disability

	Multiple Sclerosis	Arach- noiditis	Cerebral Palsy	Friedreichs Ataxia	Hunting- tons	ME	Motor Neurone	Muscular Dystrophy	Parkin- sons	Other	Total
Ohaupo	1										1
Raglan	3				3		1				7
Te Awamutu	7	1			3	1	1	2			15
Waikato West	11	1			6	1	2	2			23
Kawhia	1										1
Otorohanga	1				3						4
Taumarunui	4										4
Te Kuiti	1										1
King Country	7				3						10
Paeroa	4					1					5
Te Aroha	2						1				3
Turua	1										1
Waioa	1										1
Hauraki	8					1	1				10
Coromandel	2										2
Hahei						1					1
Tairua	1										1
Te Puru							1				1
Thames	3					3					6

Waikato Multiple Sclerosis Society  
Distribution of Disabled According to Disability

	Multiple Sclerosis	Arach- noiditis	Cerebal Palsy	Friedreichs Ataxia	Hunting- tons	HE	Motor Neurone	Muscular Dystrophy	Parkin- sons	Other	Total
Waihi									1		1
Whangamata	3										3
Whiritoa	1										1
Whitianga	1										1
Coromandel	11					4	1		1		17
Supporters											
Total	123	4	3	3	40	9	6	3	1	14	206
COGS Areas											
Kirikiroa	64	2	2	3	26	3	2			12	114
Hauraki	16					5	1		1		23
West Waikato	10		1		6		2				19
South Waikato	29	2	0		8	1	1	3		2	46
Ruapehu	4										4
Total	123	4	3	3	40	9	6	3	1	14	206

