THE QUEST FOR CONSUMER VOICE:

An Evaluation of the Implementation and Outcomes of the Health and Disability Commissioner Act (1994)

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Abstract

This research evaluated the implementation and outcomes of the Health and Disability Commissioner Act (1994) from the perspectives of a regionally based group of consumers and advocates that operate under its provisions. The legislation provides for the Health and Disability Commissioner, the Code of Health and Disability Services Consumers' Rights and advocacy services. The foundations of the Act are based on empowerment and it provides the only collective legislated rights for consumers of health and disability services, of this particular kind, in the world. The research identifies the implementation and outcomes of the Act, based on formative policy evaluation. It employed a triangulation of data utilising the methodological tools of document research and focus group meetings. Two focus group meetings were conducted, one for advocates and another for consumers. The data was analysed in six themes, allowing for the elucidation of the key findings. These themes were: the health and disability reforms; consumerism; the office of the Health and Disability Commissioner; the Code of Health and Disability Services Consumers' Rights; advocacy services and; empowerment advocacy. The key findings that resulted from investigation into these themes were utilised to conclude the research with the prescription of alternative recommendations for policy development and/or organisational structural change. The key recommendations are made in relation to: consumer participation in the health and disability sector; funding levels and organisational structural development from the office of the Health and Disability Commissioner through to advocacy services; an emphasis on the importance of, and need for, promotional activities at all levels of the organisation's service provision and; the need to investigate developing parallel systems of service delivery for Maori. Furthermore, the research noted the need for continued empirical investigation into the provision and functioning of this legislation as it continues to attract international attention and solidify its place within the New Zealand health and disability arena.

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Chapter One - Introduction

1. Research Question

The focal point of this research is the Health and Disability Commissioner Act (1994). This legislation outlines the rights of health and disability consumers receiving public or private services provided in New Zealand. The rights of consumers are regulated under the Act in the Code of Health and Disability Services Consumers' Rights. The Act details the organisational structures that support the promotion and protection of these rights coupled with the establishment of the Health and Disability Commissioner as a statutory position. The role of the Commissioner is to uphold and safeguard consumer rights by promoting the Code of Health and Disability Services Consumers' Rights and investigating complaints that allege breaches of the Code. The Act also established free advocacy services nation-wide. The advocates assist consumers in low level resolution of complaints involving breaches of the Code of Rights and promote awareness of these rights to providers of health and disability services. The advocacy services are contracted to practice empowerment advocacy[1].

This research concentrates on the implementation and outcomes of the Health and Disability Commissioner Act (1994) from the perspective of a group of consumers[2] and advocates who have been affected by its provisions. The research analyses the intended and unintended policy outcomes and identifies the positive and negative consequences of the legislation, in one region with a sample of consumers and advocates. This analysis allows for the formulation of alternative suggestions for policy development and/or organisational structural change.

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[1] Empowerment advocacy stipulates that advocates work with the consumer in a manner which supports them and gives them skills, knowledge and confidence to resolve the current issues with assistance and resolve future issues without assistance (HDC, 1996a).

[2] The term consumer is used throughout this research to refer to individuals accessing health and disability support services. The term is used to reflect the language used within the Act and to provide consistency.

The objectives of the research are:

- To provide a detailed description and analysis of the implementation of the Health and Disability Commissioner's Act (1994).
- To examine whether or not the Act met its stated policy objectives from the perspective of one group of regionally placed advocates and consumers.
- To examine whether or not the policy met the desired objectives of one group of regionally based consumers.
- To examine whether or not the legislation has met the desired objectives of one group of regionally based advocates, employed to uphold and promote the Code of Rights under the Act.
- To provide suggestions for alternative policy development and/or organisational change that could contribute to ideas about how the legislation could more effectively meet the desired goals and objectives of the policy makers, consumers and advocates.

1.1 Rationale

The Health and Disability Commissioner Act (1994) is unique and distinct from any other legal rights entitled to health and disability consumers throughout the world. It is unequalled due to its broad coverage, focus on empowerment advocacy and codifying of consumer rights. The legislation was developed and implemented during a time of significant political restructuring and philosophical transformation in New Zealand. Immense changes to the provision of health and disability services have resulted from the restructuring and the implementation of the Act. The changes to the health and disability sector brought about by the Act are primarily due to the statutory positions, organisational structures and associated functions that have emerged to ensure the promotion and protection of consumers' rights. An analysis of the political and philosophical environment from which the legislation emerged will illuminate the significance of its impact on the legislation's operationalisation.

The legislation was enacted in October 1994 after a considerable duration in the political process[3]. The Act and its regulated parts have been fully operational for just over three years. In this time there has been scarce public commentary on the impact that the legislation has had on the consumers that it was introduced to serve. The Health and Disability Commission has conducted research on the public awareness of the Code of Rights and has monitored and evaluated advocacy services through a social audit (HDC, 1996). However, no impartial non-Government research has been conducted to assess the legislation from the perspective of consumers or advocates. An analysis of the Act from these perspectives is necessary to ascertain if the legislation has met the desired objectives of consumers and advocates. Furthermore, the foundations of the Health and Disability Commissioner Act (1994) are embedded in empowerment, with advocacy services practising empowerment advocacy under the Health and Disability Commissioner's guidelines.

The concept of empowerment has developed steadily in the past few decades and is having a significant impact in the social services. There has been contentious debate about the appropriateness of the application of empowerment and what exactly the term means. This research allows for an examination of the concept of empowerment, using a specific example of empowerment advocacy. The data collected from advocates and consumers on empowerment advocacy, accompanied with the documentary research, adds to the growing literature, with specific reference to the New Zealand context. In addition, the application of empowerment advocacy to health and disability consumers was of interest to the researcher.

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[3] The Act was first introduced to Parliament in 1990 and went through a number of changes before its enactment in 1994.

1.2 Philosophical Base

A fundamental aspect of research design and implementation is the identification of the researcher's philosophical roots. The beliefs, values and world view of the researcher have the potential to impact greatly upon each level of the study. Therefore, to counteract the negative effects that may be associated with any unexamined bias and partisanship, it is important to have an understanding of where the researcher is based. This research topic was formulated for a number of reasons. During my under graduate degree I focused my studies in the area of health and disability, and have developed an interest and wide resources in the area. This interest was partly fuelled because I have a visual impairment and am a consumer of disability support services. Any developments in health/disability policy directly or indirectly influence my life through their social, economic, political and cultural implications. This led to my employment as an advocate for Advocacy Network Services Trust Inc. under the Health and Disability Commissioner Act (1994). Subsequently, I have developed a professional commitment to the field of health and disability, and in particular, to empowerment theory within the field. I am inquisitive about the application of empowerment in its various forms and how this impacts on practice with consumers. In addition, I am interested in the efficacy of this policy, as it stands as one of the only legislative standards of rights for people with health concerns and people with disabilities in the world, that is reinforced by empowerment advocacy. Consequently, I am curious about the views of other consumers of health and disability support services on empowerment advocacy. Finally, I have a desire to carry out research that I feel will benefit the field of health and disability and which is placed within a New Zealand context.

Although I have an appreciation of the necessity for social policy to be cost effective and economically rationalised in the present environment, I do not feel that policy should be limited by financial consideration. Therefore, I may be biased to emphasising the social costs and benefits of policy over economic costs and benefits. However, I am acutely aware of the necessity to make alternative theoretical and policy recommendations that are attainable and sustainable within the environment, which they are likely to be introduced. By recognising my philosophical basis for being involved in the field and for conducting this study, I am recognising that the researcher informs research. From the topic of study chosen through to issues of methodological design and participant selection, the researcher is conducting the shape and formation of the research (Guillemin & Horowitz, 1983).

My desire is to see empowerment advocacy working beneficially for consumers of health and disability support services. It may be the case that the legislation is facilitating such an outcome. If it is not, then I will be interested in speculating on where policy or organisational changes could be made.

1.3 Method

The research focuses on the implementation and outcomes of the Health and Disability Commissioner Act (1994) from the perspective of consumers and advocates. The theoretical framework for the research is formative policy evaluation[4]. This was facilitated by the use of method triangulation (Denzin, 1989), specifically, document research and focus group interviews. The document research disclosed the formation, implementation and outcomes of the legislation from the perspectives of the policy makers, consumers and advocates. This was complemented by an evaluation of the literature pertinent to the concepts of empowerment and advocacy that apply to the legislation. A further analysis of the impact of state sector reform and political philosophies created a framework for the research.

The issues identified in the document research process formulated the questions that were discussed at the focus group meetings. There were two focus group

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[4] Formative policy evaluation is examination of a particular policy or programme with the purpose being the improvement of that policy. The purpose of the research is to improve effectiveness within that setting (Patton, 1990).

meetings, one with consumers and one with advocates. Both groups were selected using purposeful sampling to allow for in-depth data to be collected based on the experiences and views of participants. The consumers and advocates were part of a sample from Advocacy Network Services Trust Inc., one of the ten advocacy services nation-wide operating under the Health and Disability Commissioner Act (1994). The data collected from these sources was then analysed by organising the data into manageable themes, determined by the major areas of information gathered in the documentary research. Each theme and its associated sub-groups were detailed to clarify the issues within and the interfaces between the themes. The data were then used to support and inform the recommendations of the research. They indicated the positive and negative consequences of the Act and identified gaps in service provision. This information and the document research enabled the researcher to make alternative suggestions for future policy development and/or organisational change.

1.4 Format of the Thesis

The structure and format of this thesis has been designed to provide a sequential explication of the information contained within. This begins in Chapter Two by discussing the research frameworks, including the methodological influences and research process, and provides an understanding of how the research was conducted to inform the flow of the evaluation that follows. Chapter Three begins the evaluation process by detailing the theoretical perspectives relevant to the legislation. These perspectives canvass the key themes, most notably empowerment, advocacy, state sector reform and consumerism. The discussion of these themes lay the foundations for the analysis and is contextualised in Chapters Four and Five.

Chapter Four examines the historical development of health and disability policy in New Zealand, with a key focus being the reforms to the health and disability sector in recent decades. This introduces the formation of the Health and Disability

Commissioner Act (1994) by examining its journey through the political process, resulting in its enactment in 1994. The history of the formation of the legislation is pivotal as it expresses the identified need for the Act and the processes by which these needs were either met or discarded. The chapter then focuses on specifying the contents of the Health and Disability Commissioner Act (1994) by detailing most of the provisions found within. Understanding the contents of the legislation is fundamental to an appreciation of the Government regulations, organisational structures, services and statutory positions that resulted. A number of specific implementation tools were utilised to command the shape and form of the legislation in practice, and are described in Chapter Five. The discussions here, include the organisational provision, duties, functioning and interfaces that exist, in addition to the adoption of specific polices and procedures.

Once this narration of the legislative landscape is detailed, an analysis of the various sources of data is explored. This analysis is situated in Chapters Six and Seven, where six key research themes are identified. The themes were derived from the literature and documents surveyed in Chapters Three through to Five and were used to inform the focus group discussions. The themes are: the health and disability sector; consumerism; the office of the Health and Disability Commissioner; the Code of Health and Disability Services Consumers' Rights; Advocacy Services and; empowerment advocacy. The analysis of the triangulation of data permits the research to involve a deep level of inquiry and explain the function of the legislation in greater detail. Chapter Eight concludes the research by stating the key findings and identifying recommendations for policy development and/or structural change. The chapter outlines these findings to summarise the outcomes of the research and lead into concluding comments.

Chapter Two - Research Framework

1. *Research Focus and Objectives*

The focus of the research was to analyse the implementation and outcomes of the Health and Disability Commissioner Act (1994). Specifically, the research intended to identify the implementation of the policy (for example, organisational structure and the functioning of the office of the Health and Disability Commissioner (HDC) and advocacy services, statutory positions, establishment of and, status of the Code of Rights). This allowed for an evaluation of the outcomes with reference to the intended and unintended objectives, goals, aims and desires of the policy makers, advocates and consumers. The research focused on a group of consumers and a group of advocates from one of the ten regions that provide advocacy services under the provisions of the legislation. A purposeful sample of consumers and advocates was selected from this one region. Based on the data collected from these groups and from document research, the study aimed to identify any positive consequences, gaps and/or deficiencies of the legislation and its associated policies. The objectives of the research were:

- To provide a detailed description and analysis of the implementation of the Health and Disability Commissioner's Act (1994).
- To examine whether or not the Act met its stated policy objectives from the perspective of one group of regionally placed advocates and consumers.
- To examine whether or not the legislation met the desired objectives of one group of consumers.
- To examine whether or not the legislation has met the desired objectives of one group of advocates, employed to uphold and promote the Code of Rights under the provisions of the Act.
- To provide suggestions for alternative organizational and policy developments and/or implementation tools to assist the legislation in meeting the desired goals and objectives of the policy makers, consumers and advocates.

This chapter will examine the methodological design and process of the research, as well as discuss ethical considerations and other research issues.

2. Methodology

The theoretical framework for this research is embedded in policy evaluation, thus the focus is on the *purpose* of the research (Patton, 1990). It is appropriate to apply evaluation research when the subject being investigated relates to social intervention. Studying social policy equates to studying social intervention, as policy can be implemented to bring about change to social structures or maintain the status quo.

> *A social intervention is an action taken within a social context for the purpose of producing some intended result. In its simplest sense, evaluation research is a process of determining whether the intended result was produced (Babbie;1992, p.347).*

There are many different ways to research policy design and implementation, depending on the question posed by the researcher. Evaluation research focuses on the processes and outcomes, intended and unintended, of programs, organisations and policies. The specific type of evaluation research that was employed in this study is what Patton (1990), calls formative policy evaluation.

> *Formative evaluation serves the purpose of improving a specific program, policy... or product. There is no attempt in formative evaluation to generalise findings beyond the setting in which one is working. The purpose of the research is to improve effectiveness within that setting (Patton,1990, p.156).*

Formative evaluation is highly applicable to studying the implementation and outcomes of social policy and relies primarily on qualitative forms of data collection. The desired goal is the improvement of human intervention based on the specific topic being studied, the context of the area, time and people affected by the intervention.

The research is not an exhaustive evaluation of the policy, rather it is an analysis of the outcomes of the policy from the perspectives of a group of consumers and advocates who are directly affected by its implementation.

Nearly all research methodologies can be applied to evaluating policy implementation and outcomes. The most appropriate depends on the nature of the research question, resources, time and will of the researcher. This research used a multi-method approach to facilitate the evaluation of the policy from the perspectives of consumers and advocates. This is commonly called triangulation, and simply means the application of a number of methods to the same subject matter (Denzin,1989). For a considerable time, researchers in the field have recommended the use of a multi-method approach to health research (Reichardt & Cook, 1979; Eriksson, 1988). The complementary nature of data from various methodologies provides the researcher with the necessary information to fully explore the stated phenomenon. There are a number of reasons why it is appropriate to use a combination of methodological tools to meet the needs of this particular research. To fully evaluate the subject matter it is necessary to approach the policy from a number of perspectives, including those of the policy makers, consumers and advocates. Each has different interests, and each engages with and is affected by the policy in differing degrees. No one methodology can adequately address this policy from all of these perspectives.

The specific type of triangulation that was employed is what Denzin (1989) refers to as *between-method triangulation*. This is the use of dissimilar methods (for example, document research and interviews), to reflect upon the same phenomenon. The rationale for using this specific type of triangulation is that it allowed for the weaknesses of one method to be assisted by the strength of another. The methods that were adopted in the data collection are documentation analysis and focus group interviews.

2.1 Research Design

The first part of the thesis focuses on the formation and implementation of the Health and Disability Commissioner Act (1994). This primarily involved document research to make sense of the policy's history in association with an examination of relevant literature and concepts. Document research involves the evaluation and analysis of written material that falls within primary, secondary and tertiary documents either publicly or privately produced, that can come from solicited or unsolicited sources[1] (Denzin, 1978; Burgess, 1990; Scott, 1990). These documents are used to comment on the phenomenon being studied and can provide researchers with broad and varied data. Documents can be analysed in terms of who produced or wrote them, what their intentions may have been in producing the document and what the document tells us. Furthermore,

> *(documents)..might be interesting for what they leave out, as well as what they contain. They do not simply reflect but also construct social reality and versions of events. It is not... assumed that documents are neutral artefacts that independently report social reality, or that analysis must be rooted in that nebulous concept practical reasoning (May, 1993, p. 138-139).*

Document analysis is a broad and flexible method of research that allows the

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[1] The documentary research carried out for this project utilised: official information and documents, such as the Act itself; academic commentaries on the various subjects identified under each theme and on the development of research methods; and statistical information and private correspondence with those employed under the various sections of the Act, for example, the Manager of Adnet, Communications Manager at the office of the Health and Disability Commissioner (HDC) and so on.

researcher to consider the ways that meanings have been constructed and the ways that meaning can be developed. This allows for theory to be tested in reference to the particular document and the social, political, cultural and economic context within which it is placed (May, 1993). The selection of documents and themes of analysis in this thesis were guided by the aims of formative policy evaluation and the identification of the policy's impact.

According to Spicker (1995) there are four principles to evaluating policy. Firstly it is necessary to identify the aims of the policy, which informed the identification of the objectives/purpose of the Act. An understanding of the operationalisation of the criteria follows this, exploring how the Act was implemented and the organisational structures and positions that facilitated this implementation. Thirdly, Spicker (1995) states that this initial exploration then allows for an identification of the results or effects. Therefore, detailing the construction of the Act and its implementation necessitated an exploration of the outcomes and their effect on the participants involved. Finally the process requires a comparison of the results with the original aims. The research facilitated this from the perspectives of consumers and advocates. It identified the stated objectives of the Act, as well as the desired objectives of consumers and advocates. From this data it was then possible to compare the similarities, differences and gaps in the policy from the points of view of a number of stakeholders.

2.1.1 Documentation Research

This method of evaluating policy was utilised by researching the documentation around the formation and the implementation of the Act. This included an understanding of the social, economic, ideological and political structures from which the Act emerged. Understanding the landscape that the legislation is placed within, was a fundamental aspect to contextualise. This was associated with the literature that explored the concepts that are the themes of the research; empowerment, advocacy and consumerism. The provisions of the Act have been outlined and complemented by an analysis of the structures that were implemented to serve these provisions. Through this process it was possible to state the identified aims of the policy and the operationalisation of these aims. A fuller evaluation of the policy, identifying outcomes and comparing these with the stated objectives of the policy was made after the data from consumers and advocates had been collected.

It was inevitable that the analysis of the Act, its organisational context, associated structures, political and environmental influences, and literature on the concepts would generate questions about the effect the policy has had on consumers and advocates. These questions also allowed for inquiry sought by the advocates and consumers. The questions were used to develop the focus group discussion points and to shape the focus group meeting interviews.

2.1.2 Focus Group Interviews

The second methodological tool that informed the research was the interviewing of advocates and consumers. The researcher held two focus groups, one for advocates and one for consumers, the purpose of which was to collect data on their impressions and experiences of the policy. Furthermore, the researcher identified what outcomes were desired by the consumers and advocates to identify the extent to which these were in line with the stated aims and objectives of the Government. This delved even deeper by questioning to what extent the formation of political and institutional arrangements had affected the perspectives of advocates and consumers. It was postulated that these questions would allow for consumers and advocates to evaluate the policy at two distinct levels. The first level drew on the experience of the advocates that are administering the provisions of the Act, primarily their practising of empowerment advocacy and the promoting and protecting of the Code of Rights. At the second level, consumers were evaluating the policy with reference to their experiences of the Code of Health and Disability Services Consumers' Rights, complaints and empowerment advocacy.

The data was collected from interviews in the form of two focus group meetings with consumers and advocates, both groups having been selected through purposeful sampling. Focus groups are a methodological tool commonly employed in data collection for qualitative research. They have six identifiable features:

1. People
2. Assembled in Groups
3. Possessing certain shared characteristics
4. Providing data
5. In a qualitative form
6. In a focused discussion (Krueger, 1994).

Focus groups were traditionally derived for marketing research in the business arena. They have increasingly been employed in the study of social sciences and, in recent years, have been applied to health research (Thomas, Steven, Browning, Dickens, Eckermann, Carey & Pollard, 1992). Focus groups allow for a discussion of a predefined topic that seek to explore the viewpoint of the participants. Although the discussion is structured and usually based around set questions or discussion points, they are open and flexible. Participants converse with each other, guided by the facilitator, to detail their experiences and knowledge of the topic area (Murphy, Cockburn & Murphy, 1992). Furthermore,

> *Focus groups provide a useful way of studying people's knowledge, opinions, constructs, ideas, feelings and motives about health and their actions as expressed in their own words and experiences (Thomas et al, 1992, p.52).*

Stewart & Shamdasani (1990) identify some of the advantages of conducting focus group interviews. Firstly, data can be gathered more quickly and economically than with individual interviews. The data collection phase of the focus groups for this research took approximately one day; a morning for the advocates and an afternoon for the consumers. These meetings generated over five hours of tape for transcription and a considerable wealth of data for the research. Secondly, the group interview required the logistical organising of one function room, with travel, time and other resources, such as transcribing the tapes, being kept to a minimum. These benefits were noted in the research in a number of ways. Most significantly, it took a relatively small period of time to organise the focus groups (6 weeks), thus reducing the time and effort of the researcher to facilitate the volume of data generated. This included organising the participants and locating a venue.

The construction of the focus group interviews also allowed for the data of a number of participants to be collected within the framework of an in-depth discussion without the associated costs. This may result in a greater number of participants being involved than is typically possible with other types of qualitative research, while maintaining direct interaction with the participants. Furthermore, participants add to this data by responding to, and building on, the responses of other group members, which opens up the discussion and may result in more data being gathered because of the diverse knowledge base and experiences of the participants. Focus groups allow for participation from a wide range of people with differing skills, abilities and needs. The information that they have to share and the interaction that they generate with other participants, can be an invaluable source of varied and broad commentary on the subject matter. The advocates in the first instance, brought different experiences and knowledge to the focus group, coupled with their diverse geographical influences.

However, it is important to note that there are also possible limitations to this methodology. An awareness of those potential shortcomings ensured that the researcher remained sensitive to the deficits, in data collection, that might be associated with the focus group method. These factors are primarily focused around the dynamics of group interviews, including issues such as dominant respondents, bias control of the group by the researcher, responses not being individual, 'group think' reducing the diversity of responses, and quiet or reluctant participants. The preparation, sampling and facilitating skills of the researcher were all-important influences in controlling the effect of these possible factors[2].

For the purpose of this research, two focus groups were organised consisting of three participants in the consumer group and seven participants in the advocate group. The first focus group included consumers of Advocacy Network Services Trust Inc.[3], a regionally contracted service, providing advocacy for the Health and Disability Commission. The second focus group consisted of advocates from Advocacy Network Services. A purposeful sample was selected from the group of consumers and advocates associated with Advocacy Network Services. A purposeful sample involves the selection of a small number of participants to allow for an in-depth study. The number of participants is reliant on the goals and design of the research. The key is selecting participants that will be able to provide detailed knowledge of the subject to be researched (Patton, 1989). This type of sampling was chosen because it is complementary to the requirements of focus group meetings. Thomas et al (1992) state that participants should be selected on the basis of their representation of key groups/views in the phenomenon being studied. It is inappropriate to select participants based on proportional representation of a wider population. After all, the application of focus group data is not appropriate where the findings are to be generalised to a larger population for statistical estimation because the number of participants that can be involved are still too limiting to survey general public opinion (Ward, Bertand & Brown, 1991).

Advocacy Network Services (Adnet) was selected because it is based in the wider Manawatu-Taranaki region, and access to participants was manageable for the researcher. The Director of Advocacy contracts ten advocacy services nation-wide on behalf of the Health and Disability Commissioner. Although each of these

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[2] The section entitled 'Focus Group Data Collection' further on in this Chapter, explains the measures taken in the research to eliminate these issues.

agencies is autonomous, they receive training and monitoring from the Director of Advocacy, and it was presumed that there was reasonable consistency across regions in service delivery. Although the data collected in the focus groups may not reflect the experiences of consumers and advocates nation-wide, it can offer significant insight into the experiences of these consumers and advocates involved in the services and provide findings to inform further research.

2.2 Rationale

There are a number of justifications for this study's theoretical base and research design. The first component is the use of a mix of qualitative (group interviews) and quantitative (document analysis) methods of research. The document research that was executed, including statistical analysis gained from these documents equates to quantitative research. This data was complemented by the qualitative method of interviewing consumers and advocates. A combination of these methodological approaches positively diversified the data utilised for the analysis and subsequent findings.

Qualitative methods were included because the research question required in-depth subject participation. The research needed to identify what participants thought and felt about the policy; why; how this was reflective of their experiences; and what they believe needs to be changed. Purposeful sampling was used for this very reason[4]. A small group of consumers and advocates that would be able to provide in-depth information on their interaction with the provisions of the legislation was desired. Qualitative methods of research allow for this level of

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[3] See Appendix Six for a description of the organisational structure and functioning of Advocacy Network Services Trust Inc. (Adnet).

[4] Furthermore, purposeful sampling was appropriate in this situation because of the researchers prior networks and relationship with the service that provided the advocates and consumers for the focus groups. The extent to which this impinged on the data collected is commented on in Chapter Eight.

participant involvement and disclosure and permit an understanding of the experiences and emotions in the subjects' own terms (Jayaratne & Stewart,1991). Furthermore, the nature of qualitative research allows for this exploration to be undertaken in a way that empowers the researcher and the participants to encourage change. Discovering information and sharing that information to allow greater accessibility to permit participation facilitates this. Access to appropriate information is one of the key steps to enable empowerment through participation in decision making processes. The goal of formative policy evaluation is to improve the effectiveness of policy. Ballard (1994) reiterated this point when discussing the use of qualitative methods with people with disabilities.

> *Researchers should engage with research participants as equals in a process of critical reflection and mutual problem solving. In this way we may hope to understand our different realities as they exist at a particular time. We can act on those understandings in order to improve policy and practice. That will lead to new circumstances that, once again, will need interpretation, reflection and action (Ballard, 1994, p. 304).*

The quantitative method of document research was also required to fulfil the needs of formative policy evaluation. A paramount requirement of the research was to have an understanding of how the policy was formulated and implemented before an analysis of the outcomes of the policy was undertaken. The foundations upon which consumers' and advocates' experiences had been based needed to be laid. This included an understanding of the concepts and the theoretical ideology that shaped the environment within which their experiences of services is located. Furthermore, it would not have been possible to suggest alternative policy developments, based on consumer and advocate responses, without knowing the dimensions of the policy as it stood. This is pivotal when we recognise the significant reforming that has occurred in the state sector since the late 1980s and, particularly in the health and disability sector, since 1993[5].

The application of these methodologies, with specific regard to the field of health and disability, is supported by the literature as being an appropriate means of data collection (Eriksson, 1988; Ward et al, 1991; Thomas et al, 1992; Murphy et al, 1992). They allow for an analysis of the documents surrounding the given topic and the voice of participants to enrich the research. This is particularly relevant when researching issues pertinent to people with disabilities, as it allows for the unveiling of the social construction and implications of disability (Morris, 1992a; Oliver, 1992). Employing only one of the methods over the other could have produced data that was not sufficient to explore an issue that affects people's lives so significantly.

The data disclosed the opinions of a small group of consumers and advocates from one of the ten regions that offer advocacy services under the Act. The results reflected the data provided by consumer and advocates, and the data collected from the documentation research. The findings do not state that the outcomes and alternative recommendations are the reflection of all consumers or advocates, but it could allow for further investigation. The research outcomes indicate that further research may be required to examine the extent to which these expressions are more widely held.

3. The Research Process

The foundations of this research are clearly laid through the examination of the theoretical framework, methodological design and stated justifications. However, it is necessary to state how these methodologies were employed in the research process, stating what occurred and how it was developed to define the research

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[5] Refer to Chapters Three and Four for a discussion of this.

question. This includes an explanation of the process of data collection, analysing the data, indicating the key findings and developing recommendations. The following sections outline the research in action in the clearest chronological order that can be achieved[6], from conception to completion.

The first stage of the research process entailed developing potential research questions. A clear goal from the outset was to develop research centred on the Health and Disability Commissioner Act (1994) and more specifically, empowerment advocacy. The exact nature of the research question needed to be tackled before any other research issues could be addressed. This initially began by drafting a research proposal on the efficacy of empowerment advocacy as practised by advocates under the Act, which comprised the basis for initial discussions with supervisors. The supervision process has been fundamental to the development of this research, and it is appropriate to detail it here, acknowledging that it was instrumental in influencing the development of the thesis on a continual basis throughout the research process.

A contractual agreement was entered into with both supervisors at the beginning of the academic year. This contract stated the expectations of the student and the supervisors, and the frequency and duration of supervision meetings. It was decided that we would meet once a month for the duration of the research. The student would supply the supervisors with an agenda prior to the meeting. Furthermore, the student, and/or supervisor's, could initiate contact, via e-mail and the telephone, in between these scheduled meetings. Supervisors would provide feedback on any work submitted to them ten days prior to the meeting, and would advise on matters pertinent to the research, beginning with assistance on defining and outlining the research question.

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[6] Some of the events stated happened concurrently, and are detailed slightly out of order in a desire to outline them in the most clear and logical manner.

Based on the information that was canvassed in the draft proposal and further discussion with the supervisors, the research question was established. Once this task had been completed it was necessary to develop strategies for data collection. A clear objective from the beginning was to involve consumers and advocates in the research design. Their inclusion was necessary to give this evaluation voice from the perspective of those who were most affected by its implementation and outcomes. A number of qualitative interview methods were discussed, and it was decided that focus groups would allow for a large number of participants to be involved, with limited commitment of time and resources. It was also necessary to include document research in the design, as the information gathered through such an endeavour would supply the data required to fulfil the evaluation of the policy. Furthermore, the document research would provide a source of information to be utilised during the focus group interviews.

Once the research questions, methodological design and supervision details were confirmed the next stage involved applying for funding. Applications for funding from the Graduate Research Fund (GRF) at Massey University were submitted and granted with monies allocated towards the transcription of the focus group tapes, photocopying, travel and other associated data collection costs.

3.1 Documentation Data Process

After the initial stages of research development, it was necessary to identify the framework of the thesis. This led to a detailed and exhaustive exploration of the relevant literature. Consequently, the document research was engaged on two levels. The first was an exploration of the literature pertinent to the concepts located within the Act. This included setting the scene of the political context within which the legislation was created and now operates. The second focus was the official documentation surrounding the formation and implementation of the legislation, including documents subsequently released by the office of the Health and Disability Commissioner.

The first phase of the document research and subsequent analysis began by identifying the relevant documents. This was guided by the phases of formative policy evaluation initially requiring an identification of the policy's aims, how they were operationalised, and the outcomes and results (Spiker,1995). This required the use of primary, secondary, contemporary and reflective documents (Sarantakos, 1993). In order to identify the aims of the policy and how these were operationalised, the legislation itself was initially considered. This was supported by other official documents that were released at the time, most of which were produced by the Health and Disability Commissioner[7]. By focusing the initial research on the Act and its associated institutional arrangements, key areas of inquiry were highlighted. These areas were separated to focus and structure the research. These included: the Act, empowerment, advocacy, statutory positions and the Code of Rights. Each of these areas was also separated to identify the significant documents that pertained to them. In doing so, it became obvious that there were some gaps in the data gathered. For example, it was necessary to gather documentation and information on the background to the legislation. This then developed into a theme on the history of health and disability policy development in New Zealand and the social, political and economic environment within which the legislation was created. As was anticipated, as each area was researched via the applicable documentation, the picture began to form, highlighting the gaps in information and the need for more areas to be examined. This also developed within subgroups of data, as theoretical data was required to contextualise the practices and processes that have resulted from the legislation.

Evaluating this data ensured that each area was researched thoroughly and allowed for the interfaces that exist between them to be established. It also

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[7] Some of the seminal documents included: The Report of the Health and Disability Commissioner to the House of Representatives (1996); Reference Manual for Advocates from HDC (1996); Discussion Document on the Draft Code of Health and Disability Service Consumers' Rights (1995).

allowed for documents to be allocated to the appropriate subgroup (for example, purchaser/provider split, contracting, access issues and so on) and then for the analysing of these documents to occur in the context of well defined boundaries. This minimised the evaluation of irrelevant materials and optimised the outputs of the research. It also allowed for writing to occur at the same time as analysis. Hence the form and structure of the thesis started to develop.

The document research produced knowledge and data in a number of areas, ranging from the elucidation of data on the construct of the Act, its operationalisation, organisational structures and practices through to the identification of some key themes. These were used to structure the document research, but were also transposed through the remainder of the research, to guide the focus group interviews and to act as themes of analysis for the data. It was decided that the six themes which were the basis of the document research would become the six sections outlined in the discussion points for the focus group meetings. This would then guide the data that was collected in the focus groups and allow for that data to be matched with the document data. Therefore, the six themes would be used to structure the research, allowing for a complete analysis of the document research and focus groups to occur concurrently.

3.2 Focus Group Data Collection

The processes that were experienced during and after the document research were also related to the involvement of consumers and advocates in the data collection. Organising the focus group meetings and collecting the document data occurred at the same time. The first task for the focus group process was to gain ethical approval and consent for the interviews. Consequently, a proposal was submitted to the Massey University Human Ethics Committee. Ethical consent was required before any data collection involving human subjects could occur. At the same time, initial contact was made with the Board of Advocacy Network Services Trust Inc. and the Director of Advocacy at the Health and Disability

Commissioner's Office[8]. They were sent a copy of the ethics proposal and a covering letter. The letter stated an outline of the research and requested the involvement of Adnet consumers and advocates. The Director of Advocacy was involved at this stage because advocacy services are required to consult before agreeing to participate in research. A second letter was sent to the Director of Advocacy stating an Official Information request[9]. Clarification over the information required and associated costs were discussed through a number of telephone conversations.

After consultation, the Board of Adnet responded that they agreed to support the research in principle, pending the approval of the proposal before the Human Ethics Committee. The proposal was not immediately approved due to some miscellaneous errors on the Information Sheet and Consent Form. These changes did not require appearance before the Committee and the appropriate amendments were made. Once the approval of the Massey University Human Ethics Committee was granted, contact with Adnet began.

A number of telephone conversations with the manager of Adnet were initiated to consult over the logistical implications of the focus group data collection. It was decided that these issues would be discussed at an advocates monthly meeting. At this meeting the research and the focus group process were discussed. Advocates had seen a copy of the Information Sheet before attending this meeting. The meeting allowed for a general discussion of the process and the parameters of the research topic. Advocates were invited to participate in a focus group meeting, as their selection, based on purposeful sampling, was straight forward. All of the advocates were included, as their numbers (N=7) fitted within the requirements for focus group meetings (Krueger, 1994). Moreover, the diversity of their knowledge

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[8] It had been decided that Adnet was the desired source of participants for the parameters of the focus group interviews and the research.

[9] The information requested was the documents pertaining to the Advocacy Social Audit Tool; statistics on the provision and allocation of advocacy services nation-wide; the Advocacy Guidelines' and policies and procedures that guided the functioning of advocacy services.

and geographical locations would raise differing perspectives. This further supported the recommendations of the literature that participants should have varied experiences and views on the stated topic. The selection of consumer participants was also discussed. It was decided that advocates would consider consumers that they felt would be willing and able to participate in a focus group. The concept of purposeful sampling was explained to the advocates. It was clearly stated that the research required consumers who would be able to demonstrate reasonable knowledge of the Act and that they would be asked to disclose their experiences of advocacy services, empowerment advocacy and the Code of Rights.

Advocates considered past and present consumers of Adnet, who they felt would fit the requirements of the focus group. From here a second meeting was called and the consumers selected by advocates were discussed, without disclosing any identifiable features. Advocates simply stated what category, for example, disability or health, the consumer came within and the length of time that they had been associated with the service. Based on this information, advocates and the researcher selected ten consumers. The advocates were provided with envelopes containing the Information Sheet, a covering letter from Adnet and a letter from the researcher. The covering letter from Adnet explained that the identity of consumers had not been disclosed to the researcher and that their privacy and confidentiality had been upheld. It also explained that advocates had selected consumers and that Adnet was supporting the research. The letter from the researcher simply stated a tentative date for the focus group meeting and invited consumers to contact the researcher if they were interested in participating in a focus group. Advocates addressed the envelopes and posted them to the consumers selected[10]. A maximum of ten consumers was required for the focus group, therefore dictating the number of mail outs that were initially posted. It was decided that further letters would be posted if the response rate was low.

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[10] Appendix Seven contains the initial mail out letters sent to consumers.

The researcher had received six responses after two weeks of the mail out to consumers. Because it was not clear that all of these consumers would be willing and/or available to participate in the focus group meeting, advocates were asked to send more invitations to consumers. In the meantime, a set date and time was arranged for the consumer focus group meeting, after consultation with those consumers who had responded.

At the same time that the consumer focus group was being arranged, all of the seven advocates associated with Adnet, contacted the researcher and indicated their willingness to participate in the advocate focus group meeting. Letters stating the group process and how the meeting would be facilitated were sent to advocates two weeks prior to the meeting[11]. This letter was intended to confirm the time, date and location of the advocate focus group meeting. It also raised the need for consideration in the group process to ensure that all attendees had an opportunity to participate. This measure was taken to minimise some of the potential negative effects of focus group interviews (for example, dominant participants and reluctant contributors). Also included in this posting were the Consent Form[12] and a copy of the discussion points that would shape the focus group.

The first focus group meeting was with advocates[13]. The meeting began with the collection of the signed Consent Forms from the participants. The process of the meeting was then discussed with reference to the discussion points and the time allocated. At this stage some ground rules for the meeting were agreed upon. These consisted of talking one at a time and allowing everyone to have the

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[11] Appendix Six contains a copy of this letter and the discussion points sent to participants. There are separate discussion points for the advocates and for the consumers meetings given that the groups were kept separate to allow for consumers to speak freely.

[12] Appendix Four contains the Consent From sent to advocates and consumers.

[13] The advocate focus group meeting was held in July, at Adnet's main office in Wanganui. The consumer focus group meeting was held in August, at a Community House in Palmerston North.

opportunity to discuss the question posed. The advocates were told that the meeting would have to be highly structured and directed by the facilitator. These rules were adhered to throughout the advocate focus group meeting and the process ran smoothly. Questions were asked in relation to each of the discussion points. There were seven advocates present at the meeting, fitting comfortably within the 5-10 members suggested for focus groups (Krueger, 1994). The meeting took approximately two and a half-hours.

After the experience of the advocate focus group meeting, it was decided that the number of participants in the consumer focus group meeting would be kept to a minimum. The consumers may have more of a story to tell, with reference to their need to have been involved with the legislation and advocacy. This information was essential, and it was important not to diminish the experiences of consumers by trying to gain too much information within a limited time frame. Furthermore, although the advocates group ran smoothly and successfully, it was difficult to facilitate the involvement of all seven participants. The advocates had existing relationships with one another and felt comfortable contributing in the group process, however this would not necessarily be replicated in the consumer group. It was decided that it would be more beneficial to have the detailed and complete involvement of fewer consumers, than a greater number of consumers who would have restricted involvement (Murphy et al, 1992). Due to the suggested guidelines of 5-10 members in a focus group meeting, it was decided that five consumers would be more than adequate to complete the data collection that was required.

Arrangements for the consumer focus group meeting were made once those approached had indicated a willingness to participate in the research. It was decided that a firm date and time needed to be set for this meeting, to allow consumers the opportunity to decide if they were available and able to attend. After initial consultation with those consumers who were contactable, it was decided that the meeting would be held in the afternoon on a weekday. The date and time of the meeting were confirmed after a venue had been organised. This consultation process took some time, especially because all of the consumers that had been in contact were keen to attend the meeting. Once the venue, date and time of the meeting had been set, participants were sent the Consent Form and Discussion Points. Furthermore, participants were provided with details stating the time, date and location of the focus group, two weeks prior to the meeting. Initially, only four consumers had indicated a willingness to participate. Only one more participant was required to reach the target of five. This final consumer made contact after the second round of Information Sheets had been sent to consumers. After the final mail out consumers were asked to confirm their attendance at the focus group meeting. All five consumers confirmed their attendance one week before the meeting, however, two days prior to the meeting one consumer withdrew. A further consumer withdrew the day of the focus group meeting. This reduced the number of participants to three[14]. There was insufficient time to organise further participants and it was decided that the focus group would go ahead regardless.

The remaining participants in the consumer focus group meeting were welcomed and their Consent Forms were collected. As with the advocate focus group, the process of the meeting was discussed and questions about how the group would operate were answered. The meeting began by members introducing themselves. It was clearly stated at this stage that consumers had the opportunity to disclose as much information about their involvement with advocacy as they desired. It was explained to the consumers that this information was not necessary for the scope of the research. However, all of the consumers chose to briefly outline their complaint and give information about their contact with Adnet. This was a positive

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[14] The *Research Issues* section includes a discussion of the implication of the withdrawal of consumers.

initiative, as it identified the issues that were concerning the consumers, and created some alliances within the group. The meeting was less structured and less formal than the advocates meeting. However, the discussion points were still worked through accordingly. The relaxed nature of the group process was possible because of the limited number of participants. The meeting took approximately two hours.

After both focus group meetings thank you letters were sent to participants. This letter reiterated that participants would have the opportunity to read any material that included their data, prior to its inclusion in the thesis. This would occur after the data was analysed and written up in conjunction with the document research analysis. All consumers were provided with Chapters Six and Seven that outline the data. They were invited to give feedback on their direct quotes and the general context within which their data had been used. If they felt that it misrepresented their views at the time then they had the opportunity to discuss this with the researcher and have comment/s removed. Participants were given a two week time frame within which to respond. This was set to allow for consultation and any amendments that may have to be made.

3.3 Analysing the Data

All of the data that was collected, whether through the document research or the focus group interviews, was categorised for analysis. The coding was based on the six themes of analysis outlined previously. These themes were determined when conducting the original document research. The structure of the discussion points given to participants of the focus group meetings was designed within these themes to assist in the analysis process. The most common purpose of document research is to obtain a variety of data on a given phenomenon. Additionally, the purpose of focus groups is to engage in an in-depth exploration of a topic about which little is known. For such research a simple descriptive narrative is quite appropriate (Stewart et al, 1990). There are various methods that can be used for the transcription, organising and analysis of data. The most appropriate depends on the purpose of the research, the complexity of the research design and the extent to which conclusions can be reached based on simple analysis. Considering the triangulation of data employed in this research, it was decided that the data analysis would utilise the same categorising mechanisms for the dual sources of data. This would allow for the data to be conjointly analysed and assist the fluidity of the research.

All the data was coded in accordance with the six themes. The six themes of analysis include:

- ☐ The health and disability reforms
- ☐ Consumerism
- ☐ The Act and organisational structure of HDC
- ☐ Advocacy services
- ☐ The Code of Rights
- ☐ Empowerment advocacy

There was limited data that fell outside of these themes[15], due to the planning and design of the research. The broad coverage of the themes allowed for almost all of the data to be included in the research, the themes were chosen because they effectively covered the area of study. The extent of focus group data that is prevalent in Chapter Six, illustrates that one of the primary focuses of the research was to give advocates and consumers 'voice' about the extent to which the legislation has affected them. Hence, their data is analysed and detailed fully.

> *Part of the research process, as we see it, is the need to negotiate meanings with subjects and allow frameworks for understanding to evolve through time. Reality is neither entirely fixed nor given for all time. The use of self – the influence/impact of self plays an important*

> *part in the unfolding of multiple realities. In this sense, research becomes part of a shared enterprise or joint search for truth, a co-production of knowledge (Shakespeare, Atkinson & French, 1993, p. 6).*

The audio-tapes of the focus group interviews were transcribed after both meetings were conducted. The transcriptions were in a similar format and could be broken down into the six themes of analysis, based on the discussion points used to guide the focus group interviews. The discussion points and subsequent themes of analysis were derived from the sections that made up the main literature review in Chapter Three and the details of the Act in Chapters Four and Five. This information was gathered as part of the document research. The tapes of the focus group meetings were transcribed literally, and no content analysis was conducted. This was decided because the qualitative data was not solely relied upon and because it was felt that the words and sentence structure of the participants gave sufficient meaning in the context that it was analysed (Tedlock, 1983; Silverman, 1994). Furthermore, it was felt that including aural dimensions, as is required with some qualitative transcription techniques, would distract the reader and had the potential to beguile what had been said (Kerr, 1996).

The method of organising the data[16] involved the cut and paste technique (Stewart, 1990). The data was reviewed and organised into categories with allocated colours for identification, based on the themes of analysis[17]. The data was reviewed and the appropriate theme colour was marked next to the data to indicate where it would be placed. Through this process it was easy to identify data that had not been coded. This data was reviewed and then placed in appropriate themes. This process also highlighted data that could be placed in two or more

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[15] Almost all of the data generated from the focus group meetings was incorporated in the research. Only data that was obscured by other noises on the tapes and/or was incomplete was discarded.

[16] Reference to the 'data' from herein pertains to the focus group interviews and the document research.

[17] The themes had structured the interview discussion points, however, the data still had to be located within these themes of analysis, as some data was spread in a number of categories and was not clearly relevant to one theme above and beyond another.

themes. This data was marked with the appropriate theme colours and place in all of the applicable themes; where it would be eventually sited was decided during the analysis and writing up phase.

The process of cutting and pasting occurred next, placing the data within the colour coded theme that it belonged to. The data was then reviewed again, based on the theme that it had been located within and the appropriateness of this location. The size and content of each theme was dependent upon its relevance to the objectives of the overall research question. Some themes developed a number of sub headings which the data was applicable to. During this allocating of data and coding process, the researcher checked that there was sufficient data to fulfil the third phase of the formative policy evaluation process that was being adhered to, that is, the comparing of the results and outcomes of the policy with the stated aims and goals. All of the themes had sub headings pertinent to this objective.

These sub headings were created through the data analysis process and continued the organising of data into smaller and smaller categories. At the end of the analysis process, the data was divided into themes and appropriate sub headings within these themes. This was a process of single analysis carried out by the researcher. Therefore, there was room for bias influence. This could have been reduced by multiple analysis by two or more researchers, however, such a task was not practicable in this study. The bias of the single analysis was counteracted to some extent by the adoption of a number of tools and processes. Firstly, the design of the research allowed for the focus group questions to be arranged within the themes of analysis framework. This limited the amount of data that would be discarded and also allowed for data to be transcribed loosely within the codified themes. Secondly, other types of coding and analysis would not have significantly removed the level of bias associated with the interpretation of the qualitative data (Stewart et al, 1990). Thirdly, the qualitative data was enforced by the mixed methodological approach being employed, namely document analysis and focus groups.

The organising of the data permitted each theme to be analysed separately, but also for the interfaces that exist between the themes to be drawn. Consequently, the data and subsequent key findings of the research are set out as clearly as possible, without fracturing the overall picture. Commentary is provided on the literature and theoretical underpinnings appropriate to each theme, coupled with the supporting document research data and focus group data. This framework also allows for the key findings to be located in each theme as a means of summarising the data analysis.

As noted above, the research utilised a multi-method approach to data collection. The first two phases of the policy evaluation, undertaken by the document research, were achieved via the identification of the aim/objectives of the policy, combined with an outline of the operationalisation of these aims and objectives. The second part of the evaluation research process is the comparison of the resulting outcomes with the aims of the policy, allowing for alternative policy recommendations to be made. This second phase is supported by the data analysis of the focus group interviews and document research. The data from advocates and consumers will be used to measure the results of the policy from their perspectives and feed the recommendation outcomes that are stated in the conclusion. This data analysis is outlined in Chapters Six and Seven.

4. Ethical Issues

As with many other research projects, there were specific ethical issues to acknowledge and consider in formulating and conducting this research. These issues were reflected on when composing the proposal for the Massey University Human Ethics Committee[18]. These included issues of participant recruitment; ensuring anonymity and confidentiality; and acquiring informed consent. Each factor was pertinent because of the nature of the qualitative component of this research. There is an inevitable intrusion into people's lives and experiences that needs to be minimised while still allowing the researcher to have access to the information required. Research of this nature is designed to give participants voice and should be designed to ensure their safety throughout the process. This section will outline the ethical steps and considerations noted throughout the research process, in conjunction with the specific methodological tools outlined above.

Access to participants was a relatively easy task, once Adnet had indicated a willingness to support the research. The manager of Adnet provided advocates with the Information Sheet and invited them to contact the researcher if they were interested in participating. Similarly, initial contact with consumers was made through Adnet. They selected a number of consumers and provided them with the Information Sheet and a covering letter informing them of the research. Through these measures the anonymity of consumers and advocates was ensured. The researcher did not have any details about the participants until they had indicated that they were interested in participating. This was important for the integrity of the research, but also for the ethical guidelines that Adnet operates under. From here the emphasis was on receiving their informed consent. All participants were provided with the Consent Form prior to the meetings. Before the interviews began, there was a discussion on the Consent Form and answers were provided for any questions that participants had. At this stage participants were reminded of their right to withdraw from the research at any stage. Consent was received from all participants before the focus group interviews commenced.

The issue of anonymity and confidentiality only became an ethical concern when considering the construction of the focus group interviews. Because participants

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[18] Appendix Three contains a copy of the proposal approved by the Massey University Human Ethics Committee.

would be interviewed in a group environment it was not possible to guarantee their anonymity and confidentiality from each other. For these reasons the ground rules of the focus group meetings had to be clearly stated. Reiterating that the experiences and opinions that were to be shared were to remain in confidence of the group and that it would be inappropriate to discuss this information outside of the meeting. In terms of the thesis and any other publications related to it, anonymity was guaranteed through the use of pseudonyms. Where quotes may have been attached to a particular subject in the text, permission was sought by the researcher for the quotes to be used. Participants were provided with a copy of the text that included their quote and asked to consent to its use. Moreover, the data gathered was stored, in secure locations, in the researcher's office and the person employed to transcribe the focus group tapes was subject to the provisions of a confidentiality agreement. The researcher will destroy the data gathered once the examiner's final report is received.

These ethical issues are primary to the process of research and the maintaining of participant safety. Their participation gave meaning to this research through their lived experiences, beliefs, impressions and knowledge. Their interaction with each other and the researcher developed data that is unique and invaluable, as it expresses their voice. The legislation is about and for them, and their impressions of its efficacy are the fundamental indicators and measures explored in this project. Through their representation in this research there is an opportunity for knowledge to be shared and to grow.

5. Research Issues

As with any research endeavour, there were a number of issues that resulted from the research design and implementation. It is important to note these issues, to signify the impact that they had on this thesis, and also to alert other researchers to the possible consequences of pursuing a similar methodological approach. These issues will be detailed in the chronological sequence that they occurred in the research process, beginning with the document research, focus group interviews and concluding with analysing the data to develop recommendations for new policy initiatives and/or structural change.

5.1 Access to Information and Document Research

Due to the nature of this research being centred on a piece of New Zealand legislation, the majority of the relevant information was easily accessible. However, it was necessary to apply for documents twice under the Official Information Act. The documents that were sought were those pertaining to the contracting and construction of advocacy services nation-wide. These documents were required because they may have indicated some of the organisational and institutional arrangements that were established to facilitate the provision of advocacy services under the Act. Upon application, the Director of Advocacy and the Communications Officer at the office of the Health and Disability Commissioner provided these documents. This, in itself, did not pose an issue in the research process. However what did, and does continue to pose an issue for this type of research, is how to source information if you are not aware what documents exist. It can be very challenging to access the appropriate documents if you only have vague indicators about the type of information that you are seeking. For example, you may require information on the consultation process that occurred between December 1994 and June 1995 with reference to the Code of Health and Disability Services Consumers' Rights. However, this information may be scattered through six different documents held at HDC. If you are in the beginning processes of the research, then you do not know how pertinent this information may be to the end result of the study. Furthermore, it may be costly to access this information (as it is legal to charge for official information requests under certain conditions)[19], which is

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[19] The relevant section of the Official Information Act, Section 15 (2), states that any charge fixed shall be reasonable and may regard to cost of the labour and materials involved. In the first official information request that I made to the Director of Advocacy at HDC, costs were associated because of the size of the documents requested and the time that it took for this information to be located and photocopied.

particularly discouraging when you establish that the information is not what you really needed.

The issue of adequate access to information is a common dilemma of document research (Sarantakos, 1993) and is coupled with other dilemmas, such as coding data (detailed below) and bias. Documents are biased purely because they represent the view of their author and any associated motivations that the author has for producing the document. This issue was encountered in the research. Documents were not necessarily deceiving or incorrect, but could be worded or represented in a way that negated or omitted other influencing facts. This caused some difficulty for the researcher when trying to assess the worth of a particular document. It is inevitable that this causes some difficulties when analysing document data. However, any possible consequences were minimised by the application of numerous documents, from varying sources, on any given area of study within the research. It was hoped that the coverage adopted may limit the production of bias data.

5.2 Focus Groups

Organising the advocate focus group was a relatively simple easy. This was ensured by the support of Adnet and the fact that the participants were an identified audience. It was clear that the advocates would fit the criteria of the purposeful sampling, because they all held similar roles within the organisation and they had a wide variety of experiences through their geographical locations and the demographics of those locations. The advocates having a regular monthly meeting, where they all gathered in one place for an entire day also aided the process. The Board of Adnet and its Manager were instrumental in the process and their co-operation and assistance was invaluable. Due to these factors, it was possible to arrange the advocates' focus group, before the consumers meeting.

However, there were issues pertinent to this former group and its functioning. The advocate focus group consisted of seven participants and for this reason, it was essential to have clear boundaries and guidelines in the facilitation of the group (Krueger, 1994). The structuring of these guidelines was ensured in two ways; the letter that was sent to advocates prior to the meeting and secondly, the discussion that occurred before the meeting. It was clearly and repeatedly stated to advocates that the researcher desired that everyone be given the opportunity to participate in the meeting. It was also stated that the facilitation would be structured to ensure that all of the discussion points could be covered within the limited time available. This approach was successful and is highly recommended when dealing with such a large number of participants at one time. It requires thorough planning and effective facilitation skills.

Due to the nature of the facilitation required in this group setting, it was a very labour intensive and demanding exercise. However, it was also recognised that the facilitation was aided by the existing relationships that advocates had. This extended to the existing relationship that the advocates had with the researcher[20]. All advocates had contact, prior to the meeting, in some cases long term professional relationships, with each other and the researcher. Therefore, the process was enhanced by the familiarity of the participants. Facilitating a group of the same size without the existing relationship between participants would be more difficult[21]. On reflection of this, it was decided that the consumer focus group meeting would need to have fewer participants, as the participants involved were likely to have no existing relationships. Coupled with this was a need to respect that consumers would be approaching their focus group and engaging in it on a different level. Whereas the advocates were discussing what were professional

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[20] Nearly all of the advocates involved in the focus group meeting knew the researcher and this inevitably impacted upon the group dynamics, as well as their initial willingness to partake in the research.

[21] This point is highly variable on the group of people in question. In some cases, working with participants with pre-existing relationships could be detrimental, if for example, there were some issues outside of the context of the research that impacted upon the interaction of those participants during the focus group interview.

issues for them, consumers would be discussing personal issues. This would no doubt alter the group dynamics and make it a clearly different type of group to facilitate. Moreover, consumers were being asked to give up their own time to participate in the focus group, and it would have been unfair to expect consumers to do this and only have a limited opportunity to participate. It was decided that the consumer focus group would have a maximum of six participants. This still fitted within the recommended sample size for focus groups (Thomas et al, 1992) and would ensure the points outlined above. In making this decision the research opened itself up to possible issues[22], though it was presumed to be a low risk decision, as advocates had indicated that a wide number of consumers would be potential participants.

Organising the consumer focus group required more time and effort on behalf of the researcher and the advocates. There were the anticipated difficulties of slow consumer response to the invitation and feedback from some consumers that they did not want to be part of the group process. However, after two mail outs, five consumers responded that they were willing and able to participate. The next major issue was deciding on a time and day that would suit as many participants as possible. It became clear that this could be difficult if a solid date was not set. The next task was deciding on a time. The meeting took place in the late afternoon. This was chosen because almost all of the participants had indicated that evenings were not convenient. Arranging the time and date of the meeting required at least two phone calls to each participant. This was a time consuming exercise because not all participants were easily contactable. However, fortunately all of the five participants would be available on the set time and date. This could have been eliminated if a greater number of mail outs had been sent to consumers, thus broadening the number of participants that could potentially attend. Furthermore, the date and time of the meeting could have been set from

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[22] The most obvious risk was that participants may withdraw and leave the focus group without sufficient time to organise replacements and fulfil the requisite number of participants for this type of data collection.

the beginning, thus disallowing any compromise and the potential difficulties of negotiating with participants.

This did not become an area of concern again until the day of the focus group interview. Unfortunately two consumers withdrew, giving short notice. One consumer had unanticipated work commitments and another became ill. There was not sufficient time to organise replacements for these two consumers, and the focus group proceeded with the remaining three participants. The late withdrawal of participants is always a possibility, particularly due to unexpected illness. However, it may be reasonable to presume that the potentiality of this is increased when the sample group involves people with health concerns and people with disabilities. Due to the withdrawal of these two consumers, the focus group did not fall within the desired sample size for focus groups, as recommended in the literature. The recommendation is for between 5-10 participants (Krueger, 1994). However, after facilitating the consumer focus group, and subsequently listening to the tapes, it was decided that enough data was generated to fulfil the needs of the research. The research has not attempted to make generalisations based on the sample size. It has been stated clearly that the research is reflecting on the experiences and perspectives of a small number of advocates and consumers within one geographical region. Therefore, the number of participants is not fundamental to the validity of the data gathered, due to the restricted claims that are made about the results. The recommended number of participants is stated to encourage the feeling of a group interchange and because it is believed that this number of participants will generate substantive data within limited timeframes and the consumption of other resources (for example, travel, equipment, transcribing). Although it is unfortunate that not all consumer participants could attend the meeting, it was not significant enough to require a further focus group meeting to be organised.

The limited number of participants in the consumer focus group meeting, meant that there was a trade off between the breadth and extensive sources of data that a number of participants would have produced versus the detailed information that was able to be sourced from a limited number of participants. It can be argued that the detail and extent of the data gathered was more intense and explicit than it may have been had the numbers had been higher (Murphy et al, 1992). The facilitating of this group was much easier than anticipated, and the group flowed and interacted in a positive manner. The reduced number of participants may have also encouraged participants to share their experiences in a fuller and more personalised way.

5.3 Data Analysis

There were issues to contemplate when analysing the data, particularly the focus group data. The first that was encountered related to organising the data into the six themes. As already stated, the interview questions were based around these themes, thus eliminating some of the difficulties of locating the data appropriately. However there were cases where data was rather broad ranging and could have been located into more than one of the themes. Where this was the case, the data that was already located under each potential theme was evaluated. Through this process it was possible to see the themes that would develop in that category. The data in question was then reviewed by considering these themes. In most cases, the data was allocated to one of the specific themes because it enhanced the flow and consistency of that theme. The goal was to disseminate the data in a clear and concise manner, thus decisions on the location of some of the more generic data was based on what it contributed to the particular theme. Any deficits that may have been perceived via this locating of the data was minimised by continually linking the themes together and reiterating the interfaces that exist between themes.

Another noted difficulty of this type of data analysis, was trying to link the focus group data with the document research. Much of the document research had been discussed throughout Chapters Three to Five as a means of laying the foundations for the focus group data. However, some new document research was also attached to the focus group data in Chapters Six and Seven.

5.4 Recommendations

There were few research issues associated with the production of the recommendations outlined in Chapter Eight. The recommendations incorporate a comparison of the aims and objectives of the policy with the outcomes as stated by advocates and consumers. The quality of the data collected allowed for these comparisons to be made, as participants were very clear about their experiences and opinions. The recommendations were based on suggested alternative policy developments and/or structural organisational changes. In the case of most of the themes, specifically themes three to six, the data indicated the direction that the recommendations would take. The only significant research issue was making recommendations on themes one and two. These involved the broader spectrum of issues associated with the health and disability reforms and the concept of consumerism. Due to the scope and focus of this research, it was not possible to make full and exhaustive recommendations, as these require specific research attention themselves. However, it was appropriate to suggest the development of further research and evaluation under the guidelines of formative policy evaluation (Patton, 1990; Spiker, 1995) and this eventuated in these themes. It was necessary to refocus on the research question and maintain a commitment to that. It was also necessary to acknowledge the limitations and boundaries of this research design and to try not to extend the research to broader parameters.

6. Conclusion

This chapter has clearly outlined the theoretical influences that were adopted to construct the methodological design of this research. Furthermore, the chapter has detailed the research in progress, stating what occurred and in what sequence. This examination is important as it elucidates the research in action, shedding light on the tools utilised to collect the data and the processes by which that data was analysed to inform the research findings. Moreover, this chapter has explained other facets of research, including ethical issues. The chapter concluded by examining the diverse range of research issues that were addressed and the strategies that were employed to overcome them in order to minimise their impact on the research outcomes. There are a number of potential areas of concern when conducting research, from the development of the research question through to the evaluation of the outcomes. Detailing the significance of these issues within the context of this research assists in the understanding of the specific inquiry that follows. Furthermore, it adds to the growing literature on specific research tools and provides others with clear examples of the methodology in action and assists in their provision for the potential limitations, thus improving the construction of methodological procedures in the future.

Chapter Three - Theoretical Perspectives

1. Introduction

This chapter explores the relevant theoretical perspectives, provides the definition of terms and details structural mechanisms in order to link the concepts that will be the themes of this research. Defining the concepts that are referred to in the research and in the Health and Disability Commissioner Act (1994) will provide a framework for an evaluation of the policy from the perspectives of consumers, advocates and the policy makers. This is facilitated by an analysis of the relevant literature, which involves a discussion of these concepts, their meaning and their various applications. It is argued that an understanding of the literature will illuminate the construct of the legislation's foundations and the possible consequences of its implementation and outcomes.

The theoretical concepts of empowerment and advocacy are underlying themes throughout and are frequently referred to in the Act, especially with reference to the organisational systems of service provision. Elucidation of these concepts will be achieved by expanding on the theoretical underpinnings; tracking the emergence of empowerment in the social services; exploring empowerment advocacy as a tool for intervention; examining its application to the health and disability arena and its practice implications. The discussion will be broadened from here, to identify the structural framework within which practice occurs in the New Zealand context. This requires a brief commentary on the theoretical underpinning and implementation of state sector reform. The recent reforms to the public sector[1] have had significant ramification for all sectors of New Zealand's functioning. The key focal point hereafter, will be the effects that have transpired for the health and

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[1] Note that the discussion in this chapter refers to the public sector and includes the public service. That is, ministries/departments, which are part of the core public service, accountable to the Minister who is in turn, accountable to the legislature. This also includes the wider state/public sector, such as agencies of the state, which operate at arms length from the political executive, for example, Crown entities and State Owned Enterprises.

disability arena. The reforms that resulted from the Health and Disability Services Act (1993), are detailed in Chapter Four. The emphasis in this chapter will be on the effect the reforms have had on the role and identity of individual service users. The issue of applying free market ideology to social welfare will be touched on, to lead into a discussion on the rise of consumerism. Questions will be asked about the extent to which health and disability service users are consumers, as opposed to citizens, and how this reflects their level of participation in the management of health and disability resources.

2. Introducing Empowerment

Empowerment is a central concept in this research, as what empowerment signifies is the foundation of the Health and Disability Commissioner Act (1994). The Act and its associated organisational structures and regulations are primarily concerned with consumer empowerment through complaints resolution. The Code of Rights and the functioning of advocacy services nationwide solidify this. At each level of the Act's operationalisation empowerment is identified, from the Health and Disability Commissioner through to the empowerment practised by advocacy services. Hence, commentary on empowerment and the diverse narration and interpretation of the concept is essential to the examination of this policy and its outcomes. The framework for this analysis begins with a generic discussion on the rise of empowerment and the emergence of empowerment theory in the social services. This becomes more focused with an examination of empowerment in practice and the specific use of empowerment through models of advocacy. There is a lack of agreement on the definition of empowerment that is illustrated throughout these sections. This disparity is central to the difficulties associated with the development of empowerment; the application of empowerment to policy; and practising empowerment advocacy.

The ambiguity associated with the concept of empowerment has developed with its favouritism, over the past few decades (Zippay,1995). While it has grown in popularity in the human services and policy development, little agreement has been made on its meaning or dimensions (Gutierrez & DeLois, 1995). As some researchers have noted:

> *...empowerment is a popular term, but there is a danger that it is just expressed within bland statements which gloss over major differences in approach and assumptions amongst those professing a commitment to its implementation (Taylor, Hodges, Lart & Means, 1992, p.2).*

Therefore, it is very difficult to find a definition of empowerment that can be universally applied to practitioners and individuals in varying fields (Sheilds, 1991). However, there is some agreement on the multiplicity of components that comprise empowerment. These components include; access, information, social action, participation, decision-making and power (Rees, 1991; Sheilds, 1991; Taylor et al, 1992; Fawcett, White, & Balcazar, 1994). These components will act as our themes to unravel the plot and disclose the story of empowerment.

2.1 Empowerment Emerging

The theoretical conceptualisation of empowerment has derived from a number of sources; such as the academic theorising of Friere and Foucault and, the social rights movements of the 1960s (Rees, 1991). By examining these influences and the work of contemporary writers, it is possible to postulate the varying constructs of empowerment and the impact that it has on practice.

Empowerment first appeared with the emergence of social movements in the 1960's (Rees, 1991). The essential focus of these movements was on the challenging of power bases and the acceptance of difference (most notably; difference in race, ethnicity and gender). This allowed for an examination of the construction of power and the diverse ways that it is applied (Solomon, 1976). It also identified the need for participation in decision-making processes.

Empowerment thus began to grow with the popularity of the struggle for group and personal power (Rees, 1991). These themes were further developed by theoretical writings in the 1970's[2]. Paulo Freire produced work that was modernist and examined the post-structural discourses of subject centred reason (Roberts, 1996). Freire (1972) focused his work on identifying how marginalised groups can transform the use of power to create opportunities for change (Munford & Sullivan, 1997). In doing so, he identified issues of oppression, the need for interactive dialogue and encouraging education by relating it to the experiences of individuals. His work intended to illuminate a democratic, critical approach to pedagogy. Furthermore, Freire focused on comprehending the discourses that serve to separate or oppress groups, emphasising the importance of power and participation. Consequently, there was recognition that dominant hegemonic societies wield the power and control that oppresses individuals and/or groups. Thus, Freire's work had significant socio-political implications by encouraging liberation through action and reflection.

Foucault (1980, 1982) also contributed to academic writings that refocused our attentions to the phenomenon of power[3]. Foucault (1980) states that understanding power requires a focus on the individual who is experiencing the effect of power (control) as well as the institution that is exercising the control. Power is not a static phenomenon, it is cyclical and individuals can be experiencing control and exercising control at the same time (Sullivan, 1996). By acknowledging that individuals experience power in their everyday lives, Foucault recognised that power is not something that some people acquire and others do not. According to Foucault (1982), the essence of power is acknowledging the participation, influence and responsibility of control that is affecting discourses, for discourse concerns itself with determining fact, priorities and responsibility (Rees,

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[2] Two of these influences will only be briefly outlined here, they introduce complex concepts that can not be fully examined in this context. For further discussions refer to the authors stated and Munford (1989).

[3] Sullivan (1996) discusses Foucault's work in greater detail than is necessitated here. Also see Haber (1994) and Allan (1996).

1991); it is the means used to regulate social norms, behaviour and practices. Given this, there needs to be a focus on the discourse that affects particular groups, to challenge the influence and power that is shaping oppression. Through Foucault's analysis of power he acknowledged the concept of issues being socially constructed, thereby encouraging the growth of commentary on power, oppression and empowerment within a social context.

These theoretical developments were paramount in encouraging the rise of empowerment. They recognised the structures that oppress individuals/groups and the complex nature of power; thus allowing for further research and literature to develop the means of challenging these structures. Sociologist's, educators, students, practitioners and social movements carried this forward (Kondrat, 1995).

2.2 Empowerment Theory

There have been numerous contributions to the development of empowerment in more recent years (Rees, 1991; Sheilds, 1991; Hall, 1992, Taylor et al, 1992; Ezell, 1994; Zippay, 1995). An examination of these conceptualisations and definitions of empowerment follows. A combination of these narratives provides an understanding of the intent of empowerment theory in community/social work practice. However, they also illustrate the lack of universal agreement on the construct of empowerment and that the application of empowerment is hindered by this disparity.

Hall (1992) sees empowerment as:

> *...individual and collective strengthening of negotiating position in relation to the negotiating position of other people, development, maturation and growth of real talents; recognition and responsibility as an equal (Hall, 1992, p.122).*

There are key words outlined in this definition. Most importantly there is a recognition of power and the diverse ways that power is manifested to control or liberate the lives of people (for example, through financial restrictions, socially constructed norms and ideas, or cultural rules and protocol). This focus on power has been examined and augmented by other contemporary writers (Ezell, 1994; Gutierrez, DeLois & GlenMaye, 1995). It appears to be the rudimentary point of agreement, as there is much disagreement on the other components that are requisite in the construct of empowerment (for example, the need for individuals to understand their own experiences or biography, in light of political influences and the prevailing dominant social ideologies). Therefore, there is scope for differing theoretical perspectives, as the concept of power itself is a diverse and complex phenomenon that has been defined and commented on in conflicting ways. Furthermore, Hall (1992) states that empowerment requires the recognition of individuals as equals, thus inferring the need for the rights of citizenship to be upheld. This is a key component of realising empowerment and will be addressed later in the chapter.

Rees (1991) has made a significant contribution to the literature on empowerment in relation to policy and practice in social welfare. He states that there are essential components that contribute to empowerment, all of which must be viewed in conjunction with one another, for empowerment to exist. Rees (1991) begins with the concept of biography, that is the application and analysis of a number of ideas and theories from various sources to create a narrative story for individuals. This requires the individual to identify their circumstances within the wider social and cultural construct of their lives, thus demanding an analysis of the environmental context of their issue/s and their personal circumstances. Considering the various theorem or ideologies that are impacting upon the issue or their lives may include an examination of a broad number of influences. Economic circumstances, political philosophy, cultural beliefs and values, social networks and supports (for themselves and/or their issue), or social rules, norms and values may all be factors. Identifying the forces that shape and mould individuals cannot stagnate at any one point in time, as the discovering of *biography* is a continual life process. Through identifying these sources, the implication is that the individual will begin to ask questions about how to reassert control and take power over their issue and/or life.

Viewing power as a *multidimensional* concept that can be liberating or restricting is also crucial. Power is a complex and embellished concept that needs to be understood by individuals for them to assert their empowerment. Power operates on a number of levels (individual, group, or state) and is closely related to authority. Whenever individuals or groups affirm power, it should never be one dimensional, as this requires compliance or control over another. There needs to be a clear distinction between power over people, that serves to restrict, and power to achieve goals, that serves to liberate. Individuals need to assess their personal power, potential for group power and the power of the state or institutions that impact upon them. If the *multidimensional* sources of power are not effectively evaluated then it can be difficult for individuals to realise personal power and thus empowerment (Rees, 1991).

The constraints and opportunities that exist through biography and an analysis of power need to be identified and understood from a political perspective, as examining power presupposes an understanding of politics. Once again there are various levels of politics, ranging from the values and ideology of state politics, to local and organisational politics. There is also the impact of personal politics, particularly when a practitioner is working with an individual using the concepts within empowerment theory. The key is the identification of political avenues and obstructions to bring about personal or group change.

Additionally, Rees (1991) states that empowerment can derive from skills. Individuals require a mix of interactive and political skills, including; evaluation, administration, negotiation and advocacy as the development of these skills will help facilitate the various levels of empowerment attainment. Furthermore, the skills of practitioners to identify and produce strategies concerned with equality and justice are paramount to individual empowerment. Skills are not just the tools that are taught to the individual, but the actions of the individual and the practitioner to recognise the interface between all of these concepts. Without the support to analyse, communicate, negotiate and reflect, empowerment is impaired.

Finally, Rees (1991) emphasises the importance of recognising the interfaces between policy and practice. This is necessary to encourage the interaction of policy with practice to encourage change. If policy is viewed as a type of social intervention that can influence change, then this occurs through practice. Both policy and practice engender each other and can influence the outcomes for individuals. Consequently, practice occurs in a context that is at least partially bound by policy parameters, for example, legislative boundaries and funding benchmarks. By recognising that practice and policy have a relationship that requires them to be viewed in relation to each other, then change can be more effectively targeted.

These concepts (biography, power, politics, skills base and the interfacing of policy and practice) need to be achieved to ensure that true empowerment is realised. Each concept represents an integral part of the process and no one concept can be removed without affecting the process. Without addressing the power of individuals and/or groups, it will be difficult for political action be asserted. Without acknowledging the influences of politics then it can difficult truly ascertain biography. Furthermore, without acknowledging the interface between policy and practice in the social services, then the opportunities to effectively challenge structures and encourage social change will be diminished. Rees (1991) does not give a specific definition of empowerment but provides a narration of the concepts that combine to allow for empowerment. Each concept is comprehensive in its own right, reiterating that the achievement of empowerment is not a simple activity but a process of multiple interactions at varying levels.

Rees' (1991) analysis, combined with the perspective of other contemporary writers can further expand the concept of empowerment. Allowing for a holistic view of the theory to emerge and lead into an examination of empowerment in practice. Empowerment is the use of specific strategies to reduce, eliminate and reverse the negative values of powerful groups in society that impact upon oppressed groups (Weaver, 1982). It requires the identification of power bases, resource bases and the means of change. The most fundamental aspect of empowerment is the transferring of power from external sites to oppressed people (Lee, 1994). Furlong (1987) views empowerment as an important goal because it avoids the polarisation of social action and individual perspectives, therefore placing work with individuals and families/whanau in a social context. In this way, those adopting an empowerment approach seek to holistically address a social issue. This carries an obligation and commitment to both maintain and improve services and dispel negative values that oppress people (Payne, 1991).

> *(In the social services) ...support grew for empowerment as an approach to democratically managing and delivering health and social care services with, rather than simply for, people in need. The democratic approach attempts to address social inequality and empower the service user (Adams, 1996, p.23).*

Empowerment theory has also been invoked by the socio-cultural perspectives that are directly influenced by radical and anti-racist theories (Dominelli, 1988). From this perspective the theory encompasses the challenging of negative myths and stigmatisation; informing people for participation in social and personal spheres; challenging and changing structures and; restoring the focus of intervention on to the individual and their family/whanau/support (Fawcett, 1994). This entails access to clear information and providing the support requisite to encouraging change at all levels (Taylor, Hodges, Lart & Means, 1992). Quite simply, empowerment theory is about allowing individual freedom through acknowledging and allowing individual power (Perkins,1995).

Solomon (1976), in seeking to explain the theory of empowerment, states that most people proceed through three levels of development:

1. Positive experiences in early family life that give them competence and confidence in social interactions, and this
2. Reinforces their ability to manage social relationships and use social institutions (for example, schools) to gain further competence with which
3. They can accept and perform well in social roles.

However, 'power blocks' have the potential to affect the development of individuals in each level. Indirect power blocks (for example, a physical disability) reduce confidence in social settings that in turn reduce the gains that can be made at the second level and eventually impact upon performance in social roles. Direct power blocks similarly affect the development process. Discrimination and oppression, for example, may restrict access to education and learning and equally affect the taking on of social roles in adulthood. The combination of direct and indirect power blocks is instrumental in affecting each individual's experience and development, therefore, identifying the immense consequence of social environments to impact on individual circumstances. This reiterates that, if practitioners only deal with an individuals issues and do not take on the social causes or social institutions that are contributing to those issues, then they can not effectively challenge power blocks and address a problem/issue thoroughly (Solomon, 1976; Payne, 1991) while encouraging empowerment.

The professional and social aims of practitioners within empowerment theory are comprehensive.

> *Empowerment practice is aimed at joining with people ...to help them gain access to power in themselves, in and with each other, and in the social, economic, and political environment (Lee, 1994, p.9).*

Hence, when working within empowerment theory the aim of the practitioner is to assist individuals in a number of tasks. First and foremost the practitioner must reiterate that the individual needs to identify themselves as the means for finding solutions to their issues. Individuals need to acquire the supports, skills and access to information that will inform their choices (Rees, 1991). Through accomplishing these tasks they will be able to indicate and initiate the change that they require. Secondly, individuals need to identify power bases as complex and changeable to differing degrees. It can be argued that, by understanding the construct of power, individuals are better equipped to challenge power bases in the most constructive way. Through acknowledging what they have the resources to change and/or what needs to be changed, the power that is controlling their lives can be challenged (Ezell, 1994). This also allows for an identification of the appropriate use of individual and/or group power. Finally, practitioners need to encourage individuals to view the practitioner as a resource, a source of knowledge and skills that the individual can use. The role of the practitioner is to share these tools with the individual and to act as a support in finding solutions (Furlong, 1987).

These aims can be achieved in practice through locating and removing blocks and finding and reinforcing supports wherever possible. A beginning may be challenging myths and negative values that serve only to oppress and diminish the eminence of individuals. This may be achieved on a personal, social and/or political level (Guiterrez, DeLois & GlenMaye, 1995). It can be argued that the social construction of oppression is often based on misconceptions and by educating our communities and, ourselves we can challenge this negative stigmatisation. This necessitates a commitment to the individuals that the practitioner is working with and to their field of practice (Gutierrez et al, 1995). Advocating for the cause and for the case are important roles of empowerment practice. The practitioner is also required to have the ability to see alternative explanations for behaviour; assess motivation and capacity for change; express empathy and understanding and; confront individuals with the realities that oppress them in a constructive way (Kondrat, 1995). The locating of the individual in their environmental context may assist in facilitating the attainment of empowerment at appropriate stages and levels. Some individuals will be able to function at a high level and achieve individual or systemic change promptly. However, others may need to be gently guided through the process of empowerment. It is suggested that through acknowledging these factors, practitioners will be able to ensure that individuals achieve empowerment, and by not conceding the complexity of factors that construct the individual's reality and their issue/s then effective change will be encumbered.

Empowering individuals involves supporting and resourcing them to cope better with their situation and its limitations and/or to work towards changing the structural causes of their personal problem (Munford & Nash, 1994). Specifically the practitioner's role is to act as a resource consultant, linking the appropriate resources[4] to the individual as a means of empowering their choices for change. Supporting this access to information, the practitioner is a teacher of processes and skills that permit the individual to take control of their issues and problems and find appropriate remedies (Payne, 1991). A fundamental aspect of utilising empowerment theory is recognising that there are stages of goal attainment. Quayoom (1990) charts the levels of participation that are primary to the attainment of empowerment.

High Level Attainment	Individuals have authority to make decisions.
	Individuals have authority to make some decisions.
	Individuals have opportunity to influence decisions.
	Individuals views are sought before making decisions.
	Decisions are explained prior to implementation.
Low Level Attainment	Information is given about decisions made.

The stages of empowerment that can be reached may be influenced by the practice techniques of the social/community worker, policy and/or by the experiences of the individual. Some individuals may find the idea of using power, gaining information and participating in decision-making very arduous. The assessment of individual circumstances is paramount before intervention strategies are planned. The practitioner must encourage what is the evolving progression of empowerment, and will have to move beyond traditional and authoritarian models of practice (Gutierrez et al, 1995).

The models of social work practice that emulate the practitioner as working for the individual, as opposed to with the individual, cannot be applied under the framework of empowerment theory. The nature of empowerment requires the practitioner and the individual to work as a team, with the practitioner being instructed by the stated needs and desired outcomes of the individual[5]. Achieving this desire for interactive intervention may prevail through appropriate models of practice being applied to empowerment theory.

2.3 Advocacy

The use of specific models of advocacy can be incorporated under empowerment theory. The interface that exists between theories and models of social intervention is illustrated by this combination (Payne, 1991). Empowerment is the theory that generalises a standardised and consistent approach to practice underpinned by specific principles and perspectives (for example, power). In this thesis, it is argued that advocacy is a model that is employed, consistent with the principles and perspectives of the theory, to instruct practice. Advocacy directs practice by offering step by step strategies (for example, information sharing, inclusion in decision-making, teaching rights and justice to achieve resolution).

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[4] It is noteworthy, that this resourcing can only occur if there are the appropriate levels of resourcing and accessibility available to the sector within which the practitioner and individual are operating.

[5] This technique relies on the premise that individuals know best their own needs, particularly those with disabilities, and that they should be able to stipulate how those needs can be most appropriately met. This does not denote that individuals must provide solutions for their issues and/or decide on the provision of appropriate services on their own. The purpose of the social intervention is to facilitate this, with the practitioners working in conjunction with the individual.

Consequently, advocacy is a process of human intervention that operationalises empowerment theory, and if successfully applied, incorporates the key elements identified in the previous sections. To clarify this relationship it is first essential to discuss the characteristics that particularise advocacy. From this we can refocus on the information discussed in the previous sections, highlighting the application of empowerment advocacy to the field of health and disability and the implications of empowerment advocacy in practice.

Much like empowerment theory, advocacy is a comparatively new approach to social intervention and gathers its origins from the rise of rights movements in the 1960s (Parson, 1994)[6]. The challenging of power bases and concern for individual rights was the catalyst for advocacy's development. A central theme in almost all the literature surrounding advocacy is the quest for social justice (Rees, 1991; Ezell, 1994; Parsons, 1994; Garner & Sandow, 1995). The need for advocacy primarily arises from the unequal construction of society and the power of public and private institutions to negatively impact upon individual(s) lives. Advocacy is about permitting equality through promoting individuals participation, information, voice and power (Ezell, 1994).

> *Advocacy should ultimately be aiming to remedy injustices, not simply to make those injustices more bearable. This means that advocacy will generally be aiming to bring about the sort of social and structural change that will give people... a more integral and pivotal place in all the many environments in which people live, work and interact (Parsons, 1994, p.40).*

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[6] Due to the recency of advocacy as a model of social intervention, there is limited information, literature and research available on the specifics of practising the various types of advocacy and the linking of advocacy models to diverse social theories. It may be argued that these limitations are deterring the further development of advocacy as an appropriate model of intervention in differing social settings.

Advocacy occurs when an individual or organisation represents the views, feelings and/or interests of a person or group. It is the recognition that an individual may not possess the skills to access their rights because of social, economic, developmental, cultural, physical or intellectual reasons (Garner & Sandow, 1995). Over time, advocacy has developed broad terms of reference, as it is applicable to a wide range of situations. The literature research demonstrates that there are predominantly two forms of advocacy, case and cause. Case advocacy refers to advocating with or for an individual and their circumstances, whereas cause advocacy is a more generic application of advocacy based on a social phenomenon (Rees, 1991). An example of case advocacy involves a situation where an individual is having difficulty accessing a particular service. The advocate may work with the consumer to resolve the issue by following processes of redress or supporting a consumer in a meeting with the service. Cause advocacy is issue based, for example, when twenty consumers are having difficulties accessing a particular service. In this instance the advocates may act as the spokesperson of the group and meet with the service to discuss the issues on their behalf. Furthermore, the advocate may organise a rally or public meeting to highlight the issue. These two types of advocacy are not mutually exclusive and may overlap depending on who is doing the advocating and on whose behalf (Bell, 1997).

There are a number of models of advocacy that have developed to meet the needs of diverse groups (Parsons, 1994). The most frequently practised models include instructed advocacy, non-instructed advocacy and systemic advocacy[7]. The application of these models may be dependent on whether the focus is cause or case advocacy. Within each of these models there are different methods of practice that may be applied.

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[7] Note that there is also self-advocacy, where the individual or groups with common concerns advocate on their own behalf, however, because this does not commonly involve the support of a social agency, it is not fully explored here.

Instructed advocacy requires the advocate to act on the lawful instructions of the individual. The advocate does not express their opinion on the action or change being sought. This type of practice presumes that the wishes of the individual to have their view articulated or advocated are a fundamental right. This requires the advocate to trust that the individual is competent in giving their instructions and has access to information that has aided their decisions. The advocate disseminates information to the individual to allow for their access and participation in decisions making processes. Moreover, the advocate may act as a sounding board for the individual, working through the various options available and practising the development of skills through such tools as role-plays. Furthermore, the advocate respects the opinion and confidentiality of the individual and does not discuss the issue without the instruction of the individual.

Non-instructed advocacy allows for advocates to act independently from the individual. That is, the individual is not a fully informed participant in the advocacy process. Advocates take over the role of representing the rights and/or needs of the individual. This type of advocacy may not follow the expressed or unexpressed wishes of the individual, but the desired outcome of the advocate. There is much scope for the personal motives of the advocate to become more important than the needs and wishes of the individual. Non-instructed advocacy is necessary in some cases where the individual is incapacitated or does not have the skills to express, articulate or advocate for themselves or with support. It is only under such circumstances that instructed advocacy is recommended.

Systemic advocacy is an advocacy process that takes on generic issues that affect an individual or group. The advocate acts as a spokesperson for a large number of individuals and is most likely to focus on structural or political issues rather than specific individual circumstances. This type of advocacy is highly beneficial to those individuals who have a collective issue/s. The advocate gives voice to the shared experience of the individuals. This type of advocacy can utilise a mix of the instructed and non-instructed models, depending on the group or individual that the advocacy is being applied to and any democratic processes that may apply.

The selection of an appropriate model of advocacy and the method by which it is practised is paramount to ensuring effective advocacy (Ezell, 1994). The application of these models is highly dependent upon the individual or group concerned and their desired outcomes. The inappropriate application of an advocacy model can perpetuate the very social injustice that it was aiming to remedy. For example, non-instructed advocacy may not be appropriate to use with an individual who was functioning at a high level of empowerment, who had access to the necessary information and was very clear about their desired outcomes. By the advocate taking control over the issue and pursuing resolution, may remove power from the individual (Rose & Black, 1985).

2.4 Advocacy as a Model of Empowerment

The adoption of advocacy practices is complementary to empowerment theory. In order for empowerment to be attained there needs to be adequate support for the individual and their family/whanau. Even individuals that have been operative at a high level of empowerment will require the support of an advocate intermittently[8]. This is especially pertinent when the individual is trying to challenge the structural causes of their issue/s (Sosin & Caulum, 1983). It can be very difficult for individuals to challenge large organisations. The support of advocacy and the skills that can be transferred to the individual through the advocacy process is consonant with the themes of empowerment attainment. To be successful in challenging large power bases, individuals need support and where applicable contact with other people with similar issues (Rose et al, 1985). A practitioner that is acting as an advocate can facilitate and assist in this process (Rees, 1991).

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[8] Regardless of the level of empowerment that the individual is functioning at, an important component is having access to information and acquiring knowledge about the given issues. Advocates are a primary source of support for this transfer of information.

Therefore, it is suggested that empowerment theory can be endorsed by the adoption of advocacy models to facilitate practice.

Empowerment theory and advocacy have cognate principles, and can both work to challenge issues experienced by individuals at a personal and political level.

> *Empowerment of people ... is a key function of all good advocacy. People are empowered when they are in a situation where their interests are important in, and have an influence over, what happens in the community around them (Parsons, 1994, p.52).*

Empowerment advocacy is a new direction that is influencing advocacy practice, particularly in the field of health and disability. This type of advocacy uses a combination of the above models and adheres to the themes of empowerment theory. A key aspect of empowerment advocacy is the emphasis on teaching individuals the skills necessary to facilitate their own empowerment. Reaching the goal of self-advocacy is paramount in practice. While there is recognition that some individuals will never be able to achieve self-advocacy in all situations given the emotional energy required, the goal then becomes a significant attainment of empowerment for the individual or group. As delineated in empowerment theory, there are levels of empowerment attainment. Empowerment advocacy focuses on consolidating the fulfilment of the highest possible empowerment level through advocacy techniques. Many of the skills and tasks outlined as being essential components of empowerment were discussed when examining empowerment theory in previous sections. The operationalising of these components is the intent of empowerment advocacy. These include; sharing resources, informing individuals for participation in decision-making processes, identifying power bases and creating realistic strategies to challenge the negative influences that are affecting the individual or group. The key principle that is the foundation of empowerment theory and empowerment advocacy is power. In particular, an acknowledgement of how power is used or could be used to create positive or negative consequences in people's lives.

Empowerment advocacy can be practised through case and cause circumstances, blending the associated models to achieve the empowerment of individuals and/or groups. It is presumed that the use of non-instructed advocacy model techniques would be limited in empowerment advocacy, unless there were very clear boundaries and guidelines. This is primarily due to the lack of participation that is required from the individual when utilising this model and the potential conflicts that may arise with the principles of empowerment being firmly placed in co-operation and participation.

To give an example of the application of empowerment advocacy we can draw on the components of empowerment detailed by Rees (1991) in the above sections. Rees states that individuals need to consider the multidimensional interaction of biography, power, politics, skill attainment and the interfaces that exist between policy and practice. An advocate can assist an individual in fulfilling these requirements, through exploring the composition of the issue that the individual is presenting with. The advocate is assisting the individual in understanding their issue and the influences that shape it. This inevitably explores the power blocks that do or do not exist. Comprehending the power issues that impact upon their lives is a complex task, that many individuals will require support in identifying. Furthermore, the advocate will discuss with the individual the political influences that are impacting upon their lives. All of these processes involve teaching the individual new skills and building upon the skills that they already possess. This may be facilitated through task setting, role-playing, mapping and other such tools of social intervention. The final task is examining the interfaces that exist between policy and practice. This occurs in the context of the agency that the advocate is working for and the other institutions that the individual has contact with.

In summary, the advocates are the support for the individual to realise their own empowerment. This may require a combination of social intervention skills and vary significantly depending on the individual and their circumstance. However, the underlying principles are resource sharing, information disseminating, teaching skills and supporting the individual to activate the changes that they desire.

2.5 Empowerment Advocacy in Health and Disability

The purpose of this research necessitates an examination of the application of empowerment advocacy in the field of health and disability. Exploring the appropriateness of theories and models to particular groups is essential because of the diverse make up of concerns that affect individuals (Oliver, 1996). This is particularly pertinent when considering people with health concerns and people with disabilities, who have historically had limited or inappropriate models of intervention applied to them (Tennant, 1989; Thomson, 1998). However, the emergence of empowerment advocacy has the potential to significantly alter their experience of the social intervention.

> *When people with disabilities, ethnic minorities, older adults, women and others lack power, they usually experience adverse conditions disproportionate to other members of society. Empowerment – the process by which people gain some control over valued events, outcomes and resources – is an important construct for understanding and improving the lives of people of marginal status (Fawcett, White & Balcazar, 1994, p.471).*

Empowerment is a perspective that has the potential to be favourably received by many people with disabilities and health concerns. It is far removed from the traditional catalytic modes of social work practice that have historically diminished the experience of disability and ill health (Tennant, 1989; Morris, 1992; Ferguson, Ferguson & Taylor, 1992; Oliver, 1996). The medical model that was commonly applied to people with disabilities had many deficits and failed to recognise the social construction of disability. Such an approach is no longer acceptable to people with disabilities whom have started to acknowledge the external determinants that disable their lives. As Taylor et al (1992) state:

> *...the 'medical' model locates the responsibility for their condition within the individual 'sufferer' but gives the power over that condition to the professional 'expert' who defines what they are and are not capable of' (Taylor, Hodeges, Lart & Means, 1992, p.485).*

Empowerment entails the recognition of the rich diversity of individuals' lives and the many different strategies that they have employed to live their life to the fullest. Through this the theory recognises the unique skills and contribution that individuals have to make, while focusing on encouraging their further development. It is an approach that has the potential to embrace the experience of disability and build upon it, rather than create modes of dependence and feelings of inadequacy that mark various other social intervention theories (Mackelprang & Salsgiver, 1996). Furthermore, empowerment theory recognises the social construction of disability and does not allow for indictments to be made based on physiological impairments. Many of the debilitating effects of disability are constructed in social, economic, cultural and political spheres and move far beyond the physiological consequences of the impairment. This causes a multitude of issues for many individuals that are commonly displaced onto the physiological condition. With the direct and indirect power blocks recognised in empowerment theory, practitioners are offered the opportunity to overcome this labelling and stigmatising of disability (Parsons, 1994). Acknowledging that issues are socially created and based can allow them to be more effectively alleviated.

For example, an individual who requires a wheelchair for mobility should not have their access to public places and buildings restricted. The social and physical environment needs to be changed in order to account for the varying needs reflected in the community. It should be no longer acceptable in modern society to disallow this individual's participation and social functioning. In this instance, the social environment, not their physiological impairment, is disabling the individual (Sunderland, 1981). Challenging these disabling social, political and economic factors is as much a responsibility for practitioners and individuals as dealing with personal issues. Thus the interface of case and cause advocacy is reiterated.

This defining of disability and the challenging of models that have tried to explain disability has redirected the liability for its construction. People with disabilities have advocated for a more social model of intervention that returns the power to individuals and places the responsibility for disability in society (Oliver, 1990).

> *In a social model of disability the principle cause of disability is situated in restrictive environments and disabling barriers wherein disability represents a complex system of social constraints imposed upon people by a highly discriminatory society (Munford, 1994, p.6).*

This model recognises that it is social institutions and service providers that need to modify to accommodate the needs of this group (Oliver, 1990). Consequently, it raises the issue of people with disabilities being denied citizenship rights[9], through social barriers that block their participation in society (Oliver, 1990).

> *We all need to explore our histories and challenge the myths. If we don't, we perpetuate a set of ideas that keeps a group of people, us, out of society. The reality is that people with disabilities face discrimination and prejudice and it is the world that needs to change (Cahill, 1991, p.10).*

To this extent empowerment theory fits with the social model of disability.

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[9] The concept of citizenship and the social, political and civil rights that are pertinent to citizenship are detailed later in this Chapter.

Therefore, it is not only appropriate to apply it to the field but in many respects is complementary to meeting the desires of the disability community. The theory is highly applicable to this group because it offers empowerment in terms of personal circumstances and social institutions. On a personal level the theory supports the opportunity for choice, independence and autonomy. These are basic human needs and rights that many individuals with a disability have historically been denied (Tennant, 1989). Through supporting individuals to question the responsibility for their disability, the impetus is removed from the individual (Ballard, 1994). This alleviates the feelings of guilt and low self worth that have been recognised as failing people with disabilities (Oliver, 1996). It allows them to start viewing themselves as equal members in society who should be afforded equal social and citizenship rights. This is coupled with the recognition that individuals, who have come to terms with their limitations, can go on to demand social justice and change when their needs are not being met. Securing social change to allow their access and participation as full members of society is the desired outcome. This may mean that information needs to be conveyed in a variety of forms (for example, audio-tape, braille, print) and that they have adequate access (for example, ramps, lifts). The allowing of this minority group to have greater expectations from the social environment recognises their significance and legitimise their interaction in society. If social institutions are not challenged and acknowledged, then personal development will continue to be restricted for people with disabilities (Morris, 1992). Even the most empowered individual will not be able to participate if they are disabled by insufficient access to social settings and participation in policy making decisions.

2.6 Practice Issues

Through understanding empowerment theory, empowerment advocacy and its application to the health and disability arena, it is possible to address some of the practice issues that commonly arise. Practice issues refer to those embracing empowerment advocacy, through self-advocacy or with the assistance of an advocate. It refers to the complications of achieving empowerment and encourages the planning and preparation that needs to be considered in all social intervention. It also refers to issues of implementation when a program of empowerment advocacy is going to be adopted by an organisation. As with all models of social intervention, there are limitations and strengths that need acknowledgement to assess the appropriateness of using the particular model in a specific situation. Many of the strengths of empowerment theory have been clearly identified within the context of the above sections, with the key elements being the examination of personal and social power to impact on a social phenomenon and a recognition of the importance of returning control and power to individuals. There are however limitations to the theory that need to be addressed so that they can be maintained and have restricted impact.

The most fundamental and limiting aspect of empowerment theory is that it has not been widely utilised in the social services and developed by practitioners[10] therein. It is suggested that this could be overcome to certain degrees by the recent advent of empowerment advocacy. However, further literature and commentary is still desired to clearly define this mode of practice, as both concepts have limited coverage. As was noted in the above sections, empowerment has no universal definition, which can be applied to its use in the social services. The defining of the concept, associated with the model of advocacy desired, is likely to differ from agency to agency. This may denote the inconsistency and uncertainty that is discouraging its practice[11].

An example of this agency application of empowerment advocacy is examined in the following chapters. The advocacy services charged with promoting and

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[10] Practitioners are used in this sense to refer to social/community workers, advocates, interest groups and individuals. You do not have to be a health or disability professional in the historical sense, to practice empowerment theory. Practitioners is used generically to apply to any person or group endeavouring to adhere to the principles of empowerment theory to facilitate their own well being and/or others.

[11] Empowerment may not necessarily be a specific model in its own right, but can be attributed to other already existing models of social intervention, for example, the task centred model.

upholding the Code of Health and Disability Services Consumers' Rights are employed to practice empowerment advocacy. How their practice is defined and standardised is based on the interpretations of the Act and the guidelines set out by the Health and Disability Commissioner. Therefore, it is highly probable that this agency is practising a mode of empowerment advocacy that will differ from that practised by a community based housing support agency for people with psychiatric disabilities. This potential for empowerment advocacy to be delivered in differing forms, needs to be addressed through further research, programme development and policy.

In terms of other observations of practising empowerment, idealistic applications of the theory will be detrimental to the process. It is a positive approach that can be hampered by reality if expectations and ideals about our world are not kept in mind. This recognition of boundaries and limitations also includes an assessment of the individuals that practitioners are working with. Not all individuals, especially some people with disabilities, will have the capacity, energy or the motivation to take on the responsibilities necessary for empowerment. The practitioner needs to seriously assess these factors and base practice around the resources the individual has to offer, in conjunction with their capacity to acquire new skills. This point reflects the importance of a focus on the stages or levels of empowerment attainment that were discussed above. The emphasis is on empowerment at the level that is required and obtainable for the individual at that particular stage (Quayoom, 1990). The responsibility for social change is primarily based on the individual. Therefore, the scale and impact of that change needs to be at a manageable level for the individual. The resulting prospect of or actual, transition of power may be very threatening for some who have been made so dependent on external forces.

Although these points have serious repercussions when applying this theory to practice they are simply reminders of the need for safeguards. What must be over riding goals when considering empowerment is that any attainment of autonomy, responsibility and control by the individual may be a positive gain. The transferring of power, regardless of how small it may appear, is the beginning of the process that can only move forward.

3. Introducing State Sector Reform

After investigating the theoretical application of empowerment advocacy in the field of health and disability, the focus needs to be broadened to acknowledge the context within which the Act and its associated services operate. In order to examine the organisational structures of agencies, such as Advocacy Network Services and the office of the Health and Disability Commissioner, it is necessary to understand the theoretical underpinnings and resulting characteristics of the institutional landscape in which they are situated. This will permit an understanding of how the organisations operate in relation to the design and implementation of policy. Furthermore, an individual accessing health and disability services will have experiences that are mediated by the institutional arrangements that currently prevail (for example, the separation of functions of policy makers, operations, purchasers and providers). In order for this research to examine the perspective of individuals who have utilised the services of the health and disability sector, it is essential to make sense of the influences that have helped shape their experiences especially, as these experiences are very much a reflection of current organisational and institutional arrangements. This requires an examination of the structural framework within which practice operates in the New Zealand context. Specifically, it calls for some commentary on the ingress and outcomes of state sector reform.

It is not necessary for the scope of this thesis to detail the complex theoretical underpinnings and composition of state sector reform in New Zealand. This has been adequately achieved by a number of commentators (Maharey, 1989; Scott & Gorringe, 1989; Scott, Bushnell & Sallee, 1990; Boston, Martin, Pallot & Walsh, 1991; Kelsey, 1993; Self, 1993; Boston, Martin, Pallot & Walsh, 1996; Shaw, 1996;

Schick, 1996). What will be included is a brief outline of the process of state sector reform with specific reference to the impact this has had on the field of health and disability. This begins with an overview of the historical and theoretical underpinning of the reforms, the process of reform and the subsequent outcomes of the process.

3.1 Theoretical Underpinnings

The state sector reforms in New Zealand did not occur in an ad hoc fashion, but were the result of considered application and adherence to specific theoretical perspectives (Boston et al 1991). The reforms were made up of a number of conceptual bases with the most fundamental influence being the public choice approach (Shaw, 1998). The public choice approach emerged from alleged deficiencies in the democratic process of representation, particularly with reference to the functioning and decision-making process of the state sector (Self, 1993). There are several variants of public choice theory, each of which are based on a number of assumptions. The variants of rational utility maximation in combination with methodological individualism[12] have had the most significant impact in the New Zealand context, are based on a number of assumptions.

Methodological individualism refers to the exercising of individual choice as the basis of collective and organisational functioning. That is, given that no collective body can decide what is in the best interests of individuals, they must define this themselves through the identification of their economic concerns. Therefore, the basic unit of social analysis is the individual (Mueller, 1989). Accompanied with this is the assumption that individuals are primarily motivated by self interest, and as such participate in political and economic activities that best serve their own interests. Therefore, they rationally assess their needs and utilise the services or

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[12] Refer to Mueller (1989), Self (1991) and Shaw (1996) for an in-depth analysis of these concepts and a full definition of the public choice approach.

goods that they require as a result of this individual analysis (Shaw, 1996). An individual's rational egoism acts as the motivational base for their 'choices' within this theory. For example, politicians may be motivated by the benefits of being voted into office legitimising their increase in political power and thus equating to utility maximisation in the form of managing staff, making financial decisions and having influence (Self, 1991). Consequently, if individuals operate in this way, by public choice theory, there is no room for public good or altruistic gestures to the community. Individuals function in accordance with their own self interest and needs.

In terms of its application to public sector reform, public choice promotes the notion that the institutional arrangements that characterise the free market are the most appropriate mechanism through which individuals might meet their needs and maximise their well-being (Self, 1993). Inasmuch as individualism is a focus, the desire, from that perspective, is to reduce the presence of the state in the lives of sovereign individuals. Therefore, Shaw (1996) concludes that:

> *,,. the public choice thesis is that all public activity can be explained solely in terms of the clearly defined economic self-interests of individuals (Shaw, 1996, p.69-70).*

3.2 Reforming the State Sector

The template for reforming the core state sector first emerged from the post-election briefing papers provided to the returning Labour government by Treasury in 1987 (*Government Management*, Treasury, 1987). Amongst other things, this document highlighted a series of perceived administrative weaknesses in the public sector and provided the analytical framework and theoretical base for structural change. The rationale behind the reforms centred on ensuring that the policy preferences of politicians were appropriately implemented by public officials, principally through securing greater accountability and efficiency on the part of the latter (Kelsey, 1993). The goal was to clearly distinguish between the political responsibilities of Ministers, as elected representatives, and bureaucrats, as appointed officials. Ministers were required to be responsible for articulating policy outcomes, whereas officials would be responsible for the implementation and administration of that policy[13]. This mission is partially captured by an observation by one of the chief architects of the reform process, who has indicated that:

> *...(the Government) was concerned with the growth of public expenditure and the necessity to search for ways to increase the effectiveness of the use of resources which are channelled through the public sector (Scott et al, 1990, p.3).*

The redesigning of the administrative institutions of the core public service was intended to achieve increased control for elected representatives (Ministers) and to reduce the assumed rent-seeking[14] that bureaucrats had been facilitating (Schick, 1996). It was a fundamental philosophical belief of the architects of the reform that bureaucrats had too much power over policy-decisions that ought to rightly be made by Ministers (Kelsey, 1993). This power was in part a function of the near-monopoly that departments have traditionally held in terms of the provision of public goods and services. It also reflected the institutional design of Government Departments, which traditionally combined responsibility for performing a range of functions within a single, large organisation. Through the combination of policy advice and operational functions in particular, departments were well placed to promote to their Ministers policy, which was compatible with the preferences of its own service-providers.

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[13] Hence reiterating the specifications laid out in the State Services Act (1988), that Ministers would specify outcomes and CEOs would manage departments.

[14] Rent-seeking refers to the alleged escalation in budgets requirements that could be sought by officials when Departments were responsible for the multi functioning of a particular state service. This alleged rent seeking was based on assumptions and was not empirically established.

The reformists in the Cabinet of the fourth Labour Government, supported by key officials, opted for organisational reform as the best means of reducing this degree of discretionary power within the public service. To this end, and so as to a) clarify the responsibility of officials and, b) ensure tighter accountability for the use of public resources; the reformers advocated that the functions of departments be organisationally separated in order to produce greater efficiency, effectiveness, accountability, and responsiveness to the preferences of Ministers (Scott et al, 1993; Boston et al, 1996). Hence, one of the central characteristics of the post-reform model is the separation of the functions of departments, with policy and operations being separated into different organisations. The organisational division of functions meant that functions were realigned in the areas of policy, operations, monitoring and so on. This was designed to achieve a greater clarity of focus on organisational activities, and therefore allow for more effective assessment of the performance of officials. The reforming was achieved by disaggregating the functions of the large Government departments and creating new, more focused entities, each being responsible for the separate functions that had previously been undertaken by the larger departments (for example, policy, monitoring, operations)[15] (PSA, 1994).

There are key features associated with the New Zealand model of state sector management. These include the adherence to the theoretical underpinnings during the implementation of restructuring. Boston et al (1996) identifies the key features by exploring the objectives and principles that were the basis of reform. From the outset the main objectives for reform were to improve efficiency, effectiveness and accountability. Moreover, there was a desire to reduce the expenditure that was currently required to operate the state sector. This was further coupled with the desire for power to be retained within the political sphere and removed from bureaucratic officials. There was a will to clarify the appropriate roles of Ministers (policy making) and officials (implementation), therefore

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[15] Boston et al (1991; 1996) provides a number of examples of the reform process that occurred.

distinguishing between policy determination and implementation. The final objective was to increase the quality of public services, thereby increasing access and responsiveness to consumer needs (Boston et al, 1996).

The principles behind these objectives are extensive. However, in brief they are underpinned by a desire for limited state activity in the provision of goods and services, and the creation, where possible, of contestable markets, both for the provision of policy advice and for goods and services. These desires reflect the assumption that other non-state agencies can provide those goods and services in a more effective and efficient manner (Burns, 1993). Wherever this was not possible, then public agencies should be constructed and operate along the same lines as private companies. This would be achieved by clearly and precisely defining the goals and responsibilities of those charged with providing services within the state sector. This includes, eradicating the potential for conflicting responsibilities held by agencies through the separation of functions, and the tightening of the lines of accountability between Ministers and their Chief Executives. The separation of these functions would be ensured to allow for independent goal attainment and responsibility. Finally, as briefly indicated above, the principles underpinning the state sector reform, required that publicly funded services would be made contestable and subject to competition within the market place, including the tendering and contracting of services (Boston et al, 1996).

Based on these philosophical agendas, objectives and principles, reforms within the public service occurred swiftly between 1987 and 1991[16] with the advent of Government policy changes, through a range of instruments (Ball, 1994). These included the introduction of significant pieces of legislation and administrative decisions. In terms of the core public services, the legislative reorganisation began

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[16] The reform process has continued to occur in the years that followed, for example, the health and disability reforms in 1993, however, major structural changes occurred within these years.

with the State Sector Act (1988) and was complemented by the Public Finance Act (1989). The focus of this section necessitates a brief explanation of what these Acts of Parliament achieved and how they reflected the political preferences for redefining the role and shape of the state sector[17].

The process of legislative reform within the core public sector began with the State Sector Act (1988), which was in part concerned with reconstituting the relationship between Ministers and CEOs of specific Government departments. Ministers were charged with the responsibility for policy setting, whereas CEOs would have the daily administrative responsibilities. Therefore, the Act tightened the vertical accountability relationship between the two parties (Kelsey, 1993). The Act and policy instruments such as Orders in Council[18], broke the public service into a number of distinct entities and changed the industrial rules that it had previously functioned under (PSA, 1994). This was swiftly followed by the Public Finance Act (1989). Here, the influence of managerialism emerged, with the reform of financial management systems. There was a move from funding inputs to funding outputs, with the accountability of the public service being measured by specific organisational performance. An outputs based appropriation system allows for funding to be allocated on the basis of the aggregated cost of output classes, rather than providing a lump sum payment, therefore, increasing the accountability of the management of officials for their performance and subsequent outputs (Boston et al, 1991; Vaillancourt-Rosenau, 1994).

These legislative changes, coupled with a series of administrative changes, such as the disaggregation of multi-function departments, were further supported by

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[17] See Boston et al (1996) for a full and conclusive analysis of the instruments that were utilised and how they were executed, to reform the state sector.

[18] The structural changes were achieved through administrative measures and did not generally require legislation (Boston, 1991)

Government policy initiatives in the 1990's that further decentralised decision-making within the public sector (PSA, 1994). These included significant reforms to the structure and funding of health and disability services. The National Government introduced sustained funding cuts and contracted out more aspects of departmental operations that had begun with the State Owned Enterprises Act (1986)[19]. Thus the transformation of the public service spread within the new legislative framework that had been introduced.

3.3 Evaluating the Reform Process

The section above serves to briefly outline the philosophical ideology behind, and process of, reform to the core state sector in the New Zealand context. It illuminates some of the mechanisms utilised to radically alter the functioning, accountability and provision of state services. However, to understand the significance and implications of these reforms in the context of this project, we need to evaluate them in terms of their theoretical basis and implementation. As stated, the formal rationale for this rapid transformation of the state sector is in its simplest form derived from the analyses and prescriptions of public choice theory. The former Treasury Secretary, Graham Scott, has justified this by arguing that the political and economic circumstances of the epoch necessitated that the reforms be undertaken[20]. Thus emphasising the Government's need to accomplish such tasks as; creating a more complex taxation system; targeting social services and; improving quality Government services while eradicating excessive administrative costs (Scott, 1996). What has resulted, whether clearly stated on the policy

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[19] The State Owned Enterprises Act (1986) identified the separation of commercial and non-commercial functions of state entities.

[20] The circumstances that Scott (1996) is referring to is the mix of economic indicators which the fourth Labour Government inherited from the Muldoon era. The Cabinet utilised that opportunity to conclude that: a) the Government should withdraw form commercial activities where commercial markets could better manage; b) More complex systems of tax administration were required to allow for the open market, and; c) Social services needed to be targeted, to allow for greater quality outputs while minimising expenditure.

agenda or not, is targeted funding, rationalisation, and the emergence of privatisation (Kelsey, 1993).

The suppositions that informed this process of reform and which drove its implementation were derived through theoretical application (for example, presumptions of rational egoism and bureaucratic rent-seeking) and were fundamentally lacking in empirical foundation.

> *Although (the theory behind the reforms) alleges serious deficiencies in New Zealand's Government, it deduces these from the logic of institutional economics, not from the systemic study of public organisations. The evidence offered of Government failure is slim... (Schick, 1996, p.26).*

Schick (1996) states clearly that although the restructuring that occurred was carried out through a variety of complex interventions, it can be distinctly summarised. The essence of the restructuring was to unpack the operations of the Government into distinct organisations with well-defined functions. The responsibility of each managerial agent in a line of command was to maintain the performance of that agency within the boundaries that were defined. The Government now performed limited functions and discharged a large portion of public responsibilities in relation to service provision. It increasingly focused its attention to the generation of policy and the purchase of outputs produced by state and non-state agencies.

This is illustrated through examining the 'votes' listed under the Government's responsibility including, for example, the health vote (the reforms were extended to health and disability policy in the 1990s)[21]. In 1993 the Government introduced a

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[21] The affect of state sector reform and, the political and philosophical ideology that it emerged from are detailed further in Chapter Four. Here there is a discussion of the history of policy development pertinent to health and disability, including the process of reform that occurred in the 1990s.

split in the function of purchaser and provider of services. This resulted in different agencies being responsible for the purchasing of services (for, example the HFA) and providing of services (for example, hospitals) through contracted agreements. 'Votes' comprise public money voted by Parliament in response to the Government's request to spend public money, and are generally made up of output classes[22]. The system itself is not particularly new. What is new (as a result of the reforms) is the system of appropriation in accordance to the aggregated cost of output classes in a particular vote, rather than providing a lump sum to a particular vote on an input basis. That is, the move from funding departments on an input basis to funding them based on costs of their outputs which are to be purchased by a particular vote Minister. The separation of purchaser and providers, with the focus on appropriating on the basis of outputs as opposed to inputs, has significantly altered the delivery of health and disability services in New Zealand. This sector has been affected by methods of public financial management (how they fund appropriations) and issues of organisational design (how they structure the public service). The machinery of Government has effectively been compartmentalised in a desire to increase efficiency and effectiveness (PSA, 1994), with the hierarchical structure permeating through the Ministry of Health, Health Funding Authority, provider groups through to service users.

The separating of functions within the health and disability sector has created both positive and negative outcomes for service users. On the one hand, some groups including minority groups (for example, Maori), have been given the opportunity to tender for services, providing them in a manner that was historically restricted by the monopoly control of Area Health Boards, thus, allowing for new and innovative systems of service delivery to be developed that most appropriately met the needs of specific service users. On the other hand, some service users have experienced the fragmentation of service delivery because their needs are not holistically provided for by one agency. Service users, who are disenchanted by

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[22] This was in line with the prescriptions outlined in the Public Finance Act (1989).

their access to quality health and disability services, are further marginalised by the approach to funding that reflects neo-classical economic principles. In the case of health and disability services, it is difficult to adjust function (service provision) to allow for financial targets to be met.

With the purchaser-provider split that was applied to health and disability, there have also been difficulties for providers. The initial introduction of four regional purchasing agencies, introduced regional variations and inequities in terms of access to publicly funded healthcare (Adams, 1996). Even, with the shift to a single purchasing body, issues still arise. Separating purchasers and providers may provide incentive for the latter to be more efficient, but they also introduce into the health and disability sector, the opportunity for purchasers to systemically under-fund providers (Schick, 1996)[23]. This can eventuate if providers get their purchase prices consistently wrong, thus running down the viability of public hospitals. It has been argued, (Coney et al, 1993) that this is the desired effect of a right wing Government, in order to justify the further privatisation of the health and disability system.

In many cases, there is limited space in the current system for the public to define the level and form of services that they expect[24]. When there is a divergence between the expectations and plans of those who receive services and those who purchase the service, it is the provider that is left with an expectations gap that they have no means of closing (Nowland-Foreman, 1998). This may subsequently result in a lack of consistent service delivery for service users.

> *The system is back to front. Instead of identifying outputs needed to achieve outcomes and contribute to key strategic results, the system*

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[23] The potential for that under-funding to occur, Schieck (1996) suggests, reflects recent Government's emphasis on the purchase interest at the expense of the ownership interest.

[24] The opportunities for participation in the health and disability sector will be canvassed in the sections that follow.

> *operates a loop mechanism. The formal process generates a set of financial allocation which then drive the functions, and the extent to which the intended results are achieved is dictated by the dollar (PSA, 1994, p.24)*

And herein lies the fundamental downfall of the reforms, with specific reference to health and disability. Is it possible to measure the economic cost and benefits against the social costs and benefits of standardised provision of quality care for all New Zealanders? Markets operate in a manner that reinforces already existing inequalities (Maharey, 1989). They are based on an individualistic ideology and do not create an opportunity for citizens to be part of families and groups that have collective needs. Furthermore, they do not provide for services that are unprofitable. Markets do not provide for public good because the competitive nature of market economics does not allow for universal service provision based on need rather than the ability to pay (Thomson, 1998). Equal access does not exist in this framework and therefore creates market failure in terms of the provision of public goods (Shaw, 1996). Therefore, the so-called 'choice' that exists in the marketplace is already limited. When we look at services such as those provided for in the health and disability sector, those choices are even further restricted, as the industry is not renowned for its profitability. The issues that state sector reform have presented for New Zealanders who access health and disability services become even more complex. Are they now consumers, service users, clients or citizens? How much voice do they have in determining the future of their service provision? Do they operate as individuals in the market place or as a collective identity? Do their rights extend to participation in the decision-making process? These questions need to be answered to illustrate what it means to access services in the health and disability arena and to contextualise the experiences of consumer and advocates who have come under the provisions of the Health and Disability Commissioner Act (1994). The following sections tackle these issues and attempt to identify some of the possible answers.

4. Introducing Consumers

The importance of state sector reform is illustrated through the diverse complexities that it has created for defining the role and input of service users. In the above sections there has been an emphasis on empowerment theory, advocacy and the application of this mode of intervention to the field of health and disability. This process has been important, as it has attempted to link the variant concepts that impact on health and disability service users, whom the Act was established to aid. The underlying emphasis throughout has been the role of the individual with whom the practitioner is working. Through the advent of state sector reform and the subsequent reforms in health and disability, the position of individuals has significantly altered. They are still the person with an ailment or issue that is seeking professional assistance, however, it is the way that they access these services and the rights and responsibilities that are associated with them that has changed. The language that is used to describe service users and the changing nature of state and institutional policy has marked this transition. Hence, the rise of consumerism has occurred, with its associated complications.

Examining the impact and outcomes that have resulted from these political and social elements is primary for understanding the experience of service users. This research is primarily based on the perspective of consumers that have utilised services under the Health and Disability Commissioner Act (1994). The experiences and views of advocates that provide services under the Act accompany this. Comprehending their perspectives necessitates an understanding of where they are located in the larger machinery of the health and disability sector. This is accompanied by the recent trends in policy and procedure that shape their experience of service delivery. These trends are most effectively reflected in the language that is used in the field.

The following section looks at summarising some of the issues noted and questions asked under state sector reform, by addressing the use of language and the advent of consumerism in health and disability. This includes an examination of citizenship rights and how these have been recast as the rights of the sovereign consumer under current health and disability policy. This leads into a discussion on the extent to which consumerism equates to or permits, participation in decision-making processes. Scrutinising the models of participation identified by Taylor, Hodges, Lart and Means (1992) contributes to this discussion, detailing whether participation or consumption defines the consumer in the prevailing political environment.

4.1 The Advent of Consumerism

Language is not value free, but a reflection of the social values, norms and ideology that are impacting upon a particular epoch. The use of specific language can promote or demote individuals and/or groups. Consequently, it can be used to perpetuate the negative stigmatisation of issues and the distribution of power (Kellner, 1988).

> *Language is to politics, what DNA is to reproduction. Both carry the codes of evolution. Words such as 'freedom' and 'citizenship' embody ideas. They determine our political culture (Lister, 1990, p.445).*

The terminology that is applied to service users has, and continues, to change frequently. It hinges on the particular group being discussed and the influence of environmental factors relevant to that group (Taylor et al, 1992). Associated with this is the changing meaning of language, dependant on who is using it. Certain terms conjure up differing images for differing people; for example, 'patient' is usually associated with the medical profession; 'client' has been associated with the business sector; and 'consumer' can refer to individuals who are purchasing a particular service or product. Patient, client and consumer are terms that have all been used, and continue to be used interchangeably, to refer to individuals accessing health and disability services. These examples illustrate the need to clearly define a term within its environmental context and from differing perspectives. The discourse of language can therefore be modified and struggled over (Kellner, 1998).

The growth of the term consumer and the rise of consumer power in the business sector has set the scene for users of public services to be viewed as consumers. This has been encouraged by Government policy, and conflicting interpretations of the term and associated language often prevails. Therefore, it is necessary to define the term consumer from the perspectives of the state and alternative philosophical perspectives.

Consumerism arose as a result of the currency of a political perspective in New Zealand, namely neo-libertarianism, which places premium on the rights of consumers of public goods and services. It is thus guided by and consistent with, the public choice preference for modified markets in the public sector (Adams, 1996). This shift was signalled in health and disability with the reforms that occurred under the Health and Disability Services Act (1993). The competition between state and non-state providers of services in the Act reflected the belief that standardised service provision was not meeting the needs of consumers. Thus the rise of consumerism, in the eyes of the state, reflected the meeting of diverse needs in the community that the public health system had not previously met.

> *The restructuring of the State has been underpinned by neo-liberalist ideals, which stresses individual rights within a market place in which consumers can make choices as to what they want to purchase and on what terms (Munford & Sullivan, 1996, p.28)*

Consumerism is inevitably associated with the language of that market place and was influenced by the political ideology at this time. The free market orientation focuses on individual freedom and responsibility, thus encouraging limited state intervention. The exercising of the choice needed to fulfil this model, aided in the transformation of citizenship to consumerism, and gave birth to consumer sovereignty in the social services (Vaillancourt Rosenau, 1994).

The Health and Disability Commissioner Act (1994) is the first piece of legislation that has referred to individuals receiving health and disability services as consumers. The term has been carried forward by the regulated Code of Rights and advocacy services. This shift in language reflects the elected, or preferred, use of the term by many other public and voluntary social service institutions. It is noteworthy, that the philosophical influences and defining of this term differ. The Government is using the term to encourage the progression of rationalised service provision. In contrast, other social services that elect this terminology may be emphasising the rise of consumer empowerment and voice.

4.2 Citizenship versus Consumer Sovereignty

The meanings associated with words are not immutable, and the contest over the meaning of terms is dependent on the prevailing balance of forces. A good case in point derives from an investigation of how the language of citizenship has been supplanted by that of consumer sovereignty[25]. Citizenship is a concept that is inherently linked to social policy (Marshall, 1950; Turner, 1990), as it is the shared status of all individuals who are full members of society. It accords rights and responsibilities that are associated with that membership. Specifically citizenship entails the extent of political, civil and social rights (Marshall, 1950; King, 1987). It is the increasing recognition of these rights, allowing social policy (for example,

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[25] The concepts of citizenship and consumer sovereignty are complex and there are a number of different views on what constitutes each (Mouffe, 1988; Bell, 1989; Maharey, 1989; Munford, 1994; Lister, 1990; Adams, 1996). Although there is not a desire to oversimplify these concepts in this thesis, it is necessary to state that the exploration of the concepts is only detailed to help explain the environment within which consumers and advocates of the Health and Disability Commissioner Act (1994) operate.

heath and disability policy) to be viewed as promoting the utilisation of the rights of individuals.

> *The idea of citizenship implies that there should be no stigma attached to the use of popular attitudes condemning dependency or as a result of deterrent administrative procedures or poor standards of provision. The quality of the public services would be the best possible, given alternative claims on public resources (Parker, 1975, p.145).*

In order for citizenship to reign individuals must have their right to participate upheld (Turner, 1990). This includes civil rights, those associated with freedom (legal rights, freedom of speech, religion and thought); social rights (economic and welfare) and; political rights (voting, democratic political participation). Marshall's (1950) typology of citizenship (social, political and civil rights) associates these rights with a particular period in history, out of which emerged the welfare state (Pierson, 1991). Marshall's inclusion of social rights, and thus access to the welfare state, denotes full citizenship status[26]. These rights are not mutually exclusive and need to be considered in relationship to one another. Participation comes about through individuals being afforded influence and involvement in planning and decision-making processes (Parker, 1975). For this participation to be ensured, individuals need access to appropriate forms of information through the exercising of their civil and/or political rights. Through their social rights, every individual should then have the supports they may require to process this information (for example, braille transcription), thereby illustrating that the combination of rights needs to be upheld for citizenship to prevail and result in the participation that is implicit with the membership. The equality implicit in citizenship requires that individuals should have access to the information that they

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[26] The significance of Marshall's classification of citizenship is that: a) he identifies social rights at the centre of debates concerning the nature of citizenship, and: b) he identifies the welfare state as a consequence of, and vehicle for, the extension of social rights (Pierson, 1991). Therefore, the level of citizenship that may be aspired to is a function of, and is circumscribed by, the institutional form of the welfare state pertaining at any given moment in history.

require to participate in the planning, structuring, administration and delivery of public services. Therefore, individuals should receive the provision of services with which they have had a direct involvement in shaping through the exertion of their participation and upholding of their civil, social and political rights.

So, to what extent can citizenship prevail when the reforms to the state sector have focused on limiting the role of the state and encouraging individualism? The philosophical perspectives that have encouraged the consumerisation of publicly funded and/or provided services view the market as the most appropriate forum for individuals' participation. They also discourage the standardised provision of state services on the grounds that this is not being responsive to the varying needs of individuals. Therefore, citizenship has been replaced by the concept of 'consumer sovereignty'; the right of the individual to standardise the content and quality of services that they receive as opposed to collective citizenship. Individuals are not required to be involved in decision-making processes to exert 'consumer sovereignty'. Instead there is a reliance on the market to shape the nature and quality of services, through competition in supply and consumer choice. The equal status of individuals is not recognised, except their equal rights to freedom and self-interest. Individuals are only entitled to what they earn through their own efforts and free exchange within the market place, they are responsible for the provision of their own needs and are no longer seen as participative members of a collectivity (Hall & Jaques, 1989). However, consumers are limited to alter health care provision through market transactions and herein lies the difficulty of asserting 'consumer sovereignty'.

Hamilton (1982) states that consumer sovereignty cannot be achieved because the conditions for its exertion are not provided for in the health arena. Given that individuals do not have access to participation in the provision and allocation of services, individually or collectively, their choices to interact in the free market environment of health and disability services is minimised. Furthermore, limited information sharing impairs participation; restricted service provision and, the maintaining of comply control in decision-making resting in the hands of purchasers and providers. Hence the concept of citizenship, particularly in health and disability, has been eroded by the advent of market orientated service provision and individualism, which further stifles participation based on the construct of consumer sovereignty. Maharey (1989) supports the argument that this view of public service provision has stifled the extent to which people can truly participate in society.

> *...if people are to be able to participate in society they must have access...to (social), civil and political rights; access to power and social support; live in an environment which is sustainable and free from conflict (Maharey, 1989, p.165).*

Here, Maharey (1989) is arguing for a return to the democratic functioning of the state, to ensure citizenship rights can once again be upheld and that entitlements can be assured[27]. He does not believe that participation can be achieved when there is an emphasis on individualism, and a denial of the shared and collective experiences of society. In a regime that defines service users as consumers, rather than citizens, individuals are restricted in participation. Their access to and participation in policy formulation is obstructed due to the reconception of their civil, political and social rights along the lines of a particular philosophical perspective. They can not effectively participate in the determination of policy that affects their lives, as collective members of specific communities or as individuals, instead they become consumers of the end result. There is a significant difference between consumption and participation. The latter allows for the former, but this does not transpire in reverse. This separation between consumption and participation is fundamental in determining the rights of consumers, as opposed to the rights of citizens.

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[27] Maharey (1989), recognised the need to factor the state in the determination of policy and service provision, however, not at the expense of service delivery that is catering to the needs of groups who have not been traditionally served by standardised provision.

4.3 The Extent of True Participation versus Consumption

To illustrate the differences between consumer sovereignty and citizenship equating to participation, we can consider the models of 'exit' and 'voice' developed by Hirschmann (1970) and applied to empowerment by Taylor, Hodges, Lart & Means (1992). When discussing consumer empowerment and the extent, to which it prevails, they identified two models, with significantly different implications for participation. These two models, 'exit' (consumer sovereignty) and 'voice' (citizenship)[28] will be examined here to illustrate some of the implications imposed on service users' by specific institutional arrangements.

Exit refers to the market approach, where the consumer is empowered by being offered choices to exit from a service if dissatisfied. It is argued that consumers operate their choices, resulting in the contracting of services that are being selected by consumers. Providers that are not satisfying consumers will be eliminated for not competing effectively in the free market environment. Therefore identifying their needs and how to meet those needs, exerting particular choices over preferences of service provider, generates consumer empowerment.

Voice refers to the democratic approach, where more services continue to operate in the public sector but consumers are offered a voice to indicate changes and improvements that need to be made to the service that they are receiving. This reflects exercising their social, civil and political citizenship rights. Therefore, consumers can not leave a service if they are dissatisfied, but can exercise their voice to ensure improvements are made within that service. Service providers have a responsibility to listen to and act on the demands of service users.

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[28] Voice does not necessarily equate to citizenship, as the expression of voice from some collective groups will not denote the democratic process of citizenship participation and it is possible for collective sovereign consumers to express voice. However, in the context of this research, the models of exit and voice have been utilised to expand on the concepts of citizenship and consumer sovereignty, to provide examples of how these different concepts can be employed. Furthermore, although the concepts are clearly separated in this section of the discussion, it is important to note that in practice these concepts are not often as clearly delineated.

A key problem with the exit approach to consumer empowerment is that it may result in some services being removed from the public sector, and if options are limited, then consumers may have to select a service that is not providing quality services, but is providing the best services given the options available. Therefore, this does not ensure that consumers are receiving services of an appropriate level of quality. Market enthusiasts would stress that consumers want to have the freedom and responsibility outlined in libertarian philosophy, to exit services and have choices (Adams, 1996). This may be true, however, the quality of services is influenced by the number of options offered, or competition prevalent, and the quality of those options. A wide number of services do not necessarily equate to a wide range of quality services.

Furthermore, in the current environment, consumers are not functioning within a perfectly competitive environment, and so there is no genuine exercise of exit available. Potentially, consumers who exit a service will simply not have an alternative service to receive, given that the economies of scale are not such as to encourage providers to perfectly tailor their services to users' needs. Therefore, most of the criticism that can be made to the free market model (imperfect competition, monopolies, imperfect consumer knowledge and information and so on) would also apply to the notion of exit.

> *To be empowered under a market model consumers have to know what services are available, there has to be a choice of services and the nature of the need has to be such that switching service providers will not have any deleterious effects (Munford et al, 1997, p.28).*

Burns (1993) identified that there are other complex matters to consider. These include; consumer loyalty; access; continuity of service provision and; the complex nature of service arrangements. Consumers may have a loyalty to their service providers, particularly if the consumer has had long term contact with the provider. This loyalty may inhibit their desire to exit. Consumers may genuinely like the provider that they have contact with, but still not be satisfied with the services that they are receiving. There are definite issues around consumer attachment and loyalty that are not taken into consideration. Additionally consumer access to information and other services may influence their choices. Physical access to services is a major issue, particularly for consumers with disabilities. This involves the physical location of the service, access in and out of the building, as well as issues pertinent to transportation. The cost of access becomes applicable here, and may impinge on the choice of consumers (Burns, 1993). Furthermore, there are other issues to consider such as; rural isolation, scattered populations and the size of populations. With the rationalising of public services in the welfare sector, access to services is becoming increasingly restricted. The service that may be selected by the consumer could have a waiting list, or limited resources to meet the demand of consumers. However, the most restricting issue of access is likely to be access to appropriate information to inform the choices of the consumer.

Continuity of service provision is fundamental in the decision-making process of consumers. This involves the transition period when consumers exit one service to enter another. The transition may disrupt service provision for the consumer. This is a serious concern for many consumers who are dependent on the support that they are receiving. A disruption to the continuity of service provision has the potential to have serious ramifications for individual functioning, independence and general wellbeing. The threat of services being even temporarily interrupted will deter a number of consumers from exercising their right to exit.

Finally, the complexity of service provision means that consumers may benefit on one level by exiting a service, but be disadvantaged on another level. Some providers cater for a wide range of consumer needs. There may have to be a trade off between having some needs met well and others not, depending on which service is elected. Consumers should be able to access services of appropriate quality and standards that holistically meet the needs that they are contracted for. The decision to exit a service is a major life choice for many consumers. Some consumers, who do not have the skills, power, knowledge, support and/or will to make these decisions, are likely to be disadvantaged. Consumers of disability support services, who may have been institutionalised for a large portion of their life, will find it difficult to make such a life changing decision. Many consumers are disempowered by years of oppression from social institutions and would be totally incapable of exercising their choice (Oliver, 1990). Appropriate long term support and advocacy would be required to assist some consumers in reaching such a level of empowerment attainment.

It is argued that the democratic process of exercising voice would eliminate some of these issues. Citizens would be empowered to bring about personal, policy and structural change within the services that they are being provided, therefore eliminating the possible life disrupting consequences of their call for better service provision and providing them with the opportunity to exercise their rights as citizens. Voice allows for a greater range of options for participation, from specific issues of service provision through to the construction of policy. This participation would move beyond the limiting consensus of policy consultation that is frequently sought by purchasers and providers and, may be offered through group voice, as opposed to individual participation.

> *While one is led to believe that disabled people are involved in decision making processes and that they are being consulted in terms of service delivery, this is often not the case especially in an environment of capped budgets and reduced state involvement (Munford et al, 1997, p.28).*

Voice would allow consumers to have access to information that is essential to ensure true participation, as opposed to mere consumption. Consumers would have the opportunity to have input into the purchasing and provision of services, through such vehicles as representation on hospital boards or purchasing agencies. Furthermore, voice may be expressed through collective consumer groups, alleviating the responsibility of individual service users. Consumers require participation and input on both levels, purchasing and providing, as neither functions in isolation; purchasing decisions dictate provision and provision is administered according to that allocation, furthermore, future outputs influence future purchasing.

However, there are associated difficulties in ensuring consumer voice that need to be acknowledged and considered if true voice is to flourish. As noted when discussing empowerment theory, consumers who have had diminutive experience with making choices and expressing needs, could find it arduous to assert the power needed in both empowerment and voice. Some consumers would have issues exercising voice for social, political, cultural, cognitive, physical or emotional reasons. This refers to the skills needed, and possible consequences involved, in participation and asserting citizenship rights. Additionally, even consumers that are functioning at a high level of empowerment and personal advocacy will have feelings of frustration and powerlessness towards the structures that disable them. It can be extremely taxing and difficult to maintain the strength and determination to exercise voice. Our lives are consumed with struggles, on various levels associated with exercising our rights. Through our interaction in social, economic, political and cultural spheres we are consistently called to justify and explain our participation. At times this is an accepted part of our lives, sharing and informing those involved in our communities for greater understanding and acceptance. At other times, it is a struggle that is tremendous to bear. Therefore, some consumers may query why people with disabilities should be further burdened with the responsibility of voice in service provision. Why should people with disabilities have to monitor and critique services and policy to ensure that our human rights are being upheld? And why should people with disabilities have to exercise the time, effort and personal resources to facilitate this burden? Moreover, not all health and disability service users have the desire to participate in the determination of service provision. Many, who are dissatisfied, do not desire membership on decision-making boards, they simply want access to quality public services.

It can be argued that the only way to counteract this burden of responsibility is for collective voice and appropriate representation to prevail when individuals choose not to take up the struggle. The collectivism identified through citizen membership in society does not call for individuals to act in isolation, as they appear to do under market models. Voice can represent a number of different things depending on whether it is exercised by individuals or groups, representative or participatory democracy (Taylor et al, 1992). The New Times literature,[29] states that citizenship can be restored as a political principle in policy formation and as a tool for the critical assessment of policy (Laclau & Mouffe, 1985). For this to occur, people need to be allowed to participate in the political processes, which effect them with a collective sense of social responsibility. The collective duties and responsibilities, in addition to the associated rights of citizenship, transfers the focus from the individual to the societal. Thus concluding that, individual liberty can only be achieved when citizens are able to actively and genuinely participate in the activity of the state on a collective basis (Mouffe, 1988).

Participation can be sought through democratic representation and/or consultation with interest groups and needs to be more clearly defined. This needs to be supported and recognised by consumers and policy makers. Furthermore, group participation needs to be acknowledged as an important component of service delivery. The organisations that can collectively represent the voice of people with disabilities need to be adequately funded and supported in our communities if citizenship rights are to be truly extended to consumers. The only hope for voice, is when it is removed from the rigid guidance of individualistic rights and responsibilities afforded in the free market of economic rationalism. Communities

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[29] The term New Times is used in this context to refer to the representation of a theoretical critique, as opposed to an emerging historical epoch characterised by a specific series of productive and political relations.

need to illustrate that welfare and wellbeing are not a private function alone, but an integral part of collective public functioning in our society (Maharey, 1989).

5. Conclusion

This chapter has discussed the literature and philosophical underpinnings of the key concepts informing the research. It began with an emphasis on the construct of empowerment theory, with the examination of the differing ways that empowerment has been defined and applied to the social services. This reiterated the lack of a universal definition of empowerment and suggested that this may impair its application to some fields of practice. The chapter then moved on to examine the use of advocacy models to complement empowerment theory and illuminated the rise of empowerment advocacy. Advocacy was used to explain how empowerment can be practised, in both case and cause circumstances. This reiterated some of the practice tools and the philosophical application of empowerment advocacy. It also re-emphasised the importance of the individual, the recognition of power and the transferring of skills from the practitioner to the individual. The discussion then examined the appropriateness of using empowerment advocacy in the specific fields of health and disability, with associated practice issues.

The focus of the chapter was broadened at this point, as it was necessary to examine the use of these practice strategies within the context of the current institutional framework. Hence, enveloping a discussion of the effects of state sector reform and the philosophical underpinnings of free market economic ideology in health and disability was undertaken. In many respects this was the crux of the chapter, as it examined the central concerns that affect individuals; that is to what extent their experience of services is influenced by the institutional arrangements that the state has implemented.

The constraints of consumer sovereignty and citizenship were explored to highlight the varying degrees of participation versus consumption that can be achieved in the arrangement of state services, allowing for commentary on the models of exit and voice as representations of the market versus democratic approaches. It was argued that the participation of service users has been unequivocally affected by the structures that deliver services and that their ability to exercise their citizenship rights; assist in decision-making process; receive information and participate in the democratic process has been hampered by the transformation of state responsibility. This has therefore resulted in the fragmentation of services and the disempowerment of service users. These discussions are central to the Health and Disability Commissioner Act (1994), as it stands, at least in part, as a complaints based piece of legislation within the health and disability sector. Furthermore, the organisational structures and services that it has provided for, practice empowerment advocacy and rely on the exercising of consumer voice. Therefore, understanding the concepts will assist in analysising to what extent this legislation can, and is, providing for the needs of health and disability service users in New Zealand.

The next chapter will identify the history of health and disability policy development in New Zealand to lead into a discussion on the formation of the Health and Disability Commissioner Act (1994). This will identify the legislation's journey through the political process and enactment. Furthermore, the chapter will identify the Sections of the Act, to detail their content and explain the positions, functions and services provided therein.

Chapter Four – The Legislation's Conception and Contents

1. Introduction

The application of the concepts of empowerment and advocacy discussed in Chapter Three began to emerge with the statutory conceptualisation of consumer rights. This process was influenced by public and private pressure in the late 1980s in New Zealand. This chapter details the conception of the Health and Disability Commissioner Act (1994), beginning with an overview of health and disability policy development in New Zealand. This discussion is pertinent as it details the specific process of reform that has occurred in health and disability as a result of the devolution of state involvement in the public sector. This further expands on the theoretical underpinnings and consequences of implementation canvassed in Chapter Three. It also serves to clarify the structural context that this legislation is situated within. The exploration leads to, and includes the publishing of the Report on the inquiry into cervical cancer at National Women's Hospital in 1988, the findings of which were the impetus for the present legislation. Its findings and influence are detailed here, with reference to consumer rights and the formation of the Bill. The chapter includes an evaluation of the political formation of the Bill and its final enactment.

The conclusion of the chapter leads logically into a discussion on the details of the legislation. This includes an examination of the purpose of the legislation and the statutory positions, functions and regulations that are established in the Act. Exploring the Sections of the Act permits a broad overview of the legislation's contents and further explicates its intended purpose. Furthermore, it provides the foundations for the implementation process that is outlined in Chapter Five.

2. Heath and Disability Policy Development

The vast changes that have occurred in health and disability policy over the past 120 years have significantly altered social perceptions of health, disability and service provision. We have seen the transformation from the deserving poor, reluctant state intervention and institutionalisation, through to the emancipatory service provision of a full welfare state. This further evolved to deinstitutionalisation, community-based care and the application of economic rationalising of health and disability services. A brief outline of the history of these health and disability policy developments contextualises the environment from which the Health and Disability Commissioner Act (1994) arose.

2.1 From 1870 - 1980

The first policy initiatives in the area of health and disability emerged in the colonial epoch. Leading up to the mid 1870s, the state played a limited role in the provision of health care for New Zealanders. Local communities and charitable trusts were responsible for the administering of care and treatment. However, in the late 1880s, the state reluctantly had to acknowledge the inadequacies and inefficiencies of charitable organisations (Tennant,1989). To alleviate these deficiencies the state established minimally resourced hospital boards under the Hospital and Charitable Institutions Act (1883). This philosophy of restricted assistance and state involvement is characteristic of the early history of health care in New Zealand.

The Labour Government was elected in 1935. This administration came into power with the set agenda of providing free public health care, funded solely by taxes. The Social Security Act (1938) initiated this policy objective and the processes for the provision of universal public health care. State involvement became intensified and the emphasis was on access to services based on need rather than the ability to pay (Ashton,1992). It was an egalitarian and humanitarian initiative that created the welfare system in New Zealand. All encompassing policies of wellbeing were paramount. This philosophical perspective heralded the Labour Government's reign for the coming decades[1].

In the 1970's the Labour Government instituted the Disabled Persons Community Welfare Act (1975). The Act was established to be administered by the Department of Social Welfare, and accounted for the needs of people with disabilities. It contained most of the requirements necessary for independence and was a significant legislative entitlement. The Act was embraced for recognising the distinct and unique needs of people with disabilities and for placing these needs under Government regulation. This was not the first legislative entitlement that people with disabilities had received, but it was the most significant in supporting their independence and autonomy. It is noteworthy, that no provisions or procedures for consumer rights were implemented in the health and disability sector during this period in New Zealand.

2.2 Reforming -1984 Onwards

By the early 1980's the public health system was reporting signs of strain, due mainly to expenditure. This marked the beginning of decentralisation and rationalised funding and provision, instigated by the Area Health Boards Act (1983). Concerns over the increase in expenditure in health were emphasised to the incoming Fourth Labour Government in 1984. In their briefing, Treasury made reference to community based care, targeting services and a purchaser/provider spilt through corporatisation. In response to this information the Labour Government began a process of review and initiated two major health taskforces to examine effectiveness, efficiency and splitting the roles of health purchasers and providers (Carr,1991).

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[1] Despite the initial resistances of physicians to state control of health care services and provision.

The Health Benefits Review Taskforce presented its report 'Choices for Health Care' in 1986. This was followed by the Hospitals and Related Services Taskforce, chaired by Alan Gibbs (prominent member of the Business Roundtable). The Gibbs Report was presented in 1988, echoing a need for the separation of the functions of purchasers and providers of health services, in order to overcome poor management[2]. Although the Labour Government chose not to implement any of the changes suggested by these taskforces, both reviews were influential in stimulating options and contemplation of change in the health arena (Ashton, 1992). Furthermore, they reflected the ideological shift that was to reshape the public sector.

The change of Government in October 1990 resulted in major reforms to health and disability services. These reforms were signalled in the 'Economic and Social Initiatives' (December 1990) package. It was announced that a health taskforce would be set up to develop new policies for health care and define the respective roles of the Government, individuals and the private sector within the public health system. The taskforce reported to the Minister of Health, Simon Upton, who released more details on intended policy changes on Budget night (July, 1991). The Minister made public the paper, 'Your Health and the Public Health'. The purpose of the paper was to comment on the Government's analysis of the state of the health system and provide an outline of the new structure that it intended to implement. Furthermore, the paper provided justifications for the proposed changes and the timeframe within which they would be implemented (Upton,1991; Shaw,1993). These changes were inevitably influenced by the Government's focus on reforming the state sector and the desire to introduce greater levels of accountability, efficiency and effectiveness in Government funded services. The exact shape of the health reforms would be determined by further taskforces.

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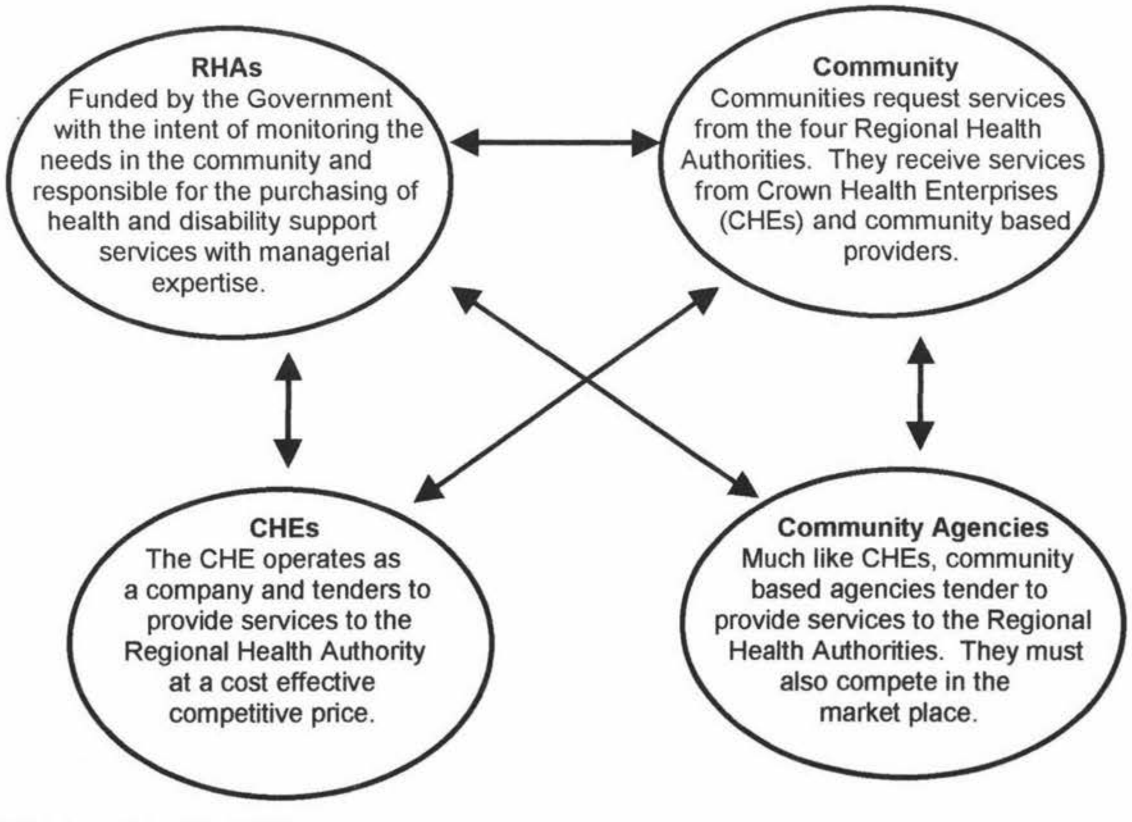
[2] This echoed much of the theoretical rationalisation that was discussed in Chapter Three, with issues over bureaucratic rent seeking and the spread of political power being attributed to the collective functioning of Government Departments. Thus the desire to separate these functions was ported by the desire for efficiency, effectiveness, accountability and the retaining of political power in the laps of elected Ministers.

The most significant implication of the proposed health reforms was the splitting of purchasers and providers. The Government proposed the establishment of four Regional Health Authorities (RHAs) under the new reforms. These agencies would be responsible for the purchasing of services. They would not provide services themselves, but negotiate service contracts with providers. These would specify the service to be delivered and the standards that must be met. Services would be purchased from a wide range of organisations, including Crown Health Enterprises (CHEs), private businesses, such as rest homes, voluntary organisations and a range of smaller providers. The Government decided that on balance the RHAs were in the best position to make sure that people would obtain the most appropriate service, and that they would make the most cost-effective choices. Figure One gives a simplified explanation of the relationship between purchasers and providers, as introduced in the Government's reforms.

Figure 1. Purchasing and Providing



RHAs
Funded by the Government with the intent of monitoring the needs in the community and responsible for the purchasing of health and disability support services with managerial expertise.

Community
Communities request services from the four Regional Health Authorities. They receive services from Crown Health Enterprises (CHEs) and community based providers.

CHEs
The CHE operates as a company and tenders to provide services to the Regional Health Authority at a cost effective competitive price.

Community Agencies
Much like CHEs, community based agencies tender to provide services to the Regional Health Authorities. They must also compete in the market place.

(Ministry of Health, 1994)

These reforms grew in scope to include the disability sector in March 1992. The Minister of Health, Simon Upton, released 'Support for Independence for People with Disabilities'. The document was the first to indicate that disability support services were to be included in the health reforms. This came about with the suggested transfer of disability support services from the Department of Social Welfare, Area Health Boards and the Ministry of Health, to the four Regional Health Authorities. The proposed change would see community based support services, move from a welfare umbrella to the health sector and concerns about this transfer began to emerge from the disability community (DPA,1993). These concerns centred around: a) rationalising and prioritising of disability support service purchasing; b) the inclusion of disability within the health framework at a time when the disability community had been working hard to break down the negative stigmatisation of disability equating to ill health; and, c) the Department of Social Welfare was generally seen as having a strong community focus and disability support philosophy that was adequately meeting the needs of service users, including the necessary contacts in the community.

Many justifications were given for the inclusion of disability in the health reforms. These were primarily outlined in 'Support for Independence for People with Disabilities: A New Deal', released by the Departments of Social Welfare and Health (1992). The main focus was on community-based care and the overall cost of managing disability support services and distributing resources appropriately. The Government stated that the purchaser/provider split that would soon apply to the health system would also benefit disability support services.

Within five months of announcing the inclusion of disability in the health reforms, the Government introduced the Health and Disability Services Bill. In doing so, it had cemented its policy agenda for the future of both health and disability services (Gray,1992). The National Government had successfully introduced policy that required limited consultation to produce a health and disability system with limited state intervention. There was much contentious debate about the lack of consultation sought by the Government and the speed within which the reforms were introduced. However, in July 1993 the Health and Disability Services Act was passed and became the major catalyst for reform to health and disability services.

3. Formulating the Health and Disability Commissioner Act

Prior to, and during the National Government's reform process, another piece of health related legislation was being formulated. This was the Health and Disability Commissioner Act. The conception of the legislation was initially introduced by the Fourth Labour Government, and continued its time in the political process after the election of the National Government in 1990. It also came under significant reform during this time. This is most clearly illustrated by following the chronological development of the legislation.

In June 1987, the then Minister of Health, Dr. Michael Bassett set up a Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and Other Related Matters. This move was in response to allegations published by *Metro* magazine in an article titled 'An Unfortunate Experiment'. The authors, Sandra Coney and Phillida Bunkle, alleged that a research project undertaken at National Women's Hospital in 1966, had not been formally terminated and resulted in a number of women developing cervical cancer (Bunkle & Coney, 1987). District Court Judge Silvia Cartwright headed the inquiry. In August 1988, after the hearing of numerous witnesses and private interviews, the findings of the inquiry were released. The Cartwright Report, as it became known, stated a number of dramatic changes that needed to be implemented to safeguard the rights of patients (Coney, 1993). Although the inquiry had primarily focused on events at National Women's Hospital and specifically cervical cancer, recommendations were made that generalised the lack of priority placed on the interests of all patients. The Inquiry and the subsequent Report had a huge public following. This emerged from the sheer number of women affected by the experiments at National Women's Hospital; active media attention and the stirring of discontent with health services for women in New Zealand (Coney,1993). These factors culminated to place reasonable political pressure on the Government to respond swiftly to the Report's findings.

There were nine Terms of Reference, published in the Report, each signalling deficits in protocol and procedure. For the purpose of this research, the most notable recommendations were those relating to patient rights. The Report recommended that; a Health Commissioner be established under the Human Rights Commissioner Act, to negotiate and mediate patient grievances. The Health Commissioner's role would also be to heighten the medical profession's awareness of patient rights. Therefore, the Human Rights Act would need to be amended to include patient rights. The specific rights that were mentioned in the Report pertained to informed consent. The Report stated that patient's autonomy and right to participate in decision making should be paramount. This included access to relevant information. Furthermore, information should be delivered to patients in their first language. Teaching and research must also abide by patient rights by seeking informed consent from the patient. Finally, the Report recommended that advocates be available to support patients in upholding their rights, including when patients are part of research and/or teaching.

The recommendation for a Health Commissioner and the associated responsibilities, was the crux of the Cartwright Report. These recommendations recognised the need for an independent, non-medical agency to promote and protect the rights of patients. Thus the impetus for political action was cast. The Labour Government responded to these recommendations promptly. Within a month the Department of Health released a policy document suggesting that a Health Commissioner and patient advocates be established. This was supplemented in October 1988, by the formation of a health working party. The participants consisted of representatives from Government departments and representatives from consumers groups. They were charged with developing a conceptual framework for a Health Commissioner. This included, how the position could best fit the desired objectives stated in the Report's recommendations and how advocates would be established to complement the role of the Commissioner. The working party reported back to the Minister of Health in March 1989. The key developments were their recommendation that a separate Health Commission be established. Thus the position would have its own legislation, as opposed to the suggestion that patient rights, advocacy and a Commissioner be established under the existing Human Rights Act.

3.1 The Bill, Consultation and Enactment

Helen Clark, the Labour Minister of Health, introduced the Health Commissioner Bill in Parliament in 1990. The Bill allowed for the establishment of the Office of the Health Commissioner. The role of the Commissioner was to prepare a draft Code of Health Consumer's Rights and to provide advocacy services that were independent of any other Government department. The Commissioner would employ advocates to promote and protect the rights of consumers, through advocating for them and ensuring that health professionals were aware of the Code of Rights. The Commissioner would also investigate consumer complaints against any health care provider in New Zealand.

Initially the Bill met very little resistance from consumer groups. However, there was considerable feedback from medical professional bodies. This created public debate about the purpose of the Bill and the rights of consumers and health professionals (Coney,1993). The debate lingered as the Bill was stalled, mainly due to the general election and the subsequent voting in of the new National Government, in October 1990. The National Government brought with it widespread changes to health and disability policy. This indicated a philosophical shift in the way that health and disability support services would be provided and delivered. Furthermore, it would have a significant impact on the formation and implementation of the Health and Disability Commissioner Act (1994).

The Bill stagnated in the Social Services Select Committee for a considerable period of time. This was no doubt caused by the priority of Government resources being focused on the larger scale changes that were to occur in the areas of health and disability. Furthermore, there were lengthy hearings from medical professional bodies and later, consumer groups. The emergence of interest from consumer groups indicated dissatisfaction with the proposed changes to the Bill. These changes were a result of the broader context of the National Government's philosophical framework for health and disability.

In August 1993, without public consultation, the Bill underwent fundamental transformation. The key modifications included:

- The inclusion of consumers of disability support services in the Bill. The official title of the Bill, and all other subsequent sections, were changed to include disability. Hence the official title became the Health and Disability Commissioner Bill. This was an obvious consequence of the Health and Disability Services Act (1993).
- Separating advocacy services from the Office of the Health and Disability Commissioner. The services would now be placed under the charge of a Director of Advocacy who would purchase advocacy services from the community. The rationale for this move was that the Health and Disability Commissioner would then remain to be seen as a non-partisan and independent agent (Birch, 1993). Furthermore, it went against Government policy for the Office of the Health and Disability Commission to be a purchaser and provider of services for consumers.
- If advocates could not resolve a complaint, then it would remain to be referred to the Office of the Health and Disability Commissioner for investigation. However, the mediation at this level would now include consultation with the relevant professional disciplinary body. Therefore, these disciplinary bodies would be involved in the resolution of consumer complaints. Previously, complaints would have been investigated and ruled upon, independent of the associated professional disciplinary body. Now, proceedings would not be

entered into unless, after consultation with the appropriate disciplinary body, the Commissioner could not obtain a satisfactory outcome. When proceedings were necessary, the Complaints Review Tribunal would handle them.

These changes significantly altered the shape of the Health and Disability Commissioner Bill. They also sparked a new series of debates on its purpose and perceived effectiveness. The inclusion of the disability sector significantly broadened the scope of the Bill. This included the type of complaints that the Commissioner would be dealing with and the category of providers. It also largely increased the number of consumers that would come under the jurisdiction of the Office of the Health and Disability Commissioner. This continued to have flow on effects for the other sections of the Bill, including the advocacy services and the Code of Rights. Advocates would now have to possess the necessary skills to work with health and disability consumers, who may have varying levels of physical, intellectual, sensory and psychological perceptions. Consequently, they would also have to promote the Code of Rights to a larger number of providers in their given regions.

A contentious point for the disability community, had been the inclusion of disability in the health arena and this extended to the Health and Disability Commissioner Bill. The proposed Code of Rights would have to be generic enough to cover the desired rights of consumers of health care services and disability support services. It was perceived that it would be difficult to include disability under this Code of Rights without perpetuating the negative myths and stigmatisation of disability and health as being closely related. This was particularly pertinent when the disability community had been clearly saying that they saw disability as being no more a subset of health than housing or education (Wicks, 1992).

The removal of the advocacy services from the direct umbrella of the Office of the Health and Disability Commissioner was consistent with the format of service provision and delivery prescribed by the Government. However, it did raise issues about the consistency of service delivery, the perceived power of the advocacy services in reinforcing the legislative regulations and the overall functioning of these agencies. The Government counteracted some of these issues by guaranteeing the independence and authority of advocacy services within the overall framework of the Health and Disability Commission.

What became the most fundamental and controversial change to the Bill was the process of complaint handling. As noted, medical professional bodies had been very active during hearings of the select committee. Their views were apparently heeded before the changes to the Bill were made. The requirement for the Health and Disability Commissioner to consult with professional disciplinary bodies significantly altered the original intent of the Bill. Consumer groups were vehemently opposed to the involvement of disciplinary bodies, as they saw it as detracting from the independence of the Commissioner. They believed that the complaints process would not be notably different from that which previously existed and the consumer would still have limited control over their complaint. Alternatively, the professional disciplinary bodies argued that complaints could not be satisfactorily assessed without the necessary professional investigation and input that they provided. The Government obviously agreed with this latter point and reiterated that the Commissioner would remain independent and would have the final casting vote over the resolution of complex cases. However, it is also important to note that the Complaints Review Tribunal would have to take into consideration the view of the disciplinary bodies findings when ruling on a case. Despite these points of contention and continuing debates over the transforming of the original bill, the Health and Disability Commissioner Bill was enacted in October 1994.

4. The Health and Disability Commissioner Act (1994)

From its initial conception in 1988, the Health and Disability Commissioner Act (1994) had experienced major transformation. This was due to the input of professional bodies, the effect of state sector reform and the political ideology of the National Government. To clarify its purpose, organisational structure and statutory positions, it is necessary to unravel the sections of the Health and Disability Commissioner Act (1994). This is facilitated by examining and defining the provisions of the Act. The following sections will focus on detailing these sections and how they interact. The goal is to provide an elucidation of the Act by outlining the legislation in a concise manner. There will be an initial definition of the terms used, expanded by an examination of the five parts of the Act and the specific functions that they detail. A further examination of how these provisions of the Act were implemented will be detailed in Chapter Five.

5. Purpose of the Act

The clearest summation of the purpose of the Health and Disability Commissioner Act (1994) can be obtained from its long title.

> *An Act to promote and protect the rights of health consumers and disability service consumers, and in particular,*
>
> *a) To secure the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights; and*
>
> *b) To provide for the appointment of a Health and Disability Commissioner to investigate complaints against persons or bodies who provide health care or disability services and to define the Commissioner's functions and powers and:*
>
> *c) To provide for the establishment of a Code of Health and Disability Services Consumers' Rights; and*
>
> *d) To provide for the promulgation of a Code of Health and Disability Services Consumers' Rights; and*
>
> *e) To provide for matters incidental thereto.*

The legislation is unique and distinct from any other legal rights guaranteeing entitlement to health and disability consumers throughout the world. It is unequalled on numerous levels: a) The legislation has very broad coverage. It includes consumers of health care and disability services, and applies to public and private providers, regardless of whether or not the service is paid for. This includes Crown agencies, such as hospitals. A key aspect to the legislation in regard to these parties, is that it applies only to the provision of services and not the quantity of services being provided. For example, the Act does not apply to waiting lists at public hospitals or the number of visits that are allocated to a specialist within a given time period; b) The legislation codifies the rights of consumers, thus making them Government regulation. These are not recommended guidelines for providers and consumers, the rights are embedded in legislation and have the associated legal strength; c) The emphasis at all levels is on the empowerment of individuals, and working with them to resolve complaints at the lowest level possible.

The purpose of the Act is reasonably clear and simple. The implementation of the objectives is a more complex process to comprehend. There are specific sections outlined in the Act that need to be defined and examined in their broader context to fully understand its intent and purpose.

5.1 Defining Terms

The definition of the terms used in the Act is paramount to understanding its functioning and its jurisdiction. Although some of the terms are not unfamiliar, they take on specific meanings with reference to the legislation. These definitions are particularly important in deciding rights. For a right to apply, all parties must fit into the definitions provided within the Act. If a party is not defined then the rights regulated through the legislation cannot be applied.

5.1.1 Consumer

The Act does not provide a generic definition of consumers, but separately defines health consumers and disability consumers. This is interesting, as a distinct definition of what the Government means by the term consumer, is difficult to ascertain. This is significant as the defining of the term consumer may help illustrate what the Government views as the appropriate role of the consumer, for example, the extent to which they are required, or entitled, to participate in decision-making processes that determine policy and provision. Nonetheless, the definitions provided in the Act state:

> *"Health consumer" includes any person on or in respect of whom any health care procedure is carried out.*
>
> *"Disability services consumer" means any person with a disability that:*
>
> *a) Reduces that persons ability to function independently: and*
>
> b) Means that the person is likely to need support for an indefinite period.

5.1.2 Provider

The defining of providers is much more extensive. Principal definitions are contained in sections two and three of the Act. A combination of these sections sees:

> *"Health care provider" means, unless the context otherwise requires:*
>
> *a) A licensee of a hospital within the meaning of the Hospitals Act 1957;*
>
> *b) A controlling authority of a hospital within the meaning of the Mental Health (Compulsory Assessment and Treatment) Act 1992;*
>
> *c) A licensee of an aged persons' home licensed under regulation*

for the time being in force pursuant to section 120A of the Health Act 1956;

d) A controlling authority of any home or premises in which five or more disabled persons who are under 17 years of age and are receiving care;

e) The Children's Health Camps Board;.

f) A Camp Committee under the Children's Health Camps Act 1972;

g) A manager of a certified institution within the meaning of the Alcoholism and Drug Addiction Act 1966;

h) Any registered health professional;

i) Any person who provides ambulance services to the public;

j) Any person employed by the School Dental Service to carry on the practice of dentistry;

k) Any other person who provides, or holds himself or herself or itself out as providing, health services to the public or to any section of the public, whether or not any charge is made for the services.

The list of providers is therefore very broad. It refers to the private and public sector and will apply even if a service is free. Furthermore, the coverage extends to alternative forms of health care, such as reflexology and homeopathy. The definition also may include a number of Government agencies, such as:

- ☐ New Zealand Income Support Services, when dealing with counselling, transport and financial assessment.
- ☐ Housing New Zealand, for example, when providing community housing for consumers
- ☐ Regional councils and territorial authorities, for example, when providing total mobility transport and pensioner housing.
- ☐ Justice Department, for example, psychological testing for people in prison.
- ☐ Ministry of Education, for example, interpreter services and special equipment.

- Accident Compensation Corporation, for example, rehabilitation, equipment and accommodation support.

While Section three of the Act limits a health provider to a person providing services to a section of the public, a disability service provider is not restricted in this way. Section two states that:

> *"Disability service provider" means any person who provides, or holds himself or herself or itself out as providing disability services.*

5.1.3 Services

There are two definitions of services provided by the Act, one for health care and the other for disability.

> *"Health care procedure" means any medical treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any person by any health care provider; and includes any provision of health services to any person by any health care provider.*

The health services indicated here include any services to promote and protect health. This includes, treatment, rehabilitation, counselling, fertility and sterilisation services. Furthermore, these health services need not be conventional medical practices, the definition extends to alternative practices, as detailed in the definition of providers.

The definition of a disability service is rather brief in comparison. It states that:

> *"Disability services" includes goods, services and facilities –*
> *a) Provided to people with disabilities for their care or support to pro-*

mote their independence; or

b) *Provided for purposes related or incidental to the care or support of people with disabilities or to the promotions of the independence of such people.*

5.1.4 Empowerment and Empowerment Advocacy

The foundation of the Health and Disability Commissioner Act (1994) is based on consumer rights. The Office of the Health and Disability Commission (hereafter HDC) views these rights as being inherently linked to the concept of empowerment. No definition of empowerment is provided within the Act. However, HDC places an emphasis on the concept of empowerment and on empowerment advocacy (HDC, 1996).

It is difficult to fully understand what is meant by the concept of empowerment without a clear definition being provided. HDC does state that:

> *It is a concept which emphasises autonomy and respect of oneself and others. To be empowered and to empower others is a skill which enhances these qualities (HDC, 1996;1.5).*

HDC goes on to give further reference to empowerment when discussing models of advocacy. It indicates a preference for empowerment advocacy, based on the outline of the Act and the Code of Health and Disability Services Consumers' Rights. The principal characteristics of empowerment advocacy are:

a) *Consumer focused and directed.*
b) *Involve working with, not for, the consumer.*
c) *Involve actions specified by the consumer.*
d) *Involve encouraging the consumer to participate in complaint resolution processes to the level of their ability or desire.*

> e) *Requires the consumer to be provided with information, assistance and support to initiate action over their concerns or complaints (HDC, 1996;6.2).*

This however, is still not a clear definition of empowerment or of empowerment advocacy, as it does not state the complex multiplicity of components that are involved with empowerment and/or the techniques that guide the practising of empowerment advocacy. The lack of a clear and distinct definition of empowerment and empowerment advocacy therefore impairs its implementation in practice.

6. *Statutory Positions*

There are three statutory positions established in the Act. The first is the Health and Disability Commissioner, to be appointed by the Governor General under direction from the Minister of Health. The other two positions are the Director of Advocacy and the Director of Proceedings. These latter positions are appointed by the Commissioner but retain independent statutory functions (HDC, 1994).

6.1 *The Role of the Health and Disability Commissioner*

The Health and Disability Commissioner Act (1994), dedicates sections 8 to 18 to outlining the appointment, status, role and functions of the Commissioner. The Commissioner is appointed for a period of up to five years and holds the status of corporation sole. The impartiality of the Commissioner is paramount. Therefore, the role operates independently from the Director of Advocacy, the Director of Proceedings and provider and consumer groups. The Commissioner is also independent from the Ministry of Health and purchasing bodies.

There are numerous functions outlined in the sections of the Act, pertaining to the role of the Commissioner. The general functions of the Commissioner are outlined in section 14. The duties detailed here include:

- Draw up a draft Code of Health and Disability Services Consumers' Rights.
- Make public statements and publish reports relating to any matter affecting consumers' rights.
- Investigate either on complaint, or on the Commissioner's own initiative, any action that is or appears to be in breach of the Code of Rights.
- Make recommendations to the Minister of Health and any other body regarding the rights of consumers.
- Mediate the resolution of complaints where it is appropriate (HDC;1994).

In order to fulfil these functions it is expected that the Commissioner will liaise and co-operate with a number of public and private agencies. The role requires a recognition of the interfaces between other statutory positions and bodies (Privacy Commissioner, Director of Mental Health, Medical Practitioners Council etc.) and various community groups and organisations. The Commissioner is also responsible for the efficient and effective management of HDC, including the functioning of the Director of Advocacy and the Director of Proceedings.

6.1.1 Director of Advocacy

Due to the impartiality sought for the Commissioner, it was necessary to establish a position for the Director of Advocacy. The initial task specified for this position would be setting up and contracting advocacy services nation-wide. These services would need to be operational in time for the release of the Code of Rights. The Director of Advocacy is responsible for the training, advising and monitoring of these services. The Director of Advocacy liaises between the advocacy services and the Commissioner, and is accountable to the Health and Disability Commissioner for fulfilling the management of the positions' functions.

6.1.2 Director of Proceedings

Similarly, the Director of Proceedings is accountable to the Health and Disability Commissioner. The role was established to ensure independent legal representation for consumers. The Director of Proceedings, upon referral from the Commissioner, decides if a legal prosecution should be brought against a provider who is in breach of the Code of Rights. The role also allows for the Director of Proceedings to act on behalf of a consumer at a professional bodies disciplinary hearing. The appointment of a Director of Proceedings did not occur until 1997, after the Code of Rights was in force.

7. Health and Disability Services Consumer's Rights

Establishing a draft Code of Health and Disability Services Consumers' Rights, was the first task of the Health and Disability Commissioner. The development of the Code was fundamental to achieving the purpose of the Act. After all, the impetus of the Act, is consumer rights and the measures that will be taken to enforce and uphold these rights. The Code, when established, would then become a Government regulation under the Health and Disability Commissioner Act (1994).

Part II of the Act (Sections 19-23) is dedicated to the process of establishing and consulting on the Code of Rights. This includes the preparation, content, review and notification of the Code. The Commissioner was guided by these sections of the Act, and the consultation process outlined therein. It was clearly stated that the Commissioner would have to develop the draft, providing justifications for the rights and what they entailed. The Commissioner would then be charged with distributing the draft code, holding public meetings, consulting with provider and consumer groups and inviting submissions. Once the Code of Rights had been consulted on the Commissioner would table it in Parliament, and it would become a Government regulation.

8. Advocacy Services

Part III of the Act refers to the establishment of advocacy services nation-wide, to employ and administer the functioning of health and disability services consumer advocates. In Section 28 of the Act, the Commissioner is authorised to create guidelines for these independent advocacy services, to be approved by the Minister of Health. The guidelines would express the intent and principles of the Act, and a consistency of standards to be met by the advocacy services. These guidelines would then become a benchmark for all services to meet.

The Director of Advocacy was charged with the contracting of these advocacy services. Furthermore, the Director would continue to have contact with the services to monitor performance standards, protocols and audits. Any consumer that has a complaint or concern about the functioning of an advocacy service can address these concerns to the Director of Advocacy.

Advocacy services are independent of the Commissioner, health and disability purchasers and providers and the Ministry of Health. The specific function of the advocates is outlined in section 30 of the Act and will be detailed further in Chapter Five.

9. Complaints and Investigation

It should be clear that part of the purpose of the advocacy services, the Health and Disability Commissioner and HDC, is to support consumers who feel that they have had a right breached. A consumer has a number of options, outlined in Section 31 of the Act, about how to address a complaint. They can, a) act independently and discuss their complaint or concern with the provider; b) elicit the support of an advocate to assist with resolving the complaint at the lowest possible level; or c) direct their complaint straight to the Commissioner. Complaints may also be referred to the Commissioner, if low level resolution can not be obtained at the advocacy stage. Furthermore, all professional disciplinary bodies are obligated to refer complaints that they receive, to the Commissioner.

The Commissioner's primary role is to investigate complaints that allege breaches of the Code of Rights. The procedures for receiving and investigating complaints is outlined in Part IV of the Health and Disability Commissioner Act (1994). Once a complaint has been received the Commissioner may refer the complaint to the appropriate advocacy service, under Section 42, to be resolved at the lowest possible level. Alternatively, the Commissioner will commence an investigation into the allegations. This may result in :

- Taking no action on the complaint because of factors such as, the amount of time that has lapsed, triviality or complaints made without good faith.
- Notifying other statutory agencies, such as the Privacy Commissioner.
- Notifying the relevant professional body and consulting with them on appropriate action.
- Arranging for mediation.
- Making recommendations to the Minister of Health or other statutory bodies and publishing reports.
- Referring the case to the Director of Proceedings for litigation by a professional disciplinary body, statutory body or the Complaints Review Tribunal.

The Commissioner has a commitment to the resolution of complaints at the lowest possible level. Ideally, a majority of complaints will be resolved by the consumer and provider, with or without the support of an advocate. However, where the seriousness of the complaint requires the involvement of the Commissioner, the emphasis will be on simple, speedy and effective resolution.

10. Miscellaneous Provisions

Part V of the Act deals with all miscellaneous provisions. This includes administrative duties and procedures, the delegation of powers, offences and liabilities. Sections 74 & 75 detail the regulating of the Code of Health and Disability Services Consumers' Rights.

11. Conclusion

This chapter began by examining the statutory conception of the Health and Disability Commissioner Act (1994). This included an examination of the history of health and disability policy development in New Zealand up until the formation of the legislation. This discussion further expanded on the theoretical underpinning and consequences of implementation that were outlined in Chapter Three, particularly the ingress of state sector reform and the impact that these reforms had on the health and disability sector. The linking of these concepts to the formation of the legislation led into an examination of the contents of the Act. This discussion then linked the policy directives with the statutory codification of the legislation.

The parts of the legislation detailed in this chapter explain the provisions of the Health and Disability Commissioner Act (1994). The legislation is extremely broad in its application to both consumers and providers and is comprehensive in its defining of parties that come within the jurisdiction of the Act. It also establishes the framework for the functioning of three statutory positions, their associated responsibilities and their organisational structure. Furthermore, it outlines the development of the Code of Rights, advocacy services, complaints and investigation. A key to fully comprehending these parts of the Act and the consequences they deliver is to examine the implementation of the Act and this will be detailed in Chapter Five.

Chapter Five – Operationalisation of the Act

1. The Act in Practice

After comprehending the concepts and provisions that comprise the Health and Disability Commissioner Act (1994) it is important to detail the operationalisation of these provisions. The process of implementing the provisions of the Act necessitated a considerable effort and has unequivocally impacted upon the outcomes experienced by consumers and advocates. The first Health and Disability Commissioner, Robyn Stent, was appointed by the Governor General in December 1994. It was imperative that the Commissioner swiftly attend to a number of tasks. First and foremost, was the establishing of the organisational structure of the Office of the Health and Disability Commissioner (hereafter HDC). The Commissioner was also required to furnish a Draft Code of Rights. The codifying of consumer rights was central to the legislation, the functioning of the Health and Disability Commissioner and HDC. Accordingly, the establishing of these rights into Government regulation was paramount to the purpose and objectives of the Act. This goal was accomplished by July 1996. The Code of Health and Disability Services Consumers' Rights was in force and advocacy services were operational.

Understanding the formation and implementation of these structures is fundamental to comprehending the outcomes that have subsequently resulted. This chapter will explore the implementation of the Act in practice, and detail its existing functions. This requires an account of the organisational structure of HDC; the regulating of the Code of Rights; contracting, establishing and administering of advocacy services; and an explanation of the complaints and investigation process. Throughout this account, the key positions that serve to ensure the functioning of the legislation will be explicated.

1.1 HDC - The Commissioner's Office

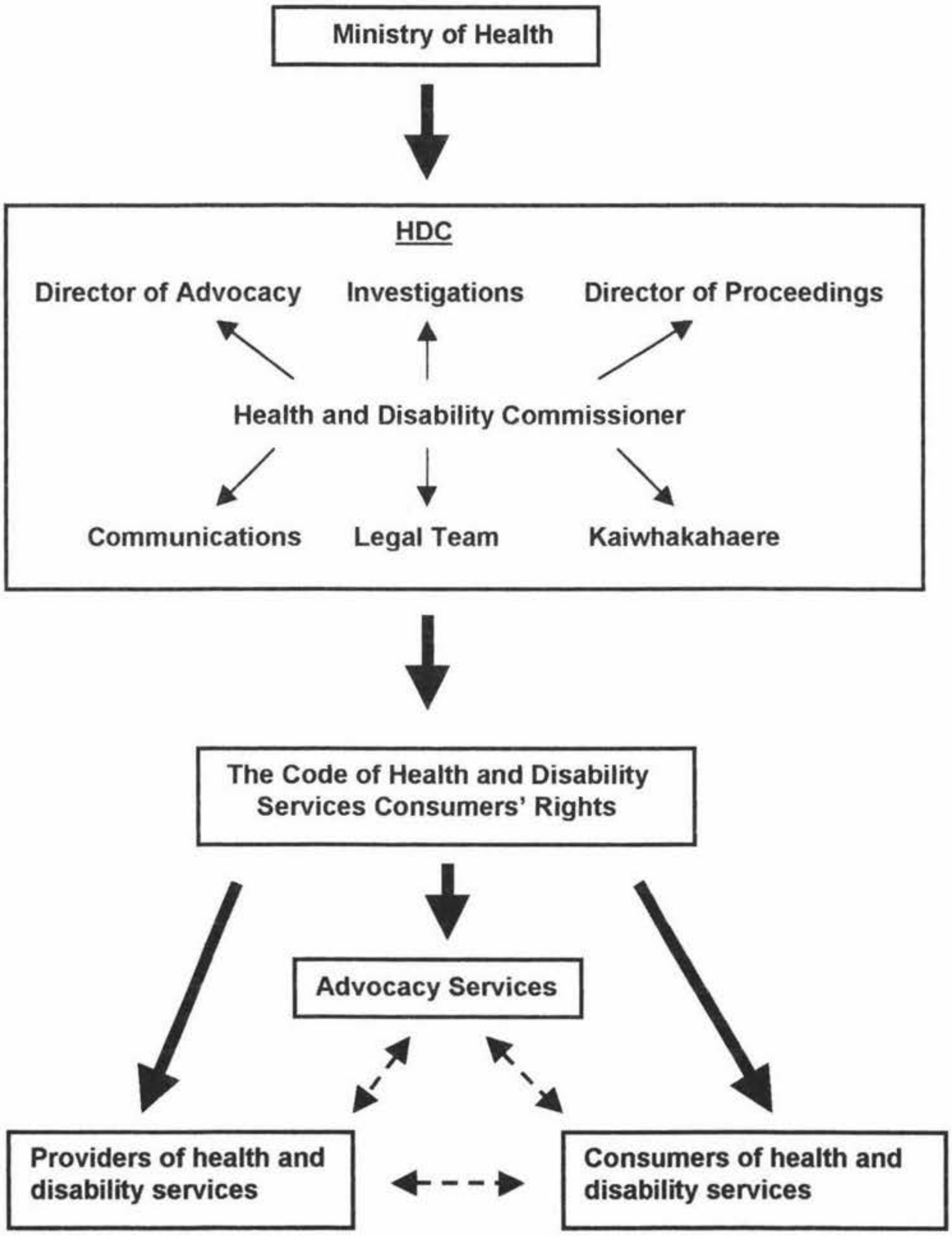
Comprehensive statutory positions, functions and structures were implemented by the Health and Disability Commissioner Act (1994). These were established to provide for the extensive support and coverage required to promote and protect consumer rights. The umbrella organisation that co-ordinates matters pertaining to the Code of Rights, advocacy services and the investigation of complaints, is HDC. The Health and Disability Commissioner holds the managerial position that oversees its operation. The pivotal functioning of HDC is underpinned by empowerment. The emphasis is on empowering consumers to know their rights and to gain the necessary skills and resources to ensure that these rights are upheld (HDC, 1996). Lowest level resolution is the aim of HDC, therefore, the office focuses its services primarily on education and communication. The goal is limited intervention, and through promoting and educating consumers and providers about the Code of Rights, it is believed that this can occur. Hence, HDC sees the emphasis on empowerment as central to the philosophy of limited intervention. Its focus is therefore prioritised on advocacy services, investigation, mediation and prosecution, in this order.

The core principles of the operation of the Health and Disability Commissioner and HDC are to empower and support individual health and disability consumers, while acting responsibly, effectively and decisively on behalf of consumers (as a legal entity empowered by an Act of Parliament). Furthermore, HDC acknowledges and actively implements the concepts of Treaty partnership and operates independently of consumer and provider groups, the Ministry of Health and purchasing agencies (HDC;1996a).

The organisational structure of HDC is outlined in Figure Two. This diagram states the relationship between the sections of the office, in relation to the Code of Rights, consumers and providers. Figure Two does not detail the interfaces that exist between the differing sections, advocacy services, providers and consumers.

These more complex relationships will be detailed throughout the chapter as each section is identified.

Figure 2. The Organisational Structure of HDC



2. Consolidating the Code of Rights

The establishment of a Code of Health and Disability Services Consumers' Rights was fundamental to achieving the purpose of the Act. Hence, the Commissioner immediately commenced work on developing a Draft Code of Rights. There were certain items which had to be included within the Draft Code, these were defined in differing Sections of the Act. The Commissioner was also granted discretion to include any matters that she felt were pertinent to health and disability consumers. The preparation of the Draft Code entailed the development of the rights and justifications for the inclusion of those rights. By March 1995, the Draft Code was ready for public consultation. It consisted of ten rights and five clauses, each of which were detailed to explain what they encompass and the Commissioner's justifications for their inclusion. The document was published in July 1995 and was made free to the public for consideration. A total of 17,000 copies were distributed and submissions were called for, stating that:

> *As this is a matter affecting every New Zealander, the Commissioner is seeking responses from as wide a range of health and disability service consumers and providers as possible (HDC,1995, p.57).*

The Commissioner and her representatives held public meetings to supplement the Draft Code of Rights. There were seventeen public meetings, hui and fono in total. The meetings allowed for an explanation of the information contained within the Draft Code and input from the public. This generated over 400 submissions being made to the Commissioner by September 1995. The feedback from the consultation and submissions illustrated that there was general public disappointment with the scope of the Draft Code. Media commentary emphasised that the Draft Code did not relate to the provision of or entitlement to services, only the quality of the services that were provided (HDC, 1996b). In a survey conducted by the Commissioner in February 1995, this concern was reiterated. Approximately 43% of the consumers polled, indicated concern about access to services in the health and disability sector, above other issues, such as respect of individuals and quality care (HDC;1996b). This indicated that a significant number of consumers were concerned with the access to services, stating that resourcing issues were as much, if not more, of a concern than other rights.

The Health and Disability Commissioner Act (1994), clearly states that there is no provision or jurisdiction for the Commissioner to rule on issues pertaining to the resourcing of health and disability services. Consequently, issues regarding such concerns were not influential in any amendments that were made to the Draft Code. Nonetheless, significant amendments were made with reference to other issues highlighted in the consultation process. The Minister of Health tabled the modified Draft Code in Parliament, on 21 November 1995.

The process of implementation would take six months, when consumer rights would become legally effective. The Draft Code was examined by a small team of independent commentators, invited by the Minister of Health to report on its perceived impact on the health and disability sector. The Government's Social Policy Committee also considered the Draft Code so that the regulations could be drafted. There were some changes made to the Draft Code during this stage of the political process. It is interesting to note, that in April 1996, the Minister of Health circulated a copy of these changes to over 60,000 providers (HDC;1996b). No consumer groups appear to have been included in this posting, or to have been informed of these changes. It is presumed that providers were granted access to these changes because they required adequate time to implement changes to policy and/or procedure. These changes would need to be in place when the Code of Rights became enforced later that year.

2.1 Codified Consumer Rights

On 1 July 1996, the Code of Health and Disability Services Consumers' Rights became legally effective, as a Government regulation under the Health and Disability Commissioner Act (1994) and appropriately the Commissioner, at a function held in the grounds adjacent to National Women's Hospital, launched the Code.

In brief, the Code of Health and Disability Services Consumers' Rights[1] outline:

Right One.	Right to be treated with respect
Right Two.	Right to freedom from discrimination, coercion, harassment and exploitation
Right Three.	Right to dignity and independence
Right Four.	Right to services of an appropriate standard
Right Five.	Right to effective communication
Right Six.	Right to be fully informed
Right Seven.	Right to make informed choice and give informed consent
Right Eight.	Right to support
Right Nine.	Right in respect of teaching or research
Right Ten.	Right to complain

From 1 July 1996 all providers of health and disability services were legally required to have policy and procedures in place that upheld these rights. This included providers of public and private, orthodox and contemporary services, regardless of whether or not the service was paid for.

3. Advocacy Services

The establishing of advocacy services also occurred in the time between the appointment of the Commissioner and the Code of Rights being enforced in July 1996. The advocacy services were contracted to promote and protect the rights of consumers, stated in the Code, through empowerment advocacy. By discussing the formation and implementation of the Act, the functioning of advocacy services will be disclosed. This includes an explanation of where advocacy services stand

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[1] See Appendix One for a full copy of the rights outlined in the Code of Health and Disability Services Consumers' Rights.

in relation to the broader organisational structure of HDC, and the Health and Disability Commissioner.

3.1 Directing Advocacy

The first Director of Advocacy, Paul Curry, was appointed in May 1995. His role was to establish advocacy agreements, promote advocacy services, facilitate advocacy training and, monitor the delivery of advocacy services. The initial goal was to contract advocacy services to be operational by the time the Code of Rights was in force in July 1996. The process of advertising for advocacy tenders began promptly in July 1995. Considerable interest was shown in the tendering process, with over three hundred individuals and agencies registering interest. However, only 72 of these agencies could display independence from health and disability purchasers and providers (HDC;1996b). It is clearly stipulated in the Act that advocacy services must be totally independent from all other sections of the health and disability arena. After consultation with the agencies that fulfilled the criteria, 36 proposals were received.

The Director of Advocacy was seeking contract agreements with agencies that would provide independent advocacy services in the ten regions spanning New Zealand. By December 1995 these agencies were identified and the process of specific advocacy agreement negotiations occurred. Each advocacy service would have a separate contractual agreement with the Director of Advocacy to provide the most appropriate advocacy service for the demographical and geographical needs in their region. Concurrently, the Director of Advocacy began promotional activities, including press releases to educate the public about the existence of advocacy. By 1 March 1996, advocacy agreements began, and all services were established (HDC:1996b). There are nine advocacy agreements that provide independent advocacy services to the ten regional areas of New Zealand[2].

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[2] See Appendix Two for a map of the advocacy services and regions that they cover.

The next task of the Director of Advocacy was to establish a training program to assist the new advocacy services, and to ensure their adherence to the guidelines of advocacy outlined by the Commissioner. This was facilitated by a one week orientation and training course held by HDC and the Director of Advocacy in March-April 1996. The ongoing training and support of advocates was the responsibility of each advocacy service, based on the services standards and competency outlined by the Director of Advocacy (HDC;1996b).

Advocacy services were contracted and operational in time for the 1 July 1996 enforcement of the Code of Health and Disability Services Consumers' Rights. The Director of Advocacy, Paul Curry, resigned after this initial set up phase had been implemented. The new Director of Advocacy is Jane Doherty.

3.2 Advocacy Guidelines

Under Section 28 of the Health and Disability Commissioner Act (1994), the Commissioner is responsible for establishing advocacy guidelines that will direct the activities of advocacy services. Contracted advocacy services are under a duty to comply with these guidelines, as they are gazetted by the Minister of Health. The guidelines include principles of operation and performance standards (HDC;1996a). The objectives of the Commissioner in producing these guidelines are: a) to promote and protect the rights of health and disability consumers; b) to facilitate the resolution of breaches to consumer rights; and c) to set standards of conduct for advocacy services, especially the employment of empowerment models of advocacy practice (HDC;1996a).

There are seventeen advocacy guidelines outlined by the Commissioner to be enforced by the Director of Advocacy, in all contracted agencies providing independent advocacy services. In brief these state that:

1. Advocates should empower consumers by encouraging and assisting them to act on their own behalf.
2. Advocates should act only on the instruction of a consumer.
3. Advocates and advocacy services should ensure that they take measures to meet the needs of all consumers, depending on their circumstances. Furthermore, the services should have established links with a broad sector of society.
4. Advocates should inform consumers of advocacy services and community supports available to them.
5. Advocacy services shall be equally accessible to all consumers, regardless of demographic or special needs of the consumer.
6. If services come under demand, advocates should give priority to consumers who are least able to advocate on their own behalf.
7. Advocates will encourage consumers to make contacts in the community for ongoing support.
8. Advocacy services should ensure that the appropriate supports are available to advocates, including such things as supervision, peer review, etc.
9. Advocacy services are contracted to provide services to consumers, not individual advocates. Consumers should be made aware of this, and that they have a choice of advocates.
10. Advocacy services should have strong networks in their communities.
11. Advocates should not offer opinions on consumer issues. They are to be instructed by the consumer, and not to act independently from the consumer.
12. When communicating with providers, advocates should make it clear that they are representing the views of the consumer, not their own opinion.
13. Advocates must comply with the Code of Rights, as is the duty of all other providers
14. Advocacy services and advocates, should not make statements to the media, these should be forwarded to the Director of Advocacy or communications at HDC.

15. Advocates shall not offer interpretations or opinions on the application of a complaint to the Code of Rights, except when pointing out relevant decisions that have been made by the Courts, Complaints Review Tribunal or the Commissioner.
16. All advocacy services should use information systems provided by HDC, for the purpose of transferring consumer information and maintaining the statistical database.
17. All generic promotional and publicity information will be produced by the Director of Advocacy, or receive approval from the Director of Advocacy (HDC,1996a).

These guidelines are the only direct input that the Health and Disability Commissioner has had on the functioning of advocacy services. The Commissioner is informed on the adherence to these guidelines through the monitoring and evaluation of advocacy services, conducted by the Director of Advocacy.

3.3 Advocacy Functions

There are ten regional advocacy agencies that provide free services to health and disability consumers throughout New Zealand. The services that they provide are in accordance with advocacy guidelines, the Act and their contracted agreements with the Director of Advocacy. These services include educational and promotional duties involving the Code of Rights, advocacy and administrative responsibilities. The requirements of advocacy services, outlined by HDC are to maintain appropriate records, participate in the national information systems, and monitor and report on the outcomes of advocacy. They must also operate independently of the Health and Disability Commissioner, the Minister of Health and all other health and/or disability providers and purchasers. Furthermore, advocacy services are required to appoint advocates and provide support, including participation in the national training developed by the Director of Advocacy (HDC, 1998).

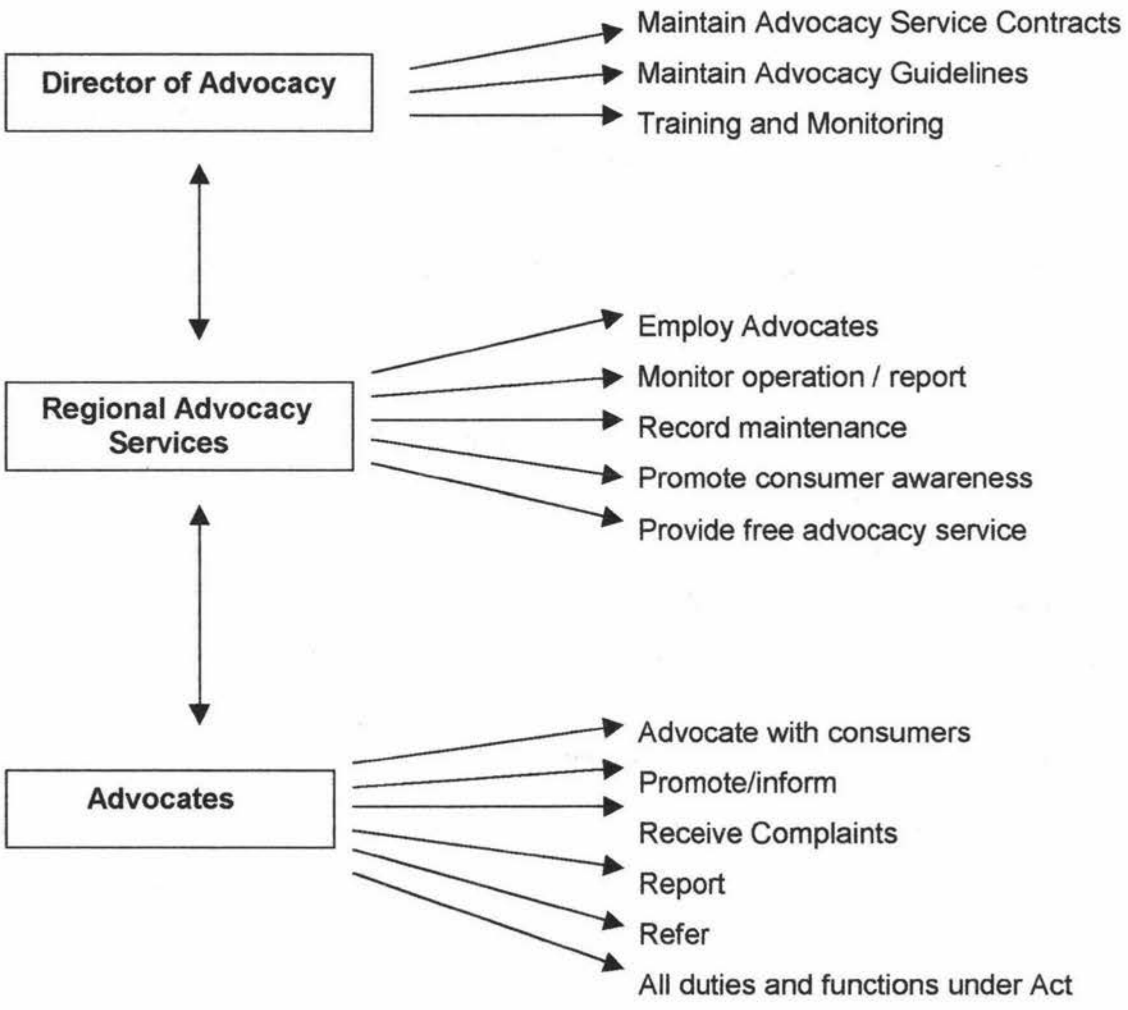
There are 33 FTE (full time equivalent) positions funded through advocacy agreements that are met by a mix of full and part time positions throughout New Zealand. The role of these advocates is to provide empowerment advocacy to consumers, as well as promote advocacy and the Code of Rights to providers and consumers in the health and disability sector. Furthermore, advocates must provide advocacy support in a manner that allows consumers to fully participate in the process of complaints resolution and/or to uphold their rights under the Code (HDC; 1998).

The functions and roles of advocates are outlined in Section 30 of the Health and Disability Commissioner Act (1994). In the supplementary notes provided to attendees of the Health and Disability Commissioner's Conference, *Issues '98,* these functions include:

- ☐ Receiving complaints from consumers, or as referred by the Commissioner or other persons.
- ☐ Informing providers and consumers of health and disability services of the rights afforded to consumers under the Code of Rights and of the availability of advocacy services.
- ☐ Assist persons who want to pursue a complaint through any formal or informal complaint procedures that exist.
- ☐ Represent, assist and/or support consumers to resolve complaints with the provider/s involved.
- ☐ Refer unresolved complaints to the Commissioner.
- ☐ Report to the Commissioner any issue relating to consumer rights, that the advocate feels needs to be brought to the attention of the Commissioner (HDC,1998).

Hence, the organisational structure and interfaces between consumers, advocates, advocacy services and the Director of Advocacy are reiterated. This is clarified in Figure Three. The diagram has been modified from the Structure Diagram produced in the document, *Operation of the Health and Disability Commissioner,* (HDC, 1996a;3.5).

Figure 3. Interfaces of Advocacy Provision



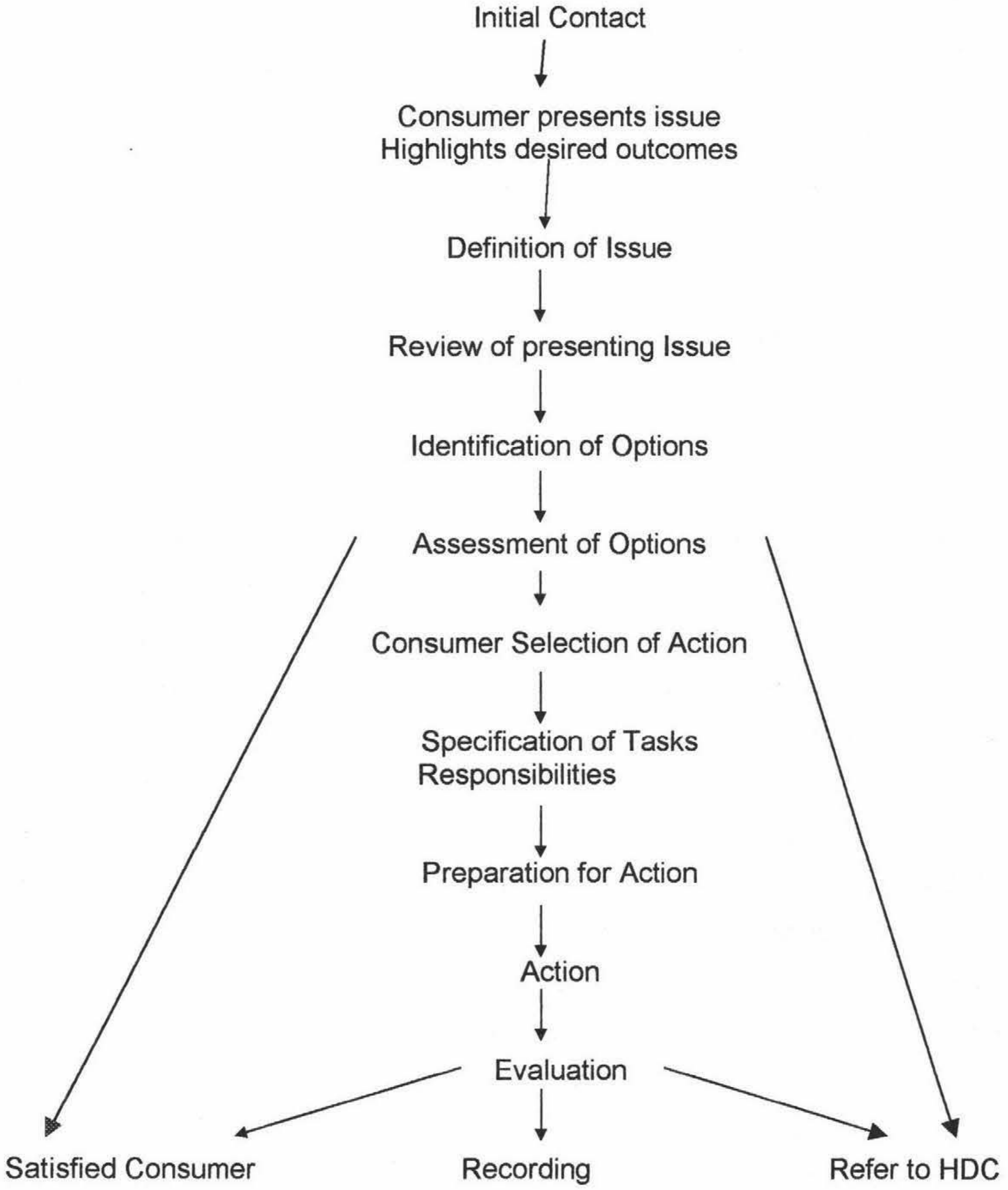
3.4 Empowerment Advocacy

A key emphasis of the Health and Disability Commissioner and her office is the concept of empowerment. This is recapitulated in the delivery of advocacy services. A fundamental provision of advocacy services is empowerment advocacy. This is stated in the advocacy guidelines and in the contracted agreements that advocacy services have with the Director of Advocacy. Consequently, advocates have been trained in empowerment practice through HDC and the Director of Advocacy. This training emphasised that the key principle of the empowerment advocacy model requires that:

> *...advocates should work with the consumer in a manner which supports them and gives them skills, knowledge and confidence to; resolve the current issue with assistance and resolve future issues without assistance (HDC, 1996, p.6.2).*

Furthermore, the key characteristics of this empowerment advocacy model are consumer focused and directed. This involves working with, not for the consumer through instructed advocacy. This incorporates following the actions specified by the consumer and encouraging the consumer to participate in the complaints resolutions process to the their highest potential level of ability. Providing the consumers with information, support and assistance to participate and make informed choices can facilitate this. The practice of empowerment advocacy adhered to by the nationwide advocacy services is in keeping with the theoretical perspectives outlined in Chapter Three. The emphasis is on challenging power bases, information, participation, attaining skills and the ultimate realisation of self-advocacy. The focal point for all advocacy intervention is the Code of Rights and the utilising of the Code to ensure that consumers are receiving services in the most appropriate manner. The specific advocates model of practice outlined in Figure Four Illustrates the steps taken to achieve this empowerment.

Figure 4. Advocacy Process



The emphasis throughout this process is consumer empowerment and the low level resolution of complaints. It is only when a complaint cannot be resolved through this process, or the seriousness of the matter calls for it, that a complaint is referred to the Health and Disability Commissioner.

4. Investigating Complaints

The Health and Disability Commissioner can receive complaints referring to breaches of the Code of Rights. These complaints can come directly from consumers or be referred through advocacy services. If it is believed that the alleged breach is of a serious nature or is complex and unlikely to be resolved at the advocacy stage, then the Commissioner will investigate. When the Commissioner receives a complaint she has a number of options to consider to determine the most appropriate action. Firstly, she may take no action because she does not feel that the complaint comes under the jurisdiction of the Code of Rights or because the complaint relates to an incident prior 1 July 1996. If there seems to be a breach of the Code then the Commissioner may refer the complaint to advocacy services under Section 42 of the Act. Advocates are therein charged with providing support in low level resolution. This action is taken when the Commissioner believes that the resolution will be most effectively sought at this level. The Commissioner may also consult with and/or refer the complaint to other relevant professional bodies or investigate the complaint to ascertain if there has been a breach of the Code of Health and Disability Services Consumers' Rights.

HDC has investigations officers employed to facilitate the investigation of complaints. The legal advisors and the Commissioner herself support these services. The investigation officers are independent and impartial. They must exercise their investigation in a fair manner, to assess whether or not a breach of the Code of Rights has occurred (HDC,1996). This process requires investigation officers to notify all parties that the complaint has been received and will be investigated. They are then charged with interviewing the provider alleged of breaching the Code of Rights and the consumer. If there are any other witnesses or parties then they will also be interviewed. The information gathered through these interviews is then collated and reported to the Commissioner. The Health and Disability Commissioner is solely responsible for deciding if there has been a breach of the Code. She makes her decision based on the recommendations and reported findings of the investigation officers. The Commissioner also has access to legal advice from the legal team at HDC who will be able to advise her on any other relevant legislation that is applicable to the particular complaint. The Commissioner then releases her opinion. The relevant parties are notified of this outcome and further action is then taken, if in the Commissioner's opinion, there has been a breach of one or more of the rights detailed in the Code of Rights. The actions taken, pending the opinion of the Commissioner, will vary resting on the findings of the investigation. If there has been a breach of the Code of Rights there are three avenues of redress. These include, referring the case to the relevant professional body, mediation and proceedings.

4.1 Role of Relevant Bodies

Interfaces exist between other agencies, professional bodies and the Health and Disability Commissioner. Either, during the process of an investigation, or as an outcome of an investigation, the Commissioner may consult with an appropriate professional body. This may be necessary to clarify technical information, identify standards and practice consistent with the profession or to consider the disciplinary options available. The decision to consult is not always left up to the discretion of the Commissioner. There are some circumstances outlined within the Act that require the Commissioner to inform other agencies for example, the Police or Coroner. The bodies consulted may include other Government rights agencies, such as the Privacy Commission, Human Rights Commission and the Ombudsmen, as well as health and disability professional bodies such as the Medical Practitioners Council. The Commissioner may seek advice or make recommendations to these bodies with reference to an investigation. For example, the Commissioner may advise a professional body to suspend a practitioner until the investigation is complete and disciplinary action has been decided upon.

The interface between the Health and Disability Commissioner and professional bodies also occurs when the professional body has received a complaint. It is specified under the Act, that all professional bodies have an obligation to inform the Commissioner of any complaints that they receive. They must also inform the complainant of their rights under the Code of Rights and of the availability of support offered by advocacy services and HDC.

4.2 Mediation

To resolve a complaint stating a breach of the Code of Rights, a mediation meeting may be called. The desired outcome of a mediation meeting is to resolve the complaint to the satisfaction and agreement of both parties. The resolution that is sought in mediation is binding, final and confidential (HDC, 1996). The role of the mediator in these meetings is to facilitate a discussion between the parties. They achieve this through setting the guidelines of the meeting and ensuring that both parties have the opportunity to raise issues pertinent to the complaint. The mediator does not act as a judge on the discussion and does not make a decision about the resolution of the complaint. This is the responsibility of the parties involved. The mediator simply facilitates the discussion to allow for resolution to occur.

The Commissioner calls for mediation when she feels that it is the most appropriate forum for dispute resolution. The Commissioner notifies the provider and the consumer of the meeting and may invite other parties that she feels would assist in the resolution process. Any information or evidence that is presented at a mediation conference is confidential and may not be used in a court of law if proceedings are still required. The decided outcome of a mediation meeting is binding, and the parties are legally bound to perform any tasks specified in the resolution. If resolution is not achieved at a mediation conference then the Commissioner may dismiss the case or refer the case to the Director of Proceedings. Alternatively the consumer is entitled to seek resolution through the civil courts.

4.3 Proceedings

After reaching an opinion on an investigation, the Health and Disability Commissioner may refer it to the Director of Proceedings for prosecution. The Director of Proceedings can bring a case against a provider in their own right, or represent or assist a consumer or a group to take action. The Director of Proceedings will assess the investigation report and opinion of the Commissioner before deciding if there is a case to be answered. If it is decided that no action will be taken, then the consumer has the right to approach the Complaints Review Tribunal or professional body independently.

If the Director of Proceedings decides to take action on a complaint s/he has three options. Firstly the Director may bring proceedings before the Complaints Review Tribunal. The tribunal is a legal entity that hears cases pertaining to the Privacy Act (1993), Human Rights Act (1993) and Health and Disability Commissioner Act (1994). The Director of Proceedings will seek damages or effective resolution with reference to the desired outcome of the consumer. However, when the public good is concerned, the Director will seek disciplinary action on the provider to restrict or suspend practice. The will of the consumer is considered in all legal actions, however, the consumer is not paramount when the public good is threatened in any way. Secondly the Director may bring proceedings before a health professional disciplinary body. The involvement of the appropriate body will allow for practitioners to be suspended from practice or, if necessary, removed from the professional register to prevent their future practice. Alternatively, the body may have the power to impose other disciplinary actions, such as fines, that they feel are appropriate. Thirdly, where applicable, the Director may take the matter through the criminal justice system. Where the complaint involves other pieces of legislation, for example, the Crimes Act (1961), the case will be brought before the court system.

5. Conclusion

This chapter has delineated the statutory positions and functions of the organisational structures established to support the implementation of the Health and Disability Commissioner Act (1994). It has detailed the initial phases of operationalisation of the Act and shown the interfaces that exist between HDC, advocacy and the Code of Rights. The legislation is complex and cumbersome, hence not all of the specifics of its contents could be, or need to be, discussed. However, the information presented here provides a discussion of the legislation's intent, structure and provision.

This chapter completes the first two requirements of the formative policy evaluation specified by Spiker (1995). That is, identifying and explaining the aims and objectives of the policy and detailing how these have been implemented. From here, the focus will be on addressing the second two phases of the policy analysis. This begins by exploring the outcomes of the policy, from the perspective of the participants, and then measuring these outcomes with the stated aims and objectives of the policy makers. Finally this evaluation allows for alternative policy recommendations and instruments for change to be developed to bring together the anticipated outcomes and the real outcomes, if any gap between those two variants is noted.

Chapter Six – Analysis of the Broader Context

1. Introduction

As outlined in Chapter Two, the data that was collected for this research has been organised into six themes for analysis[1]. They are: the health and disability reforms; consumerism; the office of the Health and Disability Commissioner; the Code of Health and Disability Services Consumers' Rights; advocacy services and; empowerment advocacy. These themes convey the data collected from the focus group interviews and the documentation analysis. The themes will be detailed in the following two Chapters, analysing the data that was generated under each, and the interfaces that exist between them. The themes will then be summarised by identifying the key findings comparing the aims and objectives of the relevant polices versus the outcomes experienced by participants in the focus group interviews. This process is a requirement under the formative evaluation research tool that has been utilised in this research to guide the exploration of the legislation and its implementation.

In this chapter, the themes outlining data on the health and disability reforms and consumerism will be analysed[2]. A large amount of the data analysed is dedicated to the experiences outlined by participants in the focus group interviews, as these findings represent the lived experiences of participants and most appropriately illustrate some of the key issues. However, other sources of data and literature are also analysed and refer to the information contained in Chapters Three through to Five. Therefore, the main purpose of this chapter is to analyse the triangulation of data gathered, explain its relevance to the research and identify the major issues

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[1] Given the researchers experience in the field and knowledge of the literature and documents pertinent to the research topic, six themes were developed that framed the questions provided in the focus group interviews. The data gathered from these meetings naturally collapsed into these six themes, and therefore they were retained to categorise all the data for analysis.

[2] The data analysed in the themes with direct reference to the legislation and its associated organisational structures, functioning and services is outlined in Chapter Seven.

associated with the implementation and outcomes of the Health and Disability Commissioner Act (1994).

2. Theme One - Health and Disability Reforms

The influence of state sector reform, specifically the reforms to the health and disability sector, have been noted throughout the research for setting the structural context within which the Health and Disability Commissioner Act (1994) emerged and was implemented. The legislation and the organisational structures that it has developed, have been significantly shaped by the dominant social, political, cultural and economic ideologies that prevail, thereby dictating the formation, implementation and outcomes of the policy. The triangulation of data that has been collected has focused on some of the specifics of the health and disability reforms, as having direct relevance to this research. This theme does not exhaustively evaluate the possible influences of the health and disability reforms, however it does identify some of the key issues from the perspectives of a group of consumers, advocates and the researcher.

2.1 Purchaser/Provider Split

As noted in Chapters Three and Four, one of the key aspects of the reforms to health and disability services was the splitting of the functions of purchasers and providers. The main impetus for this split was the desire to see purchasers of services (that is, budget holders) removed from the practical side of service delivery, thus reducing the potential for rent seeking by bureaucrats and increasing the efficiency and accountability of state funded services (Treasury, 1987). In the sector these reforms saw the inclusion of disability in health structures and the establishment of separate funding agencies (for example, Regional Health Authorities). These changes emerged under the Health and Disability Services Act (1993), aided by other implementation tools, and have continually altered as the reforms have been executed. The original four regional funding agencies have now been replaced by a central funding agency, the Health Funding Authority

(HFA)[3]. The other significant funding agency for the health and disability sector is the New Zealand Community Funding Agency (NZCFA)[4]. Regardless of the specifics of the organisational structure and functioning of the purchaser/s and the providers, there have been resulting issues from the separation of these functions identified by service users and professionals within the field. One reoccurring theme in the analysis was the confusion that the re-organising of state functions has caused, with different agencies being responsible for different functions of the overall provision of health and disability services to New Zealanders. It has created an impression of disjointed and fractured communication and functioning that inhibits the relationship between policy and practice. As one advocate noted:

> *Some of these new plans that the HFA comes out with, you wonder where they dream them up, and who dreams them up. How are they planning to implement them so that they actually work? Because some of them just seem to be too academic, you know like ideal world, ideal resources... it sounds really good, sounds quite idealistic, but you know that's all its going to be.*

The splitting of policy, funding and provision functions noted here, queries the appropriateness of a number of different agencies being involved in the broader context of decision-making for overall service delivery. The splitting of purchasers and providers in the health and disability arena has specifically resulted in a number of changes to the functioning and operation of the field, most notably in the introduction of contracts for service providers to abide by. These contracts dictate

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[3] The four Regional Health Authorities were collapsed into a single funding agency. The National Government and the NZ First party stated this policy change in Sections 2 and 3 of the Coalition Agreement for Health. A steering committee reported on the implementation of the policy changes in May 1997 and this resulted in the establishment of the Transitional Health Funding Authority (THFA) on 1 July 1997. Under the Orders of Council, Transformation '98 began on the 6 January 1998 to establish the Health Funding Authority (HFA), which became structurally operational on 1 October 1998 (Report of the Steering Group to oversee Health and Disability Changes, 1997).

[4] Note that the NZCFA is going to be further transformed at the end of 1998 and merged with the New Zealand Children and Young Persons' Service.

the service that can be provided and under what circumstances, allocating the appropriate funding for these services. The contracts are entered into between individual providers (ranging from hospitals to community based agencies) and the purchasing agency. This has raised a number of issues for those providing services and those accessing the services, as one of the largest areas of response in the focus groups came from discussions on the contracting of services under the new health and disability structures. The contracting model was designed to deliver accountable, effective and efficient delivery of services in accordance with the associated monies allocated for that provision[5] (Treasury, 1987). However, they have created issues of frustration over access to services, the consistency of service delivery and confusion for consumers about where the responsibility for services lie.

One consumer explained the complications when she was trying to access appropriate services for her daughter with a high needs disability. She details the difficulties she had with the provision of support services for the care of her daughter, when the agency concerned could not employ enough qualified staff to provide the hours of care that had been funded for under their contract.

> *The RHA funded (agency A) for 70 hours a week. What we were actually getting, if we were lucky, was 45 hours a week and that is why I couldn't cope. Every week I would dread the call, 'Sorry we cant start till nine' or 'Sorry we haven't got so and so tonight'. You know that means you're going to get two hours' sleep, (but) it isn't actually sleep waiting for someone to call out to you. You need to be hands on, you actually need that. They were funded for it, but I didn't get it.*

These feelings of frustration and difficulties with contracts continued for the consumer when agencies argued over who was contracted to provide what care.

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[5] For a detailed discussion and analysis on the contracting systems and functioning that exist in New Zealand, with specific reference to the state sector, see Boston (1996).

> *My daughter was hospitalised in the beginning of November last year and within 48 hours we were told by (agency A) that my home support people would be pulled out because we were at the hospital. I said 'that's utterly ridiculous, we have seven hours care during the day and we still need that', I said, 'how am I going to manage?' And the hospital said that they couldn't fill it, they could provide the nursing care but that was all. It took eight days for (agency A), and remember that they had already been funded to provide this care, it took them eight days to set up some sort of contract with the hospital, that allowed for only four hours' (care). That left me with 20 hours (per day) that I had to manage in hospital on my own for two weeks. And sometimes it would be, maybe twice a week, where that four hours was not supported or they couldn't find people. The charge nurse saw what a mess I was getting into, how tired I was, so they actually provided someone from the hospital to sleep over or stay awake so that I could sleep... (agency A) said that they wanted the hospital to take ownership of the insurance or whatever,... if I'd gone to stay in a motel it wouldn't have been a problem.*

It may be argued that, the passages above identify some of the systemic issues associated with the separation of functions and the requisite contracting system, illustrating that the post-reform structure can result in fragmented service delivery. Other participants noted similar difficulties with agencies under the contracting system and commented on the lack of goodwill amongst service providers and how incentives for efficiency have affected the public service.

> *Where in the past institutional organisations like (agency A) might have said, 'We're not funded for it, but we'll help you out', and another agency might return the favour in another way, that doesn't happen anymore.*

> *There is just no decency anymore. They are businesses.*

> *No one is choosing to fill the gaps...everyone has such rigid and tight guidelines now about what their role and responsibility is, what they are funded for, what they have to be accountable for, whereas 10 to 15 years ago, there was a lot more goodwill among agencies.*

The contracting systems that providers have with the funding agency have also created some uncertainty for providers. Those uncertainties disclosed in the data centred mainly on the reporting back and accountability for the funding allocated to providers. It was acknowledged that it is necessary for providers to be accountable for the funds that they have received. This ensures that Government monies have been spent in the most appropriate, effective and efficient manner, which was one of the goals of the restructuring. However, as the advocates passage below outlines, this requirement of fiscal accountability can be alienating and costly for some provider groups.

> *Well I still feel quite strongly that it (the outcomes of reform) has gone backwards... It is quite frightening to have to deal with accountability and report back and all of that. A lot of smaller groups haven't got the facilities to do that. So there has been a sort of retrenchment for those providers, voluntary providers....These groups have got to take on a model where five of them are getting funding from five bigger organisations that can cope with reporting, accountability etc, and then the smaller groups are being fed off them.*

In response to this observation, another advocate adds:

> *There are some where the amount of money that they are funding is as little as $900. It's stupid having a contract for $900, you'd be better to give it as a grant. And then the accountability, the things that they are required to do would be less, they still will have to show how the money is being spent from an audit point of view. They won't have to have a*

> *detailed contract, they wont have to spend months and months, and more money writing the contract.*

These and other issues over contract reporting were also noted in research conducted by the New Zealand Council of Christian Social Services (NZCCSS) which reviewed the relationship between voluntary social service agencies and the NZCFA (NZCCSS, 1998)[6]. Most of the agencies involved in the research (54%) stated that they felt that the reporting required under contracts with NZCFA was unreasonable in terms of the amount of information that was required. Furthermore, a majority of respondents (41%) did not feel that the reporting required was relevant to the funding that they had received (NZCCSS, 1998). These are important findings, as they indicate impractical expectations over reporting, which is an administrative task that utilises the valued resources of the organisations (staff, time and monies) when funding is already scarce. This detracts from the service delivery that the organisations are primarily focused on providing, because core service provision must be sacrificed to allow for fiscal reports to be submitted. This may be reflected through the establishment of waiting lists, the employment of less staff and/or the overall outputs produced by the service being less than optimum. Furthermore, the desired accountability behind the reporting process may only result in higher accountability to the funder at an end cost to the service users.

The issue of contract reporting is closely related to that of accountability, as contracts outline who is accountable for what function. If a provider receives funding to fulfil a particular service need, then that provider is obligated to fulfil this function, furthermore the funding agency is responsible and accountable for identifying the service needs in the community and adequately funding for those needs to be met by providers. Therefore, contracting and contract reporting are

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[6] The research was conducted in late 1997 and early 1998 using a multi method approach consisting of a survey to nearly 100 voluntary organisations, and two focus group meetings. Furthermore, the research called on document research and a review of the findings of a four year survey involving fourteen Christian social service organisations.

closely aligned to accountability. On a resourcing level this accountability generated some interesting commentary.

> *I think some areas have achieved in that they've made people become more accountable and businesslike, and you don't get this big rash of spend up year after year, because we have got some money over. People actually have to plan on a five year basis which I think is good because it makes them look at capital and those things. But in reality for the person at the end of the line, services seem to get less and less.*

So has accountability been used as a guise to cut budgets and to limit the resourcing that services get, thus impacting upon the services that they provide? As one advocate noted:

> *What the Government wants is for people to be on their own resources, one of their whole philosophies is that individuals, families, churches and voluntary groups, all pick up the social welfare system, that the state doesn't pick up. There may be accountability but it is for less money.*

It may be argued that the Government's concept of accountability does not appear to move significantly beyond providers' fiscal obligations, and is in contrast to the advocates and consumers understanding of the term. In light of the data analysis, social and service liability, accountability and responsibility to service users[7] does not appear to have increased and the guidelines and benefits are not identified as being always clearly defined.

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[7] It is acknowledged that these terms may have meant different things to the advocates and consumer participants in the focus group meetings, however it was strongly stated that consumers and advocates alike face frustrations about who takes responsibility for consumer complaints and where the lines of accountability are drawn.

> *Who is accountable for all of these different agencies responsible for different care and provision or funding provision? Where does the buck stop at the end of the day? Who is going to stand up and be counted and say we've made this decision? Who do I complain to (the funder or the provider)?*

The points made in the passages above, were also noted in the NZCCSS (1998) research and are supported by other research and literature (Kramer, 1981; Lyons, 1996; Higgens, 1997; Nowland-Foreman, 1998). Purchase-as-funding service contracting is likely to undermine the other roles of agencies. While accountability to the funder is increased, responsibility to service users can erode. The priority is accountability to the funder above and beyond other responsibilities, such as the consistency and/or quality of service provision. Furthermore, co-operation amongst services becomes less common with the priority on fiscal accountability, as measurable service outputs have increased importance (NZCCSS, 1998). This in turn leads to a type of ring fencing of agencies' activities, which results in problems for service users and inhibits their shifting from agency to agency.

2.1.1 Access to Services and Consistency of Service Delivery

The implications of the purchaser/provider split of contracted health and disability service provision have extended to issues of access. Both consumers and advocates noted several issues in line with accessibility to services, ranging from the ability to pay for appropriate care through to the restricted services that are provided. In terms of the contracting model, providers have incentives to only offer services that a) they have been funded for, b) to the consumers that the provision is targeted at and c) within the organisational and personnel structures that they have the resourcing to provide. This has resulted in some small groups of consumers falling between the gaps of service provision (Ashton, 1992). For a larger number of consumers, it has resulted in fragmented service provision, where a number of agencies need to be accessed to provide the holistic support that consumers require (Boston, 1995)[8]. The passages below give clear illustrations of these issues.

> *When we kept trying to access more services it was like, 'We can't do anything'... everywhere we went it was 'Yes we can see the problem, yes we can see the need' but no one wants the responsibility... Everyone knows that there are gaps... they're all identified, to all the meetings I was going to all over the place. 'Yes' says (local MP) 'Yes there are gaps'. (Agency B) are saying 'Yes there are gaps', (agency A) are saying 'yes there are gaps'. The gaps are with the people who are least able to speak up!*

The following passage relates to a consumer whose daughter has a high needs autistic–like disorder with associated intellectual and physical disabilities. The child was cared for at home with the support of carer relief from an outside agency. The consumer states that the agency providing the support did not always provide for her needs or her daughters needs, in terms of providing consistent services or services that were based on an adequate assessment of their situation.

> *I think that with disability (the) parents say often, 'Why would I ask for ten nappies if I didn't need them?' 'Why would I ask for this service, if I didn't need it?' 'Why would I waste my time writing letters to try to get something?' People aren't going to do that. I always think that yes, you need to have someone come in and assess what you need... how can someone come into your house and do an assessment in an hour or two hours? What we need is someone to come into our house and spend between four hours, stay the night. We used to have someone come in and they would come in from 12 to 4 and I would say, what we actually*

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[8] Note, that this reflection on the consequences of state sector reform is directly relevant to the research topic, as they indicate the sources of consumer complaints and the need for the Health and Disability Commissioner Act (1994).

> *need of you is for you to be here from 10 at night until 6 or 7 in the morning. And if you really want to work out what we need, you actually need to be here for 24 hours. Because so many times, say from 9 to 12 that shift, that's actually quite different from the 12 to 4 shift, and if someone comes in from 7 to 10, that is a whole new routine, and if you're going to come in from 10 to 2 in the morning, well normally you would be watching a child sleep, but no, you're actually trying to get that child to sleep. And from 2 to 4 in the morning you actually keep that child's temperature in control, and at 5 o'clock, if you're lucky, and everything is right, she'll actually sleep through to 7am. Now you can't talk to someone about that. They're either going to think that you're a terrible mother or that this is absolutely ridiculous. So I think that families need to be respected, families need to be serviced properly. They need to really have their needs looked at and evaluated properly and met.*

This passage identifies potential gaps in the needs assessment services that the Government introduced in 1997. It illustrates that individuals are not being offered the opportunity to state their needs and choose how to have those needs met. From an advocate's perspective, the issues of access are also identifiable. One advocate provides an example based on her experiences:

> *In the sort of cases that I've had – if you get ill on a public holiday, Saturday or Sunday, then its unlikely that things such as the CT scans will be available. They are not going to call out the radiologist at 3.00am on a Friday or Saturday morning because it costs a lot. They don't access the appropriate care, then that person dies, that person has died as a direct result of the reforms. Everything is impacting on the consumer and their accessibility.*

In response to this, another advocate adds:

> *Another thing that I think it is important to reflect on is how it has affected the health professionals because I notice that the morale is very low and especially in services like A&E... they say Dr. X, he's not on tonight, so we won't bother getting a consultant, even though a consultant only needs to be called... they know that it's expensive.... a feeling that, 'oh well, we don't know when we'll be restructuring again, so don't do everything to an excellent degree.*

The issue of access has also arisen from the introduction of user part charges on some health and disability services. These part charges were presented as a component of the reforms and have altered with the implementation process. However, in their simplest form, the part charges are based on means testing and categorise people, based on income into three groups, with charges being applied according to each income bracket. The rationale behind this policy was to evenly spread the cost and use of primary and secondary services throughout the sector, to better direct Government monies and improve access and delivery (Minister of Social Welfare, 1991). Furthermore, the policy was used as an incentive for people not to over consume scarce resources. Some of the participants in this research dispute that the greater efficiency and quality of care has been achieved.

> *...you now have to pay for an x-ray if your GP refers you (to the hospital). There are a certain number of people who are not going to have their chest x-rayed, or whatever, because they actually can't afford it and (hospital A) are asking for the cash up front. They won't x-ray you unless you have got the money. I mean that has been in the papers here. I think it's around $60, it's a lot of money, a lot of people can't afford to go to their GP, let alone pay that on top... By the time they have gone to their GPs it's $35, and maybe picked up a script for $20, it's $55, maybe half of their income went on those two things alone.*

A combination of user part charges, inappropriate needs assessment processes and limited consumer choice have all been identified in the data analysis as impacting on access to services. Furthermore, the National Health Committee (NHC,1998) commissioned a report to provide to the Minister of Health on the inequalities of health care in New Zealand. In the research a number of variants are noted as contributing to limiting access to services. These include income, poverty, employment, ethnicity, housing and social support. In particular the research notes that the allocation and provision of population based services greatly impacts upon the inequality of access and the inconsistency of service delivery (NHC, 1998). Consequently, the influence of the purchaser provider split, contracting, part charges and accessibility have also contributed to the inconsistency of service delivery experienced by service users.

Each provider is funded independently, based on their own contract, whether with the HFA or NZCFA. Therefore, some service providers may receive different levels of funding even though they are delivering the same or similar services. This may be dependant on such variants as demographics and can result in a provider in a specific area delivering services at a different level than another, even if the provision is supposed to be the same. For example, providers, such as hospitals, are allocated funding towards public health awareness and education. Other community organisations, such as Maori provider groups, also receive funding for this purpose, however the funding levels are not the same due to the different target audiences that the providers are contracted to inform. This inconsistency of funding may be justifiably based on the populations that are being targeted, however it also has the potential to endorse the inconsistency of service delivery (NHC, 1998). Furthermore, different providers (for example, hospitals) may have different priority groups or target areas to which larger amounts of their funding are attributed. Once again this is influenced by variables such as demographics or high occurrences of specific illnesses (for example, asthma). This also provides for the potentiality of inconsistent service delivery (Ratima, Durie, Allan, Morrison, Gillies & Waldon, 1995). As one advocate noted, the reforms are used to justify this inconsistency.

> *Providers often use the reforms as an excuse as well. It's an easy thing to say, 'well it's because of this, this and this', whereas it may be their practice. It's really easy to say that resource constraints don't allow us to do that, but it shouldn't be an excuse for bad service. If you can't provide a service at an appropriate level then you should be lobbying with the HFA, saying that we can't provide this service safely.*

Consumers disclosed strong and emotive sentiments when discussing the frustration of service delivery not meeting their expectations and the gaps that they had recognised in the services that were available. Their lived experiences reflected common frustrations with inconsistent service delivery, and this is aptly summarised by the following consumer:

> *Why is it so difficult? Why is it too difficult to access appropriate health? Why is it so difficult to get straight up answers when the reforms are supposed to make things easier and better for us as receivers of health and disability services?...The health reforms are supposed to make things better, they haven't done that in my evaluation.*

2.1.2 The Effects of Change

The effect of the reforms on health and disability sector has been the creation of an environment of uncertainty and dismay for the participants that were involved in this research. Furthermore, they have led, in varying degrees, to the consumers' need to utilise advocacy services, the Code of Health and Disability Services Consumers' Rights and HDC. Therefore, reflecting the direct relevance of this data to the overall research topic. The comments outlined below speak volumes about the matrix of issues that they have confronted as a group of consumers and health and disability professionals.

> *I think that one of the biggest things is the miscommunication all around the place. I can remember one week saying, 'what happens to a child that dies in ward x?', My answer was that no, they wouldn't die in ward x... it's either ICU or at home. What happened? My daughter dies in ward x...We were left to carry a dead child out of hospital, no support, no help, no nothing. What is wrong with the hospital? What is wrong with everyone?...Where's the human bit? We were left to carry a dead child out of hospital. I had made a quilt, but it was only a wheelchair quilt. So that is not going to cover a nine year old. Why couldn't a staff member, a nurse, have supported us? I am really concerned with what is happening to families. I have got a son who has to live with that the rest of his life, carrying, waiting outside the lift with his dead sister in his arms, dreading who the hell is going to walk out of that lift.*

One of the exchanges that took place between advocates reiterates these accounts and explains the need for the Health and Disability Commissioner Act (1994) in the current climate, consequently justifying the need for the free provision of advocacy services nation-wide.

> *The restructuring and the different things that are happening at the moment means that we are seeing a lot of people...they don't actually understand what's going on and they think that at the end of the day there is going to be no money and they are basically getting told that if they don't agree to it (their provision) then the funding will stop. It is like scare tactics or harassment... this is really threatening in rural communities.*

> *As an advocate you are having to be on the ball to keep people up with the changes, having to know what is going on, who is in charge, constantly aware of changes.*
>
> *It takes ages to find out all the information (and) to know which benefits are there.*
>
> *Next week it has all changed.*

2.2 Summary of Findings

As noted in Chapter Two, the formative evaluation research approach that has been adopted in this project, bases part of the analysis process on comparing the stated aims and objectives of the policy with the outcomes experienced by advocates and consumers. In the case of the health and disability reforms some serious deficiencies and gaps have been revealed through the stories of the research participants. These issues have direct relevance to the research topic, as they locate consumer complaints and the environment within which advocates operate, thereby, setting the scene for a further analysis of the specifics of the legislation. The Health and Disability Commissioner Act (1994) has, in part, been established due to the need for consumer rights to be upheld in the reformed health and disability sector. It may be argued that the need for the Act, and its associated provision, would be reduced if some of the identified issues in this section of the research did not exist.

To recap, the reforms that occurred in the health and disability sector were intended to fulfil a number of key Government objectives. These objectives are located in a number of Government polices that have been introduced since the early 1990's (Ministry of Social Welfare, 1991; Upton, 1991 & 1992; Shipley & Upton, 1992; Ministry of Health, 1994 & 1997). These were stated in Chapter Three under the evaluation of state sector reform and in Chapter Four, with an examination of the history of health and disability policy development in New Zealand. In summary, the key aims and objectives of the Government in forming the basis of the reforms were to:

- Increase efficiency, effectiveness and accountability in the public services, to better utilise the fiscal expenditure that is allocated to its functioning.
- Reduce the overall expenditure that was required to operate the public sector, supported by the influence of managerialism, with the shift to funding outputs instead of inputs.
- Separate the functions of the public sector to retain power within the political sphere, and remove it from bureaucratic officials by eliminating the opportunity for 'rent seeking'. Thereby, redefining the roles of Ministers (policy making) and the roles of officials (implementation).
- Increase the quality of public services, thereby increasing access and responsiveness to consumer needs.

These aims and objectives are underpinned by a key principle, the belief that state activity in the provision of goods and services should be limited, thereby, resulting in the creation, where possible, of contestable markets, both for the provision of policy advice and for goods and services. This supports the assumption that other non-state agencies can provide those goods and services in a more effective and efficient manner, filtering through to the belief that wherever possible, public services should be contracted on the same lines as private companies (Boston et al, 1996). The attainment of these aims and objectives was realised via a number of legislative and other regulatory instruments. In health and disability, this included the introduction of the purchaser/provider split, and competition for service delivery. Information from the participants involved in this research, coupled with other sources of data, have commented on the extent to which these aims and objectives have been consistent with the needs of service users in the health and disability sector. In summary, the data analysis has indicated that the key issues of concern are:

- ☐ That fragmented mechanisms exist for fiscal decision-making, resulting from the separation of functions, particularly the purchaser/provider split. The findings note that the lack of co-operation between purchasers and providers, coupled with the fiscal obligations of accountability, efficiency and effectiveness, may have added to issues over access to services and the inconsistency of service delivery experienced by participants.
- ☐ Confusion exists for participants about where the accountability for structural and service issues lie. Is the Ministry responsible because their policy guides service outputs? Is the purchasing agency responsible because they make decisions over fiscal allocations and hold contracts with providers? Or are the providers responsible for not adequately predicting the fiscal obligations of their service provisions and therefore having to restrict access to services and the consistency of service delivery? Alternatively it may be that all of these separate entities are responsible for the outcomes experienced by service users. In this case where are the lines of redress for complaints most appropriately placed?
- ☐ The contractual agreements that exist between purchasers and providers require standards of reporting that may be creating obligations from the provider that detract from their core business of service delivery. Furthermore, the literature reflected that contracts and reporting obligations may undermine accountability and responsibility to the service users (Kramer, 1981; Lyons, 1996; Higgens, 1997; Nowland-Foreman, 1998; NHC, 1998). Moreover, co-operation amongst services has become less common and is affecting the holistic support of service users because measurable service outputs are prioritised (NZCCSS, 1998).
- ☐ Finally, general confusion for consumers has been noted over the process of change in service delivery. Participants perceived a lack of information as contributing to this confusion. It can be argued that access to appropriate information on systemic changes is required to facilitate their access to decision-making processes and to increase their input in the future development of service delivery in New Zealand.

3. Theme Two - Consumerism

As identified in Chapter Three, the terminology that is applied to service users has, and continues, to change frequently. It hinges on the particular group being discussed and the influence of environmental factors relevant to that group (Taylor et al, 1992). Associated with this is the changing meaning of language dependent on whom is using it. Patient, client and consumer are all terms that have been used and continue to be used interchangeably, to refer to individuals accessing health and disability services. The choice of terms is largely dependent on individual preferences and agency policies, with some disagreement prevailing. The term *consumer* in the health and disability arena arose from the inclusion of political and economic assumptions in the purchasing and providing of social services (Vaillancourt et al, 1994; Adams, 1996), and was directly influenced by the philosophies and processes of reform. The competition that now exists between state and non-state agencies in the provision of services, coupled with contracting and the separation of functions (policy, funding and provision) illustrates the influence of the free market model, and the associated belief that individual service users are *consumers.* The exercising of the individual choice that is necessitated in the reformed health and disability sector and free market environment, reiterates that individuals are *consumers,* as they were supposedly able to exercise their preferences to meet their stated needs. The rise of consumerism is further supported by the legislation being evaluated in this research, as the Act and its associated regulations and policies, utilise this terminology.

The Health and Disability Commissioner Act (1994) refers to service users as *consumers.* This is most notable in the regulated Code of Health and Disability Service Consumers' Rights and is reflected consistently throughout the organisation's policies. The definition of *consumer* provided in the Act is very simplistic and generic, in that it refers to any individuals accessing health and/or disability support services[9]. This vagueness has allowed for the development of the term, and the rise of its frequent use, in the context of the legislation and its associated organisational structures and services. All of the policies, procedures and other documents produced by the office of the Health and Disability Commissioner refers to service users as *consumers*. Furthermore, advocacy services have been instructed under their contractual agreements with the Director of Advocacy to provide services to *consumers*. The frequency of the use of the term has significant implications based on the complexity of the concept, as outlined in Chapter Three. Therefore, an exploration of the politics surrounding the rise of consumerism is directly related to this research and necessitates further examination in this section through an analysis of the data that has been collected. This theme of analysis has developed a number of areas that the data is organised into, in order to disseminate the triangulation of data in a clear and concise manner, however, it is noteworthy to add that interfaces exist between these areas. This theme is not an exhaustive examination of the advent of consumerism, however it does stipulate issues associated with the term that have direct relevance to the Health and Disability Commissioner Act (1994) and the broader context of the health and disability sector.

3.1 Defining Consumerism

There has been contentious debate about the appropriateness of the use of the term *consumer* in application to a group of people who have limited choice, access to information, and participation in the processes of decision-making (Adams, 1996). This debate is hinged on the fact that the term denotes that these opportunities are available to service users in the health and disability sector. These points were established in Chapter Three, and will be supported here, as the defining of consumerism is integral to the elucidation that is required. In order to develop a discussion on this theme, participants were first asked to comment on

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[9] See Chapter Four for the definitions provided within the Health and Disability Commissioner Act (1994).

their views and definitions of the term *consumer*. This discussion contextualised the connotations explicit to participants when using the term and thus illustrated the parameters within which their responses were based. As a result some interesting and differing definitions and opinions of the term were explored

> *I actually looked it up in the dictionary, and it said that it is a person who buys or purchases something. I'm not that comfortable with that connotation and a lot of people out there aren't.*

> *Consumer as in someone out there purchasing goods in the market place – it doesn't fit.*

> *I don't like the term, I prefer patients, if I'm in hospital then I'm a patient, I'm not a consumer. I can't go and consume somewhere else – I'm sick! I'm a patient and I want to be treated that way. If I get called a consumer then people better treat me like I have some choices.*

The advocates involved in this research work within an organisational structure that has supported and promoted the use of the term *consumer*. The implications of this association do not however mean that advocates agree with some of the connotations that commonly emerge.

> *Well the term for me, I don't like it, I still identify that it would be like the Consumer Guarantees Act, or something like that, and I still see a consumer as being an individual going to the shop and buying something and I don't think if I call them a consumer, they take offence to that as well.*

> *I don't particularly like using the term, I think its not derogatory, but it's sort of, it doesn't identify how they are feeling at the time. They have a complaint and calling them a consumer, it's not identifying with them.*

> *I tend to use the word clients, because I expect you are getting a service, that's what I think of, as a client whether it is at a massage parlour or the lawyers, you are getting a service and so I suppose good service comes with rights, but consumer doesn't seem to be the right word for this service....*
>
> *You can see people cringe.*
>
> *They do! When you say consumers.*
>
> *And providers do the same as well, most of the providers that I talk to, they say that they hate the word.*

From an alternative perspective, some advocates noted the inappropriateness of any other term to describe the individuals that they have contact with.

> *As a generic term, the thing that I like about consumer, is that it crosses the wall between a person receiving a health service and a person receiving a disability service. If you use the word patient, people are still going to find that really offensive, and I guess that I don't feel comfortable with client, and that is probably to do with my own personal background because (Agency A) came out quite strongly when I worked for them, with the use of client. Again that implies a different type of a relationship with a provider. In good disability support services, at the ground level, the person providing the service is the employee of the person receiving the service. The provider's role is to do what the consumer wants/needs in order to maximise the consumers dignity and independence. I don't believe this is either a provider/client or a provider/patient role. For me, I personally find the word consumer more suitable than patient or client.*

> *It's not the best word but I suppose it can be better than the other two (patient and client).*

> *I tend to use the word complainant more than anything, but I wouldn't say it in front of the individual.*

> *I don't use it when I talk to people and I have to admit, having been in health for 22 years, I tend to think of them as patients, but I don't actually say that to people. I have heard comments about the term consumer, just in passing, as being one of those fad words. It's like when we changed the hospitals from having patients to clients, now you talk about them as being consumers.*

These passages identify some of the difficulties associated with using the term *consumer* within the health and disability sector and have raised some interesting observations about the freedom of choice that is associated with consumerism. They indicate that this freedom, or real choice at all, is not currently afforded to service users in the health and disability sector and this is thereby contributing to the lack of appropriateness of the term. Furthermore, the passages support the notion that the meaning associated with words are not immutable, and that the meaning of terms is dependant on the prevailing balance of forces (Lister, 1990). This point becomes heightened when discussing the opposing meanings of the term citizenship and consumer sovereignty.

3.1.1 Consumerism vs. Citizenship

The language of citizenship has challenged consumer sovereignty, in the present climate. Citizenship relates to the shared status of all individuals who are full members of society (King, 1987). It accords associated rights and responsibilities with this membership, including political, civil and social rights.

In Chapter Three it was acknowledged that citizenship can not reign if these rights are not upheld, in conjunction with access to appropriate forms of information to encourage access to decision-making processes (Turner, 1990). Furthermore, the rights of citizenship can not be viewed in isolation, as a combination of the rights needs to be upheld for citizenship to prevail and result in the participation that is implicit in the membership. To what extent this form of citizenship can predominate in the current climate is questionable in light of the reforms to the health and disability sector and the Government's desire to limit the role of the state.

In response to the market's challenge of citizenship, the focus has turned to the notion of consumer sovereignty. That is, the right of individuals to dictate the nature and quality of the services that they receive, as opposed to the reception of standardised collectively provided public services. Universal state provision is not viewed as being responsive to the varying needs of individuals. Instead individuals can best decide the provision that they require through their functioning in the free market of service provision. The market is the most appropriate forum for individual participation not universal provision. In fact, individuals are not required to be involved in decision-making processes to exert their consumer sovereignty. There is a reliance on the market to shape and form the quality of service provision through competition and consumer choice. As one advocate noted:

> *The bottom line is that most people wouldn't choose to be a health and disability consumer. I personally think that it is part of the new right speak that we have been landed with since the reforms and we've been asked to try and embrace it and as you can see, half of us can and half us can't. It's really been on us since the reforms and it is take it or leave it, I'm not going to use it whether they want me to or not.*

The literature detailed in Chapter Three noted a number of inadequacies of attributing consumer sovereignty to the health and disability sector (Hamilton 1982; Maharey, 1989) some of which were illuminated by the participant data. The Government's notion that individuals dictate the nature and quality of their services as opposed to the voice of collective citizenship through exercising their choice is viewed as fundamentally flawed according to the literature. This point is continually reiterated in the analysis of the data and raises some interesting debates that are supported by the literature. Furthermore, these debates relate to the differences between consumerism and citizenship.

> *If implicit in the word consumer is meant to be a choice thing, then often that doesn't apply to the health system, unless you can afford to go private. If you're reliant on the public sector, regardless of whether you live rurally or in the city, you have usually got limited choice for hospital care. And certainly if you live rurally, your choice is restricted, even in terms of a GP. So, yes, if you think of a consumer as being someone with a choice, equivalent to the choice I have about shopping at Deka or Farmers, then that is not occurring across the board of health and disability services.*

> *I think that when you call yourself a consumer, you are seeing yourself as someone with choices. But if you have an amputation, you don't have a choice, there is only one supplier of limbs and prosthetics, thinking that those people have choice is a load of rubbish.*
> *We don't have purchasing power with relation to the hospital, we couldn't go anywhere else.*
> *We couldn't get access to the services that we required, we were given a quota and that was it, I couldn't negotiate, I wasn't involved, I didn't have any choices.*

> *There are no choices associated with being a consumer. There are no choices within the health system, you get what you get.*

Given that individuals do not have access to participation in the provision and allocation of services, their choices to interact in the modified market environment of health and disability services is minimised (that is, limited entry and exit for providers, associated with limited choices for consumers) (Ashton, 1992). Therefore the identification of restricted choice stated in the above passages is closely linked with participation and will be a continuing theme throughout the remainder of this chapter.

3.1.2 Participation vs. Consumption

The discussion on consumer choice led to further commentary on the concept of individuals being able to participate in decision-making processes about services that they receive. With the notion of consumer sovereignty, participants were asked if consumers are able to do anything apart from consume the services that they have been provided? Is there any scope for consumer participation? Currently, participation is impaired by restricted processes for information to be disseminated (for example, the lack of consumer representation on major decision-making boards for purchasers, HFA, and providers, hospitals), limited service provision and the maintaining of comply control in decision-making resting in the lap of providers and purchasers (Maharey, 1989). Hence, the removal of democratic functioning in the allocation and provision of health and disability services disallows for true consumer participation (for example, the right to influence the substantive nature, and content of, publicly funded policy and services) and results in the sole consumption of services.

> *The ideal is that they do participate. The reality is that they don't. When a consumer is buying a chair they know that they have rights that that chair will be of good quality. But when we talk to consumers about*

going to the dentist, they don't know what their rights as a consumer are, they just see themselves as the patient, who don't know anything and doesn't have many rights... So when we talk about health and disability it still doesn't seem to get across to people that they have rights, it has not been conveyed to the public very well yet, so they don't even participate in decisions about their own care, let alone service provision.

I don't feel that the larger institutions or service providers have any desire for participation. Even at a practical level. Like when my son was born in Paediatrics, they were wonderful, but we didn't have any say in what was happening.

Before, I wasn't interested in policies and decisions and things, I hadn't taken a lot of notice. Since the reforms I have participated. Well, I've been to the meetings, I've filled all the forms and things in. I don't think that they actually care about what we have to say at all the meetings, it is very disillusioning.

How can we participate if we are seen as simply consuming the services. We don't do anything other than take the services that are provided, we can't be active in decision-making about those services, or participate in what structure they come from, we are simply seen as the consumers of the services.

The mission statements that they (providers) have on the wall. So long as it is only on paper it is not going to facilitate change, but if we actively measure what's happening then we will know when things are changing. That's where I think participation comes in. If there's going to be an audit, then there should be consumer participation. And what that consumer has to add to operational things would be very different.

> *All services need what is starting to happen in mental health. There is a consumer representative on the management team.*
>
> *Participation can't be left to complaining. The average person has no connection with or are really just lost and afraid to say anything... because they may have to go back there again. Participation can prevent the complaining, and wouldn't that we a better way to run the health system?*

Furthermore, it appears that consumers are not the only ones that have restricted access to processes of participation. Advocates stated that:

> *The hospitals are still making decisions in secret, so that the next layer down of management don't even know what is going on. They produce these documents that are secret until they implement them, by the time that they become public it is too late. The average person has no way to have an impact on their hospitals business plan.*
>
> *It's the same as with the Government, all of these decisions are made behind closed doors and very quickly. I personally don't think that there is any such thing as real consultation in health and disability. I think the hospitals are doing it on one level, but so are community agencies, they just have different agendas.*

The data outlined in the above passages supports the themes derived from the literature on the concepts of consumerism and citizenship, as opposed to consumption. There appear to be some fundamental limitations to the current system of functioning that disallows the exercising of individual or collective citizenship rights. This results in the creation of inconsistent, inappropriate and poor service delivery for individuals, even when they have actually managed to achieve access to services (Hamilton, 1982). Due to the lack of access to processes that ensure participation, consumer voice is not being acknowledged and limited input into the delivery of services predominates (Maharey, 1989). Furthermore, access to, and participation in, policy formation, funding decisions and service provision is obstructed due to the denial of individuals' combined citizenship rights (social, civil, political). They are not effectively participating in the determination of the outputs that affect their lives, instead they are consumers of the end result. The separation between consumption and participation is fundamental in determining the rights of consumer versus the rights of citizens (Adams, 1996), as consumption based consumerism continues to prevail, voice for groups and individuals will remain reactive.

3.1.3 Exit and Voice

The final section of the consumerism research in Chapter Three amalgamated the issue of choice and the concepts of participation versus consumption, by focusing on the models of exit and voice, modified by Taylor, Hodges, Lart & Means (1992)[10]. These models explore some of the implications imposed on service users by specific institutional arrangements. Neither exit nor voice currently prevails in the New Zealand model of health and disability service provision. There seems to be a combination of the models at best, which may be resulting in the deficits of both models impacting upon the experiences of service users without the realisation of any positive consequences. Therefore, a large proportion of the data analysed throughout this chapter is relevant to the models of exit and voice.

Exit refers to the right of the consumer to leave services that they are dissatisfied with, thus exercising their power within the market to choose the best services to meet their needs and pursuing their consumer sovereignty. There are fundamental difficulties with exit, some of which have already been expressed in the data (for example, access issues, limited choice). Market enthusiasts support the freedom

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[10] Note, that as stated in Chapter Three, these concepts are complex and are utilised in this context to explain the differences between the concepts of citizenship and consumer sovereignty. Although they are clearly separated here, they are not often as clearly delineated in practice.

and responsibilities inherent with the exit model (Adams, 1996). However, the quality of consumer choice is impinged by the number of options available to service users and the consumer's interpretation of the quality of those choices. Furthermore, genuine exit can not prevail due to the lack of competition that is currently operating in the health and disability sector in New Zealand (Munford & Sullivan, 1997).

> *I was in hospital and I couldn't leave, I was very disempowered. It was better to just put up with the level of service that was being provided than to threaten that service getting worse.*

On the other hand, voice refers to the right of service users to express their concerns with service delivery through democratic processes and other forms of participation in the operational decisions of the provider, thus allowing for the pursuit of social citizenship rights being upheld. The passages outlined above indicate a desire for the implementation of such a model. Through this, service users would be offered the opportunity to bring about personal and structural change within the services that they access. This requires the increased participation of service users and their direct input into decisions-making processes at all levels (policy, funding, and provision). Furthermore, the participation that is reflective in the voice model also encourages the rise of empowerment. As noted in Chapter Three, empowerment requires access to information, participation in decision-making processes, the exertion of power and the acknowledgement of democratic (citizenship) rights (Rees, 1991). Empowerment is thus a concept that can be amalgamated within the model of voice to ensure that individuals, communities and society have their stated needs met[11].

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[11] Note that the model of exit could also be empowering for consumers if genuine choices were available for them to decide between, as the exercising of those choices would not only improve services for the individual but would also indicate to the service that was exited, their dissatisfaction.

However, the skills, time and resources that service users would be required to possess, to exercise empowerment and voice, is one of the limitations of the model. The burden of responsibility may be more arduous than some services users are capable or prepared to shoulder. These issues were noted when discussing the limitations of empowerment theory in social practice and also apply to voice. Service users need adequate support to ensure that their involvement in voice models is safe and positive, as acting in isolation cannot always provide for this need. What can, and has been linked to voice, is the concept of citizenship and therefore the opportunity for collective reasoning, as citizens are members of a larger unit. The collective premise for the functioning of empowerment, citizenship and voice needs to be acknowledged and encouraged so that these concepts can flourish. Collective voice needs to be represented to eliminate any negative consequences for individual service users. The participants noted some of the issues associated with utilising voice in isolation, based on their experiences with laying complaints.

> *We had been a required admission because (my wife) had some complications, and we had actually made a complaint with the manager of maternity services. We went home, we had an appointment and we talked about our concerns. 'Yes, yes, yes, they said, it would be better next time'. We came back a couple of weeks later and nothing had changed. We didn't want to have to complain again, we knew that we would have to use the service again.*

> *I think that you feel particularly vulnerable because you're in hospital and you're relying on those services to provide for your care.*

> *People are too scared to complain in case they lose services.*

The collectivism possible in the concept of citizenship may be one way of overcoming the personal costs for service users in exercising voice. This collectivism does not call for individuals to act in isolation, as they appear to in the market orientated exit model. Voice can represent a number of different perspectives dependant on where it is exercised, by individuals or groups, representative or participatory democracy (Taylor et al 1992). This collectivism needs to be acknowledged and supported to ensure the safety of service users. Therefore, the organisations that can collectively voice the concerns of health and disability service users need to be adequately funded and supported in our communities if citizenship rights are to be extended to consumers. It can be argued that the only hope for voice is when it is not solely reliant on the individualistic application of rights and responsibilities afforded in the free market of economic rationalism (Taylor et al, 1992).

3.2 Summary of Findings

The Health and Disability Commissioner Act (1994) is the first piece of New Zealand legislation to refer to health and disability service users as *consumers*, with reference to the term being consistently utilised in its associated policies and regulations. The term *consumer* arose from the political ideologies embraced by the state in recent decades and economic assumptions in the purchasing and providing of social services. This research has illuminated some of the concerns held by consumers and advocates associated with the connotations implicit in the term and its associated co-term, consumer sovereignty. There has been speculation throughout this research about the value of the term *consumer*, as opposed to citizens, questioning to what extent individuals are consumers of health and disability services, and what implied choices they actually have.

The philosophical aims and objectives associated with the advent of consumerism in the health and disability sector are vague and generic. The term is linked with the development of competition in the purchasing and providing of health and disability services, thereby it is inevitably associated with the concepts of individualism and the free market. The emphasis is on individualism and the exercising of individual choice to determine the quality provision of health and disability services. Therefore the generic aims and objects of the Government are to:

- Support the philosophical belief that individuals have the rights, responsibility and ability to dictate the nature and quality of the services that they require.
- Reiterate that consumer choice and market supply can most efficiently determine the nature and quality of services.
- Encourage competition between providers to gain contracts for service provision based on the assertion of consumer choice and the notion of universal demand.

The extent to which these aims and objectives have been realised in contrast with the reality of service delivery in the current climate and the limited choice that service users have to exercise is questionable. Service users are currently limited to alter health care provision through market transactions and herein lie the difficulties of asserting consumer sovereignty. They are denied access to the decision-making processes that determine the providing and allocating of services, resulting in their limited participation and this prevents the achievement of the stated aims and objectives. The participants in this research, supported by other sources of data analysed, acknowledged their limited ability to participate on all levels to impact upon the delivery of health and disability services. In summary, the analysis has identified the following issues.

- Difficulties for service users in accepting the term consumer when that term does not represent the limited choices and participation (either directly or via their functioning in the market place) inherent in the participants' definitions.
- The identification of barriers to participation in decision-making processes, including the purchasing and provision of services, impacted upon by the reconstituting of citizenship rights and the lack of quality information disseminated to service users.
- The lack of operational exit or voice models in the New Zealand context, due to the nature of existing arrangements. Exit models can not operate when limited

competition for service provision is existing and therefore individuals' choices are significantly limited. Consequently, citizenship rights need to be afforded to service users to allow for their collective voice to be utilised to encourage the development of safe and effective voice models. The individualistic application of rights currently prevents true and safe participation, and the assertion of voice, on an equal basis for all service users in New Zealand.

4. Conclusion

The purpose of this chapter has been to analyse the range of data gathered on the health and disability reforms and the concept of consumerism. These themes were analysed by the data generated from participants in the focus group meetings alongside contemporary research and the literature that had been examined in Chapters Three and Four. The analysis process was further extended by exploring the major finding of the data analysis in relation to the stated aims and objectives of policies and comparing with the experienced outcomes of participants. This analysis has permitted the information relevant to the overall research topic to be examined in greater detail and for the prescribed requirements of the formative policy evaluation tool to be fulfilled. The themes outlined in this chapter fit within the broader context of the research that is the institutional arrangements and political and philosophical landscape, within which the Health and Disability Commissioner Act (1994) was formulated and implemented. An understanding of the data analysed in this chapter, namely the state sector reforms and consumerism, contextualises the final four themes that are to be discussed in Chapter Seven.

Chapter Seven - Analysis of the Legislation

1. Introduction

The data analysis discussed in Chapter Six will be continued in this chapter with the themes that have specific reference to the organisational structure, functions and services provided under the Health and Disability Commissioner Act (1994). Chapter Six set the scene for the broader context within which the legislation was formulated and implemented, whereas this chapter is specifically dedicated to the key aspects of the legislation. The four themes that will be analysed are: the Office of the Health and Disability Commissioner; the Code of Health and Disability Service Consumers' Rights; Advocacy Services and; Empowerment Advocacy.

The themes emerge from data based on responses from the focus group interviews, documentation research and statistical analysis. Reference will also be made to the literature covered in Chapters Three through to Five. As with the previous themes, this chapter will provide discussion of the key findings that juxtapose the aims and objectives of the policies with the experienced outcomes expressed in the research.

2. Theme Three – The Office of the Health and Disability Commissioner

The Health and Disability Commissioner Act (1994) was established within the reforming health and disability arena. It became operational at a time when change was the only constant for professionals and service users. The Act established for the statutory positions of the Health and Disability Commissioner, Director of Advocacy and the Director of Proceedings. Associated with these positions was the creation of the Commissioner's office, including investigators, legal advisors and other support staff. HDC became the umbrella organisation that would ensure the delivery of advocacy services nation-wide accompanied with the promoting and protecting of the Code of Health and Disability Services Consumers'

Rights. Moreover, HDC provides the systems and supports for the resolution of complaints that cannot be resolved at the advocacy level. Three years on, the data generated some interesting opinions as the extent to which HDC is meeting the tasks that it was established to pursue.

> *Is it (the Act) just a catch basket for the vocal minority who are informed and who make their needs heard? That to me is what it is, the way that it was set up after the inquiry into cervical cancer. There was a lot of pressure and agitation that people should have somewhere to go to voice their concerns, because people were really angry. And so I believe that it hasn't been set up for everybody, it is a mechanism to catch the vocal minority.*

To determine the information guiding the view expressed in the above passage, this theme will focus on the organisational structure, functioning and provision of services from HDC. This includes the interfaces that exist between HDC and advocacy services and the processes that are employed to provide a holistic complaints service for health and disability consumers nation-wide[1].

2.1 Organisational Structure, Functioning and Provision

HDC operates under the management of the Health and Disability Commissioner. The major function of HDC is to promote and uphold the Code of Rights through education, the free provision of advocacy services and the resolution of complaints resulting from breaches to the Code of Rights[2]. The office has been fully operational for approximately three years and has had to develop systems and procedures for the processing and resolution of complaints. Most of the data generated by consumers and advocates from discussions on the functioning and funding of HDC focused on the deficits in service provision from the organisation.

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[1] An outline of these functions was provided in Chapter Five.

[2] These duties are outlined in Section 14 of the Act.

These issues relate to the formation and implementation of the organisation, and its current functioning.

> *They (HDC) didn't take note of the level of knowledge in the community about how many complaints there would be. I mean most of us who were in the health service knew that there would be a lot of complaints. But Robyn (the Commissioner) publicly announced that they didn't realise that there was such a large group of complainants... they under funded and got it wrong.*

The fiscal allocations attributed to HDC are derived from the Minister of Health, from the 'Vote Health' budget[3]. This funding, and that of advocacy services, also causes some contention for advocates, especially when discussing the amount of money that is allocated to large investigations undertaken by the Commissioner. All advocacy services were funded under initial three-year agreements with the Director of Advocacy, who drew the funding from a designated pool allocated to the Health and Disability Commissioner. The funding of advocacy services was separated from the funding of HDC to fit within the framework of the purchaser provider split employed by the Government. HDC is the funder of advocacy services; therefore creating the separation that was required to ensure their independence.

> *It's a bit scary with the new contracting round coming up next year. A large amount of her (the Commissioner's) money is going on investigations and it could well affect the funding that we get. I mean she (the Commissioner) has already said that she thinks that advocacy services are inefficient... that concerns me because we all, and I think most advocacy services will be feeling the same way, that we've got*

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[3] The operating grant received by the office of the Health and Disability Commissioner has increased from approximately 4.5 million dollars in the 95/96 year to just over 6 million dollars in the 96/97 and 97/98 financial years (HDC, 1997).

> *inadequate funding. If she (the Commissioner) is going to have to spend her budget on big inquiries, we are going to suffer, and ultimately that means the average person on the street.*
>
> *I think the other thing at a national level, is that our funding comes from HDC and the more cases that Robyn (the Commissioner) decides to investigate, big ones like Christchurch, and now it is going to be Tauranga, are actually going to take away the amount of money that could come to advocacy or be spent on promotions.*

The large enquires that were referred to in this passage are those undertaken by the Commissioner above and beyond the normal investigations dealt with by the investigations team. Under normal circumstances the Commissioner only rules on complaints that are reported to her after an investigation by the staff at HDC. Alternatively, the Commissioner also has the role of initiating other large-scale investigations into issues of public safety: this includes investigations such as the inquiry into functioning at Christchurch Hospital[4]. The implementation of such investigations is costly to the organisation in terms of the fiscal obligation associated and the commitment of staff and other resources. Furthermore, such investigations dominate the time of the Health and Disability Commissioner while they are being executed.

Advocacy Services were originally contracted on a three-year agreement with the Director of Advocacy, this is due to be renewed in 1999. The Commissioner has stated that she believes that the current organisational structure and functioning of advocacy services creates administrative costs and structural inefficiencies (HDC,

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[4] Under a High Court ruling in 1997, the Health and Disability Commissioner had her decision to investigate issues of public safety at Christchurch Hospital upheld. The Court declared that the Commissioner has independence from all other bodies, and the right to initiate investigations on her own initiative rather than only in response to complaints received. It also confirmed that the Commissioner has the power to investigate policies and procedures, with the Code of Rights being clearly applicable to the delivery of health and disability services in institutional settings (HDC, 1997).

1997). Therefore, the passages outlined above indicate that advocacy services are cautious about the renewal and/or extension of their contracts based on the limited fiscal allocations attributed to the Commissioner, particularly when her budget has had to endure unanticipated and large systemic investigations. Advocates therefore deduce that issues of organisational and structural deficits may be related to the tight fiscal obligations experienced by HDC.

However, advocates acknowledge that they are not the only link in the chain, which is affected by resourcing.

> *HDC definitely do not have enough staff to deal with the work that they've got, so really that's resourcing affecting the system at every level.*

These resourcing issues at the HDC level have undoubtedly impacted upon the services that they deliver the timeframe for investigating complaints, and the feedback that advocates receive from consumers about their dealings with HDC. The staffing levels at HDC have continued to swell since its establishment in 1995 with most new appointments being additions to the investigation team. The office tries to maintain appropriate levels of output to meet the demand and number of complaints that they are receiving (HDC, 1997). However there still remains a fundamental inconsistency between the increased levels of staffing and the time taken for the resolution of complaints. The outputs are still not reaching an optimum level and complaints are not being resolved effectively and efficiently.

> *There have been some classic examples from consumers about the delays and the attitudes of the people that they had to deal with in the investigations teams. It has really put more stress on the consumer.*

A consumer reiterated this sentiment by saying:

> *I wish I had never gone near there. It was soul destroying and destructing, I don't think that they adhere to the Code of Rights themselves.*

However, there was a general acknowledgement that there were difficulties for HDC staff.

> *It's stressful for them too. I mean some people choose to go straight to the Commissioner, and that's fine. That might speed up their initial bit, but they don't all need to go to HDC, that is not what the legislation is about. The focus is low level resolution.*

This is a key acknowledgement, as HDC is not equipped to deal with the processing of all complaints. However, this is why advocacy services were established. Their role is to try and achieve low level resolution to possible breaches of the Code of Rights. HDC is ideally established to deal with enquiries and to process complaints that need to be investigated and mediated at a higher level, once low level resolution has been attempted. The fundamental downfall of this system, acknowledged by participants, has been the lack of information in the public arena about the Act, the Code of Rights, the functioning of HDC and the provision of advocacy services. This may be resulting in the duplication of services that may be provided by HDC and advocacy, with complaints coming to HDC and having to be processed and referred onto advocacy. Consumers are not always aware of their local advocacy service, or that advocacy has the jurisdiction to work with the Code of Rights.

> *I don't think that there is enough promotion about it, and I sometimes wonder if I didn't work in the field, whether I would know a lot about it. We have to promote how the system works. The information is in the brochures that we send out, but how many people can we really get to?*

> *We give information out but still, when I say to them (consumers) about it, they still don't seem to know about the actual Code.*

> *I think HDC should have done far more. Advertising is the most important, ...even right now, advertising in the papers, media, national television, to get to a lot of different groups. On Tanagta Pasifika and programmes like that, I am not aware that they have done anything through some of these resources which actually target some of the ethnic communities in our country. So you sort of think, on one hand they are telling us to get out there and do the leg work, but it's really difficult. People have no knowledge of us having a national existence, belonging to HDC. Its hard to make them aware that we have the backup of the legislation*[5]*.*

> *There needs to be a clear understanding in the community that advocacy services come from HDC. We're the first step, it's also about the Code of Rights. If they promoted that on a national level.*

> *Maybe they are worried that if they actively promoted advocacy then there would be too many complaints and only one FTE (full time equivalent) in the Manawatu to deal with all the complaints.*

Discussions did not cease at the recognition of the lack of promotional activities utilised by HDC. There were also suggestions for what the advertising should be.

> *If they did national advertising, I would like to see the whole focus on advocacy and just the underpinnings of the Act, the Code and HDC. The system would work better if people utilised our services more. HDC*

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[5] The Kaiwhakahaere at HDC has initiated publicity on the Code of Rights for Maori and other ethnic groups, including a number of radio interviews on Maori and Tangata Pasifika stations (HDC, 1997).

> *would be more effective. People link advocacy and HDC anyway, so that when HDC don't pull through it reflects on us. I don't want them to do a campaign on HDC and fit us (advocates) in the bottom, we want our own campaign, so that we maintain status as independent health and disability advocates.*
>
> *We can't afford to do our own advertising on a large scale. There is some charges attached to promotional material from HDC, like the new overheads. If they bring out new promotional material its not a lot of good if we have to pay for it because we haven't got the funding to purchase these things that are supposedly produced for us.*

A key aspect of the responsibility of advocacy services, HDC and the Commissioner conjointly, is to promote and protect the rights of health and disability service users. This is stated in the long title of the Act and in the contract agreements that advocacy services entered into with the Director of Advocacy. However, once again the data suggests that the resourcing seems to play a regular role in disallowing the provision of materials to facilitate this goal attainment. HDC does provide a number of pamphlets detailing information on the Code of Rights, advocacy services and the Health and Disability Commissioner. This information is coupled with posters, that providers of health and disability services are encouraged to display. The only limiting aspect to this promotional drive is that the information is only likely to reach consumers when, or if, they are accessing services. There is a large group in New Zealand that will not have access to this information in that format, either because they are not visiting a health or disability provider, therefore, accessing services on a regular basis, or because the information is disseminated in a manner that is available but difficult to access. That is information not being readily available in forms such as braille and tapes for the blind or illiterate.

The statistics provided in the Report of the Health and Disability Commissioner for the year ended 30 June 1997, reiterate the lack of knowledge about the provisions of the Health and Disability Commissioner Act (1994). In a survey carried out in June 1997, consumers (N=1,257) were asked about their awareness of the Code of Health and Disability Services Consumers' Rights, the Commissioner and advocacy services. The awareness scores are illustrated below, in Figure Five, and indicate the level of consumer awareness of these functions. The graph illustrates the figures of general knowledge on HDC, the Commissioner and the Code of Rights, and specific knowledge on the provision of advocacy.

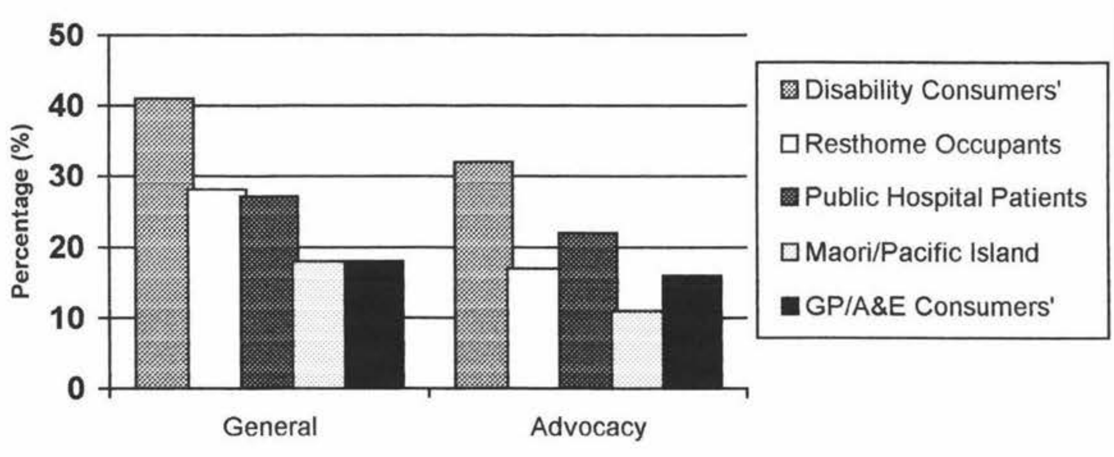

Figure 5: Consumer Awareness (1997)

2.1.1 Relationship with Advocacy

HDC and advocacy services interact on a number of levels[6], due to the organisational structure of service provision. A fundamental component of this type of organisational functioning is communication. There are ten advocacy

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[6] See Figures 3 & 4 in Chapter Five for details of the organisational structure and interfacing of HDC and advocacy services.

agencies nation-wide that provide services for HDC that are autonomous from one another and HDC. However, they must provide consistent advocacy. services under their contracted agreements to ensure equal access and service delivery to all New Zealanders. For this task to be fulfilled there needs to be strong and clear lines of communication between the advocacy services, the Director of Advocacy and HDC. In an attempt to facilitate the clarity of communication, HDC established a national database in June 1996. This database outlines all enquires and complaints received by advocacy services, by allocating a coded number to the entries that are sent through to HDC, therefore, information about enquires and complaints are accessible. The computer system also allows for internal e-mails to be sent and received, thereby, transmitting memos and publicity releases to all advocates and mangers effectively and efficiently. However, despite these efforts to ensure access to reliable communication between advocacy services and HDC, there have been consistent issues for advocates. These include communication downfalls within the structure of HDC and between advocacy and HDC.

Advocates refer cases to HDC that cannot be resolved at the lower level. Alternatively, advocates receive cases from HDC under section 42 of the Act, that the Commissioner feels can be most effectively resolved at the advocacy level. Ensuring that these cases are referred appropriately is important to the resolution of consumers' complaints, particularly the complaints that are being referred to HDC, as they are predominantly serious cases that involved breaches of the Code of Rights. The extent of miscommunication is noted in the data.

> *There seems to be a communication breakdown somewhere, and it doesn't seem to be getting any better. It's not only in terms of them communicating with us or us with them, it's affecting the client group too. They aren't getting the communication, the feedback... it affects the credibility of the whole organisation not just one group and I think that it needs to be handled.*

> *HDC need to align their processes set up their standards and works to their guidelines. We had a case where a lady had a complaint that we referred to HDC. The investigations team had it, and we got a complaint that one of the investigators was quite rude. We wrote to Jane (the Director of Advocacy) and the letter was passed on, but nothing happened. The consumer rang us again, even though officially she wasn't ours anymore, so we rang Jane (the Director of Advocacy) again and she said that the investigations people would deal with it tomorrow. Another two weeks go by and the consumer rings back and says that she hasn't heard anything. We had to keep chasing it….she could have been saved the stress and the hassle.*

The communication problems also extend to whom has ownership over information about a case once it has been referred to HDC. Advocacy services are independent from the investigation of complaints at HDC, and therefore information does not flow back to the advocacy service. However, there are some grey areas surrounding these clearly defined boundaries.

> *…they have to be able to give us information if the consumer comes back to us, we need to be able to liaise with them and not be told, I can neither confirm nor deny that your consumer has a complaint with us. That's just a load of rubbish. One of the investigators said those exact words.*

> *Any consumers that have rung me after it (the complaint) has gone to HDC and I've followed it up with investigators, I've never had a response.*

> *We recommend HDC where appropriate; it's on our back and then six months later a consumer rings and says that they haven't heard*

> *anything from HDC. You think, well what's happening, who is responsible?*

These issues of communication and organisational functioning also impact on the interfaces that exist between advocacy and HDC, where they have dual contact with a consumer. Advocacy operates independently from HDC, but it does not operate in isolation from the organisation. HDC houses the education and communication staff that guide the practices of advocates, it also has the influence to affect advocacy provision through its functioning. After all, HDC is responsible for the promoting and protecting of the Code of Rights, which is the backbone of the advocate's practice.

> *I did a promotion and a lady rang me up and said that she had one of my flyers, she said that, she recommends that people don't use our service (advocacy). I asked her why and she said that she had a complaint with HDC and that it had been there for 18 months, she was disillusioned. So they affect our work.*

> *I personally have no faith in the system, so I am slow to recommend that people go on (to HDC). I mean, I will if they ask, and I will discuss it with them. I try to not let it colour my view, I don't really have any faith in how the system works. I always say to people that they have that option, but I also tell them that if it goes that way; it's going to take a minimum of six months, and you might not hear anything in between. That's the reality.*

> *It's not clear, simple, speedy resolution of complaints like it says in the Act*[7].

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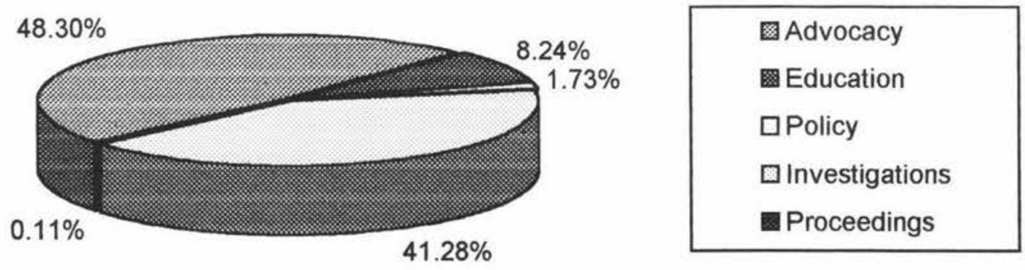
[7] Section Six of the Health and Disability Commissioner Act (1994) states that the legislation should facilitate the fair, simple, speedy and efficient resolution of complaints.

When asked for specific information about the biggest downfall between the functioning of HDC and advocacy services, the response was constructive and focused on the process of referring and receiving complaints. As it currently stands, a case is referred to HDC and assessed by the investigation team. Investigations decide if there is a need to investigate, and if so they embark on a new and independent investigation, contacting the consumer and provider/s concerned. The case can go to mediation after investigations; be resolved or go on for proceedings. Some of the advocates believe that this process disallows for some resolutions to be sought sooner, in a more cost effective and beneficial way. As illustrated in Figure Six, the outlay of funding on the provision of advocacy services and investigations equates to the largest accounting for expenditure by HDC (HDC, 1997).

Figure 6: HDC Expeniture by Output (96/97)



(HDC, 1997)

The data from the focus group interviews suggests that this may result in some duplication of service provision and in higher expenditure costs than are necessary.

> *We practice low level resolution, but there is such a big gap to investigations and then mediation. Whereas, sometimes you just need the mediation and not an independent investigation. You need to use the legislation to call a mediation to resolve the problem. Just getting the consumer and provider in the same room.*

> *HDC needs someone, who receives all the complaints from advocacy, they need someone who can read through the complaints and say that this needs to go to the most appropriate place, investigations, mediation, back to advocacy, to be resolved. Then to be able to shoot the complaint in that direction and make sure that it is followed through quickly. Depending on the individual needs of each case, it may be just that the provider won't meet the consumer. You don't need an investigation to decide that this is the case.*

> *What we have got, I understand, is one person who does mediation, and she's an investigator. You have to wait for an investigation to be complete before you can go to mediation. There may not be an established breach of the Code of Rights but that doesn't matter. It doesn't mean that you can't get resolution from mediation. The same way that we can't decide if there is a breach at the advocacy level but it doesn't meant that you can't resolve it.*

In the year ended 30 June 1997, the Commissioner received 1,000 cases. Out of these cases, 581 were closed via investigations, proceeding or other means (for example, complaint withdrawn). Only 0.8% (N=5)) of the 581 cases were referred to mediation for resolution (HDC, 1997). The percentage of cases referred was decreased in the 97/98 year, with 0.6% (N=7) of case being referred to mediation (HDC, 1998a).

2.1.2 HDC – Complaints Organisation

The issues raised in the passages above suggest some of the difficulties associated with the functioning of a complaints organisation. Even though HDC focuses on education and promotion of the Code of Rights, the fundamental functioning of the organisation is the processing and investigation of complaints over breaches of consumer rights. The consumers and advocates in this research note that there are issues associated with complaining, accompanied with issues over the gaps in the complaints services offered by HDC. In the case of one consumer, the gaps had started in the provision of services that she required in the health and disability arena; unfortunately these gaps were extended when she tried to lay complaints with HDC. The complaint centred on the lack of provision of services that had been funded and purchased. The provider was not fulfilling its contract to the funder however there is no breach to the Code of Rights if a provider does not fulfil its service contract.

> *I went to the funder, and they said that there was no problem because they had funded for the full 70 hours care, so I went to (Agency A – the provider) and they said that they couldn't fill the 70 hours. Everywhere I went it wasn't their problem... I was trying to unlock what (Agency A) was holding, where has the money gone? I'm still trying to get those answers, you have to be able to go to somebody, I've looked everywhere. I sent a six page letter to the Health and Disability Commissioner explaining it. It was entitled, a 24-hour day in the life of my daughter, or something like that. And I was talking about a day when she was well... I sent copies of other letters too. I was desperate; I was driving in the street. We went out into the country; I was looking to commit suicide. I was not getting answers. I was pleading for help and*

> *I couldn't get it. When my daughter died in my arms, it was like, phew (Agency A) will be pleased about this, they must be so relieved that they're not going to have to give us anymore support. Now it shouldn't have to be like that. I am still waiting for those answers.*

For those consumers that do come under the jurisdiction of the Code of Rights, there are still serious issues associated with complaining. Consumers shared their anxieties, fears, frustrations and concerns over utilising the Code of Rights, advocacy services and HDC. Identifying that the consequence of complaining outlined below, were a significant deterrent to ensuring their rights.

> *It takes time and resources to start the process, and then you have to keep your energy up, you still have to pay the bills and live as well as you can.*

> *There are consequences too and they raise alarm bells. I know families who are desperate but are too scared to rock the boat, in case what they are accessing is going to be taken away as a punishment. That is very much a real thing out there. There are a lot of people that are not really very happy, but they are too scared to say anything.*

> *I found it hard being in hospital with my daughter and I was really disempowered and I wasn't able to use or make a complaint because of that. It is really hard to make that step and feel that it is okay to make a complaint.*

> *I think that you feel particularly vulnerable because you are in hospital and you're relying on these services to provide for your care.*

> *It's a side of the health reforms too, because people are too scared to complain in case they lose more.*

> *Our rural hospital is supposed to be closed down, but now it has got a reprieve. You want to hang onto that service and not rock the boat by complaining it is harder for us, particularly in rural areas.*

> *It takes such a long time when you do complain; it must be very tempting for a lot of people to pull out of the race because its exhausting and it's emotionally stressful. Constantly having it in the back of your mind or the forefront of your mind for six months or more – why do they take so long?*

The length of time for complaints resolution is clearly evident when analysing the annual statistics released by HDC. Out of the 1,000 complaints received by HDC in the 96/97 year, 58% were resolved and/or closed (HDC, 1997). In the 97/98 year, 1,102 cases were received by HDC and 67% of those complaints were closed, leaving the remainder of complaints received still open and awaiting resolution (HDC, 1998a). The consequences of lengthy complaints resolution extends to frustration over the lack of answers that consumers received, whether from HDC, advocacy or the provider involved.

> *There should have to be answers at the end of the day, you want someone to be responsible for this. It isn't like you want someone to be fired, but something like a plan to help people practise better so that practise errors don't keep reoccurring, otherwise it makes the whole situation redundant because no learning has occurred for the clinician involved.*

> *I don't want anyone to go to court and lose their practising certificate, but I just want someone to accept responsibility and put things in place so that they won't happen again. That's my drive. I don't think that's hard, it's not expensive, to put someone under supervision or change the policies. And that could save someone else coming up against this*

> *situation again. I don't think that the agencies have got the drive to make changes at the moment, it seems to be the missing part of the equation.*

There was a general consensus amongst participants that the monitoring of outcomes, once achieved, was also limited by HDC. It was suggested that when resolution was sought the provider should be obligated to make changes to ensure that a similar complaint would not arise.

> *I think the rules about resolving complaints need to be tightened up. Yes, that the agency has an obligation and advocates can ensure it, there needs to be some monitoring.*
>
> *At the moment nobody has got it, nobody is taking ownership and making sure that things change.*
>
> *Even when resolution hasn't been attained, I think that there must be answers. In our experience, the company has not taken responsibility, so if a large company can't provide the answers, how can small agencies do it? We have never really had an answer as to what, or how things happened, the system does not provide answers and no one pushes for them.*

HDC investigations seek compliance by the provider for any changes to policy and/or procedure that need to occur based on the outcomes of the investigation. In some cases, this is emphasised by the involvement of the relevant professional body and their disciplinary and monitoring functions. HDC's insurance that the change will occur, comes through confidence in the resolution process, the documenting system that identifies providers that have breached the Code, and a belief that further complaints will come through the system if the provider has not improved their standards and procedures. However, advocates stated that further complaints were not always forthcoming, and that the documenting of cases at HDC does not always allow for the associations to be made when the same provider is being queried with breaching the rights of a number of consumers. Furthermore, if complaints go to advocacy and are resolved at this level, the advocate has no role in monitoring the implementation of changes to policy and/or procedure that may be required by the provider to ensure that more breaches to the Code of Rights do not occur. Furthermore, if an advocate receives a complaint that is resolved at this lower level, there is no mechanism required for the provider and the complaint to be reported to HDC. Therefore, an advocate may have dealt with a number of complaints with reference to the same provider without HDC being aware of it. Consequently, if HDC receive a complaint directly from a consumer or are referred a complaint by an advocate, they may not be aware that the provider concerned has been involved in a number of complaints already. Having access to this information would indicate to HDC that the particular provider is not ensuring the safety of consumer rights and is consistently breaching those rights. Moreover, advocates are not permitted to contact providers and randomly assess their adherence to matters pertinent to the Code of Rights or particular cases. Even if advocates unofficially take on such a role, they have no legislative or formal backing to make requests of providers; this can only occur if the complaint goes through to HDC. Therefore, they have restricted influence in ensuring that resolution is complete, without relying on the persistence of the consumer, who may be dissatisfied with the process and no longer willing to pursue the complaint. These issues were discussed in Chapter Six and will be further explored in Theme Five - Advocacy Services

2.3 *Summary of Findings*

The office of the Health and Disability Commissioner was established by statute in October 1994 to support the functions of the Health and Disability Commissioner and to operationalise the Code of Rights through developing systems of complaints resolution (HDC, 1996a). The aims and objectives of HDC are clearly stated in their mission statement, core principles of operation and in the long title of the legislation. The latter is noted because HDC represents the umbrella organisation that facilitates the legislation's implementation. It includes the statutory positions outlined in the Act and the duties associated with the Code of Rights and the resolution of consumer complaints[8]. In summary, the aims and objectives of HDC are to:

- Secure the fair, simple, speedy and efficient resolution of complaints received from consumers of health and disability services.
- Promote and protect the rights of individuals through the Code of Health and Disability Services Consumer Rights.
- Empower and support individuals throughout their contact with the organisation.
- Acknowledge and actively implement the concepts of Treaty partnership.
- Act responsibly, decisively and effectively on behalf of consumers, as a legal entity empowered by the legislation.
- Provide the services of facilitation, promotion and information; education and research, advocacy support, investigations, mediation, prosecution and; policy formation and advice.

The attainment of these functional aims and objectives was commented on when discussing the outcomes that were experienced by the research participants and by reviewing the information disseminated in Chapter Five. The analysis of their data indicated a number of limitations to the attainment of the policy expectations. The key issues were:

- The inadequate funding of HDC and advocacy services, noted as attributing to the length of time for complaints resolution and the miscommunication that occurs between the advocacy service and HDC.
- The understaffing of HDC, creating long delays in responses to complaints, experienced by consumers and advocates.

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[8] The purpose of the legislation is outlined in Chapter Four.

- Inadequate promotion of the Code of Rights and advocacy services, limiting the effectiveness of the legislation's purpose and the general public's awareness of their rights and the provision of advocacy services.
- Inefficient and fragmented systems of communication between HDC and advocacy services affecting the receiving and referring of complaints. The need for a better system of appropriating the processing of complaints for resolution.
- The need for another link in the chain between advocacy services and HDC to assist in the low-level resolution of complaints, particularly the employment of mediation.
- The associated issues of complaining not being addressed to ensure consumer safety in complaining. Complaints need to be followed up to ensure provider compliance with the agreement of complaints resolution. Furthermore, the appropriateness of operational systems and the development of parallel systems for Maori needs to be explored (Durie, 1995).

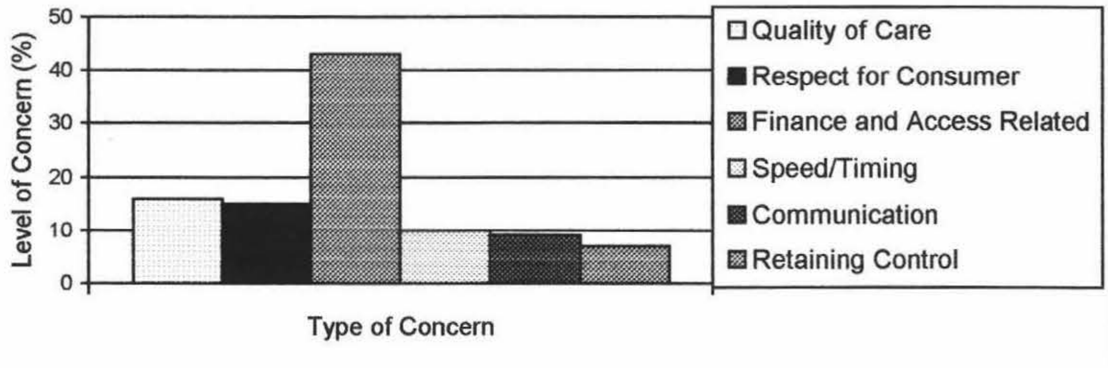
3. Theme Four – The Code of Rights

The Code of Health and Disability Services Consumers' Rights is the pivotal legislative regulation that HDC's and advocacy services systemic operations are based upon. The Code of Rights became law in July 1996 and comprehensively details the duties of providers and the ten rights of consumers of health and disability services. This section of the data analysis provides commentary on the rights stated in the Code, including consumers' and advocates' views on what could be included or excluded. This incorporates a discussion on issues of resourcing and funding that are not presently covered within the Code of Rights. The data gathered generated some interesting and exciting views and information, especially from the focus group participants. It concludes with a discussion on the application of the Code of Rights to ethnic groups, particularly Maori, outlining the policies and procedures that have been adopted by HDC to ensure the cultural safety of Maori. In accordance with the format of the other themes of data analysis located in this chapter, a summary of the key findings will be provided.

3.1 Inclusion and Exclusion of the Code of Rights

In the consultation process that occurred during the formation of the Code of Rights, a number of submissions were made with reference to funding. These submissions focused on the lack of coverage in the Code of Rights on issues pertinent to the provision and entitlement to services. Individuals and groups voiced concerns over the scope and effectiveness of the Code of Rights if resourcing issues were not to be addressed[9] (HDC, 1995) as funding issues were highlighted as being one of the most significant concerns for service users. Figure Seven reflects this by illustrating the general concerns of consumers in relation to health and disability services (HDC, 1996b). The data is based on a survey commissioned by HDC in February 1995 to indicate the focus of consumer concerns about service provision in the health and disability sector.

Figure 7: Summary of Concerns of Consumers of Health and Disability Services (1995)



(HDC, 1996b)

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[9] Refer to Chapter Five for greater detail on the consultation process that occurred.

These consumer concerns over access and resources were not provided for in the rights outlined in the Code, however it appears that they continued to be relevant for service users during and after the implementation of the legislation's supporting services. In recent research, New Zealanders are still expressing concerns about the financial costs and limited access to appropriate services. The Harvard University Commonwealth Fund telephone survey released in October 1998, states that 42% of those surveyed are concerned about being able to afford the care that they need and 38% are concerned about access to service due to the long waiting lists that exist for non-emergency care (New Zealand Herald, 1998).

Consumers in the focus group interview expressed concern about the lack of scope that the Code and the Act provide for in terms of issues surrounding access to services, funding and consumers receiving appropriate resources to support their needs. This once again reiterates the need for consumer participation in decision-making processes about the funding and provision of health and disability services.

> *It's about access, but it is also about resourcing, in terms of our needs being met, their (agency's) policy doesn't always equate to our needs or rights being met.*
>
> *It (consumers' complaint) didn't come under the Code, we were funded for services, but we weren't receiving them, that didn't come under the Code. It didn't fit; our child didn't fit into any rights to be met.*

The Code of Rights does not extend to issues of service provision, access to services or funding, it is only applicable when a service has been provided and the quality of that service is in question. With reference to other resourcing issues, an advocate stated:

> *... invalids' benefits, disability allowances, things like that, as advocates we aren't supposed to, or allowed to, officially support consumers when it comes to getting the financial resourcing that they require to support their needs. That's a flaw because their rights are infringed but we have no authority to act.*

Advocates can only support these consumers in specific circumstances, with reference to the rights detailing communication, respect, support and similar issues outlined in the Code of Rights. The question of an individual's entitlement to financial assistance or support does not fit within the jurisdiction of advocacy services, HDC or the Code of Rights. Individuals and groups predicted this limitation when the Draft Code was going through the consultation process. Although these deficits are noted, advocates had many enlightening comments to add to the discussion on resourcing issues being excluded from the Code of Rights. These comments help contextualise the complexity of resourcing/funding issues and the need to appropriately place the responsibility for tackling these issues.

> *I think we probably wouldn't have had more power to deal with those sort of issues (resourcing), than what we have got now, just because it was included in the Code. Because, lets face it, as individual advocates, how are we going to get on battling the HFA with funding issues? Ha!*

> *The Commissioner may have had more power, if it included resourcing, in that she would be able to go to her top level and say why is this not being resourced in a more appropriate way. But would that really help? Opposition MPs already do that.*

> *I'm quite glad that we don't get into access issues. We are focused on the quality of the service being provided; access issues would take so*

> *much time away from being able to help the consumer work through the quality of the services that are being provided. It's really important, that quality of service for people.*
>
> *There are times when it would be nice to have resourcing included, but I agree with what (another advocate) said earlier, it would make it very difficult as well, because you would be just opening up such a huge can of worms. I guess I just feel really awful when people ring up, and it's clearly a resource issue, and I have to say, 'Oh, I'm really sorry, I can't help you'. Especially now because even the access to the Health Funding Authority is getting harder. It doesn't look like there's going to be Community Liaison Managers in the same role that there has been. They will be fewer, and covering a larger area, so someone like (Local Community Liaison Manager) who's been reasonably accessible at the community level, will now be based in Wellington, which instantly makes her less accessible. I don't know where people are supposed to go.*

And herein lies the difficulty. It is obvious that there would be restrictions and systemic limitations to the inclusion of resourcing issues in the Code of Rights, but the concerns are not being alleviated and they need to be addressed somewhere. The role for addressing this is more appropriately placed elsewhere; however, it is not being met by the funding agency or any other Government official or Department. Local and nation-wide lobbying groups, opposition MP's and other interested members of the community are having to fulfil this role, without having the influence at the funding and policy level, that is required to find resolution. This issue needs to be addressed, as the Health and Disability Commissioner Act (1994) will continue to be undermined by these larger health and disability sector issues. The legislation's effectiveness is impinged by the restriction to identify needs and gaps, without having the opportunity to prevent these causes. If consumer participation is continually denied in the process of appropriating and allocating health and disability funding and service provision, then unfortunately the scope of the legislation and its supporting systems will be bound.

3.1.1 Clarifying the Code of Rights

A second point that was raised, when discussing the Code of Health and Disability Services Consumers' Rights, was the need for clarification on some of the rights outlined, as some confusion has the potential to arise over the interpretation of specific rights. This was acknowledged by the Commissioner (HDC, 1996b) and has led to the Commissioner publicising the opinions that she forms on specific rights breaches, to assist the generic understanding and interpretation of rights. However, due to the recency of the legislation, and the exposure of the Code of Rights, it has not been possible for the Commissioner to investigate sufficient cases to set precedents and base opinions on all of the ten rights. In the Code of Rights first year of operation, 25 cases (4%) of the 581 cases closed, resulted in a report of a breach of the Code of Rights (HDC, 1997). The limited number of identified breaches is due to a number of influences[10]. However, these statistics indicate the difficulty of clearly defining the legal implications of each of the ten rights, if more opinions are not produced in the near future.

The specific right that was discussed in the advocate focus group was Right Four – Right to Services of an Appropriate Standard[11]. In brief, this Right outlines that consumers have the right to have services provided with reasonable care and skill. Furthermore, it states that consumers have the right to have services provided that comply with legal, professional, ethical and other relevant standards. The defining of what these ethical standards are, and the appropriateness of these standards, can be difficult to judge in light of the lack of professional bodies, ethical guidelines

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[10] For example, the resolution of a complaint before an investigation is complete and the Commissioner is asked to make an opinion; complaints being referred to other appropriate professional bodies and/or agencies; the withdrawal of complaints; and complaints falling outside of the jurisdiction of the Act.

and standards that are provided for some professional groups. This is especially difficult when providers in some health and disability professional groupings are not legally required to be associated with their relevant professional body (for example, social workers), or a professional body does not exist (for example, reflexology).

> *There is nothing, although it says that you must have care and skill and so on, and it says something about ethical standards, and other sorts of standards, there is nothing clear. It doesn't spell out in the Code, what those standards are. It is really tricky. We talked about the care for the elderly, how rest homes have changed recently. They have become self-auditing, self-monitoring, so it's really hard to find out what the standards is and who is monitoring the standard. Then if a caregiver or family member comes to you and says that Auntie was left in her faeces for four hours, and I go to the manager about the complaint, it is very hard for me to know what the standard is. There is not a lot we can do without having that measure clearly defined.*
>
> *I think there needs to be something done about the standards. We need to know more about what the standards are perhaps, so that we know what they are. I don't know if you have to put them in the Code, but it certainly is a very grey area.*
>
> *People don't want to complain to test the value of the Code, these are their experiences, their lives, they want some assurance that something will be done.*

Although these concerns are valid and hold serious implications for the practice of advocates, there are no simple solutions. Most pieces of legislation have to be

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[11] Refer to Appendix One for the full Code of Health and Disability Services Consumers' Rights, including the details of Right Four.

tested in the courts to establish clear definitions and boundaries. The infancy of this Act has unfortunately limited its exposure to such scrutiny, and so uncertainty prevails. As the Commissioner clearly summated in her 96/97 annual report, '*...it takes less time to find no breach, than to find a breach of the Code of Rights'* (HDC, 1997). Furthermore these issues may be addressed as the Health and Disability Commissioner is currently conducting a review on the Code of Rights, as she is instructed to do under the legislation[12]. The Act states that the Code of Rights must be reviewed every two years to ensure its effectiveness and appropriateness in the current health and disability environment. The review process will hopefully acknowledge continued consumer concerns and look at appropriate ways to remedy these, although there is clearly no statutory mechanism for implementing any such changes.

3.1.2 Other Issues

The other two main areas of commentary when discussing the Code of Rights raised extremely important issues for consideration. The first referred to the use of the Code of Rights as a preventative measure, as opposed to a tool for complaints resolution; and the second referred to issues pertinent to Maori and other ethnic groups.

The Code of Health and Disability Services Consumers' Rights was designed to detail the reasonable expectations of consumers, and the responsibilities and duties of providers of health and disability services. The Code is accommodated within the legislative framework of the Act, with the associated support of the Commissioner; HDC and advocacy services to ensure that consumers' rights are promoted and protected appropriately. This does not mean that the Code of Rights is restricted to measuring the breaches of rights alone. The intent of the

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[12] The Commissioner is required to report to the Minister of health any findings and suggested recommendations to amend the Code of Health and Disability Services Consumers; Rights under Section 21 of the Act.

regulation was to promote consumer rights and to reduce the number of issues pertaining to inappropriate practice and procedure. Thus, the focus has to be on the Code holding status as a preventative tool, as well as a complaints resolution tool. This may eventuate with the increased awareness of the Code of Rights by providers and consumers, assuming a high degree of voluntary compliance. However, this doesn't appear to presently be the case. All of the consumers involved in this research agreed that they would have preferred the Code to have been functioning at a level that their complaints did not have to escalate or require the involvement of third parties (that is, advocacy or HDC).

> *The Code doesn't work in crisis, when the problem is happening, you don't think of it, the provider doesn't think of it. You can't call an advocate 24 hours a day, seven days a week – they aren't a crisis service. They have to pick up the pieces at the end like we do.*
>
> *People with disabilities should have the right to the same level of service and provision as other individuals without disabilities. But no they don't, they (providers) say that your child with an intellectual disability is a whole new ball game. Of course she is supposed to have the same rights, but she doesn't. When (child's name) was left to die, because there was no point in keeping her alive, I mean, we raised her, and she is on this bed dying, but you know that her rights weren't met.*

Unfortunately, some cases that are referred to advocacy and HDC have resulted in death, and the family members are left to lay complaints, and use the Code of Rights to illustrate the inappropriate services that their loved one received. It is inappropriate that this is how the Code of Rights is currently utilised. However, the hope is that there will be a time when this will not have to be its primarily purpose. The promotion of the Code of Rights as a preventative tool that ensures consumers' rights, is partly dependent on its maturation and equally on the promotional activities engaged by the organisational structures created to support it.

The second issues raised in the data, with reference to the Code of Rights, were pertinent to Maori and other ethnic groups. The Commissioner and HDC have shown a commitment to Maori from the onset of systemic formation and implementation. Te Tiriti o Waitangi is visible throughout the activities of the Commissioner and HDC coupled with the employment of a Kaiwhakahaere in the senior management team. The Kaiwhakahaere facilitates co-operation between the Commissioner and Te Puni Kokiri (Ministry of Maori Development), as well as ensuring links with major iwi throughout New Zealand. There has also been contact with Tangata Pasifika groups and other ethnic communities (HDC, 1997).

> *Maori consumer groups have expressed a sense of relief and excitement that the Code now exists.... Right 1, in particular, with its inclusion of Maori needs, values and beliefs, has ensured that Maori believe that their cultural safety is protected by the Code (HDC, 1997, p.18)*

However, advocates still noted an area of concern with reference to the application of the Code of Rights to Maori. This is an issue for their practice within the framework of the Code, and may also have implications for investigations at HDC.

> *When a consumer rings you, you don't know if they're Maori or Pakeha, and I often bring into the conversation a question about if they have a friend or family member that can go with them, because it's really good if that support person can speak on their behalf or support them. Sometimes this helps you get a bit more information about the person, whether they are Maori or Pakeha. The Code of Rights is about individuals who are receiving services and individual rights, and it does*

> *not always fit well with a culture that is based on collective rights. We have to remember this and modify our practice.*

The Commissioner has noted the historical reluctance of Maori to complain (HDC, 1996) and has endeavoured to accommodate Maori in the Code of Rights and the systemic functioning of HDC and advocacy services. This includes training for all staff at HDC, and for advocates on the Treaty of Waitangi and working with Maori (HDC, 1996a). Furthermore, the Kaiwhakahaere acts as an advisor to the Commissioner and works in with the Director of Advocacy as requested[13]. However, Maori are only specifically mentioned once in the Code of Rights, in Right One, where reference is made to the respect of their values and beliefs. The extent to which this provides for Maori still needs to be established.

3.2 Summary of Findings

The Code of Health and Disability Services Consumers' Rights is a Government regulation under the Health and Disability Commissioner Act (1994). It details the duties and obligations of providers and specifies the ten rights that consumers have when receiving health and disability services, public or private. The aims and objectives of the Code are to detail the rights of consumers of health and disability services within a legally binding document to enforce the functions of HDC, the Commissioner and advocacy services. It was an innovative approach to consumer rights as opposed to the operation of processes established in other countries, where consumer rights are collected from a number of parts of already existing laws. The Code of Rights was established to provide consumers and providers with a clear and concise understanding of their duties and responsibilities. To recap, the aims and objectives of establishing the Code of Rights were to:

- ☐ Establish a broad spectrum of rights that allowed for the quality provision of health and disability services in New Zealand.

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[13] **Issues relating to Maori and other ethnic groups will be discussed further under Category Four – Advocacy Services.**

- Act as a guide to systems of complaints resolution.
- Provide a benchmark for service providers to determine their policy and procedures.
- Ensure consumers of their legally binding rights.

These aims and objectives were achieved through the consultation and development of the Draft Code followed by its implementation as a Government regulation in 1996. The attainment of these aims and objectives is currently under review by the Health and Disability Commissioner as required by the Act. The outcomes experienced by consumers and advocates in the first two years of the Code's operation have been commented on. The findings of the data analysis indicate a general acceptance of the provisions of the Code of Rights, however specific areas of concern were voiced. The key issues were:

- Consumer concerns over the resourcing of services, these areas are not covered by the Code of Rights or any other Government Department.
- Clarification is needed over some of the provisions of the rights outlined in the Code, particularly when the Code refers to the appropriate standards of professional bodies.
- The Code of Rights is being used as a punitive tool for complaints resolution as opposed to a preventative tool ensuring quality services.
- Issues of cultural appropriateness of the Code of Rights for Maori are still outstanding and further investigation should go into the specific needs of Maori for this regulation to be appropriate for them to utilise.

4. Theme Five – Advocacy Services

A significant proportion of complaints involving alleged breaches of the Code of Health and Disability Services Consumers' Rights are received and resolved by advocacy services[14]. There are ten services that are contracted nation-wide to

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[14] In the 96/97 year, 3,953 complaints were received by advocacy service nation-wide. Only 88 (2%) were referred to HDC (HDC, 1997).

provide free advocacy services to all consumers of health and disability services, independent of providers, purchasers, HDC and the Ministry of Health. Advocacy services are directed by the advocacy guidelines produced by the Commissioner and the management and monitoring of the Director of Advocacy[15]. In summary, the 33 FTE advocates employed by advocacy services are charged with a number of functions. These include; promoting the Code of Rights to consumers and providers; receiving and assisting to resolve complaints from consumers; practising empowerment advocacy; referring cases to HDC where low level resolution can not be achieved and; referring issues of public safety and other issues relating to the Code of Rights to the Commissioner (HDC, 1998). The data relating to advocacy services collected in this research focuses on the need for advocacy service delivery and the organisational structure and functioning of advocacy services. Specific issues of practising empowerment advocacy are reserved for Theme Six – Empowerment Advocacy, and are discussed within their own category due to the significant emphasis placed on empowerment throughout the legislation and consequently in this research.

4.1 Identifying the Need for Advocacy Services

As stated in Chapter Three, advocacy occurs when an individual or organisation represents the views, feelings and/or interests of a person or group (Parsons, 1994). It is recognised that individuals may not possess the skills to access their rights, due to social, economic, developmental, cultural, emotional, physical or intellectual reasons (Garner et al, 1995). The data analysis identified the need for advocacy services by initially exploring some of the difficulties experienced by consumers when trying to pursue self-advocacy.

> *Well, an example that I have got, in my case, was talking for a child who could not speak.... So with my knowledge of what she needed, I was advocating for her. We went into hospital... I couldn't feed her, they*

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[15] These specifications are clearly outlined in Chapter Five.

> *thought that they would use a nasal gastric tube. I said that I would prefer it if they didn't. And they said, 'Oh yes, we think we will'. I said, 'Well I think you had better get her hospital notes, and look because one of her nostrils is, well you're not going to do it'. 'Alright, yeah, yeah, we'll do that', they said. So when it came time to do it, I said, 'Have you got her notes?' No they didn't. So they forced the nasal gastric tube, there was blood everywhere, which in itself was really bad for my daughter. They then turned around, and the nurse said that she had the wrong one (nostril), and proceeded with the other.... Mothers aren't being heard. That is a case of me being an advocate for my daughter and failing miserably.*

Another consumer had a similar experience when trying to advocate for his son and his family.

> *On his admission, it was documented in his clinical notes the we were over anxious parents. My concern was that I walked in with a lifeless four and a half week old and they had the nerve to call me over anxious. His presentation meant that there were blood clots coming up in his body and so we had to go through the whole abuse thing. It wasn't that we thought that that shouldn't be happening, it was just the way that it was done to us. (My wife) was really affected by the doctor's approach. At the end of the day, my ability to advocate was diminished.*

The passages above indicate the inefficiency of self-advocacy when there exists a presumption of a level playing field and when the lines of communication between the service user and the provider are not well established, as communication is a fundamental aspect of self-advocacy (Parsons, 1994; Rees, 1991). Aside from these experiences of deficient communication, consumers also associated self-advocacy with complaining and the consequential difficulties of being identified as a complainant.

> *I think that when we do it, there is a really fine line between advocacy and stirring, trouble making and over anxiety.*
>
> *I think that what is happening with families, I mean, the mother will advocate for her child to point where you're classed as a troublemaker and that's not nice. It leads the Mum to feeling pretty fragile, horrible.*

> *There is nothing worse than walking into (agency B) and them saying or thinking, 'oh no, not you again.*

> *The busy body, always making trouble, all the connotations, doesn't let sleeping dogs lie etc. Our culture is full of all of those little things, walk away and keep your dignity. I think we're fighting our culture as well as our disempowered situation. And that makes it difficult.*

These comments led the consumers into discussions on the need for advocacy support services. Their responses support the findings in the literature, that advocacy is beneficial on a number of levels, not solely based on the outcomes that are achieved, but the support that is extended during the process (Rees, 1991; Ezell, 1994; Parsons, 1994; Garner et al, 1995).

> *It's (advocacy service) a place where I can ring and say that this has happened, this is what I'd like to do, is it right, am I doing the right thing, am I coming from the right place, and is this the right way to do it? I'm just checking out that I am not going mad.*

> *The external support is something that you need, because there are certain amounts of guilt associated with doing it to (discussing the issues with) family members or your partner.*

> *When you're doing it you need to check out the reasons why you're doing it. Is it you're angry, is this the place for that? So you're wanting*

> *to do something you know you need to do, but you want be sure that you are coming from the right place and talking to the advocate helps you do that.*
>
> *As individual advocates we don't feel that we can do it for our family members, that we don't feel that we are listened to. I certainly know that just being able to talk about it, I felt that I was doing something.*

With the need for advocacy clearly expressed, the interview led into the specific services that consumers received from the HDC provision of advocacy. An analysis of the data indicates that consumers felt that the benefits transfer from support, through to appropriate actions and in some cases outcomes/resolution. When asked if having an advocate on board assisted them in feeling more empowered about their complaints, consumers noted:

> *Yes, in the case of (agency A), it made a lot of difference. As though they thought, look we have to be careful here because they have gone outside. They have brought other people into this, so this is trouble. There is a real problem here so we need to start to have a look at it*
>
> *What really happens is that Adnet travels in a lot of peoples minds, as a piece of legislation backing it up. There isn't just consumer x whinging again. This is consumer x, with their advocate and legislation. It's sad, but it's working.*

4.1.1 Delivering Advocacy Services

The ten advocacy services contracted by the Director of Advocacy provide services in a manner that is consistent with the Guidelines of Advocacy that are outlined in Chapter Five. The Health and Disability Commissioner ensures the consistent provision of quality services for all consumers through these guidelines. The advocates involved in this research explained their role as:

> *Assisting people, supporting people through problems, through concerns that they have. It is mainly supporting, walking alongside the person and not directing them, but being there with them. Giving them options and assisting. Mainly just supporting and being there for them.*
>
> *You're seeking knowledge on behalf of the consumer, so that you can pass it onto them in a way that they will understand. Rather than having them go out and look for it, and being given the information in terms that they just don't really understand, which puts them on the back foot again. Trying to talk to people at a level that, I mean we deal with a variety of people... with a variety of knowledge, so we try to adapt our style to meet the persons needs and give them the information that they will understand and help them to go forward.*

Advocates therefore disseminate information to empower the choices and knowledge base of consumers and to inform their choices. However, advocates are also required to support consumers on other levels, such as attending meetings between the consumer and the provider, or assisting the consumer in writing letters to providers, stating their concerns (HDC, 1996a).

> *When I am talking to a consumer before we go in to see a provider, I always say to them that they need to know that my role is that we give all the information to them, that they need, so that when they actually go into the meeting, they feel really strong about it. They'll know that I'll be there to support them, and also that they have the Act behind them. That actually puts them in a powerful position when they are talking to the provider, because they know they've got this law behind them. So*

> *what they're saying is that they know that they are entitled to information.*

For consumers this process is affecting their experiences of complaint's resolution, through the associated support, information sharing and the provision of their rights in statute.

> *For me it was very positive, it was ensuring that the meeting we had with (agency C) was for me, a safe place. It was (at Adnet offices) not at (agency C). I could still bring other support people if I wanted to, I thought that was really neat. The meeting was facilitated in such a way that everybody's needs were met. It was constructive and kept on track. It worked and we got answers. And we got a summary of the meeting sent out, plus the timeframe for what we expected to change before our next meeting and the dates. After x amount of time we should get an answer, if not, there was more to do. So yes, it's been something to help through the difficult times.*

Another key task of advocacy services, is the promotion of the Code of Rights and advocacy services within their regional boundaries. This includes presentations to both provider and consumer groups. The purpose of these presentations is two fold. Firstly, the presentations act as an educational tool to inform providers of their responsibilities and duties under the Code, and to inform consumers of their rights. Secondly, the presentations allow for advocacy services to inform their communities about the existence and purpose of the Code of Rights, coupled with the availability of advocacy services to assist in low level complaints resolution (HDC, 1996a). Figure Eight outlines the activities of advocacy services presenting the number of complaints, enquires and presentations accounted for in the 96/97 year of operation.

Figure 8: Activity of Advocacy Services Nation-wide (1996/97)

Advocacy Service	Complaints Received	Enquiries Received	Presentation Given
Northland	187	603	238
Auckand	1061	923	392
Waikato	77	253	122
Bay of Plenty/ Gisborne	283	440	216
Hawkes Bay	94	490	94
Taranaki,Wanganui Manawatu	744	614	773
Wellington	333	318	398
Nelson/Marlborouh	176	174	40
Canterbury/ West Coast	536	1997	331
Otago/Southland	462	565	147
TOTAL	**3,953**	**6,377**	**2,751**

(HDC, 1997)

The advocacy service from which this research drew its participants from appears to have one of the highest output ratios for complaints resolution.

> *Based on the stats that I have just put together, I think that we're working very well. 79% of our cases were resolved within 12 weeks (97/98 year) and I think that that says something about how advocacy services are working.*

4.1.2 Advocacy and Maori

As discussed under Theme Four, there are specific organisational provisions at HDC for working with Maori. Most notably, there is the Kaiwhakahaere management position, that allows for Maori links in the community to be established and the monitoring of HDC's commitment to the Treaty of Waitangi (HDC, 1997). Many of the policies pertinent to Maori and relating to the Treaty are also adopted by the advocacy services nation-wide. The advocacy region focused on for the data collection in this research has one Maori advocate and all advocates have had training on the Treaty of Waitangi and working with Maori. However, there were still some noted limitations evident with the functioning of advocates with specific reference to networking with Maori communities and providing the most culturally appropriate services.

> *We have a model here and it is about service for them (Maori)... and its about individuals and their rights, whereas we learnt from our Waitangi workshop that people who are from different cultures come from a collective way of thinking and they don't think of individual rights. So I actually often wonder, whether this is the right model for a country that is bi-cultural...*

> *We need to tap into the Maori base, (An advocate) did a check on how many consumers were Maori in our client group, 13%, well 13% of the population are Maori, so that is a reasonable sort of a stat, but I'll be interested to know where the populations are predominantly Maori, what sort of stats they're coming up with, caseloads and proportions, are they (Maori) still not using the service?*

It is difficult to ascertain if the numbers of Maori utilising health and disability services in New Zealand is proportionately reflected in the number of cases that are being dealt with by advocacy or HDC in comparison to the same figures for non-Maori. The process for the collection of ethnic data at HDC has not been robust in the 96-98 reporting years, thus inhibiting access to such information. Regardless of the lack of statistical data, the question posed is an interesting one. Is there a measurable difference between the proportional number of Maori laying complaints with HDC and/or advocacy as opposed to non-Maori? The information gathered in the focus group interviews indicates that this may be the case.

> *You have to look at the fact that we have a lot of different groups of Maori, different tribes within the area, and what's acceptable to one group may not be for another. You only have to look at Wanganui, where there's actually a united council, a Runanga here, that liaises with the city council and that sort of thing, now there is actually another group within Wanganui, that's two or three other tribes, who recently have been writing to the newspaper and saying, 'Well we don't want to get into this fund fight, but they don't represent us'. And I think you come up against that, and I've seen it on an individual basis where a really well educated Maori woman came from the Coast, and set up Kohanga which worked really well, but she had no speaking rights because she wasn't from here. I think that we could get into those difficulties with advocates as well. Because we try to be non-judgmental and all of those sorts of things, I think that we can offer a Maori advocate and often that's not taken up. No. We do offer and people don't.*

This is an interesting passage as it raises a number of issues for practitioners in the social services. As Maori have begun to be included in the development of systems of service provision, there have been noted issues on consultation and appropriate processes (Te Puni Kokiri, 1994; Durie, 1994). Much of the development that has occurred resulted from research about Maori needs and the inclusion of the Treaty of Waitangi in service policies, procedures and provision. The Royal Commission on Social Policy (1986) identified the need for the principles[16] of the Treaty of Waitangi to be incorporated in social policy, thus allowing for a reflection of these principles in practice. Since 1986, there have been some developments in parallel systems for Maori in the social services (Te Puni Kokiri, 1994; Ministry of Health, 1997) and although there are recognised issues associated with fulfilling the principles of the Treaty, this should not impair a commitment to the best possible service provision for Maori. Consultation issues have difficulties for Maori and non-Maori, as an analysis of the data suggests, and these issues will not be resolved here. However, it is noteworthy to emphasise that appropriate remedies will not be found through taking a simplistic view of ethnicity. As Durie (1995) suggests, it is necessary to acknowledge the diversity of the cultural reality of being Maori, when engaging in research, policy and service development. This includes the needs of urban Maori who are removed from their iwi base.

Although some Maori will elect to receive services within the mainstream structures that currently exist, this does not negate the necessity for the development of parallel structures (Te Puni Kokiri, 1994). Real choice, for Maori and consumers in general, is fundamentally based on the allocation of more than one option of provision to meet needs. Developing these parallel systems lies in consultation and a commitment to the diverse needs of Maori, from policy through to practice. As the following passage suggests, there are a number of hurdles that need to be acknowledged and overcome to fulfil these tasks, with specific reference to HDC and advocacy services.

> *I don't know about Wanganui, but if you've got a person from that area, working in that area, it is much easier. I don't come from Taranaki, and I don't presume to waltz in to every office, whereas if somebody was employed, say from Taranaki, they could go into all areas, even though they are from one tribe out of the whole eight, they can go anywhere, so*

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[16] The Royal Commission on Social Policy (1986) primarily focused on the principles of protection, partnership and participation for Maori upheld by the provision of the Treaty of Waitangi.

> *it makes a wee bit of difference, if you're from, easier put it that way. Bay of Plenty wouldn't be a problem. I think because Moe (the Kaiwhakahaere), because she's from Northland, she finds it easier herself, even though she's representing HDC from a national level, she finds it easier to go and do her thing up there, than if she comes down here and does everything.*

The difficulties of being taura here[17] exist for Maori advocates and the Kaiwhakahaere. The Kaiwhakahaere is currently the only person employed within HDC to focus on promotional activities, policy development and service delivery specifically for Maori. Within the different advocacy regions, there are a number of Maori advocates employed, however, their role is to promote and protect the Code of Rights through the model of empowerment advocacy outlined in their agency service agreements. A consistent inadequacy of service provision for Maori is that services are delivered within mainstream frameworks, whereas alternative practice skills and service delivery may more beneficially target Maori consumers. For parallel development to occur, Maori need to be given the equal status that is owed to them from the partnership inherent in the Treaty of Waitangi. This will not necessarily occur through the provision of a Kaiwhakahaere and the determination of some Maori and non-Maori advocates. Although the provision for the

Kaiwhakahaere is a positive step in the right direction, that position needs appropriate support to be able to function at an optimum level. There are issues of cultural safety and appropriateness that may be being undermined by the lack of support provided for the Kaiwhakahaere and other advocates working in communities with high Maori populations. It is important to remember that the provision of a Maori advisor in isolation, can not ensure culturally safe and

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[17] A person from outside the local iwi.

appropriate service delivery. A Maori advocate reiterates the problems of limited support and practice issues by stating that:

> *It's probably easier for a non-Maori to go into an area that isn't yours, than it is for me being Maori and going into that area... I've got to be very wary and one of the things that I let them know is that I'm there – I've lived there for 23 years now, you know, and been to all the Iwi meetings, but you've still got to be very careful.*

The development of appropriate service delivery for Maori is a continuous endeavour that requires the genuine commitment of resources, cultural consideration and the development of parallel systems. An encouraging sign is the awareness of advocates, identifying weaknesses and strategizing to ensure the protection, partnership and promotion of Maori.

4.1.3 Advocacy Organisational Structure and Functioning

When discussing the organisational structure and functioning of advocacy services with participants, the dominating themes from the data were funding and training. As stated in Theme Three, advocacy services are funded under their three-year contract agreements with the Director of Advocacy. The funding that was allocated to advocacy services depended on their individual tenures, including proposed establishment costs. These fiscal allocations were also based on the demographics of the areas that they would be servicing. Therefore, the contracts and associated monies were predominantly based on estimations, as the advocacy services were primarily new organisations.

Approximately one third of the operating grant received by HDC was spent on advocacy provision in its first year of operation (HDC, 1996a). This was superseded in 1997 and 1998 (HDC, 1998). Despite this financial commitment to the provision of advocacy, an analysis of the data gathered from the focus group interviews indicates that advocacy services require further funding to fulfil their service agreements and commitment to their communities. The demand for advocacy hours and the geographical location of some services is placing considerable strain on the services that they are providing.

> *I think that we need more money or more advocates, that's the main thing. We need more hours because there's areas (that) need to be covered, but I just haven't got the time to get to them... it's just too hard going, and I know that my job is to do that. My objective is to put one day aside a month to go into that area, but I have to establish myself before I can just waltz in there. Rural communities need much more networking before I can actually do what I am supposed to do.*
>
> *We've got one of the largest geographical areas (of all advocacy services) and it's hard to get out, and it worries me, it really worries me.*
>
> *There are some months when we can do more presentations, we need to do the presentations to get the word out there, but we also need to be focusing on the complaints that we already have, it's like juggling. This year the Director (of Advocacy) has come up with targets for us, which actually increase the amount of work that she (the Director of Advocacy) wants us to do. Reality is that we don't have the funding to fulfil those targets even though we want to.*

The difficulty of fulfilling the targets for presentations is that it takes advocates away from carrying out the advocacy for consumers and addressing complaints. It is difficult to promote a service that will not be able to cope with the number of complaints that may result from that promotion. On the other hand, if presentations do not continue, then advocacy hours and complaints received, may dwindle due to the lack of knowledge in the community about the provision of advocacy services and therefore fewer consumers needs will be met. Maintaining the balance between the dual functions is important, but difficult. Moreover, advocates expressed frustration over the amount of money that they receive in wages for the work that they perform.

> *I think that we need funding, not only for a better hourly rate, but we need more cents per kilometre. I also think that we need to be aware that there will be people coming up who have better training, better qualified advocates, who may have been advocates before, they won't work for this pidly amount. Most of us do it because we've got a real mission, not because we are being well paid. And that's a shame.*

> *I don't think that you should be expected to work for limited income just because you feel passionately about what you do.*

The issues of funding are not isolated and do not only pertain to sole advocacy services. On the contrary, the funding of advocacy services, although separated by the number of advocacy contracts, has some universal applications.

> *In terms of advocacy per se, I think nationally there needs to be more money. Locally there definitely needs to be more money, for the reasons that the advocates have stated. We run a really, really tight budget, and I think that doesn't allow them (advocates) to contact the people that we really need to be working for. Nationally we need more money because we can't do the promotional work that we need to do...*
> *I would prefer everyone to be fulltime. That would be my preference, then we would look at needing more hours, I mean we have a very limited budget as far as giving people training and things. It is based on the system where you can allocate 2-3% per person (on training expenses). But given that this is such a new organisation, we really need to be able to give people more. We are two years old, we need to be putting money into training... At the moment we can only allow*

> *training that is really necessary... We have to sit down and work out who really needs what, and work it out of the amount of money that we have got.*

The comments in this passage are important as they reiterate the issues of funding and promotions outlined in Theme Three (for example, the restricted public knowledge of the legislation and the limited funding that is available to promote the Code of Rights and the services appropriately), hence creating some interfaces between the themes of data analysis.

4.2 Summary of Findings

A significant number of complaints involving alleged breaches to the Code of Health and Disability Services Rights are received and resolved at the advocacy level. There are advocacy services nation-wide that provide free services to health and disability consumers as well as fulfilling the function of promotional activities in their regions. Advocacy services are directed by the guidelines specified by the Health and Disability Commissioner and are monitored by the Director of Advocacy. The emphasis is on low level resolution, however advocacy interfaces with HDC through the referring and receiving of complaints, furthermore, the functions at HDC support the delivery of advocacy services. The aims and objectives of advocacy services are stated in their contracted agreements with the Director of Advocacy, in the legislation and in the Advocacy Guidelines. In summary these aims and objectives are to:

- Receive complaints from consumers, the Commissioner and other persons.
- Inform consumers of their rights, and providers of their duties, outlined in the Code.
- Assist consumers through complaints processes.
- Represent, assist and support consumers in the low level resolution of complaints.
- Refer unresolved cases to the Commissioner at HDC.

- Report to the Commissioner on any issues of public safety or systemic concerns in their communities.

The attainment of these aims and objectives has been facilitated through the contracting of advocacy services nation-wide, with the provision of training and support from the Director of Advocacy. The consumers involved in this research had positive experiences of their involvement with advocacy services, thus reflecting that the design of the organisational structures underpinned by the legislation is working effectively. Much of the data analysed in this category supported the necessity for advocacy services, the positive consequences of their intervention and a general acknowledgement of the benefits of advocacy services. However when discussing the outcomes experienced by participants in the research, particularly advocates, some issues were identified that are limiting the attainment of the aims and objectives of the policy. The key issues of reference were:

- Ensuring the delivery of advocacy services based on an established need, and allocated appropriate and sustainable funding.
- The fragmented organisational structure and relationships between advocacy services nation-wide.
- The lack of parallel frameworks being developed, to ensure that the needs of Maori are being measured and/or met.

5. Theme Six – Empowerment Advocacy

A large section of the theoretical perspectives canvassed in Chapter Three was dedicated to the vast literature on the development, theoretical underpinnings and practising of empowerment in the social services due to the significant influence that empowerment has on the legislation, its provisions and services. The Health and Disability Commissioner Act (1994) and its associated organisational structures and services, are based on consumer rights, which the Commissioner sees as being inherently linked to empowerment (HDC, 1995). This is emphasised by the policies and procedures of HDC, including the emphasis on empowerment in the Guidelines for Advocacy produced by the Commissioner. Under the contracted service agreements that advocacy services have with the Director of Advocacy, there is a commitment to the provision of empowerment advocacy to ensure the low level resolution of complaints[18].

A clear definition of empowerment is difficult to obtain due to the multiplicity of components that are required to make up empowerment (Rees, 1991). However, these components include: an analysis of challenging power relations; access to information; participation and an analysis of environmental factors (that is, social, political, cultural, economic). Part of the difficulty of acquiring a clear and well defined explanation of empowerment is that it is a relatively new theory in the social services (Adams, 1996) and because it has the flexibility to be applied within a number of circumstances, including work with groups and individuals (Ezell, 1996). This lack of a clear definition and resulting general confusion about what empowerment means, was reflected in some of the data generated by participants in the focus group interview on what empowerment meant to them.

> *I think that empowerment comes down to basic human decency and courtesy and I think that if we start bringing it back to some real human traits that people can relate to, like say opening the door for someone is empowering. It might be empowering because the person is holding an armful of groceries. I think that before we get to empowerment we need to start talking about common decencies. There are some horrific things that are happening in health and disability at the moment that shouldn't be happening. I think that empowerment is almost like a fantasy. There are a lot of misconceptions about empowerment and what it means to different groups and I think that those misconceptions make it difficult.*

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[18] See Figure Five for an illustration of the empowerment advocacy model practice by advocacy services.

Rees (1991) supports the belief that there are misconceptions about empowerment. He views these as primarily resulting from the over simplification of empowerment and limited recognition of the multiplicity of components that form true empowerment practice.

> *In my experience, empowerment is often seen as loading responsibility on the individual or family, and that's supposed to be empowering.*
>
> *For Maori we have experienced empowerment with the concept of whanau, and the belief that whanau can look after themselves and that ends up using our cultural reality against us. This is disempowering, using empowerment to escape responsibility or accountability.*
>
> *Yes, I mean that is a negative view but that's how it seems, it's a buzz word.*

It is interesting to note that consumers, and participants in general, had a much more favourable view of empowerment advocacy, the model utilised by advocacy services nation-wide. It may be that their experience of advocacy was the first experience of the employment of empowerment within a model of intervention, as opposed to the application of empowerment as a term within the policy documents and mission statements of agencies. As the literature outlined in Chapter Three expressed, empowerment is not a concept that can be loosely attached to policy documents and result in the reflection of empowerment practice by service providers (Rees, 1991; Taylor et al, 1992; Lee, 1994). It requires an acknowledgement of a multiplicity of components, including power, politics, biography and the interfaces that exist between policy and practice. As Rees (1991) states, these components cannot be viewed in isolation if 'true' empowerment is to be achieved. Alternatively, participants may have a more favourable view of empowerment advocacy as opposed to empowerment in its own right, because it may be that the use of empowerment within the context of advocacy resulted in a more positive and functional experience for participants.

Empowerment Advocacy is the application of empowerment theory through the implementation model of advocacy, thus allowing empowerment to be informed by the practice guidelines of advocacy (Parsons, 1994). All advocacy services nation-wide have been trained in the use of empowerment advocacy to guide their practice[19]. This practice is defined as being the conjoint effort of practitioners and individuals, to help the individual gain access to resources within themselves and externally to facilitate their exercising of social, political, economic and environmental power (Lee, 1994). Advocacy is the process that provides step-by-step strategies for intervention. It is a process of human intervention that can be utilised to operationalise empowerment and, if done successfully, can result in the attainment of empowerment for individuals and/or groups[20]. Participants add to the information on empowerment advocacy through their varied comments.

> *What it means to me is, enabling someone to assist you to get something you need, and accessing support. An example of that comes to mind with (agency A), when a number of the families began to complain. They must have thought, 'Well what is happening here?' 'Why are all these people complaining?' 'What is enabling them or supporting them to complain, enabling these families to have the guts, knowledge, resources, to speak up for what they need to survive?' That is what it meant to me, allowing the support, because usually one person on their own is stressed out, grasping for things, it's a struggle, you're always stressed. Having the support of an advocate and all those resources and support systems empowers you, the family, the mother, to access or try to access what you need.*

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[19] Chapters Four and Five outlined the empowerment advocacy practice by advocacy services and embraced by HDC.

[20] See Chapter Three, p.19 for detailed discussions on the application of empowerment advocacy.

> *There is individual empowerment and group empowerment, even in advocacy. It's about support networks, hooking into organisations that you need to empower you to make the best choices and to get the best possible provisions that you possibly can.*

5.1 Practising Empowerment Advocacy

The empowerment advocacy model employed by advocacy services is succinctly detailed by some of the advocates.

> *The empowerment model is, where you can support a person by giving them information, by giving them the best knowledge, by giving them an idea of the process of how to go about things, so that they can then go from there and either with some support or with no support go and make their complaints known and have their rights met.*
>
> *In an ideal world, it is effectively doing ourselves out of a job. But that's the way it should be. Especially with there being the need for advocacy like there is.*

As noted in the review of the literature in Chapter Three, there are some limitations to practising empowerment advocacy (Payne, 1991). These include; the complications of over optimistic applications of empowerment advocacy, creating difficulties for the attainment of empowerment; practitioners/advocates not allowing consumers to be fully involved in the process of goal attainment; and, placing excessive demands and expectations on consumers when they are not equipped to make decisions at the level that may be required. These issues and others are prevalent in an analysis of the data from the focus group interviews. They are expanded due to the specific setting of empowerment advocacy within a complaints focused agency. A large amount of the data generated focuses on the strengths, limitations and frustrations of practising from a model of empowerment advocacy.

> *There are a lot of different groups of clients and it (empowerment advocacy) does work gradually. We use a number of different skills in advocacy, depending on the situation, with a view that, slowly giving them the information that they require they will be able to get it all. You may need to work with them several times, that's all about acknowledging the levels of empowerment. Empowerment doesn't mean that someone is going to have the skills, resources and knowledge to go out there straight away and do it for themselves. Them, making the choice to come to advocacy is empowerment in one way. We just use different skills to work with different types of people and use empowerment advocacy.*
>
> *One of the skills that an advocate has to develop is what the clients needs. So if I am working with a deaf client, there may be a different type of empowerment as compared to a tetraplegic. As opposed to someone who is in a rest home and doesn't want to complain at all but still needs advocacy. There are all different levels for each type of client, you have to have the skills to listen and know what level is realistic. You have to know where there skills are at, because they may be very intelligent but they might not have the right information or the self-confidence to carry on.*
>
> *And I think it is about being aware of what else has happened for that person. Because a person that might normally be an empowered individual and who, on first appearances, you might perceive as being… a well educated person who would be able to advocate for themselves, they've just been through something traumatic, at that particular time they're actually needing support from us. And maybe as the process*

> *goes through, they will pick up and be able to cope with more, sometimes more than the person who is empowered to their fullest. At the time when they have had something bad happen to them, well they can be just as disempowered as anyone else.*

> *I've found that with some professionals, just in the last six months, I've had a couple of health professionals come to me, who know the system extremely well, but because it is happening to them, they actually can't deal with it the same way that they might if it was happening to someone else.*

The comments outlined in the passages above acknowledge the flexibility of applying empowerment advocacy to a wide range of individuals with an equally wide range of concerns (Shields, 1992). The data supports the notion that there are levels of empowerment attainment and that different processes are empowering for different consumers[21] (Quayoom, 1990). Advocates also commented that their physical presence at meetings between consumers and providers, enabled empowerment, reiterating Rees' (1991) belief that empowerment is manifested in a number of different ways.

> *Our mere presence is empowering. Just the fact that we are there makes the process work better.... The consumer has got us there, they know that we exist, and that they've got rights. There are two things that the provider knows, that the consumer knows about us and their rights. If the consumer turned up on their own, the provider doesn't acknowledge that they know so much and perhaps that power thing comes in, taking advantage of the consumer.*

> *I guess that it is quite possible, and I have no way of testing this, but it is possible that if the consumer turned up with anybody else who is seen*

> *as being a professional, who's actually listening and taking notes, making the provider accountable, then they would also help.*
>
> *It is quite interesting though when you are dealing with a provider that is not very aware, doesn't know what your role as an advocate is, the limitations, they are usually very helpful. The bigger providers, like the hospitals, they are more aware of our boundaries, but often the individual ones don't. It usually results in quicker resolution.*

Despite the observations in the above passages, one of the issues of practising empowerment advocacy, as noted by the advocates in the research, is that it is difficult to measure your success, as the focus is so strongly placed on the individual attaining their goals.

> *Empowering people so that they can be better skilled to deal with their rights and issues with providers is a really difficult thing to measure. I find that it's a hard thing to measure unless you have consumers, and we've had a few, who come back, (and) each time they come back they need different support. Now that's the only way that you can really measure, but for a lot of people, they might make a complaint, especially in the health sector, they might make the complaint against the provider, then they may never never need to make another complaint in their entire life. So there's no way of measuring it. If they did make another complaint, without us, they may know how to go about it because of what we have already done, but we don't know that. Sometimes you want to know how well you have done.*

The consumer feedback surveys that the advocacy services provide to monitor their provision, and the social audit carried out by the Director of Advocacy annually, are the only measures of goal attainment (HDC, 1997). It may be that

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[21] **Chapter Three, p.18 discusses the levels of empowerment in full detail.**

these processes are not providing advocates with adequate feedback on their use of the model and its consequences. Such mechanisms as professional supervision and peer review can go a long way to assisting the development of practitioners' skill bases and encouraging their confidence in the application of particular practice methods (Payne, 1991).

The development of empowerment advocacy skills and processes have been difficult for some advocates to practice as they have spent years following alternative models of human intervention. This is particularly prevalent in the health sector, when most practitioners have been historically guided by more rigid and catalytic medical practice frameworks with more stringent boundaries and less flexibility[22].

> *I spent fourteen years in the health service and it was a total reversal of rules really. Especially where the purpose of the Act is fast, effective, speedy resolution, and there is also the philosophy of empowerment advocacy. Well you could get this speedy result today, or wait two months to empower that consumer to actually go through the process. Sometimes you have to remember that it is better for the consumer long term to assist them through the process and not do it yourself.*

This passage acknowledges the difficulties that some practitioner's face and is also beneficial, as it highlights some of the perceived deficits of practising under empowerment theory. Some practitioners may be discouraged by the level of client contact that is necessitated through practising empowerment advocacy (Gutierrez et al, 1995), as the process requires the teaching of skills and processes to inform individual choices. The primary focus needs to remain on the learning process of the individual and the skills attained through this process. An individual's first experience of empowerment

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[22] Refer to Chapter Three, specifically the section on Empowerment Advocacy in the Field of Health and Disability.

advocacy may not result in the speedy resolution of their concerns, but the attainment of empowerment levels may arguably result in the resolution of future issues in a more efficient and effective manner (Ezell, 1994).

5.2 Summary of Findings

The implementation of the Health and Disability Commissioner Act (1994) was fundamentally based on the concept of empowerment. This is extended to advocacy services who practice from a base of empowerment advocacy, that encompasses working with consumers through diverse techniques to encourage the resolution of complaints. Empowerment involves informing consumers, encouraging participation and acknowledging the diversity of power to encourage the provision of their needs. The obligation to provide empowerment advocacy is stated in the Health and Disability Commissioner's Advocacy Guidelines and in the contract agreements that the services have with the Director of Advocacy. The aims and objectives of this model are that advocates will:

- Work with, not for, consumers through instructed advocacy.
- Support consumers without making judgements.
- Give consumers skills, knowledge, and confidence.
- Encourage the consumer to participate in complaints resolution processes to the level of their ability (HDC, 1996a).

The extent to which these aims and objectives are being achieved is highly dependent on the advocacy services and their practice techniques. The consumers involved in this research had positive comments to make with reference to the advocacy models practised by the service that they had contact with, illustrating that these aims and objectives are relevant to their experienced outcomes. Furthermore, advocates noted the flexibility of practising empowerment advocacy and the diverse opportunities that it provides to assist resolution. This suggests that the model is appropriately applied to this service setting and is working beneficially to aid the activities of consumer and providers. There were two issues that can be explored, however, to continue the development of this model in practice. Those were:

- Limited feedback for advocates on the outcomes of practising empowerment advocacy can result in some concerns about their practice techniques and the benefits or otherwise for consumers.
- The length of time that empowerment advocacy necessitates in some instances, detracts from the fair, simple and speedy resolution of complaints and it can be difficult to focus on the process as opposed to the outcome.

6. Conclusion

The data analysis that has been disseminated throughout this chapter has provided real examples of the concepts and issues that have been discussed throughout the research by detailing the lived experiences of participants. This information was exposed through a series of themes of data analysis that reflect the organisational structure, regulation and services provided by the legislation. The analysis utilised data drawn from the focus group interviews, document research and some statistical analysis in combination, to elucidate the relevant issues. In so doing, the complementary nature of personal stories and literature to illustrate the reality of service provision within current institutional arrangements. The summary of findings provided at the end of each theme, provide a number of questions about how to bridge the gap between policy objectives and experienced outcomes. Those questions are not necessarily answerable in the context of this research, however, they still serve a valuable role by requiring some contemplation by policy makers, funders, service providers, consumers and further researchers.

Comparing the data analysis chapters have served the purpose of fulfilling the third goal in the formative policy evaluation tool utilised to guide this research, that is, the aims and objectives of the policy/policies with the experienced outcomes of those the policy was implemented to assist. The final goal in this project is to explore these findings and suggest some alternative sources for policy development and or structural change to assist the legislation in fulfilling its potential realisation.

Chapter Eight - Conclusion

1. The Research Process

The purpose of this research was to evaluate the implementation and outcomes of the Health and Disability Commissioner Act (1994) from the perspectives of a regionally based group of advocates and consumers. This was facilitated through the employment of a multi-method research design, utilising document research in conjunction with data from two focus group interviews. The dual sources of data provided an analysis of the legislation from a theoretical perspective, identifying its aims and objectives, through to its formalisation, operationalisation and functioning. The outcomes experienced by consumers and advocates were explored within the context of the theoretical material and the legislation's parameters.

The design and methodological implementation of this research was outlined in Chapter Two, and was based on a formative policy evaluation framework. There are four goals to achieve under this type of policy evaluation, namely: determining the aims and objectives of the policy makers; detailing the implementation of these aims and objectives; analysing the extent to which these aims and objectives met the needs and expectations of the policy's target audience, and finally; setting out alternative suggestions for future policy development, where the aims and objectives of the policy makers were not achieved, or fell short of the needs of those for which the policy was established to provide. The complementary nature of the methodologies utilised, permitted an evaluation of the policy from its conception through to implementation and service outcomes; therefore, as the chapters of the thesis unfolded, so too did the evaluation process.

This began in Chapter Three with the use of documentary research to explore the theoretical perspectives relevant to the legislation. These perspectives canvassed the key themes that would form the research evaluation, most notably empowerment and empowerment advocacy, the state sector reforms and the concept of consumerism. These concepts were then contextualised in Chapters Four and Five. Chapter Four examined the historical development of health and disability policy in New Zealand, with a key focus being the reforms to the health and disability sector in recent decades. This introduced the formation of the current legislation, examining its journey through the political process, resulting in its enactment in 1994. The history of the formation of the legislation was pivotal, as it expressed the identified need for the Act, and the processes by which these needs were either met or discarded. The chapter then outlined the contents of the Health and Disability Commissioner Act (1994) and detailed most of the provisions found within. Understanding the contents of the legislation was fundamental to an appreciation of the Government regulation, organisational structures, services and positions that were developed. A number of specific implementation tools were utilised to design the shape and form of the legislation in practice, these were examined in Chapter Five. The discussions here included the organisational provisions, duties, functioning and interfaces that exist, in addition to the adoption of specific policies and procedures.

Once an account of the legislative landscape had been established, an analysis of the various sources of data was provided. This analysis was provided for in Chapters Six and Seven, through the use of six key research themes. These areas of inquiry were developed from the documentary data and guided the interview questions that were provided for advocates and consumers, thereby allowing the focus group data to be collected in categories. This greatly assisted the organisation of the data for analysis and the process was highly beneficial as it allowed for the consumers' and advocates' data to be situated within the context that it was collected. The analysis of the data permitted the research to engage with the topic at a deeper level of inquiry and explain the functioning of the legislation in greater detail. Furthermore it indicated key findings that recommendations and further inquiry could be based on.

The remainder of this chapter will identify some of outcomes of the research, ranging from commentary on the theoretical material utilised; the key findings of the data analysis; the need for, and potential scope of, further research and concluding comments. In fulfilling the requirement of this research, with specific reference to the process of formative policy evaluation, the key findings will be restated to contextualise some key recommendations for alternative policy development and/or structural change. These recommendations are broadly couched, and reflect some of the developments that could occur to enhance aspects of the legislation.

2. Key Findings and Recommendations

A number of key issues were raised in the presentation of the research themes in Chapters Six and Seven. These primarily focused on an exploration of the lived experiences of research participants and were placed alongside the aims and objectives of the policies that have been implemented. This section of the conclusion will identify some of the key findings pertinent to the implementation of the legislation, and provide some alternative recommendations for policy development and/or structural change. The findings that will be discussed here are those that most adequately reflect the issues and that, via the recommendations for change, will impact upon and address other research findings.

2.1 Finding One - Participation

It can be argued that the first and most encompassing finding in this research was established in Themes One and Two, namely the data on the health and disability reforms and consumerism. These two themes identified the broader context within which the legislation is placed and currently operates. Throughout the findings disseminated in these two themes, an underlying issue involves consumer participation, with particular emphasis on consumer voice. This is pivotal to the research topic, as the legislation under evaluation has developed the framework for a complaints organisation that relies on consumer voice and participation. Furthermore, the attainment of participation, or lack thereof, impacts upon issues of service delivery, access, consistency in provision and other outcomes noted in the research findings that are directly relevant to the legislation. In summary the key findings of this research identify three areas of concern, that inhibit consumer participation, based on the institutional design of the health and disability sector. These are important findings to revisit, as the structure of the health and disability sector as it currently stands underpins the inability of the Health and Disability Commissioner Act (1994) to fulfil its optimum level of functioning. The legislation is restricted to identifying the shortcomings of service provision issues at an agency level as opposed to a more preventative mandate that would require consumer participation.

The identified limitations of the current institutional arrangements in the health and disability sector, canvassed in the research, focus on the limited representation of consumers on decision-making boards; the ramifications of the purchaser/provider split, and; the subsequent power vested in the purchasing agency. The first point relates to the immediate restriction of consumer participation in decision-making processes. This was brought about by the removal of democratically elected consumer representatives on major decision-making boards (for example, the boards of the HFA and Health and Hospital services boards, formerly CHEs). It may be argued that through the removal of this entitlement, service users have lost their ability to contribute to the processes that determine service outcomes and that they have had an avenue of consumer voice blocked. This thereby, significantly reduces their access to information and their ability to influence decisions that involve the allocation and consumption of public funds in the health and disability arena.

Secondly, there were the identified issues associated with the purchaser/provider split. Although this split has resulted in increased accountability for publicly funded goods and services, it has also created a distance between service users and key policy decision-makers. The fragmented nature of the current system creates policy development at a number of levels (for example, Government policy, purchaser policy, provider policy and so on) and creates difficulties for consumer access and participation. In order for consumers to have voice in the development and implementation of these policies, they must have access to information from a number of sources and the right to participation in the decision-making processes adopted by each of these bodies (for example, the Ministry, HFA, providers and so on). Furthermore, the splitting of functions has vested immense powers in the purchasing agency (HFA), which, although it operates within the broad strategic framework approved by the Minister of Health, exercises major discretion over decisions regarding what services are required to best meet the Government's specified outcomes. The combination of these factors have arisen from the reforms to the health and disability sector and have resulted in issues for service users about their choices and the opportunities they have for participation and consumer voice.

This research indicates that the attainment of consumer sovereignty is prevented by a lack of consumer choice and the undemocratic processes of decision-making that currently predominates, which has the effect of limiting the participation of service users. Therefore, neither of the models of exit or voice proposed in the literature are currently operational in New Zealand. Consumer voice is encouraged by the Health and Disability Commissioner Act (1994), however, the findings indicate a number of negative consequences for service users when voicing their complaints, such as: hostility from the provider, fear over the withdrawal of service provision and/or a further decrease in the standard of service provided. Hence, the prevailing philosophical and institutional arrangements do not contextualise the appropriate use of voice and inhibit the potential of the legislation to contribute to the rights of consumers being upheld. Furthermore, it is necessary to acknowledge that rights-based approaches, such the Code of Rights, are restricted without genuine avenues for consumer participation into decision-making processes. If the legislation is not supported in a framework that values participation, then the Act will be restricted to respond to the inadequacies of health and disability service provision, as opposed to influencing the policies that shape these outcomes[1]. Active participation in decision-making processes is therefore integral to citizenship. Guarantees that people will be able to exercise their voices in defining what for them constitutes well-being, and are able to exercise a degree of choice and influence over both the planning and implementation of policies which affect them is central to engaging citizens in appropriately constructed political processes (Munford, 1994).

Consumer sovereignty cannot exist without participation, even if service users have increased choices, as consumers may not be enabled to have an effective say about what constitute those choices. As citizens, opposed to pure consumers, we have a legitimate interest in the substantive content of and, procedural manner in which, public policy is made by elected political representatives and the officials that serve those representatives. If a focus on consumer rights excludes any consideration of the public and their participation in the formation and implementation of public policy, then consumers can do no more than chose services from a restricted selection that they have no control over producing. This does not constitute consumer choice in a truly competitive market environment, and such an opportunity is unlikely given the limited size and nature of service provision in New Zealand's modified health and disability sector. Therefore, in order to address some of the issues identified in the research findings, and to address the structural limitations impinging on the Health and Disability Commissioner Act (1994), it is necessary to acknowledge the deficits of the health and disability sector that restrict citizen participation.

Although these issues can be identified in the research findings, it is beyond the scope of this research to make recommendations to alleviate some of these concerns, as they centre on the complex structure of the health and disability

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[1] This point acknowledges the punitive use of the Health and Disability Commissioner Act (1994), as opposed to the possible use of the legislation on more preventative grounds.

sector[2]. Such recommendations are more appropriately established from full and conclusive research on the specifics of these institutional arrangements. Critical inquiry into the attainment of participation for service users in the health and disability sector is required to construct any recommendations for institutional and structural change. The findings of this research support the need for such investigations and acknowledge the impact that this broader context has on the Health and Disability Commissioner Act (1994). Furthermore, the research acknowledges that some of the options for redressing the concerns over consumer participation are unlikely to be considered, for example, the further structural reform to collapse the funding/purchaser/provider split back into a single agency[3]. Therefore, the recommendations are that:

- ☐ The Minister of Health investigate the need for, and possible benefits of, commissioning a report on the role of service users in the health and disability sector. This research needs to identify where the level of participation for service users currently lies and how best to develop that participation to ensure consumer sovereignty and/or voice.
- ☐ There are models for developing policy which formally include participation, from whatever mix of interests happen to be germane to the particular policy issue (for example, the corporatist model). The Minister of Health may investigate the feasibility of developing policy frameworks that incorporates the inclusion of citizen participation in approaches to policy development and implementation, as it is believed that such participation should be encouraged when deciding on the use of public funds.

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[2] The concepts of citizenship and consumer sovereignty are complex and require full investigation within their own right. The flow on issue of the appropriate scope and form of individual or collective participation in decision-making processes is also complex and can represent a double edged sword when providing recommendations. Although this research does not seek to provide answers to some of the issues discussed, it has illustrated the complexity of the issues, and some of the possible sites for further empirical inquiry.

[3] In the Annual Report of the State Services Commission (97/98), the Commissioner indicates that major organisational change is no longer an appropriate response to problems within the public sector (State Services Commission, 1998).

- The Minister of Health investigate the possibility of reconfiguring the composition of purchaser and provider boards, so that there is a provision made for community/citizen participation and representation.
- The Government acknowledges the call for further evaluation and policy development in state services, reflecting on the effectiveness of reform, and the quality of services that have resulted, as advised in the Annual Report of the State Services Commission (1998).

2.2 Finding Two – Funding and Organisational Structure

A number of issues relating to funding were noted in the findings, as is reasonably anticipated when evaluating the implementation and outcomes of a Government organisation. These issues were located in three distinct functions of the organisation and its services, they were: the activities of the Health and Disability Commissioner; the staffing levels in the investigations team at HDC and; the provision of advocacy services. These three functions interact on a number of levels, therefore they have been brought together under this section, as the stated recommendations will have general implications and flow on effects.

HDC funds advocacy services through a pool of money allocated to the Director of Advocacy. Services were contracted on a three-year agreement and this is up for review in 1999. The key findings of the research indicated uncertainty about the allocation of funding that HDC will attribute to the provision of advocacy services in the new contracting round. This uncertainty was primarily motivated by an awareness of the increased fiscal obligations of the Health and Disability Commissioner. These increased obligations include the large investigations undertaken by the Commissioner in recent years (for example, issues of public safety at Christchurch Hospital). The operational cost of such investigations is significant, and is not specifically provided for in the Commissioner's budget. This indicates that some expenditure costs need to be recovered in other areas of the organisation's operation to accommodate the fiscal consequences of these investigations[4]. A significant proportion of the Commissioner's annual fiscal allocation is attributed to the continued provision of free advocacy services nation-wide[5]. The fiscal sustainability of this provision, in light of the Commissioner's growing expenditure and comments on the inefficiency of advocacy service provision, needs to be addressed. Moreover, the findings indicate that increased funding also needs to be allocated to the function of investigating complaints at the HDC level, as the current employment ratios do not appear to be adequately dealing with the number of investigations that are required, hence impinging upon the timeframe for consumer resolution[6]. As additional employees are continually required in this section of the organisation, the fiscal obligation for that provision will add to the increase in expenditure. How this will be sustained, given the development of other increased fiscal outputs (for example, the Commissioner's large scale investigations) throughout the organisation is not clear. Therefore, the following key recommendations for suggested policy development and/or structural change are:

- The Health and Disability Commissioner may need to seek clarity on it's role in the investigation of issues of public safety from the Minister of Health. The High Court (1997)[7] has ruled that such investigations are an appropriate function of the position, however if fiscal allocations are not going to be made to independently support the provision of this service, then the organisational structure of HDC and its associated services will suffer. It may be necessary for this function to be independently funded from outside of the operating

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[4] The Health and Disability Commissioner noted the effect of these large scale investigations in her recently published Annual Report for the 1997/98 financial year, in which she states that a challenge for the future is ensuring a balance between small complaints and large systemic investigations (HDC, 1998b).

[5] 48% of the annual budget of HDC was allocated to advocacy provision in 96/97 and, 43% in the 97/98 financial year (HDC, 1997; HDC, 1998b).

[6] Based on the statistics provided in the Commissioner's Annual Report for the 97/98 year, a substantial number of complaints received by the investigations team in each three monthly quarter are not resolved within the quarter that they were received and, can take up to 52 weeks to resolve (HDC, 1998b).

[7] Nicholls and Brown vs. Health and Disability Commissioner, High Court, Christchurch, 12 March 1997, M No. 74/97.

budget that is currently allocated to the office of the Health and Disability Commissioner.

- ☐ It may be beneficial for the Director of Advocacy to investigate the feasibility of amalgamating the ten independent advocacy service nation-wide into one organisational structure[8]. The contracting of individual advocacy agreements, duplication of policy, administration and other operational resources, is a significant drain on the operating budget of the office of the Health and Disability Commissioner and this may be reduced by such an endeavour. The fiscal ramifications of the amalgamation would not necessarily increase the overall obligation that currently exists, and may allow for the extension of FTE (full time equivalent) advocacy positions nation-wide. Furthermore, the amalgamation may result in higher standards of consistency with advocacy service provision, through the production of one set of operating guidelines and policies. The amalgamation would also reduce the number of advocacy hours that are currently consumed by performing administrative service functions and may result in higher output and outcome ratios.

2.3 Finding Three – Promotional Activities

A key finding in the research, which appeared in a number of themes, was the lack of adequate promotion for HDC and advocacy services. Research commissioned by HDC (HDC, 1997; HDC, 1998b), and the research reported here, indicate that there is limited public awareness of the rights stipulated in the Code of Health and Disability Services Consumers' Rights and the free provision of advocacy services nation-wide. One of HDC's duties is to promote consumer rights and supply consumers and providers with adequate information and education. Furthermore, advocacy services are required, through their contractual agreements, to perform presentations in their communities to facilitate education for consumers and

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[8] Alternatively, larger advocacy regions could be established, reducing the number of contracts that would be operational. For example, upper North Island, lower North Island, upper South Island and so on.

providers. Although a number of measures have been employed to ensure the promotion of the Code of Rights and advocacy services, there is still limited public knowledge and awareness (HDC, 1997; HDC, 1998b). For the legislation and its associated services and provisions to be utilised optimally, consumers and providers need to be aware of its existence and application to their circumstances. The findings suggest that an increase in nation-wide promotional activities would significantly increase the number of consumers that utilise the associated services[9]. The promotion of the legislation needs to occur on three levels: a) the organisation structure and functioning of the office of the Health and Disability Commissioner; b) the Code of Health and Disability Services Consumers' Rights and; c) the free provision of advocacy services nation-wide to assist in low-level complaints resolution.

Additionally, it may be argued that the adoption of promotional activities that reach a broader spectrum of consumers and providers in New Zealand, may aid the aims of the legislation by reducing the number of alleged breaches to the Code of Rights. Providers need to be aware of their responsibilities and duties under the Act in order to provide for those obligations. If providers are clear of their roles and the provisions of the legislation, then it is speculated that a greater number of providers will make the necessary changes to policy and/or procedure to ensure that they are acting within their lawful responsibilities. It can be argued that this could potentially diminish the number of alleged breaches to the Code of Rights and the number of complaints that are received by HDC and advocacy services. The significance of this potential diminishing of complaints cannot be over stated, as a fundamental aim of the Health and Disability Commissioner is to reduce the number of breaches to the Code of Rights that occurs at any given time (HDC, 1997). Therefore, the recommendations are based on assuring the attainment of these goals.

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[9] Note that the changes suggested in Finding Two would need to be acted upon before HDC or advocacy services could adequate deal with an increase in consumer complaints.

- HDC's education and communications sections may need to investigate more appropriate methods for disseminating information on the Code of Rights and advocacy services to the public via the employment of a number of research tools, for example, opinion polls, surveys and statistical analysis.
- The Health and Disability Commissioner may consider placing a greater emphasis on the promotion of advocacy services to consumers and providers, by linking the functions of advocacy services to HDC through such mechanisms as public addresses and media releases. The Health and Disability Commissioner may also achieve this by making public a larger number of her findings in cases where there has been an established breach of the Code of Rights, therefore, setting precedents for guiding the actions of consumers and providers. As the legislation continues to mature and a broader range of complaints is canvassed, it is likely that this activity will become more attainable for the Commissioner.
- The Director of Advocacy may consider providing any new resources to advocacy services free of charge, to ensure the consistent content of their promotional activities and the professional presentation of information. The budget that the Director of Advocacy has to monitor may absorb this cost, or it may be seen as an appropriate fiscal responsibility of the office of the Health and Disability Commissioner.

2.4 Finding Four – The Act and Maori

A number of specific issues were identified in the key findings of the research with reference to Maori. These surround the appropriateness of systems for application to Maori consumers within HDC's framework, the Code of Rights and the provision of advocacy services. HDC employs the management position of a Kaiwhakahaere to liaise with iwi and to develop policies that align the practices of HDC with the principles inherent in the Treaty of Waitangi. However, this position operates in isolation and is not adequately supported to canvass the diverse needs of Maori nation-wide. The development of parallel structures for Maori cannot be attributed fairly to one FTE (full time equivalent) position. The National Advisory Committee on Core Health and Disability Support Services commissioned a report entitled *He Anga Whakamana,* outlining frameworks for the delivery of disability support services in 1995. This Report identifies the systems and procedures that should be adopted to meet the needs of Maori in the health and disability sector. Such tools do not appear to be currently utilised by the office of the Health and Disability Commissioner in the development of service systems. This extends to advocacy services, where the findings indicate that advocates are having difficulties with consultation, establishing networks and providing for the diverse cultural needs of Maori. Output measures and other service guidelines further impinge on such issues, by providing a disincentive for advocacy services to spend time networking in their communities. Finally, the findings indicate that there are limitations with the appropriateness of the Code of Rights with reference to Maori. These issues were fundamentally based around the individualistic approach of the Code and the historical reluctance of Maori to complain (HDC, 1997). Maori are specifically referred to in only one of the ten rights outlined in the Code and some questions were raised about the appropriateness of this allocation.

These three sites of concern for Maori are important findings in light of the principle of Treaty partnership inherent in the operating policies of the office of the Health and Disability Commissioner, and reflect that there are associated issues with not allocating specific service delivery for Maori. Therefore, recommendations can be made to encourage further investigation and systemic development:

- ☐ The Health and Disability Commissioner may consider the need for further development of systems and procedures specifically for Maori, including the appropriate support for the Kaiwhakahaere. The provision of this position is a positive step toward providing services that are accessible and appropriate to all New Zealanders, however it may be necessary to increase this obligation, through the employment of support staff for the Kaiwhakahaere, if the agency's aims and objectives are to be realised.

- The Health and Disability Commissioner is currently reviewing the Code of Health and Disability Services Consumers' Rights. Such a review may identify the appropriateness of the Code in application to Maori and address the needs of Maori above and beyond the individualistic application of rights. If this feedback is available to the Commissioner for reflection then policy development may result. If this information is not provided, then it may be necessary to incorporate forums for Maori, for example hui nation-wide, in future reviews of the Code.
- Advocacy services currently receive training on working with Maori and the Treaty of Waitangi. It may be advisable for the Director of Advocacy to canvass the need for more specific training for advocacy services, on matters such as, establishing networks in Maori communities. Furthermore, it may be possible to negotiate with the Kaiwhakahaere and any support staff under her jurisdiction about providing consultancy services for advocates.

3. Reflecting on the Theoretical Material

Aside from the recommendations that can be suggested, one of the interesting observations that is permitted in research of this nature is the identification of the theoretical underpinnings of the subject matter in comparison to its practice outcomes. Sometimes the theory and the practice marry together quite clearly and successfully, and at other times there are still identifiable gaps between the theoretical frameworks and the reality of practice. The exploration of theoretical perspectives is useful when conducting research on, or within, the subject matter that the theory relates to, as it may identify the historical development of the theory, the key identifiable features of the theory and the methods by which these theoretical ideas may be implemented in practice. The most significant theoretical and practice comparison in this research was noted when exploring the literature on empowerment and advocacy and collecting the data from consumers and advocates who have practised under empowerment advocacy. As noted in Chapter One, the researcher was interested in identifying the efficacy of empowerment advocacy in the social services, and particularly its application to the diverse needs of health and disability service users.

The literature in Chapter Three began by detailing the emergence of empowerment in the social services and developed further to discuss the application of empowerment theory to the models of advocacy. The practising of neither empowerment nor advocacy, are exhaustively commented on in the literature and there are a number of limitations to the depth of inquiry that comments on the techniques that can be utilised to practice these concepts. The limited commentary is particularly pertinent to advocacy and the techniques for practising the various models of advocacy. However, it is not necessarily surprising that the literature on practising these theories is limited, especially considering that both empowerment and advocacy are relatively new approaches to social intervention, particularly when they are brought together.

The literature canvassed in Chapter Three was useful in guiding an investigation into the adoption of empowerment advocacy in the practice context of HDC and advocacy services. Furthermore, the data generated from the focus group meetings helped elucidate what empowerment advocacy is, how it is practised and what the associated benefits and limitations are. Specifically, the consumers' data identified a number of positive consequences associated with empowerment advocacy[10], which was an encouraging finding, as it supports the assumptions of the literature and may advance further investigation into the practice technique, thereby broadening its application to the social services.

This research is unique in exploring the use of empowerment advocacy in a specific service setting, and through this exploration it can be argued that it has extended the theoretical material through providing insights into the practising of

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[10] For example, participation, access to information, increased opportunities to express their needs, expectations and identify power relations.

the technique. This research is an initial introduction to the possible developments that can, and need to, occur.

First and foremost, more research and literature needs to be produced to discuss the linking of empowerment theory to the models of advocacy practice. It is essential to focus on what empowerment theory is, when applying it to the models of advocacy. As Rees (1991) has clearly stipulated, 'true' empowerment theory comprises many parts, some of which go beyond the specifics of access to services and service provision, (for example, biography, power relations and the interfaces between policy and practice) and these express the need for democratic participation[11]. Due to the importance of these components it is necessary to acknowledge that the institutional arrangements that prevail in the New Zealand context (for example, the purchaser/provider split) may preclude genuine citizen input on decision-making. These thereby, effectively limit the practising of empowerment advocacy to issues of information and/or access to what is available. Some of the goals of empowerment theory may be restricted due to these boundaries if there is not a reassertion of the right of members of the public to have input into decision-making that determines policy priorities in relation to service provision, whether publicly or privately provided[12].

Empowerment advocacy cannot truly reflect the adoption of empowerment theory without being applied beyond the social service that it is being practised within, as doing so denotes the multiplicity of components that are required to achieve empowerment, whether through the models of advocacy or otherwise. Therefore, it is important to restate here that individual empowerment is more than what is offered by the social intervention utilised by a specific social service, and that the skills learnt through such interventions need to be carried on by the individual in other facets of their lives. Furthermore, practitioners are required to have an

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[11] This is the theoretical lynchpin between empowerment advocacy and the relevant institutional arrangements, suggesting the shortcomings of consumer sovereignty when participation is limited.
[12] Note the need for citizen participation discussed under Finding One – Participation.

understanding of more than the techniques utilised to practice empowerment advocacy, but also a political analysis of the field and the sources of power that may be being utilised to oppress the individual and/or group or at least to restrict their 'voice'.

Beyond this acknowledgement of the complexity of empowerment theory, information on the step by step process of practising empowerment advocacy needs to be developed to overcome some of the fragmented theoretical material that is currently available. Presently, the literature either primarily focuses on empowerment or advocacy, and there is very little detail on the combination of empowerment as the guiding theory and advocacy as the model for practice. The call for the development of empowerment advocacy in practice settings is supported by the findings of the research, particularly the benefits noted by participants who have been potentially exposed to a variety of other social intervention techniques within the health and disability sector[13]. Furthermore, advocates noted that the flexibility, participation and resulting outcomes from the use of empowerment advocacy were some of the positive consequences for practitioners. There is the potential for this technique to be employed in other social settings[14] and practitioners do not currently have access to enough information to guide such practice development. Advocacy and empowerment advocacy are flexible intervention techniques that may be utilised to assist the development of consumer voice within these services. Practitioners need to be encouraged to take the opportunity to assist consumers through teaching the specific skills and processes involved in empowerment advocacy as, the attainment of these skills has the potential to impact upon the social functioning and operation of consumers in all facets of their lives. This is particularly beneficial when working with people with disabilities, as regardless of their individual

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[13] For example, medical based social work models that see the practitioner as working for the consumer, as opposed to with the consumer.

[14] For example, Mental Health Services, community based health and disability agencies such as the Royal New Zealand Foundation for the Blind and community based generic social work services.

circumstances, the issues that they encounter combined with their functioning in an able bodied world, are not solely associated to their physiological condition or contact with a specific social service[15]. Thereby, utilising empowerment advocacy may offer practitioners the opportunity to teach these individuals' skills and processes that will assist them in demanding participation and access as citizens in all domains of their lives.

Coupled with the development of clearer practise guidelines for empowerment advocacy to benefit practitioners and consumers alike, it would be beneficial if further research was conducted on the application of empowerment advocacy in a number of practice settings[16]. This could begin with a further evaluation of empowerment advocacy with consumers of HDC advocacy services, as they are a target audience due to the existing use of the technique by that service. The perspectives of a number of consumers would help identify the strengths and limitations of empowerment advocacy in greater detail and would complement the development of systems within that service, but also the development of similar programmes in other social settings. There is potentially a large number of consumers, with varying needs, that could be canvassed given the broad spectrum of consumers that advocacy services have contact with. This would allow for varied commentary on the application of the technique and may indicate the flexibility of applying empowerment advocacy to specific cultural settings (for example, Maori and Pacific Island people). Furthermore, research involving the advocates could provide information on the difficulties associated with practising empowerment advocacy and the techniques that may be employed to overcome or

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[15] This point acknowledges the social construction of disability outlined in Chapter Three.

[16] The need for research into empowerment advocacy should be publicly funded, through HDC or other avenues. Further inquiry would be intrinsically valuable, as the findings of this research indicate that the technique is complementary to the needs of a broad range of consumers. The Government's historical reluctance to fund particular research initiatives does not mean that these initiatives are not worthwhile, or that public funds should not be made available in the future.

limit these effects. Thereby, encouraging the development of further commentary on the specifics of empowerment advocacy in practice.

Through encouraging the development of further research and literature on empowerment advocacy it is anticipated that service users in a number of settings may experience the positive consequences of this social intervention technique. Empowerment advocacy has the potential to enhance service outcomes and outputs and social service researchers and professionals need to be encouraged to explore this technique for the betterment of practice standards.

4. Methodology

The methodologies utilised in this research have been useful in providing the diverse range of information that was required to evaluate a piece of legislation and its associated policies. Through conducting the research under the guidance of these methodologies a number of significant lessons have been learnt and knowledge developed. The first was an acknowledgement of the planning that is required when conducting research of this nature. It was highly beneficial to have a clear and well-defined research objective, matched with the appropriate methodologies that would facilitate the attainment of the data required. The decision to acquire data from complementary sources helped the research process in a number of ways. It provided for the detailed background information that laid the foundations of the legislation and a comprehension of what the key themes were likely to be. Furthermore, documents were analysed as part of the data collected and provided insights into specific aspects of the research topic that allowed for the depth of knowledge that was required to assess the legislation from the perspectives of consumers and advocates.

The data gathered from the focus group meetings was pivotal to this research, as the voice of those who are directly affected by the legislation's provisions was needed to truly evaluate the Act. Their data provided lived experiences to add to an understanding of the theoretical material that had been discussed. Furthermore, it provided insights into some areas of the legislation that would not have been available from other sources of data (for example, official information provided by HDC on the specific policies and procedures that are utilised to guide its operational practice). The focus groups also proved to be an efficient method of data collection and provided in-depth data whilst consuming limited resources. For this to happen successfully, it was necessary to be highly organised. The planning of the focus group meetings, in terms of the participants and venue were key duties that assisted in the smooth running of the meetings, as was the structured facilitation format that was utilised. Furthermore, a large proportion of the documentary research was canvassed prior to the meetings and this was also beneficial, as it allowed for the development of discussion points that covered the key areas of inquiry.

The researchers past contact with Adnet and the advocates aided the organising of the focus groups. It is important to note these existing relationships, because the support and assistance provided from Adnet was invaluable in assisting the research process and outcomes. It is fair to assume that the advocate focus group meeting would not have been as successful without this support. The existence of these prior relationships had a bearing on how the advocates approached the meeting, and it may be that they were forthcoming with information because of this familiarity and because of their knowledge of the researcher's philosophical base and involvement in the disability community. Moreover, the advocates may have framed their responses in a different way based on their perceptions of what the desired data was, given their knowledge of the researcher's background. To the extent that the substantive nature of the interview data is at least in part a function of the relationship between the interviewer and interviewees, stating the prior relationships acknowledges the context within which the data was generated. Furthermore, their experiences of the focus group meeting, coupled with their prior relationship with the researcher, may have affected the co-operation that existed when it came to organising the consumer focus group meeting.

The focus group process was a successful and effective means of data collection and is highly recommended when it is possible to organise, structure and facilitate such meetings clearly and efficiently. This was achieved in this research despite the disappointment that only a limited number of consumers chose to participate in the second focus group meeting. That was in part due to the limited number of consumers that had been arranged to participate in the meeting and due to the unreliability and uncertainty that can occur when working with human subjects. With hindsight, there was very little that could have been done to prevent this outcome. It may have been possible to organise more consumers to attend the meeting, however, this may have resulted in a larger number of consumers attending than was desired and would have impacted on the facilitation of the meeting. Alleviating the possibility of this outcome depends on the individual researcher and whether they have a priority for effectiveness or efficiency. It is noteworthy that research participants may always withdraw from the research process and it is not possible to take the involvement of research participants as a definite eventuality, even if they have indicated that they are willing and able to partake.

The findings that have resulted from this research are based on a combination of the focus group data and documentary research and have been combined to fulfil the requirements of formative policy evaluation. They provide a historical and theoretical foundation to the legislation that is complemented by the data provided by the research participants. This identified gaps or deficits in service delivery, as well as the positive outcomes and experiences of consumers who have had experience of the legislation in action. The triangulation was highly successful in terms of the data provided, but also for fulfilling the needs of the research by maintaining an emphasis on consumers' experiences of health and disability services in New Zealand.

5. Further Research Opportunities

Due to its size and nature, this research has been limited in investigating all of the possible consequences of the Health and Disability Commissioner Act (1994). It focused on the participation of a small group of consumers and advocates from one regional service and the evaluation of a number of key documents and relevant literature. The methodological techniques adopted particularly the composition of the focus group meetings, inevitably impacted on the data generated[17]. Furthermore, there has been no attempt to generalise the stated findings above and beyond this context, hence the broad nature of some of the recommendations that were established. These recommendations do not present conclusive evidence, but rather point to further documentation and policy research, evaluation and analysis.

The key emphasis for the researcher was to give a group of consumers and advocates voice in the process of evaluating a piece of legislation that has directly influenced their experiences. This has been achieved, however it does not denote that further research is not necessary. As with a number of policy evaluations, one of the key findings of this research is that further research is required, including the investigation of the feasibility and appropriateness of the recommendations stated in this Chapter. Moreover, the call for further research goes beyond this, as the perspectives of more consumers and advocates need to be taken into consideration. The scope and nature of future research can broaden the parameters of this thesis by looking at the correlation of national issues and/or by specifically identifying a target group (for example, Maori or people with disabilities) and examining the legislation from their perspectives. This would considerably deepen the scope of consumer voice on the legislation and its service provisions. Furthermore, in-depth research into the strategic systems of operation at the office

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[17] The composition and size of the focus group interviews was commented on above, and in detail in Chapter Two, when discussing specific research issues. The most noteworthy point was the limited number of participants in the consumer focus group due to the unanticipated withdrawal of two members, however this limitation did not disqualify the data that was generated.

of the Health and Disability Commissioner would elucidate some specific policy and/or procedural changes that would enhance its functions.

Another avenue for research is an examination of the potential of the legislation. It is currently functioning at a low level due to its infancy; a lack of legal precedents to guide the Commissioner, advocates, consumers and providers and; experiencing inefficiencies due to organisational shortcomings. Investigation into the possible flexibility and application of the legislation would considerably aid health and disability service users and the functioning of the organisational structures that support the Act. The potential focus of further research is unlimited due to the possible avenues of inquiry and the lack of empirical data on this new and innovative piece of legislation. The research findings strongly support the development of future investigations, as such inquiries will benefit consumers, the field and potentially the development of comparative legislation internationally.

In a broader context, this research has highlighted the need for further investigation on the affects of social policy development in the health and disability sector in the past decade. The institutional arrangement of health and disability policy development, service purchasing and provision has been commented on in this research, as identifying some of the limitation of the legislation under review and as being responsible for some of the concerns identified by consumers and advocates. A fuller evaluation of the effects of these policy initiatives on service users would be beneficial in identifying some of the shortcomings of the current structure and operation of the sector. Furthermore, research is required to investigate the position and function of consumers within this context, particularly their opportunities for participation, as noted in section 2.1 of this chapter.

It may be argued that there are a number of consumers who desire quality service provision to holistically provide for their varying needs above and beyond their desire to participate in the determination of policy and funding decision that allocate these services. Ideally, what is required is an environment that allows for feedback and genuine consultation with consumers, but does not rely upon or require the expression of voice or exit in order to provide quality services. Research on the appropriate role of consumers and how this type of service provision can be appropriately achieved, needs to be encouraged. This would significantly aid consumers, the sector and the Health and Disability Commissioner Act (1994), as the greatest good that can result from the legislation is its future redundancy. An Act that focuses on the investigation of consumer complaints against health and disability providers will only be required for as long as inequalities and inappropriate standards in service delivery prevail.

6. Concluding Comments

The field of health and disability has been under significant transformation in the past decade, which has altered the formation and implementation of policy. The restructuring of the state sector has considerably influenced these changes and has created a competitive environment for the funding and provision of services. This restructuring has also affected the services received by New Zealanders and the level of input that they have the potential to contribute in decision-making processes. Such changes have created uncertainty and discontent for many who no longer feel secure in their provision of appropriate health and disability services. However, the market orientated health and disability sector has also gained, through the formation and implementation of a significant piece of legislation, which has the potential to redress the concerns of health and disability service users in New Zealand and provide an opportunity to encourage consumer voice.

By exploring the key findings and associated recommendations made in the above sections, it is clear that there are some policy and organisational changes that need to occur in order for the Health and Disability Commissioner Act (1994) to reach its optimum potential. Most notably, there is a recognition that the health and disability sector within which the legislation is placed, follows a set of institutional arrangements and processes that currently disallow the full enactment of a rights-based piece of legislation. Inadequate funding impinges on service delivery and providers are limited to reduce the impact that this has on service user's, given the restricted control they have over their contractual arrangements. Therefore, although it is noted that there needs to be changes made to the operationalisation of the legislation, it is also recognised that these changes need to occur in conjunction with changes to the broader structure of the health and disability sector, particularly the development of frameworks for consumer participation.

It is clear that despite these findings, the overall structure and functioning of the legislation's provisions has successfully met the needs of health and disability service users. The legislation was based on an innovative design to provide for consumer rights within supporting organisational structures and with the governance of a Commissioner. This allocation of positions, structures and support mechanisms for consumers indicated a willingness to ensure the maintenance of the associated rights for the betterment of the sector. As a result, the legislation is positively impacting upon the resolution of complaints and aiding the voice of a significant number of New Zealanders. Furthermore, the legislation has put the rights of health and disability service users on the agenda. This in itself positively impacts upon the sector, as it clearly indicates that the maintenance of these rights is of primary consideration. It may be argued that it results in more options for these historically marginalised groups of consumers through the provision of processes to address their concerns. It raises their expectations of services from the health and disability sector and can serve as an avenue to improve overall service provision. The legislation is the platform that service users may poetically be able to use to assist their increased voice in the funding, allocation and provision of services.

Although the legislation is not the answer to all of the questions posed by service users, it is a functional tool to assist their quest for redress. We cannot underestimate the impact that the legislation has had on the sector, especially on the professional bodies that monitor the functioning of service providers, as their processes of complaint resolution continue to be aligned with the Code of Rights. Therefore, the legislation calls for accountability, consistent professional standards and the return of some basic human rights (for example, respect, clear communication and informed consent). It is envisaged that these positive gains will only continue to develop and benefit service users, as the legislation matures and appropriate processes continue to evolve.

Despite the benefits and gains that have been realised by the formation and implementation of the Health and Disability Commissioner Act (1994) there are still positive developments that can and should be made. The legislation remains in its infancy and requires more time to develop its place in the sector. The benefits of the legislation will become more apparent the longer the organisational structures and services have to mature and develop through processes of monitoring and review. For example, the Commissioner will have the opportunity to release a greater number, and range of, opinions on breaches to the Code of Rights, which will establish jurisprudence and guide consumers and providers to understand their rights and responsibilities. Another likely benefit is the development of empowerment advocacy systems of service delivery over time, as advocates become familiar with the specific practice skills and techniques associated with this new form of social intervention. Moreover, the Act currently lies in unexplored legislative territory and this offers endless opportunities for its continued augmentation, given some political commitment to the achievement of this outcome. Further analysis and evaluation can assist this development and explore the possible flexibility of the Act. These developments need to be supported and encouraged as posing exciting and innovative possibilities for complaints resolution, as complacency will only serve to undermine the potentiality of the Act.

The Health and Disability Commissioner Act (1994) is one of the few piece of legislation in the world to collectively stipulate the legally entitled rights of health and disability consumers. The innovation of this initiative should continue with the development of the legislation in practice. This piece of New Zealand social policy has, and will continue, to generate international interest and has the opportunity to encourage the emergence of consumer voice.

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Appendix One - The Code of Rights

The Code of Health and Disability Services Consumers' Rights outlines that:

Consumers have Rights and Providers have Duties:

1. Every consumer has the rights in this Code.
2. Every provider is subject to the duties in this Code.
3. Every provider must take action to –
    a) Inform consumers of their rights; and
    b) Enable consumers to exercise their rights.

Rights of Consumers and Duties of Providers:

The rights of consumers and the duties of providers under this Code are as follows:

- **Right 1**

Right to be Treated with Respect

1. Every consumer has the right to be treated with respect.
2. Every consumer has the right to have his or her privacy respected.
3. Every consumer has the right to be provided with services that take into account the needs, values and beliefs of different cultural, religious, social and ethnic groups including the needs, values and beliefs of Maori.

- **Right 2**

Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation

Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation.

- **Right 3**

Right to Dignity and Independence

Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual.

- **Right 4**

Right to Services of an Appropriate Standard

1. Every consumer has the right to have services provided with reasonable care and skill.
2. Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.
3. Every consumer has the right to have services provided in a manner consistent with his or her needs.
4. Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.
5. Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

- **Right 5**

Right to Effective Communication

1. Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.
2. Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly and effectively.

- **Right 6**

Right to be Fully Informed

1. Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including –
    a) An explanation of his or her condition; and
    b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits and costs of each option; and
    c) Advice of the estimated time within which the services will be provided; and
    d) Notification of any proposed participation in teaching or research,

   including whether the research requires and has received ethical approval; and

   e) Any other information required by legal, professional, ethical, and other relevant standards; and
   f) The results of tests; and
   g) The results of procedures.

2. Before making a choice or giving consent, every consumer has the right to information that a reasonable consumer, in that consumer's circumstances, may need to make an informed choice or give informed consent.
3. Every consumer has the right to honest and accurate answers to questions relating to services, including questions about –
   a) The identity and qualifications of the provider; and
   b) The recommendations of the provider; and
   c) How to obtain an opinion from another provider; and
   d) The results of research.
4. Every consumer has the right to receive, on request, a written summary of information provided.

☐ **Right 7**

Right to Make an Informed Choice and Give Informed Consent

1. Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of the code provides otherwise.
2. Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
3. Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competency.
4. Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where –

  a) It is in the best interests of the consumer; and
  b) Reasonable steps have been taken to ascertain the views of the consumer; and
  c) Either, -
    i) If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
    ii) If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and are available to advise the provider.

5. Every consumer may use an advanced directive in accordance with the common law.
6. Where informed consent to a health care procedure is required, it must be in writing if –
    a) The consumer is to participate in any research; or
    b) The procedure is experimental; or
    c) The consumer will be under general anaesthetic; or
    d) There is a significant risk of adverse effects on the consumer.
7. Every consumer has the right to refuse services and to withdraw consent to services.
8. Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.
9. Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
10. Any body parts or bodily substances removed or obtained in the course of a health care procedure may be stored, preserved, or utilised only with the informed consent of the consumer.

- **Right 8**

Right to Support

Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be reasonably infringed.

- **Right 9**

Rights in Respect of Teaching or Research

The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.

- **Right 10**

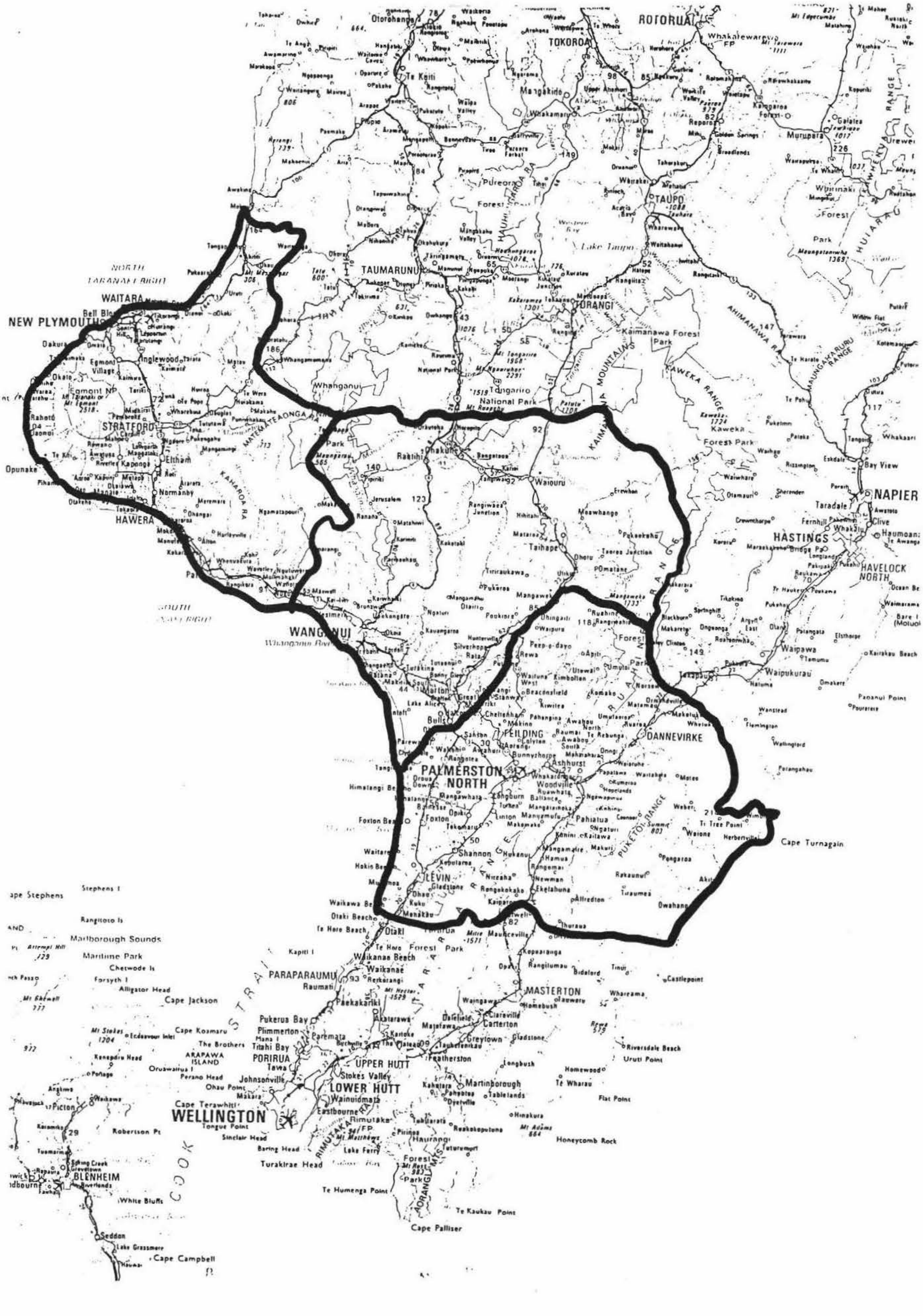
Right to Complain

1. Every consumer has the right to complain about a provider in any form appropriate to the consumer.
2. Every consumer may make a complaint to –
    a)The individual or individuals who provided the service complained of; and
    b) Any person authorised to receive complaints about the provider; and
    c) Any other appropriate person; including –
        i) An independent advocate provided under the Health and Disability Commissioner Act (1994); and
        ii) The Health and Disability Commissioner.
3. Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.
4. Every provider must inform a consumer about progress on the consumer's complaint at intervals of no more than one month.
5. Every provider must comply with all other relevant rights in this Code when dealing with complaints.
6. Every provider, unless an employee of a provider, must have a complaints procedure that ensures that –
    a) The complaint is acknowledged in writing within working days of receipt, unless it has been resolved to the satisfaction of the consumer within that period; and

- b) The consumer is informed of any relevant internal and external complaints procedures, including the availability of –
    - i) Independent advocates provided under the Health and Disability Commissioner Act (1994); and
    - ii) The Health and Disability Commissioner; and
- c) The consumer's complaint and the actions of the provider regarding that complaint are documented; and
- d) The consumer receives all information held by the provider that is or may be relevant to the complaint.

7. Within ten working days of giving written acknowledgement of a complaint, the provider must –
    - a) Decide whether the provider –
        - i) Accepts that the complaint is justified; or
        - ii) Does not accept that the complaint is justified; or
    - b) If it is decided that more time is needed to investigate the complaint –
        - i) Determine how much additional time is needed; and
        - ii) If that additional time is more than 20 working days, inform the consumer of that determination and of the reasons for it.
8. As soon as is practicable after a provider decides whether or not it accepts that a complaint is justified, the provider must inform the consumer of –
    - a) The reason for the decision; and
    - b) Any actions the provider proposes to take; and
    - c) Any appeal procedures the provider has in place.

Appendix Two - Map of Advocacy Network Services Region



Appendix Three - Ethical Proposal

MASSEY UNIVERSITY
APPLICATION TO HUMAN ETHICS COMMITTEE

Name:	Natalie Wealleans
Status of Applicant:	Masters Student
Department:	School of Policy Studies and Social Work
Employment:	Not Applicable
Project Status:	Masters of Social Work Thesis
Funding Source:	
Supervisors:	Associate Professor Robyn Munford Mr. Richard Shaw
Title of Research:	An Analysis of the Implementation and Outcomes of the Health and Disability Commissioner's Act (1994).
Attachments:	Information Sheet Consent Form

Signatures: **Researcher** ______________________

Supervisors ______________________

____

Date: 14 May 1998

1. DESCRIPTION

1.1 Justification

The Health and Disability Commissioner Act (1994) is a world first in promoting and protecting the rights of consumers of health and disability support services. Research and commentary on the formation, implementation and outcomes of the Act is scarce. This thesis will use policy evaluation research to examine the implementation of the policy and analyse the outcomes from the perspectives of consumers and advocates. This requires input from consumers of services and the advocates that administer part of the legislation. This information will highlight positive and negative aspects of the policy, coupled with possible alternatives for future policy development.

1.2 Objectives

- To provide a detailed analysis of the implementation of the Health and Disability Commissioner's Act (1994).
- To examine whether or not the Act met its stated policy objectives from the perspective of advocates and consumers.
- To examine whether or not the policy met the desired objectives of consumers.
- To examine whether or not the legislation has met the desired objectives of advocates, employed to uphold and promote the Code of Rights under the Act.
- To provide suggestions for alternative policy developments and/or implementation tools to assist the legislation in meeting the desired goals and objects of the policy, consumers and advocates.

1.3 Procedures for Recruiting Participants and Obtaining Informed Consent

- Two focus groups will be held to gather information and data. These groups will consist of advocates in one group and consumers in the other.
- Participants will be recruited from a sample in the lower North Island region. The service that is contracted by the Health and Disability Commission to provide services in this region is Advocacy Network Services (ADNET). They cover Tararua, Manawatu, Wanganui, Taranaki and Horowhenua.

- The board of ADNET and the Director of Advocacy at the Health and Disability Commission (HDC) will be contacted and asked to participate in the research, by allowing the researcher access to participants. If permission is granted then the manager of ADNET will be asked to provide advocates in this service with the Information Sheet on the research. Advocates will then be invited to contact the researcher who will clarify the information, and invite them to participate in the focus group.
- ADNET will also be asked to contact several consumers and provide them with the Information Sheet and an invitation to contact the researcher. The researcher will clarify the information stated in the Information Sheet and invite consumers to attend a consumer focus group.
- Informed consent will be obtained before the focus groups. The Consent Form will be posted to participants when they have indicated a willingness to participate in the research. They will have the opportunity to discuss with the researcher any concerns they have about participating in the research.

1.4 Procedure in Which Research Participants will be Involved

- Participants will be asked to attend a focus group meeting. This meeting will last approx. 2 hours in duration.
- Further contact may be required subject to the experiences and/or wishes of focus group participants. This will be negotiated with participants.
- The meeting will be facilitated by the researcher.
- There will be a list of set questions that the participants will have been sent prior to the meeting.
- The researcher will facilitate a discussion based on these questions.
- This meeting will be audio recorded for the purpose of transcribing the information gathered. If someone, other than the researcher, is employed to transcribe the audio tapes, then this person will be subject to the provisions of a confidentiality agreement.
- Participants may withdraw from the research at any stage of their involvement.

- The consumers' focus group will be made up of health and disability consumers. Therefore, participants will be invited to bring interpreters/support people if necessary. These support people will be required to sign a Consent Form before the focus group meeting.

1.5 Procedure for Handling Information and Material

The information gathered from the focus groups will be transcribed from the tapes recorded. This transcription will not identify individual participants and their confidentiality and anonymity is guaranteed. Participants will be identified by pseudonyms. The final research information will be used to fulfil the partial requirements for the Masters of Social Work. The information may potentially be used for subsequent publications by the researcher and supervisors. No information will be published that will indicate the identity of participants.
Steps taken to secure data will include:

- Secure storage of both tapes and transcripts in separate locations in the researcher office.
- Separate storage of paper and disk copies of interview transcripts.
- Destruction of the tape recordings of interviews once the thesis has been completed and the examination process concluded (unless interviewees choose to have recordings returned to them or archived).

2 ETHICAL CONCERNS

2.1 Access to Participants

- Access to participants is at this stage primarily reliant on the approval of HDC and the involvement of Advocacy Network Services (ADNET). The advocates and consumers that will participate in the two focus groups will be gathered from ADNET.
- Both groups will be provided with an Information Sheet. In the first instance, with advocates, the Information Sheet will be given to advocates by the

manager of the service at a monthly meeting. With consumers, ADNET will be asked to address the Information Sheet to consumers and ask for their permission to be contacted by the researcher.

- ☐ Once contact has been made between the researcher and the participants, they will be provided with the Consent Form.
- ☐ If Advocacy Network Services does not want to participate in the recruiting of participants, then it will be necessary for the researcher to advertise for participants. This would involve taking out advertisements in regional newspapers, community newsletters and on noticeboards at social service agencies. The advertisements would simply state the nature of the research and the desire for consumers past and/or present of ADNET to contact the researcher if they are interested in participating. Participants would then be sent the information sheet, consent form and question sheet prior to the arranged meeting time.
- ☐ If the advocates employed by ADNET are not willing to participate in the research, or ADNET prohibits their involvement, then the focus group will not occur.

2.2 Informed Consent

All of the participants will be provided with an Information Sheet on the research. If they agree to participate their consent will be sought. They will be provided with the Consent Form prior to their participation in the focus group meeting. It will be made clear to all participants that they can withdraw from the research at any stage and that they can ask the researcher questions about the research and their involvement at any stage.

2.3 Anonymity and Confidentiality.

All participants in the focus groups will be ensured anonymity and confidentiality. The transcribing of the tapes of the focus groups will provide pseudonyms. The data will be aggregated and where quotes are used pseudonyms will be used. Where quotes are used within the text, permission will be sought by the researcher. Participants will be provided with the text that includes their quote and will be asked to consent to the use of the quote. At no time will participants' identity be exposed. Furthermore, collected data will be stored appropriately to safeguard the information.

2.4 Potential Harm to Participants

Because of the undertaking to provide confidentiality, anonymity and given the safe storage of data, there will be no harm to participants.

2.5 Potential Harm to Researcher

No harm to the researcher is envisaged.

2.6 Potential Harm to the University

No harm to the university can be identified.

2.7 Participants' Right to Withdraw

Consumers and advocates can decline involvement. Participants will be informed of their rights when they receive their Information Sheet and Consent Form. All participants can withdraw from all or part of the research at any stage of their involvement.

2.8 Uses of the Information

The information gathered while doing this research will only be used for the masters thesis and for any subsequent publications that result from the thesis. A copy of the thesis will be located at the regional office of ADNET and be made available to all participants to access.

2.9 Conflict of Interest/Roles

The research is being carried out to fulfil the requirements for the Masters of Social Work and presents no conflict of interest for the researcher.

2.10 Other Ethical Concerns

No other ethical concerns are identifiable.

3. LEGAL CONCERNS

3.1 Legislation

3.1.1 Intellectual Property Legislation, e.g. Copyright Act (1994).

All research data, analysis and reports will belong to the researcher.

3.1.2 Human Rights Act (1993)

Participants will be treated with dignity and respect. There is no mechanism within the research for participants to be discriminated against. All measures that are practicable will be employed to ensure the needs of consumers and advocated are met for their equal participation.

3.1.3 Privacy Act (1993)

All of the information collected will only be used for stated purposes, and will not be privy to any other parties in the raw form. Participants will be asked to give their consent for the information they provide to be used within the parameters of the study.

In accordance with the Health Information Privacy Code, ADNET will not provide the researcher with information that identifies consumers or allows the researcher to contact consumers, until consumers have given their consent to ADNET.

3.1.4 Health and Safety Employment Act (1992)

No relevance to the present study.

3.1.5 Accident Rehabilitation and Compensation Insurance Act (1992)

No relevance to the present study.

3.1.6 Employment Contracts Act (1991)

No relevance to the present study.

3.2 Other Legal Issues

None.

4. CULTURAL CONCERNS

The focus of the research is such that no major cultural issues will be encountered.

5. OTHER ETHICAL BODIES RELEVANT TO THIS RESEARCH

There are no other ethical bodies relevant to this research. However, the ethical policies that guide the activities of the Health and Disability Commission and Advocacy Network Services will be taken into consideration and will not be breached while conducting this research.

6. OTHER RELEVANT ISSUES

None.

Appendix Four - Information Sheet and Consent Form

An Analysis of the Implementation and Outcomes Of the Health and Disability Commissioner Act (1994)

INFORMATION SHEET

Researcher:	Natalie Wealleans
Contact Details:	School of Policy Studies and Social Work, Massey University, Private Bag 11 222, Palmerston North
Phone:	06 356 2800
Supervisors:	Ass. Prof. Robyn Munford Richard Shaw
Phone:	06 356 9099

I am a Masters of Social Work student and am conducting this research to complete my thesis. The research examines the implementation and outcomes of the Health and Disability Commissioner Act (1994). This includes, the Code of Rights and advocacy services. I wish to evaluate the extent to which the legislation has lived up to your expectations.

I am going to evaluate the legislation by analysing the policy and by holding two focus groups. There will be a focus group for advocates and a focus group for consumers. The questions that will be asked will be about your experiences. You will be provided with these questions before the meeting. I will facilitate this meeting by asking the questions and generating a discussion about the questions. The discussion will be audio taped to help with writing up the information gathered. I will discuss with you the need for audio taping before you give consent and agree to participate in the research. If you would not like to be audio taped then the recorder may be turned off. However, given that this may disrupt the process of the focus group you may decide not to participate in the research. The meeting will take approximately two hours. Further meetings may be required subject to the experiences and/or wishes of the focus group participants. This will be addressed at the end of the first focus group. You do not have to attend more than one focus group meeting if you do not wish to.

As an advocate or as a consumer, you are invited to take part in one of these focus groups. You have been selected for the research because it is believed that you have valuable knowledge and experiences to share. Advocates have been selected by the Board and manager of Adnet. Consumers have been selected by advocates, from the data base of consumers that have accessed the service of Adnet..

Your formal consent will be obtained before the meeting. I will send you a Consent Form, and the questions that will be discussed at the meeting. You can contact me if you have any questions about the Consent Form or the research. If you need an interpreter, or would like to bring a support person, then please contact me so that this can arranged. Your support person will also be asked to fill in a Consent Form. You can withdraw from the meeting at any stage or opt not to answer certain questions.

Should you elect to be involved in this research and attend a focus group meeting, then you will have access to a copy of the summary research findings if you request it. Alternatively, a copy of my research will be given to Advocacy Network Services, and will be available for you to read.

I will transcribe the audio tapes used and then destroy them. You will not be identified in the research. The information gathered, including the tapes and the transcription disks and paper copies, will be securely stored until the research is completed. Once the research is completed the data will be destroyed by the researcher. The information gathered will only be used for the research project and any publications resulting from the research project. If I quote you in the research, I will use a pseudonym, and you will be asked to consent to the quote being included before the thesis is published.

If you would like to participate in the research or wish to raise further questions with me before deciding whether or not to participate, then please contact me.

An Analysis of the Implementation and Outcomes Of the Health and Disability Commissioner Act (1994)

CONSENT FORM

I have read the information sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used. The information will be used only for this research and any publications arising from this research project.

I understand that if I do not wish to be audio taped the tape can be turned off. This will be discussed prior to the focus group meetings.

I agree to undertake in this study under the conditions set out in the Information Sheet.

Signed: ______________________________

Name: ______________________________

Date: ______________________________

Appendix Five - Letters and Discussion Points for Participants

This appendix includes the letters sent to the two participant groups, advocates and consumers. As well as, the discussion points. There are different letters and discussion points for the two focus groups.

School of Policy Studies and Social Work
Massey University
Private Bag 11 222
Palmerston North
Ph: 06 356 2800

1 July 1998

Dear Advocates

I would like to confirm that the Advocate focus group Meeting will be held on Wednesday, 22 July, 10.00am at the Adnet Offices in Wanganui.

The meeting will begin with a general discussion on the format to be followed, with any questions that you have about the research, meeting or your participation being answered. I will also collect your signed consent forms.

The meeting will have to be structured to get through the questions and we will set some ground rules on the day, to ensure that everyone is given the opportunity to participate.

Please find enclosed a copy of the Consent Form and Discussion Points for Advocate focus group Meeting.

I really appreciate your willingness to be involved in this research. Your input is absolutely invaluable to the outcomes and will make a significant contribution to the data collected. Thank you for agreeing to participate. I look forward to seeing you at the meeting.

Regards

Natalie Wealleans

Advocacy Focus Group Discussion Points

1. Consumerism

What does the term 'consumer' mean for you?

In your view, is 'consumer' an appropriate term to use to describe peoples' relationship with the disability/health system?

Does this notion suggest that citizens are able to do anything other than consume services?

2. Health Reforms

To what extent have the reforms to health and disability impacted on peoples' ability to participate in decisions about service delivery?

How have the reforms impacted on the environment that you practice in?

3. Advocacy

What is advocacy?

4. Empowerment

What is empowerment and how does it work?

5. Code of Rights

If you were creating a Code of Rights for consumers, what would you include? e.g. resourcing?

6. Structure of HDC

Does the organisational structure of HDC work effectively?

School of Policy Studies and Social Work
Massey University
Private Bag 11 222
Palmerston North
Ph: 06 356 2800

24 July 1998

Dear Consumer

Thank you for indicating a willingness to participate in a focus group meeting for my research.

I would like to confirm that the Consumers' Focus Group Meeting will be held on Tuesday, 4 August 1998 at 155 Grey Street, Palmerston North. This is the same location as the Adnet offices, and we will be using one of the rooms in the house. The focus group will begin at 3.00pm and take approximately two hours.

The meeting will begin with a general discussion on the format to be followed, with any questions that you have about the research, meeting or your participation being answered. I will also collect your signed consent forms.

The meeting will have to be structured to get through the questions and we will set some ground rules on the day, to ensure that everyone is given the opportunity to participate. We will take a short break mid-way to have a cup of tea or coffee.

Please find enclosed a copy of the Consent Form and Discussion Points for the Consumers' Focus Group Meeting.

I really appreciate your willingness to be involved in this research. Your input is absolutely invaluable to the outcomes and will make a significant contribution to the data collected.

If you have any queries, then please do not hesitate to contact me. I would also appreciate it if you could please give me a quick call to confirm that you will be able to attend.

Thank you for agreeing to participate. I look forward to seeing you at the meeting.

Yours sincerely

Natalie Wealleans

Consumer Focus Group Discussion Points

1. Consumerism
What does the term 'consumer' mean for you?

In your view, is 'consumer' an appropriate term to use to describe peoples' relationship with the disability/health system?

Does this notion suggest that citizens are able to do anything other than consume services?

2. Health Reforms
To what extent have the reforms to health and disability impacted on peoples' ability to participate in decisions about service delivery?

How have the reforms impacted on the services that you or your family members receive?

3. Empowerment
What does empowerment mean and in your experience how does it work?

4. Code of Rights
If you were creating a Code of Rights for consumers, what would you include? e.g. resourcing?

5. Advocacy
What does advocacy mean to you?

Do advocacy services work, why, why not?

6. The Health and Disability Commissioner Act
The stated purpose of the Act was to set up the Code of Rights, HDC and Advocacy Services to promote and protect the rights of consumers of health and disability services through the fair, simple, speedy and efficient resolution of complaints.

Are consumers' rights being promoted and protected effectively? Why, why not?

Are complaints being resolved in a fair, simple, speedy and efficient manner?

Would your desired objectives/purpose of the Act differ from what the Government have stated? If so how and why?

Appendix Six - Advocacy Network Services Trust Inc.

The Director of Advocacy, on behalf of the Health and Disability Commissioner has contracted Advocacy Network Services Trust Inc. (Adnet). Their duty is to provide advocacy services, as stated under the Act, to consumers of health and disability services in their region. Adnet is a non-profit organisation that was established in April 1996 and has been providing services since 1 July 1996. The region that they cover includes New Plymouth, Wanganui, Manawatu, Tararua, Horowhenua, Rangitikei and the southern end of the Ruapheu District[1]. The estimated population of this region is 332,542 people (Adnet, 1997).

Adnet is funded through its contract for one full time equivalent (FTE) advocate per 110,000 people. There are 3 FTE positions at Adnet, with six advocates making up the positions. The spread of advocates allows Adnet to have offices in Palmerston North, New Plymouth, Stratford and Wanganui. The latter is the main office of Adnet and houses an advocate, the manager and the administrative assistant.

A Board of Trustees directs the operation of Adnet. There are ten trustees in total. Only two trustees are permitted to be employed by, or on contract with, providers of health and disability services. The remaining eight must be otherwise removed from professional contact with the health and disability services arena. This stipulation is clearly stated in the contract agreement that Adnet has with the Director of Advocacy. The Trust Deed states that the criteria for trustee appointment to the Board includes:

- Legal knowledge relevant to the objects
- Knowledge of health and disability services
- Knowledge of disability perspectives
- Knowledge of Maori health perspectives

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[1] Appendix Two contains a detailed map of this region.

- ☐ Management and commercial knowledge and experience
- ☐ Commercial and financial management experience.

The original members of the Board were hand picked by those responsible for securing the contract with the Director of Advocacy. Four of these members have resigned. New trustees are recruited by advertising in regional newspapers. There are also two Maori advisers to the Board.

The mission statement of Advocacy Network Services Trust Inc. is:

> *'To empower consumers of health and disability services to voice their complaints and concerns by the provision of information and support that allows for resolution at the lowest possible level.'*

Adnet is contracted to provide advocacy to consumers, promote the Code of Rights to consumers and providers, receive enquiries and receive and refer cases to the Health and Disability Commissioner. These functions are audited and monitored by the manager of Adnet and the Board on a regular basis. The Director of Advocacy also audits them on an annual basis.

Appendix Seven - Initial Mail Out to Consumers

The initial mail out to consumers' consisted of a covering letter from Adnet, a letter from the researcher and the Information Sheet

School of Policy Studies and Social Work
Massey University
Private Bag 11 222
Pamerston North
Ph: 06 356 2800

10 July 1998

Dear Consumers

Please find enclosed a copy of the Information Sheet for my research. This letter and Information Sheet are an invitation for you to attend a focus group meeting and participate in the research.

I have scheduled a tentative date for the consumer focus group meeting on Tuesday, 4 August 1998. The meeting would be sometime in the afternoon. This is not a set date or time. These will be confirmed after consultation with you on what is the most convenient. The meeting will be held in Palmerston North.

Most of the information that you should require is on the Information Sheet. However, if you have specific questions that you would like to ask before deciding to participate, then please do not hesitate to contact me. Your prompt response to this invitation would be most appreciated.

I look forward to hearing from you soon.

Yours sincerely

Natalie Wealleans

Advocacy Network Services (Adnet)
PO Box 782
Wanganui
Ph: (06) 3480074
Fax: (06) 3480473

Dear Sir/Madam

Adnet is currently supporting Natalie Wealleans in her research project for her thesis at Massey University. Natalie's project is directed at the implementation of the Health and Disability Commissioner Act (1994) and includes advocacy.

You have been selected by one of our advocates as a person who may be willing to participate in Natalie's project. I can assure you the researcher has not be involved in the selection process and therefore has not had access to information held by Adnet. Your identity has not been revealed to the researcher, therefore if you choose not to participate she will not be able to contact you.

Attached to this letter is an information sheet and covering letter from Natalie. If you choose to participate you may contact Natalie directly, if you do not want to be involved it would be appreciated if you would let one of the advocates know by phoning Palmerston North (06) 353 7236 or 0800 423 638. The reason I ask you to let us know if you don't want to participate is to enable us to offer the opportunity to other consumer's, who have contact with Adnet.

I would like to take the opportunity to thank you for using our service and hope you will be able to participate in supporting Natalie in her research.

Yours sincerely

Stacy Wilson
Manager