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# **FROM THE WARD TO THE HOME:**

## **Caring for a Family Member Diagnosed with Schizophrenia in New Zealand**

This thesis presented in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Social Policy and Social Work at Massey University by

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## ABSTRACT

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The research question examined in this thesis is: 'What are the characteristics and complexities of the informal care provided within a family to a member diagnosed with schizophrenia, in New Zealand? This research question is divided into two parts. The first part examines the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia and the second part explores how this care provision is influenced by the social, political, cultural, legal and economic context of New Zealand. This research is important because first, very little is known about the process and interpretation of care provided to a family member diagnosed with schizophrenia and second, New Zealand places great emphasis upon deinstitutionalisation and community care.

Ten women and four of their husbands were invited to participate in this research. These women were the primary informal care-givers of a family member who had experienced the cyclical acute and chronic episodes of schizophrenia. The women's husbands filled a secondary supporting role in relation to the women. The women met to identify themes related to their informal care provision. These themes were translated into an interview guide which acted as a prompt for the researcher while the women and men were articulating their stories of care-giving.

Foremost amongst the findings of this research was that the dominant understandings of care should be extended in order to reflect the informal care provided to a family member diagnosed with schizophrenia. The men supported the women's care provision which reflected their family member's unpredictable, changeable and cyclical symptoms of schizophrenia. It was characterised by the primacy of supervision and monitoring and was provided on a continual (flat-line) basis. It was also established that the women were finding it increasingly difficult to meet their informal caring responsibilities, these responsibilities being increased and extended by the Government's actions to reduce both state expenditure and state caring responsibilities. The

difficulty the women were experiencing in meeting the complex and changing care needs of their family member indicated that a continuum of care needs to be provided. It is argued that a continuum of care will need to include early intervention services, a range of community-based and institutionally-based mental health services, and a review of the definition of 'mentally disordered' contained within the Mental Health (Compulsory Assessment and Treatment) Act 1992. In order to coordinate and provide such a continuum of care, state, community and family caring responsibilities need to be combined, these three caring agents working collaboratively.

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## ACKNOWLEDGMENTS

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When beginning the task of completing this thesis, I had little appreciation of how difficult, and at times, how daunting this task would be. It was the encouragement and support of many people which facilitated the completion of this thesis. It is to some of these people that I now express my appreciation.

The richness and detail presented in this thesis stems primarily from the experiences, feelings, and thoughts expressed by the women and men who participated in this research. Each one of these individuals shared aspects of their lives through telling me their stories of the care they provided to their family member diagnosed with schizophrenia. I acknowledge their commitment to their caring work and wish them well as they face future challenges this commitment will undoubtedly bring them.

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I gained both a national and local understanding of the complexities of providing care to a family member diagnosed with schizophrenia, in New Zealand, by my involvement with Schizophrenia Fellowship. The assistance and support Schizophrenia Fellowship provided the participants is highlighted in this thesis.

On a day-to-day basis I was given much assistance and personal support from friends and members of my family. Your reward for this assistance and support will be seeing me engage the world with the time I used to spend working on my thesis. The possibilities are endless.

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## INTRODUCING THE THESIS

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This thesis examines the characteristics and complexities of the care provided within a family to a member diagnosed with schizophrenia, in New Zealand. The following discussion provides an overview of this research. Initially, the discussion identifies and briefly describes the way in which New Zealand has in the past and is currently meeting the needs of both those individuals exhibiting the symptoms of mental illness and their care-givers<sup>1</sup>. This examination will refer to both mental health policy and service provision. Attention is then turned to the research question of this thesis which is, 'What are the characteristics and complexities of the care provided within a family to a member diagnosed with schizophrenia, in New Zealand?' It is proposed that the research question can be divided into two parts. Specifically, 'What are the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia?' and 'How is this care provision influenced by the social, political, cultural, legal and economic context of New Zealand?' The implications of these two components for this research are outlined. Finally, the format of this thesis is described.

### **New Zealand's Mental Health Policy and Service Provision**

This research has been completed at a time when mental illness has consistently featured in New Zealand's media and political arenas. This is evidenced by the commission of yet another inquiry into New Zealand's mental health services, in November 1995, lead by Judge Mason (The Dominion, 1995c). The attention directed towards mental illness has both driven, and responded to, the concern and interest held by the general public. This concern and interest has primarily arisen from the increased contact the general public has been having with individuals exhibiting the symptoms of mental illness. As will be confirmed below, changes in policy have meant that mental illness is not as concealed or as controlled as it was previously under the policies of institutionalisation<sup>2</sup>. The

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<sup>1</sup> The term 'care-giver' refers to that person, typically a woman, who provides care and support to another who requires it. Other terms utilised in this thesis which are synonymous with the term 'care-giver' are 'carer', and 'care-provider'.

<sup>2</sup> Institutionalisation is the process whereby people are cared for custodially, within institutions removed from their community.

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boundaries indicative of institutional care, which used to control schizophrenia and the people exhibiting its symptoms, are not present in 'the community'. Attention will now turn to acknowledging the changes which have occurred in New Zealand's mental health policy and service provision. This discussion highlights the need to identify and acknowledge the various contradictions and conflicts which permeate the debates about the direction New Zealand's mental health services should take.

### **Deinstitutionalisation and Community Care**

New Zealand has followed other countries in the Western world in no longer considering institutionalisation to be the most effective way of providing services to those individuals who require care. In reflecting this, New Zealand's mental health services have been directed by an adherence to both deinstitutionalisation and community care. These policies will be discussed below.

#### *Deinstitutionalisation*

Deinstitutionalisation has involved the dual process of releasing patients from New Zealand's large geographically isolated psychiatric institutions, and not admitting persons as long-term patients unless absolutely necessary. It will be argued in this thesis that legislation, such as the Mental Health (Compulsory Assessment and Treatment) Act 1992 (New Zealand Government, 1992), has led to 'absolutely necessary' referring to those situations in which an individual is a danger to themselves or members of their community. In other words, the threshold for entry into New Zealand's mental health services has been increased. This increase reportedly has meant that individuals who have voluntarily approached their local mental health services have been turned away, that is until they themselves have reached crisis point (Chapple, 1994; Christchurch Press, 1995; O'Hare, 1994; Mason, 1994; The Dominion, 1995d). Those who exhibit the symptoms of schizophrenia are particularly affected by the focus the mental health system currently is placing upon those individuals in crisis. The unpredictability and changeability of these symptoms mean that the care needs of a person can dramatically increase in a short period of time. While many individuals can be talked into approaching the mental health system when their symptoms of schizophrenia are less acute, the same individuals are typically unable to understand or accept that they need professional help while exhibiting

the acute symptoms of schizophrenia, such as hallucinations<sup>3</sup> and delusions<sup>4</sup>. One consequence of the focus upon crises is that informal care-givers are having to deal with the fluctuations in their care-recipient's<sup>5</sup> behaviours and thoughts; these fluctuations being triggered in part by the uncertainty and changing environment characteristic of a community setting.

Deinstitutionalisation in New Zealand is a planned process. At the height of institutionalisation New Zealand had one private hospital and nine public psychiatric hospitals (Dowland & McKinlay, 1985). New Zealand's fifteen psychiatric units also provided some residential care. The number of functioning psychiatric hospitals has been steadily reducing. Slowly replacing these institutions have been smaller more locally based secure units. It is within these units that acute care is provided. Discussion in this thesis will note the concern about whether the number of beds available in secure units are adequate enough to meet client need (Burns et al, 1994). In continuing with the process of reducing the number of large and geographically isolated psychiatric institutions, those still operating in New Zealand have been provided, by the state, with a time line which stipulates the pace at which these facilities will be closed.

### *Community Care*

Paralleling the closing of New Zealand's traditional institutions have been proposals for developing New Zealand's community mental health services. These proposals advocate the trend towards 'community care'. Reflecting the lack of consensus about the definition of 'community' (Pearson, 1990; Peters & Marshall, 1988; Shirley, 1979), these proposals appear to advocate both care in the community and care by the community. Care in the community refers to where services will be provided, whereas care by the community refers to who will undertake the caring work (Abrams, 1977; Finch, 1990; Lewis & Meredith, 1988). The tensions between care in the community and care by the community are understood when considering the wider political and economic context in which

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<sup>3</sup> Hallucinations are when an individual sees, hears, smells, feels, tastes sensory perceptions which are not present.

<sup>4</sup> Delusions are false and persistent beliefs not substantiated by a person's culture or environment.

<sup>5</sup> The term 'care-recipient' refers to that person in a caring relationship who, as a consequence of some impairment, requires care from another. Other terms utilised in this thesis which are synonymous with 'care-recipient' are 'cared for' and 'family member'.

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community care is being advocated<sup>6</sup>. For example, it can be argued that it is unlikely for care in the community to be fully supported when the Government is advocating reduced state expenditure and reduced state responsibility for care provision.

The tensions between care in the community and care by the community are reflected in the inadequacies of New Zealand's community-based mental health services. Reviews over time have consistently found these services to be uncoordinated, inaccessible and unintegrated (National Advisory Committee on Core Health and Disability Support Services<sup>7</sup>, 1993). The reality of these inadequacies is experienced by many people with a psychiatric disability on a daily basis. These individuals receive little if no professional support and treatment. Often their accommodation is sub-standard, their basic needs not being met. The consequences of the lack of professional involvement some individuals receive, and the complex nature of disorders such as schizophrenia, have been highlighted by frequent media reports describing acts such as murder or suicide committed by people diagnosed with schizophrenia (Wanganui Chronicle 1995a, 1995b).

Policy documents have indicated that New Zealand's community-based mental health services will include an integration of environmental and clinical support services (Central Health Authority<sup>8</sup>, 1994a). Environmental support includes: support for independent living; supported housing; day services; respite care; carer support; and, client support networks. Clinical support includes: acute care; community mental health teams; intensive care; and, primary health care. While there is state acknowledgment that New Zealand's community mental health services need to be integrated, concern is expressed about how comprehensive this integration will be. First, concern has been expressed that the level of environmental and clinical support, which is targeted for, is too low (Burns et al, 1994). Mental health services then may still not be adequate enough leaving many New Zealanders exhibiting the symptoms of mental illness without professional support. Second, as noted above, there have been numerous

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<sup>6</sup> This context is described more fully further on in this thesis.

<sup>7</sup> The National Advisory Committee on Core Health and Disability Support Services is now referred to as National Advisory Committee.

<sup>8</sup> The Central Health Authority is now referred to as CRHA.

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reviews about New Zealand's mental health services, these reviews calling for an integrated mental health system. The recommendations and insights forwarded by these reviews largely have been shelved and not actualised. Therefore, there is some hesitancy to believe that state acknowledgment for the need to provide integrated mental health services will be acted upon. With this history, it will be interesting to hear the findings of the current inquiry led by Judge Mason and see the extent to which Government adheres to the recommendations this inquiry makes. Third, the question is constantly raised as to why the integrated mental health services, currently proposed in New Zealand's policy documents, have not previously been developed. This is particularly the case when acknowledging that New Zealand has followed the direction its overseas counterparts have taken regarding mental health services. New Zealand should have learnt from the experiences of these counterparts instead of following directly in their footsteps.

### **The Effectiveness of Proposed Policy Changes**

In acknowledging the current difficulties and inadequacies associated with the mental health arena, the New Zealand Government has identified mental health as a priority health issue (Minister of Health, 1994b). In giving mental health a priority status, the New Zealand Government has conceded that changes need to be made with regard to the way people with a psychiatric disability are treated. In order to make such changes, increased funding has been allocated to the mental health arena. This increase in funding is a positive response when acknowledging that funding for mental health has historically been lower than the funding provided to other disability areas (Bascand, 1993; Minister of Health, 1994). However, it can be argued that providing increased funding to New Zealand's mental health services will not in itself improve the life circumstances of people diagnosed with schizophrenia and their informal care-givers. Challenges also need to be made for example to the stigma and discrimination which surrounds the diagnosis schizophrenia<sup>9</sup>. This stigma and discrimination often leads to fear, rejection and neglect of both those individuals who exhibit the symptoms of schizophrenia and their care-givers (Miller, 1995; National Mental Health Consortium, 1989)<sup>10</sup>. This has been illustrated in New Zealand by the

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<sup>9</sup> This stigma and discrimination typically arises from the incorrect understandings people hold about this disorder. Examples of such incorrect understandings are provided below.

<sup>10</sup> The current inadequacies of New Zealand's mental health services supports this statement.

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NIMBY<sup>11</sup> response. As individuals have been released from the various public psychiatric institutions around the country, neighbourhoods have rallied together to express their disapproval of a 'schizophrenic' or 'nutter' living next door. Feeding the NIMBY response have been those regrettable events reported in the media which have arisen generally as a consequence of a lack of professional support services (Wanganui Chronicle 1995a, 1995b). The NIMBY response indicates that the stigma and discrimination which surrounds mental illness need to be eradicated if either care by the community or care in the community is to be effectively implemented for people affected by mental illness.

The adequacy of proposed service levels for New Zealand's mental health services over the next three to ten years is again raised<sup>12</sup>. While mental health, or more specifically mental illness, has been firmly placed upon the political agenda, the question is asked as to whether the proposed changes will be significant enough to improve the lives of those persons diagnosed with schizophrenia and their care-givers. This is particularly the case when acknowledging the continuum of care required for schizophrenia alone (McGeorge & Fernando, 1993). As confirmed below, coupled with the variable prognosis or outcome of the diagnosis schizophrenia is the changeability and unpredictability which characterise the symptoms of this disorder<sup>13</sup>.

## **The Research Question**

As was noted above, this research examines the characteristics and complexities of the informal care provided within a family to a member diagnosed with schizophrenia, in New Zealand. The research question could be divided into two parts. First, what are the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia? And second, how is this care provision influenced by the social, political, cultural, legal and economic context of New Zealand? The following discussion will identify and discuss the key facets of this research question.

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<sup>11</sup> NIMBY is a mnemonic standing for 'Not In My Backyard'.

<sup>12</sup> The proposed strategic directions for New Zealand's mental health services are outlined in Chapter Three.

<sup>13</sup> These features of schizophrenia are discussed further on below.

## The Nature of Schizophrenia

Underpinning the first component of the research question is the premise that a care-recipient's schizophrenia may uniquely influence and shape the unpaid care they receive. Therefore, in order to examine the characteristics and complexities of the unpaid care provided to a family member diagnosed with schizophrenia, an understanding of schizophrenia itself is required. Historically there have been many different understandings and definitions of the diagnosis schizophrenia. Still prominent today are the following incorrect understandings: that schizophrenia is a split personality; that all people exhibiting the symptoms of schizophrenia are uncontrollable madmen who commit excessively violent acts; and, that people diagnosed with schizophrenia are spiritually possessed (Jones, 1995). Each of these understandings currently compete with the definition of schizophrenia forwarded in this thesis. The definition used in this thesis comes from the Diagnostic and Statistical Manual of Mental Disorders revised third edition<sup>14</sup> (DSM-III-R; American Psychiatric Association, 1987). The DSM-III-R contains the criteria most frequently used by mental health professionals to diagnose those individuals receiving care in the caring relationships examined in this research. DSM-III-R defines schizophrenia by the following symptoms: hallucinations; delusions; incoherence or marked loosening of associations<sup>15</sup>; catatonic behaviour<sup>16</sup>; flat or grossly inappropriate affect<sup>17</sup>; and, impairment in social functioning (American Psychiatric Association, 1987).

The complexity of schizophrenia is illustrated when acknowledging that the symptoms of schizophrenia can vary in type, intensity, duration, and frequency both between and within a person. Those individuals who are continually impaired by the symptoms of schizophrenia typically experience a cyclical pattern

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<sup>14</sup> The Diagnostic and Statistical Manual of Mental Disorders revised third edition is now referred to as the DSM-III-R.

<sup>15</sup> These symptoms refer to the individual's thinking. Incoherence is defined by Davison and Neale (1986:338): "*Although the patient may make repeated reference to central ideas or a theme, the images and fragments of thought are not connected*". Loose association refers to when an individual is unable to communicate consistently about one topic. Instead, the person's communication reflects a stream of consciousness where ideas run on from each other.

<sup>16</sup> While catatonic, the individual seems lifeless with no movement being exhibited by the person.

<sup>17</sup> Grossly inappropriate affect refers to when an individual's emotional responses are blunted or increased to an inappropriate level.

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of acute and chronic episodes<sup>18</sup> (Kaplan & Sadock, 1991). While two people may have the diagnosis of schizophrenia, these people may not have any symptoms in common.

While it is said that about one person in every hundred will exhibit the symptoms of schizophrenia during their lifetime (American Psychiatric Association, 1994a), the prognosis or outcome of the diagnosis schizophrenia is variable. About twenty to thirty percent of people diagnosed with schizophrenia are able to lead 'normal' lives after their first episode unimpeded by the symptoms of schizophrenia. Twenty to thirty percent continue to experience the symptoms of schizophrenia and forty to sixty percent of people diagnosed with schizophrenia continue to be significantly impaired by their symptoms for the rest of their lives (Kaplan & Sadock, 1991) This research examines the care provided to those persons in the last category.

As discussion in this thesis will illustrate, the treatments and services available for managing the symptoms of schizophrenia have reflected the different ways in which schizophrenia has been understood and defined over time. Currently neuroleptic medication is considered to be the most effective treatment for reducing the effects of these symptoms (Chouinard et al, 1993; Taylor, 1989). This is particularly the case with the newer neuroleptic medications which are effective on both the psychotic and non-psychotic symptoms of schizophrenia.

While the understanding of schizophrenia presented in DSM-III-R is typically supported by Western-based cultures, other cultures tend to explain schizophrenia differently. This will be highlighted when considering the different ways in which Maori<sup>19</sup> and *tau-iwi*<sup>20</sup> in New Zealand define health and illness. The question is raised in this thesis as to whether a care-giver's understanding of the disorder schizophrenia impacts upon their perception and experience of care-giving.

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<sup>18</sup> Acute episodes are characterised by psychotic symptoms such as hallucinations and delusions. Chronic episodes are when an individual is still impaired by the non-psychotic symptoms of schizophrenia.

<sup>19</sup> Maori are the indigenous people of New Zealand.

<sup>20</sup> *Tau-iwi* are those individuals who reside in New Zealand who are not related to the indigenous people of New Zealand. Other terms which are synonymous with *tau-iwi* are non-Maori and *pakeha*.

## The Nature of Informal Care

As well as requiring an understanding of schizophrenia, the first component of the research question necessitates an examination of care-giving work, specifically unpaid care provided to individuals, typically members of the family, who require assistance<sup>21</sup>. It has been feminist researchers and writers who have undertaken a detailed examination of both the facets of unpaid care and of who provides this care. Certain themes consistently arise from feminist caring literature. Foremost amongst these themes is first, the over-representation of women amongst those who undertake unpaid caring work (Dalley, 1988; Graham, 1983,1991; Hogan, 1990; Munford, 1989; Opie, 1991; Schultz & Schultz, 1990; Ungerson, 1983), and second, the physical, emotional and psychological costs women experience as a consequence of their care provision (Munford, 1989; Opie, 1992; Parker, 1985; Qureshi & Walker, 1989). Feminists have argued that it is women who, as a consequence of their unpaid care, are restricted on a daily basis by the routine nature of their care provision. The routinisation of women's care arises from their care-recipient's relatively constant need for personal care tasks such as feeding, toileting and dressing<sup>22</sup> (Twigg & Atkin, 1995).

An examination of the literature shows that feminist researchers have focused their attention on the care provided to a family member diagnosed with an intellectual, physical or age-related disability. Only very recently have feminist researchers and writers examined the care provided to persons with a psychiatric disability (Women's Affairs Victoria, 1994). This recent examination has indicated that there may be distinct differences in the characteristics of the care provided to a person with a psychiatric disability. For example, it has been proposed that personal care tasks are not the mainstay of this care (Twigg & Atkin, 1995). Proposals such as this, combined with an understanding of the unique characteristics of schizophrenia, suggest that traditional feminist understandings of unpaid care may need to be extended in order to better describe and explain the care examined in this thesis.

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<sup>21</sup> This unpaid care is also known as informal care.

<sup>22</sup> Exceptions to this consistency are noted. For example the care provided to individuals with dementia type illness and challenging behaviours can be characterised by some unpredictability.

Other researchers have examined the informal care provided to a family member diagnosed with schizophrenia. This research has acknowledged how some of the unique characteristics of schizophrenia impact upon this care provision. One of these characteristics is the unpredictability of the symptoms of schizophrenia. This unpredictability has been found to increase the burden that 'the family' experiences in their provision of care (Torrey, 1983). While acknowledging some of the ways in which the symptoms of schizophrenia impact upon the provision of unpaid care, existing research on schizophrenia and care has paid little attention to the process and interpretation of this care-giving work (Atkinson & Coia, 1995; Perring, Twigg & Atkin, 1990; Twigg & Atkin, 1995). In reflecting the fact that schizophrenia primarily has been researched by the professions of psychiatry and medicine, this research typically has utilised various scales and psychometric tests in order to establish the nature of care (Bulger et al, 1993). The results of these scales and tests provides little information about the day-to-day experiences and understandings of those who provide care to a family member diagnosed with schizophrenia (Atkinson, 1986).

While information about the process and interpretation of schizophrenia care has been limited, so to has the examination about how this care is distributed within 'the family'. Unlike feminist researchers, researchers on schizophrenia and care have not moved beyond 'the family' when considering the provision of care. Feminist caring research suggests that a more detailed analysis needs to be undertaken to ascertain the type and degree of care different family members provide.

### **The Context of Care**

The second component of the research question considers how the unpaid care provided to a family member diagnosed with schizophrenia is influenced by the New Zealand context. This thesis examines how the social, political, cultural, legal and economic context impacts upon the provision of unpaid care to a family member diagnosed with schizophrenia. When considering the New Zealand context particular trends, policies and themes come to the fore. Prominent amongst these are the implementation of deinstitutionalisation and community care, the inadequacies of New Zealand's mental health system, the identification of mental health as a health priority, and, the New Zealand Government's advocacy and implementation of market liberalism and Post-Fordism. The first

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three of these have already been discussed above. The implementation of market liberalism and Post-Fordism will briefly be discussed below.

Economic and social policies introduced by the 1935 Labour Government led New Zealand to be considered the social laboratory of the world (Shannon, 1991). New Zealanders were guaranteed the receipt of state welfare provision in all social service areas<sup>23</sup> from 'the cradle to the grave' (Kunowski, 1988; Oliver, 1988). The 1984 Labour Government challenged this understanding by advocating the implementation of market liberalism in all of New Zealand's economic and social policies. In other words, reduced state expenditure and increased individual responsibility for meeting welfare needs was emphasised (Douglas, 1993; Moore, 1993; Shannon, 1991; Shirley, 1992; Upton, 1987). The National Government has adhered to the principles of market liberalism, combining these principles with Post-Fordism. In adhering to market liberalism the state has tightened the eligibility and entitlement criteria for welfare services. This is evidenced, for example, by the 1991 benefit cuts and increased housing rentals and health costs (Barker, 1992; Bowie, 1992; Craig, Briar, Brosnahan & O'Brien, 1992; Kelsey, 1993). The state then has been devolving its caring responsibilities to the community and the family at a time these caring agents are finding it difficult to access the resources required to meet their member's needs. Further increasing the difficulty care-givers face is the adherence to Post-Fordism. For example, the state has actively contracted out its responsibility for service provision to an array of providers who have successfully competed for state contracts. These contracts specifically outline the type and volume of services which will be purchased by the state. The traditional universal benchmarks which have directed New Zealanders through their welfare system have been removed. It will be argued that this has increased the difficulty and uncertainty care-givers experience in providing informal care to a family member diagnosed with schizophrenia.

### **The Format of This Thesis**

The material presented in this thesis is grouped into four sections entitled 'Setting the Scene', 'Methodological Issues', 'The Lived Experience' and 'Looking Forward:

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<sup>23</sup> Specifically, health, housing, education and social security.

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Theory and Practice'. Each of the chapters, encompassed within these four sections, will be identified and described below.

Section one includes Chapters One to Four. The title of the first chapter is 'Schizophrenia Examined'. As the title suggests, the purpose of Chapter One is to examine and describe the particular characteristics of the disorder schizophrenia. First the definition of schizophrenia utilised in this thesis is provided. As was noted above, this definition is included in the DSM-III-R. Following this, the incidence, aetiology (cause), prognosis (outcome) and treatment of schizophrenia are described, respectively. The different explanations and understandings of schizophrenia are highlighted in each of these sections. These different understandings are further examined in the following section entitled "The Discourses of 'Disability', 'Mental Illness', and 'Schizophrenia'". 'Discourses' refer to the social construction of knowledge and practices (Fairclough, 1992). This section then identifies the multiple understandings and practices which surround 'disability', 'mental illness', and 'schizophrenia'. The question is raised as to why the dominant discourses of these concepts are accepted and maintained.

In Chapter Two, entitled 'The Nature of Care', the findings of a review of feminist caring literature and of the research on schizophrenia and care are presented. Discussion in this chapter begins with considering the question 'What is Care?' Potential similarities and differences in the unpaid care provided to a family member with an intellectual, physical, or age-related disability and the unpaid care provided to a family member diagnosed with schizophrenia are identified and described. These similarities and differences suggest that traditional feminist understandings of caring work may need to be extended in order to reflect the care examined in this thesis. After considering the characteristics and complexities of informal care, attention is turned to the question of 'Who Cares?' It is noted that feminists repeatedly have identified the over-representation of women amongst those who provide care. The distinct differences found by feminists between the care provision of women and men are described. Further differences between the care provided by parents and siblings are also outlined. Finally, it is noted that research on schizophrenia and care typically has not examined how care has been distributed within 'the family'. This restricted analysis has limited the understanding gained from existing research about the care provided to a family member diagnosed with schizophrenia. Finally, the

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attempts of some feminists to supersede the socially constructed public/private split are described (Baines, Evans, & Neysmith, 1992; Graham, 1991; Ungerson, 1990, 1995; Waerness, 1984). These feminists have proposed that the care provided by women should be considered as work regardless of whether this care takes place in the private sphere of home and family or the public sphere of paid work.

Chapter Three, entitled 'The Context of Care', moves beyond individual caring relationships to consider the context in which these caring relationships are situated. The volume of material to be considered necessitated that this material be divided into three parts. The first part is entitled 'The Agents of Care'. This title refers to the state, the community, and the family's role in the provision of care. The way in which the responsibility for meeting the welfare needs of New Zealanders has fluctuated over time between the state, the community, and the family is described. Particular attention is paid to the current combination of state, community and family responsibility for care

provision. It is noted that in following monetarist philosophy, the state is currently devolving its responsibility for the provision of care to the ill-defined community and family. This devolution of responsibility is occurring despite overseas calls for the merging of state, community and family responsibility for care (Cass, 1994). The implications of the current distribution of caring responsibilities between the state, the community and the family, for those women providing informal care to a family member diagnosed with schizophrenia are noted.

Part two of Chapter Three is entitled 'Policy and Practice'. The link is made between the Government's assumptions, about how care should be divided between the state, the community and the family, and the configuration of New Zealand's health and mental health services. Discussion begins by identifying the significance of the unique document, the Treaty of Waitangi, to New Zealand. It is argued that any discussion of New Zealand's health and mental health services must refer to the Treaty of Waitangi. Following this discussion, a brief history of New Zealand's health sector is provided. Particular attention is paid to how New Zealand's health services are currently arranged and delivered. New Zealand's mental health services are then described. The implementation of institutionalisation, deinstitutionalisation and community care in New Zealand's

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mental health arena is described in detail. Finally, legislation relevant to the health and specifically the mental health arena is identified and discussed. This legislation includes: the Mental Health (Compulsory Assessment and Treatment) Act 1992; the Privacy Act 1993; and the Human Rights Act 1993. Particular attention is paid to how New Zealand's social policy and service provision influences and shapes the care women provide to a family member diagnosed with schizophrenia.

'Future Issues' is the title of part three of Chapter Three. The future direction of New Zealand's mental health services is discussed. This discussion is facilitated by critiquing two consensus development documents, entitled 'Management of Major Psychoses' (McGeorge & Fernando, 1993) and 'Living At Home' (Naylor & Lardner, 1994). It is from consensus development documents that recommendations for the Minister of Health are derived. Future decisions for New Zealand's mental health services could be based upon the material presented in 'Management of Major Psychosis' and 'Living at Home'. The document 'Looking Forward: Strategic directions for the mental health services' (Minister of Health, 1994b) is also critiqued. 'Looking Forward' contains the strategies proposed by the current Minister of Health for improving New Zealand's mental health services to year 2000.

'A Framework For Analysis' is the last chapter in Section One. The discussion and analysis of the theory and policy presented in Chapters One, Two and Three are integrated in order to develop an analytical framework for examining what is currently known about 'care'. This analytical framework is presented in the form of what I have called the 'framework for analysis of care'. This framework consists of three main components, namely 'what is care', 'who cares', and the 'context of care'. The framework will be used to show the relationship between theoretical perspectives on care, the development of policy and its implementation, and the experiences of those who provide care to a family member diagnosed with schizophrenia. This dialogue will show how frameworks for analysis must reflect the characteristics and complexities of the informal care provided to a family member diagnosed with schizophrenia.

Section Two entitled 'Methodological Issues' contains Chapter Five. The fifth chapter entitled 'The Research Process', examines the methodological issues

surrounding the research in this thesis. It is explained that the methodology of this thesis utilised various research techniques, these techniques themselves arising from positivist, interpretive and participatory research paradigms and feminist principles. The first method of data collection involved reviewing both the existing literature on providing care to a family member diagnosed with schizophrenia and feminist research on care-giving<sup>24</sup>. As already noted, this review indicated some of the possible similarities and differences between these two bodies of literature and therefore potential similarities and differences between the care provided to a family member with an intellectual, physical or age-related disability and the care provided to a family member diagnosed with schizophrenia. Following this review, a questionnaire on needs of care providers of people diagnosed with schizophrenia was utilised as the primary method of recruiting participants for this research. The last question of this questionnaire asked for an indication as to whether the respondent wanted to participate in further research, namely the research for this thesis. Those care-givers who indicated that they wanted to participate in this research were invited to meet as a group<sup>25</sup>. At this first group meeting the care-givers were asked to identify those issues they felt needed to be examined in this research. This information was then utilised by myself to develop an interview guide which, in turn, was used as a prompt for the women when they told their stories about their care-giving experiences and how these experiences were influenced by the context

in which their caring relationships were situated. The method of storytelling was then utilised on a one-to-one basis with the women's husbands<sup>26</sup>. Involving the men allowed consideration of the similarities and differences between the women and their husbands experiences of care-giving. The women and men, respectively, met as a group to both discuss the findings of this research and consider the merits of future action which could improve their own and the experiences of others providing care to a family member diagnosed with schizophrenia.

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<sup>24</sup> As was noted above, only recently has research with a feminist focus examined the care provided to persons with a psychiatric disability.

<sup>25</sup> All of these care-givers were women.

<sup>26</sup> As will be explained in Chapter Four, the women requested that the men be called their husbands as opposed to using other terminology such as 'partners'.

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Section Three entitled 'The Lived Experience' includes Chapters Six, Seven and Eight. These three chapters describe the feelings, thoughts, actions and experiences of the participants of this research as described in their stories. Chapter Six, is entitled 'A Conundrum'. As is explained in that chapter, 'conundrum' is synonymous with puzzle or mystery. 'Conundrum' is the word many of the participants utilised when referring to their experiences before the diagnosis of schizophrenia was provided by the mental health profession to explain their family member's unusual and socially inappropriate behaviours and thoughts. These initial experiences of caring were associated by the participants with confusion, a lack of understanding of both schizophrenia and their family member, and trial and error. The material presented within this chapter describes the women's attempts to both define and respond to the conundrum their family member's unusual behaviours and thoughts had become. The women's isolation and lack of support in their provision of care to their family member is highlighted.

'Assuming Responsibility' is the title of Chapter Seven. The participants' feelings, thoughts, actions, and experiences described in this chapter begin with the diagnosis of schizophrenia being given to their family member by the mental health profession. The material presented in this chapter is divided into three parts. The first part, 'Naming the Moment', describes the participants' attempts to define and understand their family member's schizophrenia. Much of part one of this chapter is spent on translating the formal criteria of schizophrenia contained in DSM-III-R into the day-to-day experiences of the participants and their family members. Part two of this chapter is entitled "Choosing' to Care'. That 'choosing' is in inverted commas indicates that the women participating in this research felt certain pressures upon them to become their family member's informal care-giver. The main pressures identified by the women are discussed. Following this, the fact that the men filled a secondary supporting role while

the women assumed responsibility is described. 'Responding To The Decision To Care' is the third and final part to Chapter Seven. Part three continues to identify and describe those themes, issues and experiences the participants associated specifically with the women assuming responsibility.

Chapter Eight, entitled 'Being on Call', is the final chapter encompassed in the third section. This chapter describes the two events which allowed the women to

reduce their involvement in their provision of care. One of the events was when their family member took responsibility for their own health needs. The second event was when their family member entered long-stay institutionally-based mental health services. The tenacity of the women being able to first, reduce their care provision and second, continue to disengage in part from their care is highlighted. The fact that the men also reduced involvement in their supporting role while the women were on call is identified.

The fourth and final section, 'Looking Forward: Policy and Practice', includes the chapter also entitled 'Looking Forward: Policy and Practice'. It is in this fourth section of the thesis that the main findings of this research are revisited and extended. This discussion is guided by 'the framework for analysis of informal care provided within a family to a member diagnosed with schizophrenia'. This framework was developed in response to the participants' experiences and understandings of their informal care provision to their family member. The framework both helps us to remember the participants' accounts of their care provision and provides structure for understanding and researching the care provided within a family to a member diagnosed with schizophrenia. After considering the main findings of this research, the research process utilised in this thesis is reflected upon. Finally, issues for future research are identified and discussed.

## **S**ection One:

# **Setting**

# **the**

# **Scene**

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## 1. 'SCHIZOPHRENIA' EXAMINED

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This thesis examines the unpaid care provided within a family to a member diagnosed with schizophrenia, specifically within the New Zealand context. In order to successfully undertake this examination, an understanding of schizophrenia is required. In discussing schizophrenia in this chapter, particular reference is made to the definition provided by the Diagnostic and Statistical Manual for Mental Disorders (revised third edition; DSM-III-R; American Psychiatric Association, 1987). These were the criteria most frequently utilised by mental health professionals in New Zealand at the time those persons with schizophrenia, in the caring relationships explored in this research, were diagnosed. After schizophrenia has been defined, the incidence of this disorder is considered. The aetiology of schizophrenia is then discussed under the following categories: genetics; biochemicals; the family; cognitive; neurological; sociological; and the diathesis-stress model. The discussion of aetiology highlights both the lack of consensus about a single causal factor for schizophrenia and the understanding that schizophrenia is a heterogeneous disorder (Reed Healthcare Australia, no date; see also Bentall, 1992). Attention is then turned to the prognosis or possible future outcomes of the diagnosis of schizophrenia. As will be established, the prognosis of this diagnosis varies for each person depending on a combination of their personal and social characteristics. The treatment of schizophrenia is then briefly outlined. The importance placed on psychoactive medication as a strategy for reducing or controlling the symptoms of schizophrenia is stressed in this section.

Given that schizophrenia is predominantly researched and considered by medicine and psychiatry, discussion about the definition, incidence, aetiology, prognosis, and, treatment of schizophrenia contains terminology associated with these professions. Because this terminology has limited the accessibility of information explaining schizophrenia in the past, every attempt has been made in this thesis to ensure that this terminology is clearly explained.

This discussion is followed by acknowledging the discourses which influence the meanings and practices associated with 'disability', 'mental illness' and

'schizophrenia'. Discourses refer to the social construction of knowledge and practices. While multiple discourses exist, some are accepted as 'truths'. It can be argued that these 'truths',

which eventually become considered as commonsense and natural, regulate all social interaction (Opie, 1995). As Fairclough (1992:3-4) has proposed:

*Discourses do not just reflect or represent social entities and relations, they construct or 'constitute' them; different discourses constitute key entities (be they 'mental illness', 'citizenship' or 'literacy') in different ways, and position people in different ways as social agents (e.g. as doctors or patients)...*

The acceptance of one set of understandings and practices over other sets of understandings and practices highlights the operation of power relations (Munford, 1989, 1994). When considering those discourses which have been accepted as 'truths', the question is raised as to who benefits and who is disadvantaged from these discourses. An examination of the discourses which influence the way 'disability', 'mental illness', and 'schizophrenia' are understood and defined provides a window through which to view the way in which interactions between those who provide and receive care are negotiated and regulated (Munford, 1995).

Several implications for the informal care provided to a family member diagnosed with schizophrenia are also inherent in the discussion about the definition, incidence, aetiology, prognosis, and treatment of schizophrenia and the discourses which influence the way in which 'disability', 'mental illness' and 'schizophrenia' are defined and understood. These implications are identified in order to assist the reader to consider both the unique characteristics of schizophrenia and how these characteristics might impact upon the provision of informal care to a family member exhibiting the symptoms of this disorder.

### **Definitions of Schizophrenia**

The western clinical history of schizophrenia began with Emil Kraepelin who developed the name 'dementia praecox', meaning early madness, to describe an illness characterised by hallucinations, emotional dysfunction, and delusions. According to Kraepelin, early onset was an inevitable characteristic of this

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condition. Kraepelin also argued that dementia praecox was linked with the deterioration of the person's personality. The ideas and assumptions underlying the concept of dementia praecox laid the foundation for the present views of schizophrenia, the definition of schizophrenia having been continually redefined since (Kaplan & Sadock, 1991). This lack of consistency when defining schizophrenia has almost certainly hampered the efforts of researchers in establishing the aetiology and therefore effective treatment of schizophrenia<sup>27</sup>. It could be asked then whether both those individuals exhibiting the symptoms of schizophrenia and their informal care-givers experience improvements in their quality of life as quickly as they could do if the definition of schizophrenia was more consistent.

In the past, an absence of clear and agreed upon diagnostic criteria for schizophrenia resulted in extensive misuse and abuse of this term. Not only are there intranational and international differences in the definition and diagnosis of schizophrenia (Farrell, 1991; Howells & Guirguis, 1985) but the label 'schizophrenic' has also been used as a method to discredit persons, such as those who had unpopular views in Russia (Farrell, 1991; Torrey, 1983). Not surprisingly, there have been calls to re-evaluate the definition of schizophrenia, its validity and reliability (Bentall, 1992; Birchwood et al, 1988; Howells, 1991; Murray & Foerster, 1987; Strauss & Carpenter, 1981). These calls have increased with the proposal that schizophrenia "*is a variety of illnesses in each of which there may be somewhat different symptoms and for which the causes may also be different*" (Seeman, Littman, Plummer, Thornton, & Jefferies, 1982:3). Indeed, two people given the diagnosis schizophrenia may have no symptoms in common. Symptoms vary not only between individuals but also within an individual. The symptoms exhibited by an individual may vary in type, intensity, frequency and duration.

Despite the abundance of existing research regarding schizophrenia, this disorder is still largely considered a mystery (Bleuler, 1984).

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<sup>27</sup> An example of such effective treatment is the newer neuroleptic medications. These are discussed further on in this chapter.

As already noted, the DSM-III-R was first published in 1986. This manual contained the criteria most frequently utilised by mental health professionals at the time that those individuals of the caring relationships examined in this research were diagnosed with schizophrenia. The diagnostic criteria for schizophrenia from the (DSM-III-R) are as follows:

- 1) *two of the following:*
  - a) *delusions;*
  - b) *prominent hallucinations (throughout the day for several days or several times a week for several weeks, each hallucinatory experience not being limited to a few brief moments);*
  - c) *incoherence or marked loosening of associations;*
  - d) *catatonic behaviour;*
  - e) *flat or grossly inappropriate affect;*
- 2) *bizarre delusions (i.e., involving a phenomenon that the person's culture would regard as totally implausible e.g., thought broadcasting, being controlled by a dead person);*
- 3) *prominent hallucinations (as defined in [1b] above) of a voice with content having no apparent relation to depression or elation, or a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other (American Psychiatric Association, 1987:113-114).*

The three diagnostic criteria of DSM-III-R are accompanied by further guidelines. These guidelines are required since none of the symptoms listed above are unique to schizophrenia. To ensure that the diagnosis of schizophrenia is applied correctly, the DSM-III-R multi-axial classification criteria state that a person can only be defined as 'schizophrenic' if the following conditions also apply: impairment in the person's life functioning; the ruling out of schizoaffective disorder<sup>28</sup>, and mood disorders<sup>29</sup>; continuous signs of symptoms for at least six months; the ruling out of an organic

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<sup>28</sup> Schizoaffective disorder is characterised by a person exhibiting the symptoms of schizophrenia concurrently with a mood disorder (American Psychiatric Association, 1994).

<sup>29</sup> Examples of mood disorders are depression or mania, or both of these known as bipolar disorder (American Psychiatric Association, 1994).

(physical) cause; and the presence of prominent delusions and hallucinations if there is a history of autistic disorder<sup>30</sup> (American Psychiatric Association, 1987)<sup>31</sup>. The DSM-III-R multi-axial classification criteria for schizophrenia mean that multiple conditions must be met before the diagnosis of schizophrenia will be applied. This requirement may mean that considerable time could pass before the diagnosis of schizophrenia is considered to be appropriate. This difficulty in receiving the diagnosis schizophrenia would almost certainly have implications for the provision of informal care. One possible implication could be that the care-giver is required to provide care to a family member, who is exhibiting unusual behaviours and thoughts, without confirmation of what is wrong with them<sup>32</sup>. The absence of a diagnosis may mean that the care-giver is alone in their care provision. Without the diagnosis of schizophrenia the care-giver does not have access to required support and mental health services.

The symptoms of schizophrenia have also been classified as either negative or positive (Davison & Neale, 1986; Johnstone, 1989; Wing, 1992). Negative symptoms are those which involve a behavioural deficit such as flat or grossly inappropriate affect. Positive symptoms are characterised by behavioural excesses. Hallucinations and delusions are examples of positive symptoms.

As noted above, the symptoms of schizophrenia are characterised by fluctuations in their type, intensity, frequency, and duration. These fluctuations tend to fit within an overall pattern of alternating acute and chronic episodes. Acute episodes occur when fully developed psychotic (positive) symptoms, particularly hallucinations and delusions, are exhibited by a person. It is during acute episodes that individuals have traditionally been admitted to institutionally-based mental health services<sup>33</sup>. The positive symptoms of schizophrenia are reduced

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<sup>30</sup> Autism, for example, is characterised by impairment in both social interaction and communication, and repetitive patterns of behaviour (American Psychiatric Association, 1994).

<sup>31</sup> The DSM-III-R diagnostic criteria have been superseded by DSM-IV. The DSM-IV criteria of schizophrenia is slightly more inclusive. For example, instead of requiring flat or grossly inappropriate affect (point (e) in the above DSM-III-R definition), DSM-IV requires the presence of negative symptoms per se. The DSM-IV diagnosis of schizophrenia may be more readily applied.

<sup>32</sup> Other potential implications arising from the difficulty of receiving a timely diagnosis of schizophrenia will also be examined in this research.

<sup>33</sup> As will be confirmed further on in this chapter, public psychiatric hospitals have been the traditional form of institutionally-based mental health services in New Zealand.

during chronic episodes. However, the negative symptoms, such as a person's lack of motivation or blunted emotions, continue to impair the individual's functioning. The changeability of the symptoms of schizophrenia could

also impact upon the informal care an individual exhibiting these symptoms receives. For example, one would assume that a care-giver would need to monitor their family member in order to determine whether they are experiencing an acute or chronic episode of schizophrenia. In response to this monitoring, the care-giver would then need to adjust their care provision in order to provide the level and type of care required by their family member.

### **The Incidence of Schizophrenia**

Typically, the incidence of schizophrenia is reported to occur worldwide around the rate of one person in every hundred (American Psychiatric Association, 1994a). While there are no clear gender differences in the prevalence of schizophrenia, it is important to note that the age of onset of schizophrenia for women is predominantly twenty-five to thirty-five years, for men fifteen to twenty-five years (American Psychiatric Association, 1994a; Reed Healthcare Australia, no date). As will be noted below, this difference in the age of onset has differing consequences for men and women in terms of their prognosis. Males are typically more adversely affected by schizophrenia than their female counterparts (Kaplan & Sadock, 1991). This is explained by the fact that males tend to exhibit the symptoms of schizophrenia at a time when social and life skills are developed. Women typically have developed these skills by the time they exhibit the symptoms of schizophrenia. This discussion on the incidence of schizophrenia suggests that informal care-givers will typically be providing ongoing care to a male as a consequence of males being more affected, in terms of their everyday functioning, by the symptoms of schizophrenia.

### **Aetiology of Schizophrenia**

Discussion about the aetiology or cause of schizophrenia has over the years generated much debate. This debate is reflected in the diverse areas upon which investigation for the cause of schizophrenia has focused. This section will briefly identify and describe the following suggested causes of schizophrenia: genetics;

biochemical; the family; behavioural; cognitive; neurological; and, sociological factors. The diathesis-stress model is also described and discussed.

### Genetics

Geneticists have investigated schizophrenia by observing the rates of schizophrenia across families (Bernheim & Lewine, 1979). Evidence provided by investigating the prevalence of schizophrenia in specific populations (see Table 1 below), and adoption studies (Kety, Rosenthal, Wender, & Schulsinger, 1968; Rosenthal, Wender, Kety, Schulsinger, Welner, & Ostergaard, 1968; Wender, Rosenthal, Kety, Schulsinger, & Welner, 1974), suggest that genetics plays a definite role in the development of schizophrenia. A pure genetic explanation for schizophrenia would have a concordance rate of 100 percent in monozygotic twins. In other words, every time that one identical twin had schizophrenia, so would the other twin. As is indicated in Table 1 below, the concordance rate for monozygotic twins has been found to be forty-seven percent. This means that genetics does not completely explain the presence of schizophrenia.

**Table 1.** The prevalence of schizophrenia in specific populations (Kaplan & Sadock, 1991:328)<sup>34</sup>.

POPULATION	PREVALENCE (%)
* General population	1.0
* Nontwin sibling of a schizophrenia patient	8.0
* Child with one schizophrenic parent	12.0
* Dizygotic twin of a schizophrenic patient	12.0
* Child of two schizophrenic parents	40.0
* Monozygotic twin of a schizophrenic patient	47.0

### Biochemical

It is a person's biochemistry which is the focus of biochemical explanations for the cause of schizophrenia. Ever since the first clinical definition of schizophrenia, focus has been on a biochemical cause. Kraepelin speculated about poisons secreted from the sex glands, and Jung proposed the effects of 'toxin X' (Davison

<sup>34</sup> Statistics focusing on the prevalence of schizophrenia in families vary depending on which studies are cited (Keefe & Harvey, 1994).

& Neale, 1986). Nearly every known neurotransmitter, the body's chemical messengers, has been studied for its possible link to schizophrenia (Kaplan & Sadock, 1991). The neurotransmitter dopamine has held a prominent position in this biochemical research. Findings of this research suggest a link between schizophrenia and an excess of dopamine in particular parts of the brain (Kaplan & Sadock, 1991). The newer more effective neuroleptic medications however act to block both dopamine and serotonin receptors (Janssen-Cilag, no date; Meltzer, 1992a; Reed Healthcare Australia, no date). The most researched neurotransmitters besides dopamine are: serotonin; phenylethylamine (PEA); noradrenaline; methylated amines; acetylcholine; gamma-aminobutyric acid (GABA); and, neuropeptides. Although results of these studies have yet to provide a body of reliable and valid evidence (Birchwood et al, 1988), the most effective treatment currently available for schizophrenia primarily attempts to control the symptoms of schizophrenia by acting upon neurotransmitters and their receptor sites. As will be explained below, neuroleptic medications, or drug therapy, are considered to be the most effective treatment for schizophrenia.

### **Role of the Family**

'The family' has traditionally been considered a causal agent of an individual's schizophrenia. This is highlighted, by Lamb, Hoffman, Hoffman, & Oliphant's (1986) who make the comment that families have been blamed for their family member's schizophrenia. Four main theories have related family influences to the existence of schizophrenia:

- 1) 'Schizophrenogenic mother' was a term developed by Fromm-Reichmann (1948):

*...to denote a domineering, cold, rejecting, possessive, guilt-producing person, who in combination with a passive, detached, and ineffective father, causes her male offspring to feel confused and inadequate and ultimately to become schizophrenic (Goldenberg & Goldenberg, 1985:99).*

Although the 'schizophrenogenic mother' theory describes a combination of a cold domineering mother, and a passive detached father, the implications of this theory have been particularly harsh for mothers. As the title 'schizophrenogenic mother' suggests, mothers in particular have been

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considered to be the causative agent within the family. The current understanding is that there is no scientific evidence to support the 'schizophrenogenic mother' theory (Keefe & Harvey, 1994). However, discussion in this chapter will argue that despite this understanding, mothers are still considered by lay persons and some mental health professionals as a causative agent of a family member's schizophrenia. Further, it will be asserted that this understanding has hindered the informal care provision of mothers to their adult children.

- 2) The 'double bind' communication theory proposes that a child exhibits the symptoms of schizophrenia when they continually are put in the position where they must choose between two alternatives, each alternative resulting in negative consequences (Bateson, Jackson, Haley & Weakland, 1956). An example of the

double-bind communication theory is when a mother intimates to her child that she wants to embrace the child. However, when the child attempts to hug his mother the mother withdraws from her child's touch. In this case, the child disobeys his mother's verbal or non-verbal instructions no matter what action he takes.

- 3) Families which are either 'schismatic' or 'skewed' have been considered to have the potential to cause schizophrenia among their members. 'Schismatic families' are those in which one parent becomes overly close to their child, causing a schism between the parents. In 'skewed families' a power struggle exists between the parents (Lidz, Cornelison, Fleck & Terry, 1957).
- 4) The 'expressed emotion' (EE) theory proposes that persons diagnosed with schizophrenia are more likely to experience relapse if their environment is negatively charged, especially with negative criticism (Brown, Mench, Carstairs, Wing, 1962). Although the EE theory does not identify the family as the cause of their member's schizophrenia, this theory does implicate the family in maintaining the expression of the symptoms of schizophrenia. Hatfield (1987:341) has argued that the EE theory has the following implication for families:

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*Families who have long protested the idea that they are pathological agents in the cause of mental illness are now faced with the notion that they are pathological agents in maintaining it.*

In endeavouring to prevent their family member from experiencing an acute episode of schizophrenia, it is likely that care-givers, aware of the EE theory, would monitor the emotional environment within the household. It could also be argued that in maintaining a stable and positive emotional environment, the care-givers' own emotional expression around the family members could come under scrutiny. Care-givers may need to constantly monitor and restrict their own emotions in order to ensure that they do not negatively charge their family members' environment.

One main question about the validity of these theories describing the role of the family in relation to schizophrenia, is whether these family patterns are actually the cause of, or the response to, a family member being diagnosed with schizophrenia. Further implications for informal care provision of the discourses associated with these theories about family aetiology will be noted further on in this chapter.

In summary, the 'schizophrenogenic mother' theory, double-bind communication theory, and 'schismatic' and 'skewed' family theory, are considered weak explanations for the causation of schizophrenia (Davison & Neale, 1986; Goldenberg & Goldenberg, 1985; Higgens, 1966; Keefe & Harvey, 1994; Straus & Carpenter, 1981). The level of expressed emotion within the family does however seem to have some influence on whether an individual continues to express schizophrenic symptoms and their rate of relapse (Atkinson, 1986; Hudson, 1982; Kuipers & Bebbington, 1987; Seeman et al, 1982).

### **Cognitive**

Cognitive theory looks at the inability of those who exhibit the symptoms of schizophrenia to maintain attention and filter out distracting stimuli. For example, McGhie and Chapman (1961) have assumed that the basic problem in schizophrenia is an inability to select, focus on and regulate incoming information.

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The effects of these attentional deficits have been identified by, for example, Gold and Harvey (1993). These researchers found that people exhibiting the symptoms of schizophrenia reliably demonstrated deficits in their attention, memory and problem solving. Despite the various evidence associated with the attentional deficit theory (Hudson, 1982; Perry & Braff, 1994; Shean, 1978), there still needs to be some form of longitudinal study to produce stronger evidence. It is equally plausible, for example, that these phenomena are a result of a deeper process also producing schizophrenia.

### **Neurological**

Some research has indicated that persons diagnosed with schizophrenia are likely to have neurological differences in their brain, not found in the 'normal' population. Examples of these differences are: atrophy of the hippocampus, thalamus and cerebral cortex; reduced levels of brain metabolism especially in the temporal and frontal areas of the brain, and larger ventricles (Davison & Neale, 1986; Kalat, 1992; Keefe & Harvey, 1994; Lezak, 1995; Nestor, Shenton, McCarley, & Haimson, 1993). Again, the question needs to be answered as to whether these neurological differences explain the schizophrenia, or if the schizophrenia explains the neurological differences.

### **Sociological**

Sociological theories move away from the tradition of focussing on the individual in order to explain mental illness. Szasz (1976) for example, states that schizophrenia is a myth. It is not a disease, since no physical cause can be found, but instead is the result of disagreement between the powerful and the less powerful. The label of 'schizophrenic' is applied in order to control behaviour which challenges the status quo. Szasz's (1976) view of schizophrenia is largely ignored by researchers today. There is evidence for both the social causation hypothesis (Cochrane, 1983) which proposes that being in a lower socio-economic class is a significant factor in causing illness, and the social selection hypothesis (Gottesman & Shields, 1982) which states that having a psychiatric illness results in a person having a lower socio-economic position. Although it seems as though the social selection hypothesis is more valid, it is asserted that the social

causation and the social selection hypotheses are not mutually exclusive. In other words, both theories are equally capable of explaining how schizophrenia occurs (Cochrane, 1983).

### Diathesis-stress

The diathesis-stress model links both physiological and environmental factors in explaining the cause of schizophrenia. Atkinson (1986:35) has explained that underlying the diathesis-stress model is the assumption:

*...that to develop schizophrenia an individual needs to have a genetic predisposition to develop the disorder which is triggered by an environmental stress of some kind. This stress might come from upbringing, lifestyle, maturation and, indeed, anything in the individual's milieu.*

Table 2 illustrates how diatheses and stressors interact. If a person is predisposed to a certain disorder, their environment will either reduce or increase the magnitude of this disorder. The diathesis-stress model is supported by the research examining the role of genetics in the cause of schizophrenia. As was noted above, this research (Kaplan & Sadock, 1991) has indicated that some other factor(s) combine with genetics in order for an individual to exhibit the symptoms of schizophrenia.

**Table 2.** Components of the Diathesis-Stress Model.

<b>Diathesis</b>		<b>Stressors</b>		<b>Outcome</b>
Genetic disposition	+	Environmental stressors	=	Disease/disorder

To conclude, there is no unitary, universally accepted explanation for schizophrenia. Reflecting this lack of consensus is the advice that a multi-dimensional approach should be utilised when considering the aetiology of schizophrenia (Bellack 1984). Utilising an eclectic approach to explain schizophrenia is also supported by the current view that schizophrenia is a heterogenous disorder "*...complicated by its complex and variable aetiology*". (Reed Healthcare Australia, no date:4; see also Bentall, 1992).

## The Prognosis of Schizophrenia

The complex nature of schizophrenia is again highlighted when considering the prognosis of this disorder. There is not one uniform outcome associated with the diagnosis of schizophrenia (Keefe & Harvey, 1994). As Miller (1995:13) has explained:

*A proportion of persons who develop this illness may recover completely. Others come to lead relatively normal lives, though they are required to take medicines for many years. Many others suffer repeated periods of serious illness, and become impaired to some degree for the rest of their lives.*

The wide variations in the possible outcomes of the diagnosis schizophrenia are highlighted in Kaplan and Sadock's (1991:332) following comment:

*The range of recovery rates in the literature is 10 to 60 percent, and a reasonable estimate is that 20 to 30 percent are able to lead somewhat normal lives. Approximately 20 to 30 percent of patients continue to experience moderate symptoms, and 40 to 60 percent of patients remain significantly impaired by their illness for their entire lives.*

The prognosis or outcome of the diagnosis schizophrenia can be determined for each individual by establishing the presence of and combination of various factors. Table 3 below, taken from Kaplan and Sadock (1991:332), lists the following combinations for either a good or poor prognosis.

**Table 3.** Features weighting toward good or poor prognosis in schizophrenia.

Good Prognosis	Poor Prognosis
* Late onset	* Young onset
* Obvious precipitating factors	* No precipitating factors
* Acute onset	* Insidious onset
* Good premorbid social, sexual and work history	* Poor premorbid social, sexual and work history
* Affective symptoms (especially depression)	* Withdrawn, autistic behaviour
* Married	* Single, divorced, or widowed
* Family history of mood disorders	* Family history of schizophrenia
* Good support systems	* Poor support systems
* Positive symptoms	* Negative symptoms
	* Neurological signs and symptoms
	* History of prenatal trauma
	* No remissions in three years
	* Many relapses
	* History of assaultiveness

This information regarding prognosis suggests that males, who tend to exhibit the symptoms of schizophrenia earlier, typically have a poorer prognosis than their female counterparts. The above discussion on the incidence and prognosis of schizophrenia suggests that those persons who require ongoing care and support, as a consequence of their symptoms of schizophrenia, are likely to be male. This suggests that consideration of gender issues will need to be undertaken when examining the care provided to a family member diagnosed with schizophrenia. Specifically, attention will need to be directed towards establishing whether the predominance of males amongst those who receive care uniquely influences and shapes the nature of the care provided to a family member diagnosed with schizophrenia.

## Treatment of Schizophrenia

Each of the theories on the aetiology of schizophrenia outlined above, has been used as the foundation for the development of treatment strategies for schizophrenia. Just as some of these theories are considered to be more credible than others, some treatments for schizophrenia are considered more effective than others. Over time, the treatment of schizophrenia itself has been unfitting and even inhuman. Some of these now disreputable treatments are identified in the following statement by Anderson, Reiss, and Hogarty (1986:vii):

*...[treatment] has ranged from burning at the stake to passage on the 'ship of fools', from the 'dunking stools' of colonial America to early 20th-century innovations such as the daily enema and complete dental extraction. In recent years we have emphasised electric shock, insulin coma, chemical restraint, lobotomy, and physical isolation.*

As new information about schizophrenia and more advanced technology has become available, there has been a parallel change in the treatment of schizophrenia. Today, the most often used and effective treatment of schizophrenia is drug therapy, better known as neuroleptic medication. Traditionally neuroleptic medication has been characterised by its ability to reduce the positive symptoms of schizophrenia. The effect on negative symptoms has however been limited (Chouinard et al, 1993; Taylor, 1989). The implication of this for the care examined in this thesis is that care and assistance is needed even when treatment has been received by the family member.

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The understanding that schizophrenia is a heterogeneous disorder suggests that prescribing medication for the symptoms of schizophrenia may not be a simple process. It may be that some medications are more effective for some individuals than others. Furthermore, the most effective dosage level may vary from individual to individual. This suggests that informal care-givers, who would spend considerable time with the family member, would play a vital role in informing the prescriber of the effectiveness of various medications for controlling the family member's symptoms. The emphasis placed upon neuroleptic medication for reducing the positive symptoms of schizophrenia means that compliance<sup>35</sup> to such medication is considered by the medical profession and often family members as imperative (Falloon, Boyd & McGill, 1984). The consequence of non-compliance has been highlighted by Hatfield (no date:1): "*Once medications have been discontinued, patients become psychotic again, create a great deal of turmoil for themselves and their families, and often cycle back into the hospital*". It is well known that people experiencing schizophrenia are often non-compliant because of the many side-effects associated with this medication (Hatfield, no date)<sup>36</sup>. The following side-effects can be experienced as a result of taking neuroleptic drugs: dry mouth and eyes; blurry vision; stiffness; increased appetite; tardive dyskinesia (involuntary movements such as tremors); impotence; constipation; nausea; fatigue; and, hypertension (Falloon, et al, 1984; Kalat, 1992; Kaplan & Sadock, 1991).

Despite these problems, neuroleptic medication has facilitated the process of deinstitutionalisation<sup>37</sup> or the removal of persons from institutionally-based mental health services. As such medications controlled and reduced the symptoms of schizophrenia, the incarceration of individuals for long periods of time within psychiatric institutions could no longer be justified (Committee of Inquiry into

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<sup>35</sup> Compliance refers to the willingness of persons to regularly take medication at the doses they have been prescribed.

<sup>36</sup> Other reasons for the non-compliance of people diagnosed with schizophrenia are identified further on in this chapter.

<sup>37</sup> Deinstitutionalisation is discussed more fully in Chapter Three.

Procedures Used in Certain Psychiatric Hospitals in Relation to Admission, Discharge or Release on Leave of Certain classes of Patients<sup>38</sup>, 1988). The economic benefits of neuroleptic medication as a treatment for schizophrenia undoubtedly have been noted also when considering both the direct and indirect costs of schizophrenia. When speaking about the American context, Kaplan and Sadock (1991:324) have proposed that:

*Schizophrenic patients occupy approximately 59 percent of all mental hospital beds and account for approximately 16 percent of all psychiatric patients who receive any type of treatment. Schizophrenia is the most expensive of all mental disorders in direct treatment costs, loss of productivity, and expenditures for public assistance...*

The United States is not the only country to consider schizophrenia to be a costly illness (Rubio-Stipeć, Stipeć & Canino, 1994). In using 1989 figures, which were the most recent figures available in New Zealand, Miller (1995:15) has asserted that:

*...direct costs (of treatment programmes either in hospital or in the community) totalled greater than \$150 million. Indirect costs to the country, including the loss of productivity from lost earnings in 40 per cent of those who receive the diagnosis of schizophrenia, were estimated at a total of \$324 million. The total cost to the country of this relatively common illness in 1989 was in the order of \$400-600 million.*

It is interesting to note that consideration of the direct and indirect costs of schizophrenia are calculated solely with regard to the individual diagnosed with schizophrenia. However, the costs of schizophrenia would increase dramatically if the costs associated with the informal care-givers of people diagnosed with schizophrenia were taken into account.

Issues surrounding treatment and quality of life for both those persons diagnosed with schizophrenia and their care-givers have been raised with the recent

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<sup>38</sup> The Committee of Inquiry into Procedures Used in Certain Psychiatric Hospitals in Relation to Admission, Discharge or Release on Leave of Certain classes of Patients is now referred to as the Committee of Inquiry.

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introduction of clozapine<sup>39</sup> and risperdal<sup>40</sup> to New Zealand<sup>41</sup>. First, both of these neuroleptic medications have been found to effectively reduce both the positive and negative symptoms of schizophrenia (Lindenmayer, Grochowski & Mabusat, 1994; Lindstrom & von-Knorring, 1994). Furthermore, access to these medications has been associated with improved prognosis (Janssen-Cilag, no date; Meltzer, 1992). Individuals do not have to struggle to the same extent with the negative symptoms of schizophrenia which with previous medication would remain largely unaffected during the chronic episodes of this disorder (Choulnard et al, 1993; Taylor, 1989).

Second, compliance to clozapine and risperdal has also been found to be higher than traditional neuroleptics. Side-effects associated with traditional neuroleptic medication are either fewer in number or reduced significantly. The latter is particularly the case with movement type side-effects such as tardive dyskinesia (Reed Healthcare Australia, no date). This is not to say that clozapine and risperdal are completely free of side-effects. Use of clozapine has introduced a new side-effect called agranulocytosis which is an immune-system disorder found to be fatal if not detected early on. Anyone who uses clozapine needs to have their white blood cell count screened as regularly as weekly to prevent the development of this side-effect. The risk of agranulocytosis has restricted the use of clozapine. As Krupp and Barnes (1992:40) have explained: "*Because of the risk of agranulocytosis, clozapine should only be used in schizophrenic patients who are resistant to, or intolerant of, conventional antipsychotic medications*". Not surprisingly then, in comparison to clozapine, risperdal is a more popular medication. While an individual may still experience the side-effects of agitation, sleeplessness, anxiety and headaches (Janssen Cilag, no date), there are no blood or urine tests directly linked to the taking of risperdal (Janssen Cilag, no date; Reed Healthcare Australia, no date).

The improvements in the prognosis of schizophrenia and compliance associated with clozapine and risperdal suggest that access to these treatments, would significantly reduce the level of care informal care-givers would need to provide.

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<sup>39</sup> Clozapine is also known as clozaril.

<sup>40</sup> Risperdal is also known as risperadone.

<sup>41</sup> Other new anti-psychotic medications are being trialed including olanzapine, ziprasidone, sertindole and seroquel.

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These improvements also lead to the assumption that informal care-givers of a family member diagnosed with schizophrenia would be extremely interested in ensuring that their family member had access to the newer neuroleptic medications.

### **The Discourses of 'Disability', 'Mental Illness' and 'Schizophrenia'**

In order to facilitate the translation of the above material into the lived experiences of both those persons diagnosed with schizophrenia and their informal care-givers, the discourses which influence the meanings and practices associated with 'disability', 'mental illness' and 'schizophrenia' will be discussed. There are multiple understandings and practices associated with all social phenomena. These discourses each propose different responses and outcomes. While multiple understandings and practices exist, some are considered as more acceptable than others. When discourses are accepted as either 'truths' or commonsense responses, consideration needs to be made as to whose interests are being served by this acceptance. This question will be kept at the forefront when considering how people with disabilities<sup>42</sup>, and more specifically people with schizophrenia and their informal care-givers, are regulated by the dominant discourses. Furthermore, consideration will be given to how these discourses influence and shape the informal care provided to a family member diagnosed with schizophrenia.

The need to consider the way in which people with disabilities have been defined and understood arises from the fact that schizophrenia is classified, both theoretically and in policy documents, as disability, specifically psychiatric disability. People with disabilities increasingly have highlighted how their restricted participation in society is the outcome of societal structures rather than a personal problem (Ballard, 1994). Morris' (1993a:x) following explanation clearly highlights the basic understanding of a social, as opposed to a medical, definition of disability:

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<sup>42</sup> I have chosen to use the terminology 'people with disabilities' or 'people diagnosed with schizophrenia' instead of for example, 'disabled people' or 'schizophrenics'. The former is utilised in an attempt to acknowledge the personhood of those individuals whose daily functioning is impaired rather than focusing on the disability itself. While taking this position, it is important to acknowledge that people with a disability are reclaiming the terminology 'disabled people' as a way of owning their own experiences of living with a disability (Morris, 1993a).

*Impairment refers to the functional limitation(s) which affect a person's body, whereas disability refers to the loss or limitation of opportunities owing to social, physical and attitudinal barriers. Thus an inability to walk is an impairment, whereas an inability to enter a building because the entrance is up a flight of steps is a disability. An inability to speak is an impairment but an inability to communicate because appropriate technical aids are not made available is a disability. An inability to move one's body is an impairment but an inability to get out of bed because appropriate physical help is not available is a disability.*

Inherent in Morris' (1993a) explanation is the understanding that 'disability' has been maintained and at times worsened by the lack of resources made available to people with an impairment. Therefore, resources need to be accessed in order to reduce the presence of disability in people's lives. This understanding of disability has major implications for the allocation and distribution of New Zealand's resources.

It can be argued that the considerable amount of resources required to support people with disabilities to gain their independence in part explains why people with disabilities are considered to be dependent and perceived as burdens. Challenges have been made by people with disabilities to the assumption that people with disabilities are necessarily dependent and a burden. For example, Georgeson (1994:70) has challenged policy makers to reject the current dominant discourses of 'disability' and to acknowledge the value of the lives of people with disabilities:

*...policy makers need to move away from seeing disabled people from within a medical model perspective, that is, to no longer see disability as a personal tragedy, and to see the lives of all disabled people as being valued.*

As well as being regulated by the discourses of 'disability', people diagnosed with schizophrenia, and their care-givers, are further defined and understood by the discourses specifically associated with 'mental illness'. As the discussion on the treatment of schizophrenia indicated, mental illness has traditionally been less accepted and understood than those illnesses which arise from an organic (physical) cause (Brigham, 1847). At times people exhibiting the symptoms of mental illness have been defined and treated as less than human (Anderson et al, 1986). Foucault (1967:72) in his work entitled 'Madness and civilisation: A history

of insanity in the age of reason', argued that in the past the mentally ill were viewed not as people who were unwell, but as animals:

*Madness borrowed its face from the mask of the beast. Those chained to the cell walls were no longer men whose minds had wandered, but beasts preyed upon by a natural frenzy...This model of animality prevailed in the asylums and gave them their cagelike aspect, their look of the menagerie.*

While people exhibiting the symptoms of mental illness are not generally viewed as animals today, interactions with these persons are generally regulated by various misconceptions about mental illness. Butler (1993:IX) has highlighted many of these misconceptions with the following comment:

*Mention 'mental illness' or 'the mentally ill' in ordinary conversation and it conjures up powerful and conflicting images. These include pictures of people incarcerated in isolated institutions; pathetic sad individuals, incoherent and impoverished people talking loudly in public places, lonely people cut off from society or those whose behaviour is dangerous or volatile. These stereotypes serve to reinforce the view that there is a single group of people called 'the mentally ill' who deserve pity or fear in equal measure.*

These misconceptions associate 'mental illness' with burden and dependence. Just as with people with disabilities, it is assumed that people exhibiting the symptoms of mental illness are unable to make valuable contributions to their society. Instead, the understanding exists that society needs to ensure that secure institutions are maintained in order to house the mentally ill. Challenging these understandings are the statistics on the prognosis of schizophrenia. These statistics indicate (Kaplan & Sadock, 1991) that there typically is no uniform outcome associated with mental illness. While some people are able to live a 'normal' life after their one and only episode of schizophrenia, other people are significantly impaired by the symptoms of this disorder for the rest of their lives.

Miller (1995:6), a New Zealand writer, has noted the fear associated with 'the mentally ill' in New Zealand by proposing that: *"One of the difficulties...is that many of the public in New Zealand and other countries, still regard people who are mentally ill (or who have been mentally ill) with great fear"*. People exhibiting the

*mentally ill (or who have been mentally ill) with great fear*<sup>a</sup>. People exhibiting the symptoms of mental illness have traditionally been considered to be more violent and to engage in criminal activity more regularly than the those individuals not exhibiting the symptoms of mental illness (CRHA, 1995c). As Mullen (1992:146) has explained:

*Integral to the ordinary person's view of mental illness is a loss of self control and disturbed, if not frankly violent, behaviour. In the popular imagination violence and madness walk hand-in-hand. Although public attitudes are becoming less negative, the fear of the unpredictability and potential for violence of the mentally ill remains... These fears are fed by the media.*

The way in which the media feeds the ignorance and fear spoken of by Miller (1995) and Mullen (1992) is clearly evident in the following sonnet quoted in the Wanganui Midweek (1995:7)<sup>43</sup>:

*The policy on mental care defeats  
its purpose with a callousness that chills,  
regarding, as it does, all mental ills  
as problems cost-efficiency deletes.  
To save on staff and nourishment and sheets  
they're closing down asylums in the hills,  
distributing the medicine and pills  
and turning inmates loose upon the streets.  
Our leaders now would have us understand,  
when murders, rapes and suicides increase,  
that all is not as bad as it appears.  
So what if there's a confrontation and  
some nutter's blown to pieces by the police?  
It's cheaper, 'cos he might have lived for years!*

As the National coordinators of Schizophrenia Fellowship NZ Inc have argued, material such as this supports the understanding that people diagnosed with schizophrenia should be feared:

*We do not dispute the fact that mental health services are insufficiently funded. However, this scare-mongering piece of nonsense isn't going to solve any problems, except fuel the popular public perception of mentally ill people as violent*

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<sup>43</sup> The Wanganui Midweek is a weekly community newspaper.

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*'nutters' who should be back in institutions (Wanganui Chronicle, 1995h:4)<sup>44</sup>.*

According to Miller, this fear arises from the lack of accurate knowledge people have about mental illness. The National Mental Health Consortium (1989:45) has asserted that the practical outcome of the wider public's ignorance and fear regarding mental illness is social isolation: "*There is widespread ignorance and fear about psychiatric disability which in turn often leads to rejection and neglect*".

In acknowledging the ignorance and fear associated with schizophrenia, it will be argued in this thesis that the dominant discourses of 'mental illness' have led to New Zealand's mental health services being historically poorly funded (Bascand, 1993) and developed (National Advisory Committee, 1993) in comparison to general health services. Just as people with disabilities have been restricted by social structures (Morris, 1993a), the quality of life of the 'mentally ill' and their care-givers has been significantly reduced by a lack of available and accessible services. It seems that more concern and resources are directed towards meeting the general health needs of New Zealanders as opposed to improving the prognosis of mental illness<sup>45</sup>. Consideration in this research would need to determine the extent to which the inadequacies of New Zealand's mental health services have increased the responsibility of informal care-givers to provide care to their family member diagnosed with schizophrenia.

Challenges have been made to the way in which people with a psychiatric disability are viewed, considered and restricted by the discourses of mental illness. As Zifcak (1994:2) has explained:

*...we need, each one of us, to confront our own attitudes to people with psychiatric disabilities. For it is not only their illness*

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<sup>44</sup> Further evidence of the media supporting the understanding that people with schizophrenia and related disorders are always dangerous and unpredictable is provided when discussing the actions of people such as Eric Gellatly who left the sports store he had previously holed himself up in and shot indiscriminately before he was shot dead by police (Wanganui Chronicle 1995a), and Stephen Staynor who allegedly kidnapped an eleven year old boy with the intent to commit sexual violation (Wanganui Chronicle, 1995i). These experiences are further described and discussed in Chapter Three.

<sup>45</sup> Discussion in this thesis challenges the assumption that people exhibiting the symptoms of mental illness, specifically schizophrenia, are of less value than those people needing for example a hip replacement, or a broken arm set, or medication for diabetes.

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*but our prejudice and fear which defines them. In focusing on their difference we deny their similarity.*

Despite these challenges, the prejudice and fear associated with mental illness continue to dominate. The question is raised as to why these misconceptions are maintained and supported. Those persons exhibiting the symptoms of mental illness have benefited from neither the fear, ignorance, discrimination or stigma they face nor from the relative lack of care they have received from New Zealand's mental health services. The care-givers of these individuals have had to invest heavily in their care provision as a consequence of the lack of resources and understanding the New Zealand public has provided those people exhibiting the symptoms of schizophrenia. It can be argued that New Zealand society as a whole has not benefited. For example, resulting professional practices based upon the dominant discourses of 'mental illness', primarily institutionalisation, have financially been a costly option.

People diagnosed with schizophrenia are further defined, understood and regulated by the discourses of 'schizophrenia'. One of the dominant discourses of schizophrenia is the understanding that schizophrenia is the worst type of mental illness a person could experience. As already noted, since the name 'dementia praecox' (Kaplan & Sadock, 1991) schizophrenia has been understood to mean the early and inevitable deterioration of a person's personality. Schizophrenia then has been associated with a lack of hope. This lack of hope has been maintained by the symptoms of schizophrenia being both resistant to traditional neuroleptic medication and so outside the typical experiences of the 'normal' population. Also maintaining the lack of hope associated with schizophrenia has been the research on schizophrenia and care. In speaking about the themes arising from this research Atkinson and Coia (1995:103) have proposed that: "*Only two aspects of the caring relationship have been considered in some detail, burden and dependency*". 'Burden' typically means 'family burden' which in turn refers to the difficulties experienced by 'the family' as a consequence of their care provision to a family member diagnosed with schizophrenia. 'Dependency' refers to the dependence of the family member exhibiting the symptoms of schizophrenia.

Just as with 'disability' and 'mental illness' generally, it will be argued in this thesis that the lack of hope and the themes of dependency and burden associated with schizophrenia have been translated into the difficulty experienced in securing adequate and accessible resources for individuals before their symptoms of schizophrenia fall into a pattern of acute and chronic episodes. It can be argued that improving the prognosis of schizophrenia by providing the required mental health services would, in the long term, make financial savings. As was noted earlier, currently there are considerable direct and indirect costs of schizophrenia (Miller, 1995).

Jones' (1995:1) following comment further highlights other understandings which are more specific to schizophrenia:

*Once upon a time there was a disease called schizophrenia. For many years this disease had been misunderstood. It was perceived as a split of personality rather than a split from reality. People with the disease were thought to be morally weak or religiously possessed. Relatives of people with the disease were thought to have done something wrong to cause the person to have developed the illness.*

Each of these understandings has been associated with particular practices. This assertion is supported by considering the understanding that 'the family' is a causal agent of schizophrenia. The practices which have been based upon the family's causal role<sup>46</sup> have consistently adversely affected 'the family's' provision of informal care to their family member. The traditional poor alliance between families and mental health professionals is a case in point. Dealing with uncooperative mental health professionals has been identified in the literature on schizophrenia and care to add significantly to 'the family's' burden<sup>47</sup> (Bernheim, 1990; Brooker, 1990; Holden & Lewine, 1982; Morris, Clarke & Bingham, 1989; Willis, 1982). Beels and McFarlane (1982:54) have argued for example that: "*Scientific theories that propose the family itself as a contributing factor have*

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<sup>46</sup> Previous discussion in this chapter explained that the way in which 'the family' has been understood to cause schizophrenia has depended on whether the 'schizophrenic mother' theory, the 'double-bind' communication theory, 'schismatic' or 'skewed' families, or the 'emotional expression' theory has been in vogue.

<sup>47</sup> As Atkinson and Coia's (1995:103) comment explained, family burden has been one of the main issues focussed on in research on schizophrenia and care.

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*eroded the alliance between professionals and family members and added to the burden of family guilt*. A similar view of interaction between relatives and mental health professionals has been provided by Fadden, Bebbington, and Kuipers (1987:285):

*The view that relatives may have a deleterious influence on the course of illness is reflected in the behaviour of many mental health professionals in the clinic, who may give an impression of blaming them or of regarding them only as exploitable sources of information.*

This comment of Fadden et al's (1987) indicates that the dominant discourses of schizophrenia can be deleterious to the care relatives provide to their family member. This is highlighted further by the questions families often ask about the role they play in their family member's prognosis. As Mittleman (1985:300-301) has explained:

*The guilt is with us always: What did we do to create this situation? Were we too lenient and lacking in discipline? Were we too strict? Did we love our children enough? Did we love our children too much? Did we hold on too tightly and identify ourselves with them? Am I perpetuating the illness? Are we doing enough now? Is there a better hospital, a better doctor, a better treatment?*

Inherent within this discussion is the acknowledgment that 'the family' and mental health professionals have historically advocated competing discourses. This is despite the valuable role informal care-givers can play in monitoring their family member and providing assistance<sup>48</sup>. Again the question is raised as to who benefits from these dominant discourses. Is it mental health professionals, care-givers, people diagnosed with schizophrenia, the state, the public, or some other interest group?

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<sup>48</sup> An example of the importance of informal care-givers and mental health professionals working collaboratively was provided when the prescription of neuroleptic medication was discussed.

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## Schizophrenia Defined: The Key Themes

Material in this chapter was presented in order to develop an understanding of the disorder schizophrenia. This understanding is required in order to facilitate the examination and description of the unpaid care provided within a family, to a member diagnosed with schizophrenia, specifically within the New Zealand context. The discussion in this chapter identified several themes which are likely to have implications for the provision of unpaid care provided within a family to a member diagnosed with schizophrenia. Each of these themes will be revisited below.

Consideration of the criteria which needed to be met before the DSM-III-R diagnosis of schizophrenia was applied indicated that receipt of the diagnosis schizophrenia would not always be a straightforward process. The difficulty surrounding the assignment of the diagnosis schizophrenia suggests that informal care-givers may be providing increasing amounts of care to their family member, as their family member's symptoms worsen, without an accurate understanding of why this level and type of care is required. Furthermore, the absence of a diagnosis could mean that informal care-givers are unassisted in their care provision despite their family member exhibiting complex and changing symptoms. For example, without the diagnosis of schizophrenia, access to New Zealand's formal mental health services is limited and neuroleptic medication is unlikely to be prescribed.

The theme of unpredictability is constantly associated with the symptoms of schizophrenia. As was noted, the symptoms of schizophrenia may not only differ between individuals, but also within an individual in type, intensity, duration and frequency. A cyclical pattern of acute and chronic episodes is indicative of schizophrenia. This information suggests that care provided to a family member is unlikely to be predictable and therefore scheduled. It would seem that care-givers would need to be able to alter the type and the level of care they provide to reflect their family member's symptoms.

The ineffectiveness of traditional neuroleptic medications upon the negative symptoms of schizophrenia (Choulhard et al, 1993; Taylor, 1989), and the likelihood of non-compliance (Hatfield, no date) suggests that the symptoms of

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schizophrenia may be continually present in those caring relationships in which informal care is provided to a family member diagnosed with schizophrenia. It would seem then that care-givers may need to manage their family member's symptoms of schizophrenia constantly.

Coupled with the increased effectiveness of newer medications (Lindenmayer et al, 1994; Lindstrom & von-Knorrning, 1994) is greater compliance as a consequence of the fewer side-effects associated with these medications (Reed Healthcare Australia, no date). Discussion of these factors suggested that care-givers might advocate for the accessibility of these medications for their family member diagnosed with schizophrenia.

Discussion of the incidence and prognosis of schizophrenia indicated that gender issues could be of particular importance when examining the care provided to a family member diagnosed with schizophrenia. The family member is likely to be a younger male.

Discussion of the dominant discourses which influence the way 'schizophrenia' (Atkinson & Coia, 1995; Fadden et al, 1987; Jones, 1995; Mittleman, 1985), is defined and understood noted that these discourses both directly and indirectly influence the informal care provided within a family to a member diagnosed with schizophrenia. The direct impact of these discourses was particularly highlighted when discussing the role of 'the family' in the aetiology of schizophrenia. It is possible that 'the family' may not receive the empathy, understanding or support it requires in order to provide quality care to their member diagnosed with schizophrenia. The indirect impact of these discourses was identified when acknowledging that the inadequacies of New Zealand's mental health services have, in part, been in response to the lack of hope, dependence and burden associated with schizophrenia. As already noted, these inadequacies would almost certainly place more responsibility upon informal care-givers to provide care to their family member.

The material in this chapter has suggested that characteristics unique to schizophrenia, such as the unpredictability of the symptoms, could influence and shape the care provided to a family member diagnosed with schizophrenia. This research will ascertain first, whether these and other characteristics of

schizophrenia impact upon the care provided within a family to a member diagnosed with schizophrenia, and second, the extent and nature of this impact. This analysis will be undertaken in the following chapters of this thesis.

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## 2. THE NATURE OF CARE

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The purpose of this research is to develop an understanding of the unpaid care provided within a family to a member diagnosed with schizophrenia, specifically within the New Zealand context. In developing such an understanding, the characteristics and complexities of the care provided in these caring relationships need to be described and analysed. Examination also needs to be directed towards establishing who provides this care, and on what basis.

It is within this chapter that an examination is undertaken to establish the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia. Various analytical frameworks within feminist caring literature<sup>49</sup> inform this examination of the 'what' aspect of care, or in other words, what the care provided to a family member diagnosed with schizophrenia consists of. Each of these analytical frameworks facilitates the identification and description of the possible characteristics and complexities of the care examined in this thesis. Relevant concepts within existing schizophrenia caring literature are also described.

Following a discussion on the 'what' aspect of care, the 'who' aspect of care is considered. In other words, consideration is given to who performs care work. In this section, attention is directed primarily towards those answers provided within feminist caring literature. Gender divisions within caring work are discussed, and in particular, the over-representation of women is noted. Further analysis of this 'who' aspect of care is then undertaken by examining existing schizophrenia caring literature. Specifically, the role that parents and 'the family' have played as providers of care is explored.

Finally, attention is turned to defining and discussing the public/private split. Some of the strategies feminists have proposed to challenge the conceptual public/private split in order first, to highlight the value of women's unpaid caring work and second, to question the over-representation of women amongst informal care-givers are then identified and described. These strategies include consideration of: the breadth of women's care provision (Abel and Nelson, 1990;

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<sup>49</sup> The primacy of feminist caring literature in this chapter is explained below.

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Baines, Evans & Neysmith, 1993; Ungerson, 1990); the distribution of power between those who provide and those who receive care (Waerness, 1984); and, the commodification of care (Ungerson, 1995). This discussion will highlight the extent to which the conceptual public/private split influences the 'what' and 'who' aspects of care<sup>50</sup>.

Undertaking an examination of the 'what' and 'who' aspects of informal care, in order to establish the nature of the unpaid care provided within a family to a member diagnosed with schizophrenia, is important for several reasons. First, schizophrenia research has primarily focused either on the disorder itself or on the person diagnosed with schizophrenia. Examination of the informal care provided to an individual exhibiting the symptoms of schizophrenia has been relatively limited. It has been explained already that research on schizophrenia and care has focused primarily either on the dependency of the family members or on the burden experienced by 'the family' as a consequence of its care provision (Atkinson & Coia, 1995). The following comment indicates that research on schizophrenia and care has generally not extended beyond this dual focus:

*Where is the descriptive or analytical research which explores why a (for example) mother and son stay together in what to outsiders is a mutually dependent and mutually destructive relationship? There are first-person accounts from people with schizophrenia about their illness, their treatment by professionals and by 'the system'. Families appear, relationships are discussed, but the 'care' aspects tend to receive little attention (Atkinson & Coia, 1995:103).*

The attention paid to schizophrenia itself and those who exhibit its symptoms reflects that schizophrenia has traditionally been researched by the professions of medicine and psychiatry. As a consequence of schizophrenia being situated and viewed within a medical perspective, the positivist research paradigm<sup>51</sup> typically has been utilised to direct the research on schizophrenia. The primacy of the positivist research paradigm in schizophrenia research has meant that the process and interpretation of the care provided to a family member diagnosed with

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<sup>50</sup> Other factors which influence and shape the unpaid caring work described in this chapter will be examined further on in this thesis.

<sup>51</sup> The positivist research paradigm is described and discussed further on in this thesis.

schizophrenia has generally been overlooked (Atkinson & Coia, 1995; Perring et al, 1990; Twigg & Atkin, 1995).

For almost two decades, feminists have been critically examining the care provided to a family member with an intellectual, physical or age-related disability (Lewis & Meredith, 1988; Munford, 1989; Opie, 1991). However, acknowledgment of the nature and the symptoms of schizophrenia suggest that existing feminist analytical frameworks, regarding unpaid care, may not adequately describe and explain the unpaid care provided within a family to a member diagnosed with schizophrenia. For example, the cyclical and unpredictable nature of the symptoms of schizophrenia could necessitate an extension of existing feminist analytical caring frameworks.

While little has been recorded about the complexities of the unpaid care provided to a family member diagnosed with schizophrenia, detail is also lacking regarding the manner in which this caring work is distributed within 'the family'. When considering the 'who' aspect of this care, the smallest unit of analysis typically has been 'the family'<sup>52</sup> and then 'parents' (Atkinson, 1986; Bulger et al, 1993; Falloon et al, 1984; Lefley, 1987). Examination of this caring work will confirm whether 'the family', 'parents', or women are the actual agents which provide informal care to a family member diagnosed with schizophrenia. In undertaking this examination it will be acknowledged that feminist caring literature identifies the prominent role of women within the family in providing unpaid caring work to people with a disability (Dalley, 1988; Graham, 1983,1991; Hogan, 1990; Munford, 1989; Opie, 1991; Schultz & Schultz, 1990; Ungerson, 1983).

Feminist researchers have undertaken detailed examinations of both the '*what*' and '*who*' aspects of care. The detail and interpretation provided by feminists about the '*what*' and '*who*' aspects of care will provide a map for exploring and negotiating the care provided to a family member diagnosed with schizophrenia.

## **What is Care?**

There is no unitary definition of care as is reflected in the various ways that the term 'care' is utilised in both related literature and on a day-to-day basis within New Zealand. However, two main themes predominate when care is discussed. First,

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<sup>52</sup> 'The family' refers to all of those individuals defined as the care-recipient's family.

caring involves interaction between two or more persons. Second, caring involves the bi-directional process of giving and receiving. These themes provide a starting point from which an exploration of the 'what' facets of care will proceed.

As already noted, existing research on schizophrenia and care has not generally provided a detailed analysis of the characteristics and complexities of the informal care provided within the family to a member diagnosed with schizophrenia beyond dependence and burden. (Atkinson & Coia, 1995; Perring et al, 1990). In response to this, feminist conceptualisations of care will inform the examination of the 'what' aspects of unpaid caring work. Discussion of the 'what' facets of care initially focuses upon Ungerson's (1983) concepts of 'caring for'<sup>53</sup> and 'caring about'<sup>54</sup>. The acceptance of Ungerson's (1983) concepts for distinguishing between the tasks and feelings associated with providing care to a family member with an intellectual, physical, or age-related disability, is highlighted in noting the extent to which these concepts have been utilised by other feminist researchers and writers (Briggs & Oliver, 1985; Lewis & Meredith, 1988; Munford, 1989; Opie, 1991, 1992; Twigg & Atkin, 1995). The concepts of 'caring for' and 'caring about' are relevant to this research in that they provide an initial framework for examining the tasks and feelings associated with the care provided to a family member diagnosed with schizophrenia.

The equivalent terms to Ungerson's 'caring for' and 'caring about' within existing schizophrenia and care research are also identified and described. In describing objective family burden<sup>55</sup> and subjective family burden<sup>56</sup>, existing research on schizophrenia and care is drawn upon (Arieti, 1984; Atkinson, 1986; Beels & McFarlane, 1982; Bernheim, 1990; Brooker, 1990; Dearth, Labenski, Mott & Pellegrini, 1986; Deveson, 1985; Doll, 1976; Falloon et al, 1984; Hatfield, 1978, 1979; Holden & Lewine, 1982; Howe, 1991; Lamb & Oliphant, 1978; Lefley, 1987;

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<sup>53</sup> Throughout the rest of this thesis, the term 'caring for', in inverted commas, refers specifically to the expenditure of energy, goods and services via the provision of care (Ungerson, 1983). 'Caring for' refers primarily to the tasks undertaken in the provision of care.

<sup>54</sup> Throughout the rest of this thesis, the term 'caring about' in inverted commas, refers specifically to the emotions associated with the provision of care (Ungerson, 1983) such as compassion, guilt, concern, and resentment.

<sup>55</sup> Objective family burden is defined as "*the effects on financial state, health, and leisure of the family*" (Martyns-Yellows, 1992:779).

<sup>56</sup> Subjective family burden is defined as "*the feeling of actually carrying a burden*" (Martyns-Yellows, 1992:779).

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Mittleman, 1985; Morris et al, 1989; Torrey, 1983; Wahl & Harman, 1989; Walsh, 1985; Willis, 1982)<sup>57</sup>.

Attention is then turned to how the personal characteristics and support needs of the care-recipient, impact upon the provision of care (Ascher-Svanum & Sobel, 1989; Bulger et al, 1993; Kaplan & Sadock, 1991; Lewis & Meredith, 1988; Munford, 1989; Opie, 1991; Winefield & Harvey, 1994; Women's Affairs Victoria, 1994). Particular attention is paid to the age, gender and disability of care-recipients.

Next, the tensions which exist between the rights of those who provide care, and the rights of those who receive care (Ungerson, 1993) are acknowledged. The difficulty associated with meeting the rights of care-givers while simultaneously meeting the rights of care-recipients is highlighted. Twigg and Atkin's (1995) call for a 'duality of focus' is noted.

Waerness' (1984) work, which conceptualises care according to its purpose, is then drawn upon. Specifically, this section identifies how care provided to persons with a need for care can typically be categorised with either 'growth', 'stagnation', or 'deterioration'. Waerness' concepts of 'growth', 'stagnation', and, 'deterioration' provide the opportunity to step back from considering the more specific characteristics of unpaid caring work in order to draw connections between various caring relationships.

In continuing to move from the micro to the macro factors of the 'what' aspect of unpaid care, the interconnectedness between 'the personal' or individual caring relationships, and 'the political' or the social, cultural, political, legal and economic context in which the caring relationship is situated, is then highlighted. Discussion of Munford's (1992), Opie's (1992), and Traustadottir's (1991) work facilitates this connection.

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<sup>57</sup> This discussion will highlight how researchers of schizophrenia and care, when considering objective and subjective burden, have referred to 'the family' as the smallest unit of analysis. This is in contrast to feminist researchers who have identified that particular tasks and feelings are associated with particular individuals within the family. This difference is further discussed in the section entitled 'Who Cares?'

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## Caring For/Caring About

According to Ungerson (1983), caring involves necessarily both 'caring for' and 'caring about'. Ungerson's (1983) concepts provide the initial framework for examining the particular tasks and feelings involved in providing care to a family member with an intellectual, physical, or age-related disability. After describing what is associated with 'caring for' and 'caring about' in feminist caring literature, attention is then turned to those tasks and feelings associated with the provision of care to a family member diagnosed with schizophrenia.

The concepts of 'caring for' and 'caring about' (Ungerson, 1983), are mirrored in the existing literature on schizophrenia and care with its focus on objective family burden and subjective family burden. Reflecting the primacy of the positivist research paradigm within schizophrenia care research, the objective and subjective family burden care-givers experience has primarily been determined by various psychometric measures (Bulger et al, 1993). As Atkinson (1986:97) has argued, the consequence of research data evolving from these psychometric measures is that little detailed information is conveyed regarding what 'objective' and 'subjective' family burden means for 'the family' on a day-to-day basis: *"No amount of research data on families expressed as percentages of the group bearing a burden, can convey what it means in real terms to the family"*.

### *Caring For*

While noting the occurrence of some unpredictable behaviour, as a consequence, for example, of illnesses such as dementia (Opie, 1991, 1992), women 'caring for' persons with an intellectual, physical, or age-related disability are generally aware of the type and level of care they will need to provide on an ongoing basis. Feminist examination of the caring tasks associated with 'caring for' generally has highlighted the predictability associated with these tasks (Briggs & Oliver, 1985; Munford, 1989). The overall predictability in the type and level of caring tasks required, is reflected in the description of established routines which care-givers generally adhere to (Munford, 1989; Opie, 1992). These established routines both highlight the restriction that these care-givers experience on a day-to-day basis (Munford, 1989), and mirror the fact that the needs of those persons with an

intellectual, physical or age-related disability seldom change considerably from day to day or month to month<sup>58</sup>.

'Caring for', within feminist caring research, has primarily been associated with personal care needs such as toileting, dressing and feeding. This has been highlighted by Twigg and Atkin (1995:31):

*Physical tending is sometimes regarded as the defining feature of informal care, and the literature has emphasised the hard physical labour that can be involved in caring and its impact on the carer's life and health...*

When considering Twigg and Atkin's (1995) comment, it is important to remember that the feminist unpaid caring literature has focused primarily on care provided to persons with an intellectual, physical or age-related disability. For example, Lois Newson, one of Opie's (1991:17-18) participants, spoke of the care she provided on a daily basis to her husband who suffered from an Alzheimers-type dementia:

*Well, if he is awake, then I get him up when I get up before eight. I get him dressed, changed...because he is incontinent at night. So I get him washed, change the bed and then I put him back into bed for his breakfast...that might take me 20 minutes...then I bring him his breakfast....*

The consistency, use of routines, and visibility of caring tasks is reflected in these care-givers being easily and consistently viewed as either 'full-time'<sup>59</sup> or 'part-time'<sup>60</sup> care-givers. An observer viewing these caring relationships from outside can easily note the physically demanding caring work being undertaken by the care-givers.

While acknowledgment of the physical, emotional and psychological costs of unpaid caring work has been an important part of the feminist analysis of care (Munford, 1989; Opie, 1992; Parker, 1985; Qureshi & Walker, 1989), burden has been the primary focus of the schizophrenia caring literature (Atkinson & Coia,

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<sup>58</sup> Again exceptions to this overall predictability exist. Dementia and some challenging behaviours are a case in point.

<sup>59</sup> A 'full-time' carer is an individual who is primarily responsible for providing the majority of a person's unpaid care.

<sup>60</sup> A 'part-time' carer is an individual who provides some, but not the majority, of a person's unpaid care.

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1995). The concept of 'caring for' has been paralleled within the literature on schizophrenia and care by the focus on objective family burden. In practice, objective family burden has been associated with: facing unco-operative mental health professionals (Bernheim, 1990; Brooker, 1990; Holden & Lewine, 1982; Morris et al, 1989; Willis, 1982); dealing with the stigma associated with mental illness generally and schizophrenia specifically (Wahl & Harman, 1989); a restricted life-style (Hatfield, 1979); financial difficulties resulting from the care-giver role; and, lack of access to respite care (Hatfield, 1979; Lamb & Oliphant, 1978).

Although there is limited detail in existing schizophrenia and care literature on what 'caring for' actually involves, personal care tasks such as washing and toileting, are generally not noted in discussions regarding care provided to a family member diagnosed with schizophrenia. Instead, the idea that 'caring for' involves more supervision and monitoring is projected (Perring et al, 1990). It appears that care provided to a family member diagnosed with schizophrenia may revolve around taking responsibility for the family member rather than engaging in personal care tasks. The lack of personal care tasks in the care provided to a family member diagnosed with schizophrenia raises the question as to whether this unpaid work should even be defined as care. Twigg and Atkin (1995:105), for example, have noted that personal care tasks:

*..are rarely of central importance in relation to mental health problems and are commonly absent. As a result, caring for someone with mental health problems is often not regarded as 'caring' at all.*

It would appear that the assumption within Twigg and Atkin's (1995) comment is that care is typically defined by the presence of personal care tasks. This assumption could have considerable implications for those persons who provide care to a family member with a psychiatric disability. The caring work of supervision and monitoring is not as easily identified as those caring tasks associated with personal care needs. The relative invisibility of supervision and monitoring tasks means these tasks are more likely to be overlooked by observers from outside the caring relationship, the work of care-givers not being acknowledged or supported. Therefore, the needs of these care-givers, arising

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from their provision of care to a family member diagnosed with schizophrenia, are unlikely to be identified or met. A possible further consequence of the relative invisibility of the caring tasks of supervision and monitoring could be a reluctance to categorise individuals providing care to a family member diagnosed with schizophrenia as either full-time or part-time care-givers. The status accorded to care-givers providing schizophrenia care will be explored in this research.

Discussion in existing schizophrenia caring literature, highlights the unpredictability associated with the symptoms of schizophrenia (Torrey, 1983). This unpredictability was noted in the previous chapter, when describing the fluctuations in the type, intensity, duration, and frequency of the symptoms of schizophrenia. Dealing with the unpredictability of their family member's symptoms has been assessed by care-givers as the most difficult aspect of schizophrenia and the source of greatest tension (Torrey, 1983). It appears that, whereas care-givers discussed in feminist literature are generally aware of the type and level of care they will typically need to provide<sup>61</sup>, care-givers in schizophrenia caring literature tend not to have this awareness. As a consequence of the unique symptoms of schizophrenia with their cyclical, unpredictable and constantly changeable nature, care-givers are uncertain of the extent to which they need to provide care to their family member. Attention then needs to be paid to how the unpredictability and changeability of these caring tasks influences the informal care provided to a family member diagnosed with schizophrenia.

### *Caring About*

Paralleling the focus on 'caring for' within feminist caring literature is the attention paid to 'caring about'. Feminist research has found that the emotions care-givers experience when 'caring about' a family member are often contradictory (Briggs & Oliver, 1985; Opie, 1991; Ungerson, 1987). Lewis and Meredith (1988:6-7) have described the feelings that daughters 'caring for' their mothers at home can experience:

*Carers may feel very bitter about...material losses. They may also nevertheless feel glad that they cared. The strain on their material resources, their own health, and the possible tensions*

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<sup>61</sup> Again exceptions to this overall predictability exist such as with the care provided to an individual with a dementia type illness or challenging behaviours.

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*between the work of caring and other aspects of their lives has to be balanced against the powerful injunction to care and the guilt if it is ignored.*

The nature of the care-giver's emotions then reflect the ambivalent situations they experience when caring. Munford (1989) highlighted this ambivalence when discussing her concepts of 'mutuality and conflict'. These concepts were developed via the examination of power relations surrounding women who provide care to a family member with an intellectual disability. An example of an ambivalent situation provided by Munford is when those same men who monitored and controlled the routines of care, supported and assisted the women in their care. The women then: *"...were simultaneously subjected and supported"* (Munford, 1992:172). The ambivalence the women detected in the situations around them ensured that they would continue to provide care to their family member with an intellectual disability. For example, Munford (1992:228) explained: *"It was difficult for women to challenge those people with whom they had shared many happy times"*.

While feminist caring research has highlighted the ambivalence associated with 'caring about' a family member with an intellectual, physical or age-related disability, research on care and schizophrenia has also highlighted the contradictory feelings care-givers experience (Dearth, et al, 1986). However, in examining the subjective family burden, or the feelings associated with the provision of care to a family member diagnosed with schizophrenia, particular attention has been paid by researchers to the negative feelings expressed by care-givers. As Hatfield (1979:339) proposed:

*Caregivers found stress nearly unbearable at times producing severe physical and emotional strain, and finally resulting in feelings of utter defeat. Anxiety was consistent, accentuated by the unpredictability of events. There was worry about the future and fear of planning for it.*

Specifically, subjective family burden has been associated in existing literature with: agonising over whether to fill a provider role (Arieti, 1984; Beels & McFarlane, 1982); concern over who will provide care to the family member in the future (Lefley, 1987); confusion over the lack of reliable and accessible information about

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schizophrenia (Falloon et al; Howe, 1991); adjusting to symptoms of schizophrenia (Torrey, 1983); difficulties in the caring relationship stemming from past experiences between the carer and the family member (Mittleman, 1985; Walsh, 1985); determining the role the family has played in causing 'the family' member's schizophrenia (Beels & McFarlane, 1982; Deveson, 1985); the undervaluation and invisibility of care-giver effort, skill and knowledge (Atkinson, 1986; Doll, 1976); role adjustment and overload (Deveson, 1985); and, concern over whether other members of the family will develop schizophrenia (Atkinson, 1986). The emotions care-givers have associated with providing care to a family member diagnosed with schizophrenia typically are related to the unique characteristics of schizophrenia. For example, concern over whether other members of the family will develop schizophrenia reflects the hereditary component of schizophrenia. Also, as will be explored in the next section, concern about who will provide care in the future is related to the time of onset of schizophrenia. This research will consider how further characteristics of schizophrenia impact upon the 'caring about' aspects of those who provide care to a family member diagnosed with schizophrenia.

This research will also consider whether a care-giver's understanding of the Expressed Emotion theory influences the way in which they 'care about' their family member. As already noted, the Expressed Emotion theory proposes that individuals diagnosed with schizophrenia are more likely to experience relapse if their environment is negatively charged, especially with criticism (Brown et al, 1962). This would suggest that care-givers need to be careful about the extent to which they express the negative feelings they associate with their care provision if they do not want to risk their family member relapsing.

### **The Profile of Care-Recipients**

As the above discussion has highlighted, 'caring for' and 'caring about' or 'objective family burden' and 'subjective family burden', tend to reflect the personal characteristics of the family member receiving care, including their age, gender, and the type and degree of disability. It is within this next section that the characteristics of those persons who receive care are identified.

Young children and older adults predominate amongst those persons who receive care in existing feminist caring literature (Lewis & Meredith, 1988; Munford, 1989; Opie, 1991). This consistency suggests that women are expected to provide care

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to their children when the children are young, take a break from intense caring when their children's need for care has reduced, and then later undertake another intense period of caring for elderly parents (in-law). This pattern of care has been represented by a U-shape. This U-shape reflects two intense periods of caring separated with a period of less intense caring during a woman's middle years (Women's Affairs Victoria, 1994). The nature of some disabilities suggests however that care may be more continual than the U-shape indicates. For example, some people with an intellectual disability require assistance throughout the various stages of their life.

While care-recipients in existing feminist literature are predominantly young children or older adults, existing literature on schizophrenia and care has reported that it is predominantly adult sons who receive ongoing care and support. For example in Bulger et al's (1993) research, adult sons were over-represented among those who received care (sixty five percent). Winefield and Harvey's (1994) research found a similar pattern with seventy five percent of those who received care being male with an average age of thirty eight years. The over-representation of men relative to women diagnosed with schizophrenia who receive informal care can be explained by the poorer prognosis for males (Kaplan & Sadock, 1991). As already explained, males tend to experience schizophrenia at a time associated with the development of interpersonal and life skills (American Psychiatric Association, 1994a; Reed Healthcare Australia, no date). The years between fifteen and twenty five also often establish the beginning of a person's work career. Interference with this pattern of development means that males tend to require more support and assistance than their female counterparts who usually exhibit the symptoms of schizophrenia later in life.

The adult status of the men and women receiving care could have particular implications for the provision of care. One implication of the adult status of those men and women receiving care is that the expected pattern of informal care is challenged. Instead of the U-shape pattern of care provision (Women's Affairs Victoria, 1994), care may be required to be provided on a continual (flat-line) basis. Ascher-Svanum and Sobel (1989:844) have highlighted this point in suggesting that:

*...the deinstitutionalisation movement and its emphasis on family and community care have resulted in an extension of women's culturally prescribed nurturant role beyond the child-rearing years. They are expected to manage and care for their mentally ill offspring and relatives, possibly a lifelong career.*

The provision of care to a family member diagnosed with schizophrenia reflecting a continual (flat-line) basis suggests that care-givers also continually experience objective and subjective burden<sup>62</sup> during the majority of their adult lives. Therefore, the quality of life these care-givers' experience could be notably diminished by their care provision. This is particularly the case if the needs of these care-givers are ignored as a consequence of the relative invisibility of their care provision. Examination in this research will determine whether the young adult status of those who receive care has further implications for their informal care-givers and the care these care-givers provide.

### **Rights of Care-Givers Versus Rights of Care-Recipients**

Inherent within the discussion of the U-shape or flat-line pattern of care are the tensions which arise between the care-recipient's need for care, and the care-giver's ability to provide this care. Ungerson (1993), in her discussion on caring and citizenship, has addressed the tension between the perspectives and needs of care-givers and those who receive care. She has highlighted the complexity involved in constructing established sets of rights for care-givers and the cared-for. For example, arrangements which would best benefit care-givers can be detrimental to those who receive care. Ungerson (1993:145) has provided the following example of this situation:

*...it is arguable that it is in carers' interests, and that they should have the right, to be freed from caring, at least for, say, one week in six, by placing their dependent persons in respite care, or by having someone to replace them in their own homes while they go away. But it could equally well be argued that dependent people should not have to suffer the disruption of continuously changing where they live, or having strangers enter their homes in order to care for them in the most personal and intimate ways.*

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<sup>62</sup> These terms have already been defined.

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Atkinson's (1989) article entitled 'Responsibility To Carers -- An Ethical Dilemma', highlights many of the tensions between the rights and needs of individuals diagnosed with schizophrenia, and those members of the family who provide their informal care. As the following example highlights, the majority of these tensions revolve around the collection and dissemination of information<sup>63</sup>. While a person diagnosed with schizophrenia may demand "...*informed consent, the right to refuse treatment and the right to confidentiality*" (Atkinson, 1989:602), those members of the family who provide unpaid care to this person often argue that they should have access to information regarding their family member's health status:

*...relatives rightly point out, many [of them] are the agents of primary care for the patient. Such information includes being told the diagnosis, treatment plans including medication, and in some instances being consulted about all aspects of the patient's care (Atkinson, 1989:603).*

The tensions which exist between the rights of care-givers and the rights of care-receivers may be magnified when examining caring relationships in which the family member is diagnosed with schizophrenia. This assertion is made in acknowledging the nature of the symptoms of schizophrenia and is supported by the following example. Previous discussion of these symptoms indicated that a family member may perceive a completely different reality to those around him or her as a consequence of, for example, their hallucinations or delusions. Therefore, a family member may not be able to make an informed decision about whether their informal care-giver should receive information about their health status. As a consequence of this, care-givers may be placed in the compromising situation where they are expected to assume responsibility for meeting their family member's welfare needs, without any information about their family member's diagnosis, prognosis, or treatment.

The different views, experiences and needs of those persons providing and receiving care require what Twigg and Atkin (1995:7) have called "...*an essential duality of focus...*". As Twigg and Atkin (1995:7) have explained, a duality of focus includes considering the experiences and needs of both those who receive and

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<sup>63</sup> The importance that people with a psychiatric disability place upon privacy regarding the collection and dissemination of their information is further explored later in this thesis.

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provide care: "*Caring takes place in a relationship, and one cannot focus on the interests of either the carer or the cared-for person to the exclusion of the other*"<sup>64</sup>.

### **The Purpose of Care**

So far, three different dimensions of the 'what' aspect of unpaid caring work have been identified and described -- specifically the tasks and feelings associated with unpaid care, the profile of persons receiving care, and, the tensions which exist between those who provide care and those who receive care. Each of these dimensions discussed a specific aspect of care and therefore added to the overall picture of caring work. Waerness (1984) has provided a further dimension of care, specifically the purpose for which care is undertaken. Waerness has proposed that care-giving work, or the care provided to a person who requires care and support, can be distinguished by three purposes. While other researchers, such as Munford and Opie, have considered generally the purpose of care, it has been Waerness who has focussed specifically on this aspect of caring work.

One purpose of care-giving work is 'growth' or 'results'. As the terms 'growth' and 'results' suggest, the outcome of this care-giving work is that the person receiving care eventually becomes self-sufficient. Second, Waerness (1984) connects care-giving work with 'stagnation'. This care-giving work is provided in order to maintain the care-recipient's level of functioning. This type of care-giving work is based upon the understanding that the person receiving care will not gain independence. Finally, care-giving work is connected to 'deterioration'. The level of functioning of the person receiving care becomes worse despite the care-giver's efforts. Conceptualising care by its purpose provides another framework by which caring work can be viewed and analysed.

It is uncertain as to how applicable Waerness' categories of 'growth', 'stagnation' and 'deterioration' will be to the care provided to a family member diagnosed with schizophrenia. For example, because schizophrenia is a heterogenous disorder (Bentall, 1992), there is no uniform outcome to the diagnosis schizophrenia (Kaplan & Sadock, 1991; Miller, 1995). While some care could be categorised as 'growth', such as that provided to a family member who has had their first and only

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<sup>64</sup> It is in the following chapter that steps which have been taken, via policy developments, in order to ensure a duality of focus in service provision are outlined.

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episode of schizophrenia, the category of 'stagnation' may be more applicable to the care provided to an individual who experiences the cyclical acute and chronic episodes which characterise schizophrenia. The applicability of Waerness' (1984) purposes of care will be considered in this research.

Waerness (1984) has argued that there is a connection between the purpose of care-giving work and the distribution of services and resources to those in the caring relationship. For example, Waerness has proposed that more services and resources are allocated to those caring relationships categorised by 'growth' than those categorised by 'deterioration'. This connection between the purpose of care and the allocation of resources has already been suggested. It is argued further on in this thesis that the ignorance, fear, rejection and neglect associated with mental illness has been reflected in the way New Zealand's formal mental health services historically have been poorly funded and developed (Bascand, 1993; National Advisory Committee, 1993). A connection is made between the inadequacies in New Zealand's formal mental health services and the pressure informal care-givers experience to provide care to a family member diagnosed with schizophrenia.

### **The Personal is Political**

Discussion has revolved around those dimensions of unpaid caring work which pertain to the features of individual caring relationships. Feminists, however, have furthered our understanding of unpaid care by highlighting how 'the personal is political'. Feminists have explained the similarities in the 'caring for' and 'caring about' components of individual caring relationships by noting how these components of care have been influenced by the social, political, cultural, and economic context in which these caring relationships are situated. For example, Opie (1992) has drawn upon Ungerson's (1983) conceptualisation of care by acknowledging the emotional and physical labour involved in providing care to the confused elderly. In making the personal political, Opie (1992) extended her initial examination by situating this caring work within the wider context of community care policy, service provision, and present ideology. Specifically, Opie (1992:1-2) focused simultaneously:

*..on microsocial practices within the individual family in order to illuminate the nuances, contradictions, conflict, pain and love embedded in caring, and on the siting of these practices and experiences within the social, economic and political contexts surrounding and interacting with families caring for dependent members.*

Opie's work adds to the analytical framework examining the what care consists of by highlighting the influence of micro aspects (the caring relationship) on macro aspects (policy and service provision) of care and vice versa<sup>65</sup>.

One way in which care-givers make the link between the personal and the political is by joining with others both to initiate change which will improve their own caring relationship and to ensure that their caring counterparts do not experience the difficulty they have had in receiving the resources and support they require. Traustadottir<sup>66</sup> (1991:217) has spoken about this 'extended caring role':

*When the mothers extend their care beyond their own child to broader community or societal concerns. That is, they start caring about what happens to people with disabilities in general and the way that society as a whole treats them...One form of this extended caring role is when the mothers go beyond their own children and become advocates for change on behalf of people with disabilities in general.*

The links that care-givers make between the personal and the political reinforces Munford's (1992) view that care-givers should not be viewed solely as victims. In filling an extended caring role (Traustadottir, 1991) care-givers are able first to identify those factors which restrict their care provision and second to develop and implement solutions which counteract these restrictions. Munford's (1992:173) research proposes that:

*The research functioned to make women visible; to not only detail negative aspects of women's existence, but to celebrate their achievements. We must not always portray women as*

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<sup>65</sup> As already noted, the material presented further on in this thesis identifies and analyses the way in which New Zealand's social, political, cultural, legal and economic context impacts upon the provision of care within individual caring relationships.

<sup>66</sup> Traustadottir (1991) researched the care women provided to children with disabilities between two and sixteen years.

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*'victims'; but also show how these women have begun to take control of their own lives and if they cannot, what is it that prevents them from doing so.*

Munford (1992) is not the only feminist who has stressed the importance of not portraying women as victims (Stacey, 1981; Stanley & Wise, 1983). As Lerner (1986:5) has argued: "*Women are essential and central to creating society; they are and always have been actors and agents in history*". The active role that women have played suggests the need to determine the ways in which women care-givers have acted as change agents. In other words, what action have women taken to alter and improve both their own caring relationship and the caring relationships of others.

Discussion on 'the personal is political' has highlighted how important it is to acknowledge how individual caring relationships, and the care provided within them, are influenced by the socioeconomic context in which they are situated. It was noted that the opportunity for changing this socioeconomic context, and therefore to improve the conditions of caring work, exists and has previously been utilised by care-givers. However, one might wonder whether care-givers of a family member diagnosed with schizophrenia would take advantage of such an opportunity. Discussion in the previous chapter identified the stigma, discrimination and fear associated with mental illness generally and specifically schizophrenia (Miller, 1995; National Mental Health Consortium, 1989; Zifcak, 1994). It was noted that this stigma, discrimination and fear has not remained solely with the individuals exhibiting the symptoms of schizophrenia but has extended to their informal care-givers. This has been the case particularly as a consequence of now outdated theories about the role of 'the family' in the aetiology of schizophrenia. Therefore, while making 'the personal political' may be a mechanism for initiating positive change, publicly identifying yourself as a care-giver of a family member diagnosed with schizophrenia could be associated with negative social outcomes. Furthermore, the dominant discourses of schizophrenia, specifically those of dependence and burden, may mean that little support would be raised for change, for example, increasing the allocation of resources towards those persons directly affected by schizophrenia. The negative social outcomes associated with identifying as a care-giver of a family member diagnosed with schizophrenia may outweigh the degree of positive change achieved while making 'the personal political'. This research will examine

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the extent to which care-givers of a family member diagnosed with schizophrenia make the link between the personal and the political in order to positively change the socioeconomic context in which their caring relationships are situated.

## **Who Cares?**

In having identified and described the characteristics and complexities of the unpaid care provided to a family member with either an intellectual, physical or age-related disability or a family member diagnosed with schizophrenia, examination in this section will establish who actually provides this caring work. This examination begins by detailing the sexual division of labour in caring work reported by feminists (Dalley, 1988; Graham, 1983,1991; Hogan, 1990; Munford, 1989; Opie, 1991; Schultz & Schultz, 1990; Ungerson, 1983). Attention is then directed towards establishing whether it is women who predominantly provide informal care to a family member diagnosed with schizophrenia. Following this, the role that parents and 'the family', respectively, have played in providing care to a family member diagnosed with schizophrenia is examined. This examination identifies the fact that 'the family' has traditionally been the smallest unit of analysis within research on schizophrenia and care. How informal care is distributed within 'the family' has not typically been considered. Furthermore, this examination provides an opportunity to explore briefly how 'the family', with regard to care, has been considered and understood in New Zealand.

## **Women**

That it is typically women who provide informal care was alluded to throughout the preceding discussion of the 'what' facets of care. It was feminist researchers and writers, who initially noted this division of labour in unpaid caring work. Feminist researchers and writers have constantly highlighted the over-representation of women undertaking informal care (Dalley, 1988; Graham, 1983,1991; Hogan, 1990; Munford, 1989; Opie, 1991; Schultz & Schultz, 1990; Ungerson, 1983). For example, Croft (1986:24) has asserted that:

*We should not be embarrassed to say that it is on women's sweat and tears and frequently dashed hopes and plans that the gentlemanly and distanced official and managerial debates and prescriptions about caring and welfare rely.*

Although care is not undertaken exclusively by women (Parker, 1992), *"Caring is associated with women and the places where women are found"* (Graham, 1983:16), that is, the family and the home. Women gain their social identity (as nurturing and loving), and entrance to both the public sphere (as social workers, nurses, teachers) and the private sphere (as mothers and wives) by taking up the caring role<sup>67</sup>.

Finch and Mason (1993) have noted the connection between the formation of women's identity and the tendency for women to continue to provide care. They (1993:170) have argued that via the exchange of care and support: *"...peoples identities are being constructed, confirmed and reconstructed"*. If the caring part of a woman's identity is important and valued to her, *"...it eventually becomes too expensive to withdraw from those commitments through which that identity is expressed and confirmed"*. Therefore, a woman who was considered by those around her as altruistic and selfless, resulting from the part she had played in her son's care, would be less likely to stop providing care to her son if she valued this particular construction of her identity.

In discussing the connection between a woman's identity and care, Finch and Mason (1993) implicitly referred to the role agents, outside the caring relationship, have in determining who cares. The understanding that a woman's decision to care is influenced by those around her is consistent with Finch's (1989) work on how the decision of who cares is made. For example, Finch (1989) has argued that the question of who cares is not settled by adhering to an established set of rules. Instead, Finch (1989) has proposed that this question is answered by a process of negotiation, including persuasion, manipulation, and coercion. These *"negotiations proceed by developing shared definitions of what constitutes a 'need' for support and who has the 'capacity' to provide it"* (Finch, 1989:194).

According to Finch (1989) negotiations are not based solely on the particular circumstances which exist at the time of making the decision of who cares. These negotiations are also based on the interpersonal histories of the parties negotiating. As opposed to the understanding that women drift into a caring role,

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<sup>67</sup> Discussion of both the private sphere and the public sphere is provided below.

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Finch (1989) has argued that this process is better understood by drawing upon the concept of 'cumulative commitments'. This concept refers to interaction between persons over time which establishes (both unconsciously and consciously) recognised precedents about who should care. These precedents can be drawn upon during specific negotiations<sup>68</sup>.

The above discussion suggests that consideration of who provides care to a family member diagnosed with schizophrenia will need to identify the past and current caring responsibilities of the care-giver and their significant others. It can be assumed that the care-giver may not have willingly decided to fill their care-giver role. Instead this decision may have been the result of negotiation, including persuasion, manipulation, and coercion between themselves and their significant others.

Despite consistently uncovering a sexual division of labour in caring work, feminists have challenged the understanding that caring is the natural activity of women (Baines et al, 1992). In making this challenge, feminists have not developed a simple unitary explanation for women's over-representation in unpaid caring work. Instead, in making the link between the personal and the political, feminists have argued that various social, political, cultural and economic factors combine to influence women's participation in informal care (Bowman & Virtue, 1993; Croft, 1986; Dalley, 1988; Finch & Groves, 1980; Qureshi & Walker, 1989). The development of various rules about who cares, and the level and type of care they should undertake (Ungerson, 1983) is an example of such factors. One of these rules is that women intuitively and instinctively know how to care (Needleman & Nelson, 1986; Pitkeathley, 1991). According to Ungerson (1983), these rules have developed into taboos which exist around the activities of care. For example, it is more acceptable for women to bathe persons of either sex, and to touch another's body parts considered private, when undertaking caring activities, than it is for men. The existence of such norms makes it difficult to challenge the expectation that women will care. This is particularly the case regarding the care provided to a family member with an intellectual, physical, or age-related disability. This care involves tasks revolving around the activities of

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<sup>68</sup> Having given up paid work to provide care to children or having engaged in paid caring work, such as nursing, are examples of such precedents.

toileting, washing, feeding and dressing (Twigg & Atkin, 1995). However, discussion of the primacy of supervision and monitoring tasks, which reportedly characterise the care provided to a family member diagnosed with schizophrenia (Perring et al, 1990), questions the relative applicability of such caring taboos.

Despite the reported lack of personal care tasks in the care provided to a family member diagnosed with schizophrenia, examination has revealed that it is typically women, who provide the main component of this care. Specifically, the results of Ascher-Svanum and Sobel's (1989:844) research suggested that:

*Women are three times as likely as men to be the primary caregivers for their nonmarried adult mentally ill relatives during hospitalisation regardless of the patient's diagnosis, age, gender, number of previous hospitalisations, or years since first treatment for psychiatric problems.*

The predominance of women as care-givers for those persons experiencing a mental illness has been confirmed by research based in New Zealand. In studying "...forty two Auckland families caring for a long term mentally ill member" (Warren, 1994/1995:15), Warren (1994/1995:16) found that it was primarily women who provided care to the family member experiencing mental illness: "*Despite the rhetoric, 'community care' often boils down to care by women in the immediate family*". The link that Ascher-Svanum and Sobel (1989) and Warren (1994/1995) have found between women and the care provided to persons with a psychiatric disability is reflected in recent overseas feminist research on care. This research has found that women provide care to persons with a psychiatric disability more so than for persons with other disabilities (Women's Affairs Victoria, 1994).

### **Differences Between The Care of Women And Men**

As well as asserting that it is women who predominantly provide informal caring work, feminists have proposed that differences exist in the way women and men care, these differences being justified for example by existing caring taboos. One of these reported differences relates to society's expectations about whether women and men should both 'care for' and 'care about'. Whereas "...*caring for and caring about are deemed to form a unitary integral part of a woman's nature*" (Dalley, 1988:8), men are primarily expected to be only responsible for the person they 'care about' (organise care -- either paid [for example home help] or unpaid

[for example a wife or sister]). In other words, men typically are not expected to actually undertake caring tasks for the person they 'care about' themselves. The man who both 'cares for' and 'cares about' is considered unconventional (Dalley, 1988; Ungerson, 1983), effeminate (Game & Pringle, 1983) or saintly. One consequence of men not being expected to both 'care for' and 'care about' is the greater degree of choice men have, in comparison to women, about whether and when to provide informal care. When men do both 'care for' and 'care about', they usually undertake their caring responsibilities in their later years after their paid work is finished, and situate their care in the same context as their paid work (Ungerson, 1987). Ungerson (1987:65) explained her view of men's caring:

*I suggest that the male life cycle contains definite 'start-up' and 'cut-off' points oriented around paid work. Full-time paid work almost always acts as a buffer between the social and family circumstances of a man and his availability for caring. Once the period in the cycle of full-time paid work is over, a man suddenly becomes available for full-time caring.*

The understanding that full-time paid employment is the primary responsibility of men is reinforced by the traditional roles of women and men within the nuclear family and the restricted participation of women, in comparison to their male counterparts, within the paid work 'arena'<sup>69</sup> (Craig, 1991; Dunn, Pole, & Rouse, 1992; Statistics New Zealand, 1993; Statistics New Zealand, 1995). For example, when 'the family' is discussed further on in this section, it will be noted that while women have traditionally filled the role of home-maker and nurturer, men typically have been considered to be the wage earner of the family (Swain, 1990)<sup>70</sup>.

Second men not being expected to both 'care for' and 'care about' is reflected in the way services are distributed. Men reportedly are offered and provided with more services to support them in their caring role (Abel, 1987; Cecil, Offer & St Leger, 1987). This is despite men being more likely than women to be able financially to purchase care or the resources they need to provide care themselves

<sup>69</sup> The participation of women in the paid work arena is discussed in the following section.

<sup>70</sup> Changes which have occurred to the traditional home maker role of women and the wage earner role of men will also be described below.

(Land, 1978)<sup>71</sup>. However, according to Twigg and Atkin (1995) whether a care-giver is female or male is just one of the factors considered when resources and services are allocated. Other factors include:

*...the attitude adopted by the carer to his or her caring role; the views of the cared-for person and other kin; the impact of different relationships, of what we term 'moral status', and of the existence or otherwise of a separate future for the cared-for person<sup>72</sup>, as well as more social structural factors such as gender, age, class and race (Twigg & Atkin, 1995:5).*

A further difference between the caring work of women and men is associated with who receives their care. Arber and Gilbert (1993) have argued that men typically provide care for spouses as opposed to persons of other kinship relations. Finch (1986:15) has also noted the tendency for men to provide care to spouses: "*The relatives [who provide care] are almost always women, apart from men who care for disabled wives (apparently the only relatively common form of male caring)*".

The differences in the type and level of care undertaken by women and men were described in the Women's Affairs Victoria (1994) study which examined the economic and social impacts of caring. Whereas women undertook direct caring activities, such as personal care and meal preparation, men were typically involved in house and garden maintenance. This latter activity could not only be done at the convenience of the men, but also "*...dramatically increases the overall percentage of male carers and skews the involvement of men in caring responsibilities*" (Women's Affairs Victoria, 1994:6).

However, the traditional feminist focus on the primacy of women's care has been cautioned (Twigg & Atkin, 1995). The valuable contribution of male care-givers to the provision of informal care has increasingly been noted (Arber & Gilbert, 1993). In fact, Fisher (1994:677) has argued that recent evidence from research

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<sup>71</sup> Comparisons of the income received by men and women undertaken when discussing the public/private split will highlight the lower financial reimbursement women receive for their paid work. Women's economic dependency (Easting, 1992; Glendinning, 1992) upon either the state or a partner as a consequence of their unpaid caring responsibilities means they have less opportunity to decide only to 'care about' in comparison to their male counterparts.

<sup>72</sup> Twigg and Atkin's (1995) comment also draws the link between the purpose of care and service provision (Waerness, 1984). As already noted, this connection will be examined in the following chapter.

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examining the care provided to older spouses has particular implications for the reconceptualisation of the link between gender and care:

*...the analysis has shown that we will have to develop a new appreciation of the caring capacities of men, particularly older husbands. There are circumstances where men accept the obligation to care, undertake intimate personal care, and derive identity and reward from their caring work. In doing so, they seem driven by similar motives and to experience similar struggles as do women.*

Arguments such as Fisher's (1994) suggest that the role men play in the provision of care needs further examination. This is particularly the case when considering the care examined in this thesis. The primary focus on 'the family' in the literature available on schizophrenia and care means that potential differences and similarities in the care which women and men provide to a family member diagnosed with schizophrenia generally have not been examined in detail.

Further, recent critique of feminist conceptualisations of care have argued that, in focusing on gender, feminists have neglected the influence of race, class, and disability. As Graham (1993:126) explained: "*...perspectives are grounded in studies where most (if not all) of the respondents are white, heterosexual women whose lives are structured by the giving of care within their families*". Feminist caring research tends to focus on the caring experiences of one group of women (white, middle-class, heterosexual), but generalises its findings to the caring experiences of all women (Graham, 1991). Critiques such as these reinforce the importance of viewing the many dimensions beyond gender which bound the lives and experiences of women. Caring research with a multi-dimensional focus will also determine whether the assumptions we hold about the circumstances of women are indeed valid (Tirrito & Nathanson, 1994). For example, when considering the influence of culture it can be asked whether the importance Maori place upon the *whanau* and *hapu*<sup>73</sup> mean that Maori women feel bounded to the role of care-giver to the same extent as women who identify as *taiwi*. Furthermore, the collective nature of the *whanau* may mean that Maori women are more supported in their care provision than their *taiwi* counterparts.

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<sup>73</sup> These family forms being defined further on in this thesis.

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## Parents/Siblings

The above discussion identified that the particular characteristics of schizophrenia suggest that the question of who provides care needs to be considered further. An example of such characteristics is the time at which the symptoms of schizophrenia usually begin to be exhibited. As already noted, the age of onset of schizophrenia for men is predominantly fifteen to twenty-five years, for women twenty-five to thirty-five years (American Psychiatric Association, 1994a; Reed Healthcare Australia, no date). The age of onset raises both the question of who will assume responsibility for their family member when they initially begin to exhibit the symptoms of schizophrenia, and who will provide their family member's care in the future. This section will continue to identify and describe who actually provides caring work by examining the role of parents and siblings in the provision of care. This examination will begin by initially presenting feminist literature on parental and sibling care. Following this, the role that parents and siblings play in the provision of care to a family member diagnosed with schizophrenia will be identified.

The primary role of parents in the provision of care and support generally has been identified in Finch's (1989) work. She examined British research in order to establish what kind of support was exchanged between kinship groups in adult life. Support was divided by Finch (1989) into categories of economic support, accommodation, personal care, practical support and child care, and, emotional and moral support. She found that the parent-child relationship is the kin relationship in which kin support in its various forms is most likely to be exchanged. More specifically, the exchange of kin support is likely to flow from the parents to the children (except sometimes when the parents are elderly).

Other kin relationships were secondary to the parent-child relationships in which obligation and duty was primarily expressed. For example, Finch (1989:45) compared the parent-child relationship with support provided between siblings:

*Support between siblings contrasts with support between parents and children in two important ways. First, it seems less reliable, in the sense that whether it is offered depends very much upon personal circumstances and personal liking, at least for the majority white community. Except perhaps in rather trivial matters, there is no real sense that one can expect assistance just because they are your brother or your sister. Second, it much more obviously is two-way support, built upon reciprocal exchange between people who are in equivalent*

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*positions in genealogical terms. One would predict that where a particular sibling is not willing or able to give support, they are unlikely to receive it, except perhaps if they have given assistance in the past.*

Finch (1989:38) concluded that, to a certain extent, kin support was unpredictable:

*...we cannot predict simply from knowing that someone has a sister, or a father, or five grandchildren, what assistance if any is passing between them now, or has ever done. Nor is it easy to predict what will happen when a particular set of circumstances arise where a person needs some help.*

Finch and Mason (1993) undertook research on relationships and responsibilities between adult kin in Britain. They found among other things that kin did act as a 'safety net' for members in need, but only as a last resort.

Research on schizophrenia and care has begun to examine the unpaid care provided by parents. For example, in Bulger, et al's (1993) research, entitled 'Burdens and Gratifications of Caregiving: Appraisal of parental care of adults with schizophrenia', fifty nine of the sixty care-giver parents were mothers. Campbell, Drake, Janke, McKay, Norrie, Stablęs & Weston (1987) found, in their study on the problems and service needs of New Zealand care-givers, that eighty six percent of their respondents were parents, seventy-four percent of their participants were women. In existing research on schizophrenia and care, parents providing care have been found to be in their later years, generally in their mid-fifties to mid-sixties (Lefley 1987). The age of these parents is explained by schizophrenia occurring primarily during an individual's late teens to mid-twenties.

Lefley (1987) has defined elderly parents providing care to adult children diagnosed with schizophrenia as an emerging social problem. These parents are dealing with the complexities of the symptoms of schizophrenia at a time when they are least able to do so.

*It also seems unconscionable for society to impose this burden on elderly parents at a time in life when they have the least energy to devote to such a physically and psychologically draining task, and the most right to enjoy their waning years free of turmoil and pain (Lefley, 1987:1069).*

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In discussing these issues, Lefley (1987) has questioned the suitability of community care<sup>74</sup> being based on caring relationships where the person receiving care will almost certainly outlive the care-giver. Warren (1994/1995:16) has spoken about this issue:

*Apart from the personal tragedy, the most frightening thing about this study is the discovery of a whole generation of 'caregivers' who will soon need care themselves, leaving a generation of highly dependent, relatively youthful people in need of years of care. I am not advocating the return of the Dickensian institutions of the past; rather, a rational and ordered approach to 'community care' that takes into account the work being done, unpaid and unacknowledged by families, that cannot and will not continue in perpetuity.*

Lefley's (1987) arguments have suggested that there is a need to examine whether the age-related characteristics of care-givers influence the type and level of care they provide to their family member diagnosed with schizophrenia. This examination would need to include questions such as 'Do those mothers who provide care to their adult sons diagnosed with schizophrenia find it increasingly difficult to meet their caring responsibilities as a consequence of the physical changes their bodies experience as part of the aging process?', and, 'Are these women prepared to commit their retirement years to caring, after having spent their young and middle adult years providing care to their family member?' These questions are particularly important in the light of the emphasis the New Zealand Government is placing upon 'the family' as the primary care-giver (Department of Social Welfare, 1995). As will be argued below, responsibility for care traditionally has been unequally distributed within the family; women predominantly filling the role of caretaker or home maker (Swain, 1990). Despite the findings of researchers such as Lefley (1987) and Warren (1994/1995) it appears that increased pressure is being placed upon women to provide care to their family member exhibiting the complex and unpredictable symptoms of schizophrenia.

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<sup>74</sup> Community care is examined further on in this thesis.

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The potential life-span of both the parents and the adult son or daughter diagnosed with schizophrenia, and the chronic nature<sup>75</sup> of some individuals' schizophrenia, also raises the question of who will provide care to the family member when the parents are unable to do so as a consequence of old age or death. This question is asked so frequently in the literature on schizophrenia and care that the mnemonic WIAG has been developed. This mnemonic stands for When I Am Gone (Lefley, 1987). Surprisingly, despite the tension which parents providing care to a son or daughter diagnosed with schizophrenia associate with WIAG, no research ascertaining how likely it is that siblings, the next obvious family care-givers, will take responsibility for the family member's care could be found.

### **The Family**

While recent examination has established that it is women, typically mothers who provide care to a family member diagnosed with schizophrenia, research on schizophrenia and care has traditionally focused on 'the family'. The importance of acknowledging and supporting 'family' care has been argued in related literature from outside New Zealand. These arguments are based, for example, on acknowledging that over half of persons diagnosed with schizophrenia return to live with their families after hospitalisation (Anderson et al, 1986; Kuipers, 1993; Smith & Birchwood, 1987; Staznickas, McNeil, Binder, 1993). However, emphasis placed upon 'the family' has hindered examination of the way in which care is distributed within the family. While feminist researchers have found distinct differences in the amount and type of care women and men provide to a family member with an intellectual, physical or age-related disability, it has not been determined whether these differences exist in the care provided to a family member diagnosed with schizophrenia. The applicability of the material presented above regarding the role of women, men, parents, and siblings in the provision of care, needs to be determined in this research if the distribution of unpaid caring work to a family member diagnosed with schizophrenia is to be fully understood.

Despite 'the family' typically being considered as the main provider of care to a family member diagnosed with schizophrenia, little indication has been provided about 'the family's' composition. 'The family' in New Zealand has typically been

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<sup>75</sup> As was explained previously, for some people, their schizophrenia continues to impair their functioning for the rest of their lives (Kaplan and Sadock, 1991; Miller, 1995).

considered to be nuclear in form. This has been highlighted by Swain (1990:11) who has said:

*In our everyday usage 'the family' seems to mean contemporary middle class Pakeha<sup>76</sup> - the dominant majority - 'the nuclear family' with a male breadwinner, a female caretaker, and (ideally) two children (one of each sex, the boy being firstborn). This kind of family often seems to be regarded as 'normal'.*

Demographic data for New Zealand clearly indicates that the nuclear family is no longer the predominant family form within New Zealand (Social Development Council, 1991). For example, divorce has increased from 1986 by 29.2 percent, while separation from a legal spouse increased in the same period by twenty two percent (New Zealand Department of Statistics<sup>77</sup>, 1992). During the same time, the one parent family increased by 27.8 percent and two parent families decreased by 4.1 percent (NZDS, 1992).

As Selby's (1994:151) following statement highlights, family forms differing from the nuclear family not only exist, but play an active role in the lives of their members:

*The whanau is not only an historical family unit. It is a living vibrant, demanding, supportive, active unit which plays an important role in the lives of tangata whenua. To be part of a large whanau makes us rich. To be ignorant of our whanau makes us poor.*

The whanau is the traditional family form of the *tangata whenua* or *Maori*, the indigenous people of New Zealand. Walker (1990) has described the *whanau* as an extended family consisting of three generations. The *whanau* is the smallest unit within the traditional Maori social structure which is collectively-based. The *hapu* (sub-tribe) consist of a collection of *whanau* while the *iwi* (tribe) is a collection of *hapu*.

The importance of this kinship structure for Maori has been identified by Bradley (1994:182):

<sup>76</sup> Pakeha being a term used synonymously with '*tau-iwi*'.

<sup>77</sup> The New Zealand Department of Statistics is now referred to as NZDS.

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*The process of weaving the threads of kinship together is of primary importance to the strength of Maori communities. It is the foundation of maintaining one's self-concept and self-esteem. Knowing who you belong to and who belongs to you forms the basis of how one fits into the scheme of things; the community of people and subsequent ecological whanau.*

Bradley's (1994) and Selby's (1994) comments suggest that consideration of the *whanau* would be an important part of examining the care provided to a Maori family member diagnosed with schizophrenia. Inherent in these comments is the understanding that Maori receive a large degree of their support from their *whanau*.

An indication of the role 'the family' has played in the provision of care in New Zealand is further examined when the combinations of state, community, and family care responsibilities are examined in the following chapter.

### **Challenging the Public/Private Split**

Until now, discussion has examined both the characteristics and complexities of informal care and who provides this unpaid caring work. This section explores how increasingly feminists have been challenging the conceptual public/private split in order first, to highlight the value of both women's paid and unpaid caring work and second, to question the over-representation of women in care-giver roles. The public/private split refers to how care and other phenomenon have been categorised to either the 'public' sphere such as the paid work arena, or the 'private' sphere generally encompassing 'the family'. For example, Cox and James (1987:2) have highlighted the pervasiveness of the concepts of 'public' and 'private':

*In using the terms public and private we are not talking about one pair of opposites alone. They epitomise other pairs of concepts which divide the world into dualistic categories: society/family, work/domesticity, production/reproduction, culture/nature, outer/inner, impersonal/personal, freedom/necessity...the list is not complete.*

Each component of a pair of opposites is gendered and assigned a value. Those components associated with the public tend to typify masculinity and be more

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valued than those associated with the private which tend to typify femininity. Feminist writers have asserted that the public/private split, and the associated naming and gendering of opposites, is not natural or God-given but is a social construction (Stacey, 1981). As Game and Pringle (1983:21) have explained: "*Certainly the relation between public and private is historically determined. There is nothing fixed or inevitable about it*".

Changes currently occurring in the assignment of caring responsibilities, between the state, the community and the family<sup>78</sup>, indicate that the boundaries of what is considered 'private', and what is considered 'public', are fluid and moveable. For example, care provision in the private sphere is affected by changes in the public sphere and vice versa. Acknowledging the flexibility of the public/private split should not however, negate the isolation that women may feel as a consequence of their informal caring work. While the concept of the public/private split is being debated and developed it is, nevertheless, a useful conceptual tool which contributes to our understanding of the experiences of care-givers and those they assist.

In challenging the naturalness of the public/private split, feminists have also challenged the understanding that care is a natural activity of women. As well as arguing that women do not intuitively and instinctively know how to care, feminists have asserted that informal care is a form of work despite its presence within the realm of the family. It is in this section that attention is paid to the mechanisms feminists have proposed for considering informal care in a way which transcends the public/private split. These mechanisms include: acknowledging how women's caring responsibilities traverse the conceptual public/private split (Baines, Evans & Neysmith, 1993; Graham, 1991; Ungerson, 1990); acknowledging the symmetry of power between the care-giver and the care-recipient regardless of whether the caring relationship is situated in the public or private sector (Dalley, 1993; Edgar, 1992; Waerness, 1984); and, the commodification of care (Ungerson, 1995).

### **The Breadth of Women's Caring Work**

Increasingly feminist researchers have noted how women's caring work crosses the socially constructed public/private split. The way in which women's caring work

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<sup>78</sup> These changes are described and critiqued further on in this thesis.

responsibilities cross public and private boundaries has been articulated by Baines et al (1993:11):

*It is done as mothers, daughters, and wives in the context of individual relationships, in the community as volunteers, through the professions of nursing, social work, and teaching, and as low-wage workers in hospitals, child-care centres, and homemaking services.*

Description of the breadth of women's unpaid care has also been provided by Abel and Nelson (1990:6):

*...caregiving transcends the bifurcation between public and private. Women perform similar caregiving activities in the domestic domain and public arena. Specific tasks shift back and forth between one realm and another.*

In noting the breadth of women's caring work, feminists have been examining the similarities and differences between the paid and unpaid caring work of women. Ungerson's (1990) typology of the working conditions of both formal and informal care-givers, presented in Table 4, provides examples of some of the differences feminist researchers have found between the formal and informal caring work of women.

**Table 4.** Working conditions: Formal and informal care (Ungerson, 1990:24).

Formal Care	Informal Care
Division of labour	Very limited division of labour depending on provision of support services
Dispersed responsibility	Total responsibility
Limited working hours	'On call' at all times
Substitutability and cover when ill	No substitutability or cover when ill
Multiplicity of clients	Very few clients (usually only one)
Social networks with other workers workplace	No social network at workplace; possible isolatic
Potential for economic and union organisati at workplace	Limited potential for organisation and only through political process
Accountability and hierarchy	Almost complete autonomy
Waged	No payment, except through benefit system

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Statistics regarding the paid and unpaid<sup>79</sup> work of women highlight the extent to which the caring work of New Zealand women traverses the public/private split. The intersection between women's paid and unpaid caring responsibilities will now be briefly examined.

Since World War II, New Zealand women have increasingly been entering the realm of paid work (Briar, 1994,1995; Statistics New Zealand, 1993). In following the work patterns of women in other developed countries (Castles, 1993; Taeuber, 1991), the entry of New Zealand women into the paid labour force has been facilitated by the expansion of the service sector<sup>80</sup> (Statistics New Zealand, 1993). One consequence of women entering the paid workforce primarily via the service sector is that a vertical gender segregation exists with women and men being consistently concentrated in certain kinds of jobs (McKinnon, 1979; Novitz, 1987). In New Zealand, women predominate within the community, and social and personal service sectors (NZDS, 1993; NZDS & Ministry of Women's Affairs, 1990; Horsfield, 1988; Statistics New Zealand, 1993; Statistics New Zealand, 1995). Specifically, at the time of the 1991 census, 35.9 percent of women in full-time employment were concentrated in community, social and personal services (Statistics New Zealand, 1995)<sup>81</sup>. In comparison, 18.5 percent of men were employed in the community, social and personal services at this time (Statistics New Zealand, 1995).

Women's participation in the paid workforce is further limited, in comparison to their participation of their male counterparts, by the horizontal segregation which also exists within New Zealand's paid work arena. Distinct differences exist between the positions women and men hold in their various occupations. Within the

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<sup>79</sup> Unpaid work generally encompasses household and family caring duties as well as voluntary work.

<sup>80</sup> The service sector was the only industry sector in New Zealand which expanded over the 1980s (Statistics New Zealand, 1993), a period of economic downturn.

<sup>81</sup> While New Zealand women have consistently predominated within the community, personal and community services, examination of New Zealand's employment statistics indicates that women are entering the business and financial services, and industry and property (Statistics New Zealand, 1995).

community, and social and personal services, women are more likely to be in service delivery as opposed to senior and policy, decision making positions (Craig, 1991; Dunn et al, 1992; Munford, 1989, 1992). Despite women having "...*increased their representation in a number of administrative, managerial or supervisory occupations over the past twenty years*" (Statistics New Zealand, 1993:94), women still tend to fill positions at the lower end of the organisational hierarchy. Women then are not only primarily responsible for unpaid care, but also predominate amongst those who undertake low paid caring work. When considering the role of women in unpaid care provision, it was noted that practical paid caring experience is a precedent (Finch, 1989) when negotiating who should provide informal care. Therefore, it can be argued that women's paid caring work can be considered as preparation for future informal care provision when the need arises. Furthermore, the unpaid caring responsibilities of women may restrict their ability to engage in paid work (McDonald, 1994). This restriction may be perceived by decision makers as either a lack of commitment by women, or an inability to commit to their paid work. Either of these understandings would almost certainly lead to women not being considered for promotions.

That women are unable to fully participate in paid work as a consequence of their unpaid caring responsibilities is supported by statistics which clearly indicate that New Zealand women are more likely to be working part-time<sup>82</sup> in comparison to New Zealand men who predominantly work full-time<sup>83</sup> (Dunn, et al, 1992; Easting, 1992; Horsfield, 1988; Ministry of Women's Affairs, 1992). Specifically, at the time of the New Zealand 1991 census, 45.2 percent of women worked full-time and 53.5 percent worked part-time (Statistics New Zealand, 1993)<sup>84</sup>. Women (and most men who do both 'care for' and 'care about') often forego the benefits associated with

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<sup>82</sup> Part-time work is defined as one to twenty nine hours of paid work per week (Statistics New Zealand, 1995).

<sup>83</sup> Full-time work is defined as thirty or more hours of paid work per week (Statistics New Zealand, 1995).

<sup>84</sup> While noting that New Zealand women typically work part-time, the number of men working part-time is significantly increasing. Specifically, the number of men working part-time increased overall by 24.1 percent between 1986 and 1991. This is compared to an increase for women of 9.4 percent during the same time period (NZDS, 1993a).

full-time paid employment for the increased flexibility associated with part-time work. As Land (1978:281) has argued:

*It is clear that many women and the majority of men with sole responsibility for the care of dependent children or adults exchange some flexibility in work hours for considerably lower pay and prospects except when demand for their labour is exceptionally high, as it was during the Second World War.*

The fact that women typically engage in part-time work to accommodate their unpaid caring responsibilities is highlighted when acknowledging that New Zealand women are more likely to work part-time if they have children under the age of twelve years (Statistics New Zealand, 1993). In comparison, Sweden, which provides more extensive child care provisions than New Zealand, has a greater labour force participation of its women (Statistics New Zealand, 1993). The ability of women to engage in part-time work is probably facilitated by the overall predictability of their unpaid caring work, predictable in the sense that the needs of those persons with an intellectual, physical, or age-related disability seldom change considerably on an ongoing basis. The relative unpredictability and changeability associated with the symptoms of schizophrenia raises the question as to whether women providing unpaid care to a family member diagnosed with schizophrenia would be able to commit themselves to regular paid, even part-time, work.

The incomes that women receive reflect both the positions women hold and the limited hours they typically work in the paid work arena. In New Zealand, in 1991 "*Employed males received a total annual median income of \$26,460 compared with \$17,689 received by employed females*" (NZDS, 1993a:11). As already noted, Maori women feature worse than *tau-iwi* women. "*The total median annual total income for Maori women in 1991 was...88 percent of that for non-Maori women and 77 percent of Maori men's*" (Statistics New Zealand, 1993)<sup>85</sup>. The lower wages

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<sup>85</sup> Consistently the theme is arising that Maori women have a poorer participation in the paid work arena than their *tau-iwi* counterparts. The cultural and socioeconomic differences between Maori and *tau-iwi* women highlights the importance of exploring how these factors influence and shape the unpaid care of both Maori and *tau-iwi* women.

women earn appear to influence the decision of who will provide the informal care required by members of the family. Specifically, in comparison to their male counterparts, the wages that women earn generally are not adequate enough to support both themselves and those dependents they provide care to (Novitz, 1987). Women's lower wages mean that the opportunity cost of men leaving paid work to provide informal care is greater than if women do. Easting (1992:123), in discussing the decision of who will care for a child, said the following:

*Faced with the choice of which parent will do the caring and which parent will earn the money in a labour market characterised by male patterns of existence as well as by low pay and a small range of occupational choices for women, parents will recognise that the opportunity costs for men to stay at home will be higher than those for women.*

Novitz (1987:29) has explained the lower financial reimbursement women receive for their paid work in comparison to men by "...a product of ideology about the family which assumes women's economic dependence on men...". Traditionally, women's wages have been maintained at a lower rate than men's as a consequence of the understanding that men need to receive the family wage in order to support themselves and their dependent wife and children (Briar, 1992).

Economic dependence on an other, usually a male partner or the state (Glendinning, 1992), is a consequence of women both 'caring for' and 'caring about' their relatives needing ongoing support and assistance. Recent research by Fleming and Easting (1994) highlighted how vulnerable women can be when economically dependent upon a male partner. Fleming and Easting's (1994) research on intra family income and resource allocation, established that income is not always managed or allocated equally within the family. As Fleming and Easting's (1994:133) following explanation highlights, inequalities in the control and distribution of family income were generally to the benefit of men:

*Participants in the New Zealand study were clearly influenced by values that gave the male earner priority of access and control of money. In 'pooling' couples, there was often a tension between the expressed belief that the money was jointly owned, and the conflicting belief that the man as main earner had the most right to the money. The belief that the money was shared defined it broadly as a common pool to*

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*meet collective needs, but the precedence given to the man as the main earner meant he had more say in setting priorities, and a greater amount for personal spending.*

While the caring work that women undertake in the formal sector has been researched<sup>86</sup>, New Zealand has followed other developed countries in the Western world in largely ignoring the nature and extent of women's unpaid work (Davies & Jackson, 1994). Questions, such as 'What does unpaid work involve?', and 'How is unpaid work distributed?', were both unasked and unanswered until feminist analysis of housework and informal care, and the recent implementation of time-use studies. The lack of attention which has been directed towards unpaid work by non-feminist researchers reflects the low value which has traditionally been associated with unpaid work in the Western world (Castles, 1993; Craig, 1991; Royal Commission on Social Policy, 1988; Statistics New Zealand, 1993). The lack of attention non-feminist researchers have directed towards unpaid work is reflected in the lack of detail known about the care provided to a family member diagnosed with schizophrenia.

Just as there are distinct differences in the paid work of women and men, time-use studies (Bittman, 1992; Statistics New Zealand, 1993; Women's Affairs Victoria, 1994) have uncovered a gender division of labour which exists in household and family care duties. Some of the specific characteristics of this gender division of labour have already been noted when considering the different ways in which women and men care. For example, men tend to undertake maintenance, repair and garden work as opposed to the nurturing, tending work typically undertaken by women (Women's Affairs Victoria, 1994). It is women who tend to be primarily responsible for undertaking personal care tasks. For women, their unpaid work in the private sphere is considered, often by themselves as well as by their society at large, as their primary responsibility. As Finch and Mason (1993:350) have stated: "*Women will put family responsibilities first, especially when put under pressure by lack of publicly provided services...*".

The over-representation of women's participation in voluntary and community work has also been noted (Cull, 1992). For example, the New Zealand Association of Citizen's Advice Bureaux (1993) has indicated that eighty-five percent of their

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<sup>86</sup> The statistics presented in this section testify to this.

volunteers are women. Malcolm, Rivers and Smyth (1993) have stated that there are two-and-a-half times as many women as there are men in the voluntary sector<sup>87</sup>. The over-representation of women in voluntary and community work could be explained by Traustadottir's (1991) idea of an 'extended caring role'. As Traustadottir (1991:217) has explained, the 'extended caring role':

*...can provide opportunities for more flexibility than the traditional mothering role, and mothers of children with disabilities are sometimes able to extend their caring role to activities that are much more like a professional career than traditional mothering work...[These mothers] go to meetings, lobby legislators, pressure the school board, argue with government officials, organise parent's groups and so on.*

In acknowledging the extent to which women's caring responsibilities traverse the public/private split, calls have been made for a framework by which the similarities in the breadth of women's caring work can be examined (Graham, 1991; Ungerson, 1990, 1995; Waerness, 1984). As Baines et al (1993:31) have proposed:

*The concept of separate spheres may hinder rather than further our understanding of activities that involve both labour and love. Such a classification clarifies some of the divisions that exist today but it does not necessarily help us to transcend the traditional dualism of public/private, paid/unpaid work, and family/state.*

Ungerson (1990) has argued that continuing to distinguish between care in the private and public sphere, while emphasising the love and labour involved in the former, has the danger of entrapping women in their caring role within the family. For example, in discussing whether community care policies are a mechanism for reducing expenditure, Ungerson (1995:43) has explained that emphasis on the love and labour components of informal care could justify symbolic payments:

*Much of the argument that payments [for what was previously considered informal care] will lead to cost escalation rather than underwrite cost containment depends, of course, on the level of*

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<sup>87</sup> As well as identifying a gender division, studies undertaken in New Zealand have uncovered different patterns of unpaid work for Maori and *tau-iwi*. Both Maori women and men undertake more unpaid work than their *tau-iwi* counterparts (Horsfield & Evans, 1988; Statistics New Zealand, 1993).

*payments available and whether it is possible for governments to hold the line that these payments are in some sense symbolic rather than realistically designed to represent, or in turn pay for, market-related wages. The way in which the line can be held is to present the work of care within the private domain as something that differs qualitatively from the work of care carried out in the public domain.*

Symbolic payments would retain women's economic dependence within the family (Glendinning, 1992) and therefore reinforce the expectation that it is women who should care as a consequence of the opportunity costs of men leaving their paid work (Easting, 1992)<sup>88</sup>.

Ungerson (1990) has proposed that all care should be considered first as work regardless of the sphere in which it takes place. Instead of focusing on the false conceptual division of the formal and informal, attention should be paid to considering informal and formal care together, noting their similarities and differences. Ungerson (1990:16) has proposed that the implications of this proposal are that:

*...if caring is fully recognised as work, irrespective of the context within which it takes place, then the questions as to whether or not caring should be paid for, at what rate, and operated under what working conditions, can be considered with much greater clarity<sup>89</sup>.*

### **The Symmetry of Power**

While some feminists have identified the breadth of women's caring work, Waerness' (1984) contribution towards considering women's care outside of the private/public split has been to analyse caring work with reference to the symmetry of power, or how power is distributed amongst the various persons within caring relationships. In focussing on the symmetry of power, Waerness has constructed three categories to which caring relationships can be assigned<sup>90</sup>. One of these

<sup>88</sup> Discussion of symbolic and market rate payments is continued below.

<sup>89</sup> Those issues regarding payment for care per se are examined more fully below.

<sup>90</sup> Feminist writers such as Munford and Opie have also considered the operation of power with regard to the provision of care. Waerness' (1984) categories, however, provide a conceptual tool for considering the caring relationships examined in this thesis. As is argued below, the changing nature of the family member's symptoms may mean that caring relationships, in which a family member is diagnosed with schizophrenia, move over time between Waerness' (1984) categories.

categories is titled 'personal service'. Care in this category is provided to strong, healthy persons (usually men). Waerness (1984:70-71) has explained that fetching slippers and serving coffee to an individual who could undertake these tasks themselves is an example of personal service work:

*Such services may not always be an expression of caring for the one receiving them. When women provide these services for husbands or other adult healthy members of the family, it can be experienced as something they are 'forced' to do, not as a consequence of their concern for others' well-being, but as a consequence of their subordinate position in the family.*

As was explained when the purpose of care-giving work was examined, the second category of 'care-giving work' encompasses the care provided to a person who requires care and support. What distinguishes care-giving work from personal service work then is that the former is provided to those who cannot undertake this work themselves. For example, the tasks of fetching slippers and serving coffee is defined as care-giving work if the person receiving this care is unable to undertake these tasks themselves. Care-giving work "...mainly concerns the children, the ill, the disabled and the old" (Waerness, 1984:71).

The third category, 'spontaneous care', encompasses care which is undertaken spontaneously or impulsively without the expectation that this care will continue. Waerness' (1984) example of spontaneous care is when a stranger is helped because they have too much to carry, this help being provided on a one-off basis.

The differences in power between persons in each of these different caring relationships is acknowledged, as is the degree of autonomy held by the care-giver and care-receiver. Waerness (1984:71) has highlighted the different degrees of power and autonomy held by those persons receiving and providing care when distinguishing between personal services and care-giving work:

*The one receiving personal service most often is the one of superior status. It is a sign of higher social status to receive more than one provides of this type of service. In an asymmetrical caring relation, however, the opposite is mostly the case. The dependency and helplessness of the cared for, makes him or her the subordinate in relation to the care-giver.*

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When considering an asymmetrical relationship, it would be argued that an individual's subordinate position both arises from their need for assistance and reinforces the understanding that this individual is dependent. Understanding this bi-directional process is important when considering the care provided to a family member diagnosed with schizophrenia. As already noted, the themes of dependency and burden predominate amongst the dominant discourses of 'schizophrenia' (Atkinson & Coia, 1995). These discourses, however, do not acknowledge the changing nature of schizophrenia. As an individual's symptoms vary in type, intensity, frequency, and duration, their need for assistance would also increase and decrease. One would assume that the degree of power and autonomy held by the individual and their care-giver would also change. Atkinson and Coia (1995:105) suggested this might be the case when discussing Perring et al's (1990) understanding that 'caring for' a family member diagnosed with schizophrenia involves assuming responsibility for the dependent family member:

*However this dependency does vary with the course of the illness. Carers take on new tasks and responsibilities in respect of their relative, resulting in changes in their relationship. Either or both sides might resent the shift in responsibility and thus in the dynamics of power in the relationship.*

This research will need to examine the changing nature of the symptoms of schizophrenia and how this correlates with shifts in the degree of power and autonomy held by the care-giver and the care-recipient. The cyclical acute and chronic episodes of schizophrenia translate into the care-recipient having a significant change in need for assistance and support. This frequent and significant fluctuating change in the care-recipient's need for assistance and support could heighten the struggles between care-giver and care-receiver to either increase or decrease their respective power and autonomy. Such struggles may be an inherent part of the caring relationship as is the primacy of supervision and monitoring tasks.

While Waerness' (1988) categories focus upon the different levels of power and dependency between individuals in caring relationships, it is increasingly being argued that, in order to challenge the conceptual public/private split, it must be acknowledged that care, dependence and interdependence touches all of our lives. Dalley (1993:152) has argued for example, that: *"...a life of total independence would mean isolation and separation"*. Further, Dalley (1993:152) has acknowledged that: *"...dependence and interdependence [are] facets of all human relationships..."*. In following a similar line of argument, Edgar (1992:42) has said:

*Our starting point has to be that caring is not just a burden or a problem, or a cost to private time and public revenue. Rather, it is central to the human condition and rests upon our essential inter-dependency and the inevitable caring about other people that rises from our close relationship with them. This is as much true of men as it is for women, though we seem to have forgotten those underlying reciprocities.*

An acceptance of interdependency and dependency as the norm of human relationships rather than the exception provides an avenue for acknowledging and improving the circumstances both of those who provide care and of those who receive care.

### **The Commodification of Care**

In a recent article, Ungerson (1995) has challenged the practical legitimacy of the conceptual public/private split, by examining the 'commodification of care' previously conceptualised by feminists as informal care. Ungerson (1995) has described how developing systems of payment for care in Britain and some European countries are facilitating the dissolution of the conceptual boundaries between the private and public spheres. Specifically Ungerson (1995) has distinguished between conditional payments or 'quasi-wages payments for care' and unconditional payments or 'care-allowance payments for care'.

According to Ungerson (1995:34) payment provided to volunteers is generally conditional in the sense that payments are provided: *"...on evidence that specific work has been undertaken and successfully carried through - a customer has been got out of bed, a meal has been made and fed to the dependent person"*. Payment to care-recipients are also conditional when recognising that increasingly

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payments have been made to care-recipients on the proviso that care-recipients use this payment to purchase their own care. However, as Ungerson (1995:37) has noted:

*Since the sums involved are small the most typical form of purchase is by largely symbolic payments to people whom they have known for many years, rather than to strangers working at the 'rate for the job'.*

The implication within this statement is that it will typically be the caring work of members of the family which will be purchased by care-recipients, rather than those who sell their caring labour in the market place. This could be the case, particularly when considering the care provided to a family member diagnosed with schizophrenia. When discussing the discourses of schizophrenia, it was noted that people exhibiting the symptoms of this disorder generally experience stigma and discrimination. The various misconceptions regarding schizophrenia (Jones, 1995) would almost certainly mean that paid care-givers would not identify individuals diagnosed with schizophrenia as the client group they wish to work with most. This reluctance of paid care-givers would place increased pressure and responsibility upon members of the family to take up the role of care-giver.

The conditional nature of payments made to volunteers and payments made to care-recipients have been termed by Ungerson (1995) as 'quasi-wages payments for care'. According to Ungerson (1995:39):

*The use of the term 'quasi-wage' indicates that many of these payments are symbolic and unrelated to market levels of wages, but, like wages, are conditional on certain tasks being fulfilled and subject to formal and informal contract.*

Ungerson (1995) has distinguished between these conditional quasi-wage payments, and the unconditional payments provided to care-givers. Payments to care-givers are typically based on the proximity of the care-giver to an individual with a proven disability. As Ungerson (1995:38) has explained:

*Once those minimal conditions are fulfilled, an allowance or benefit, payable to the carer, is put in place and no further*

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*questions asked. In that sense, the 'payment' is not made in exchange for services rendered.*

The term 'carer-allowance payments for care' has been provided by Ungerson to refer to payments provided to care-givers.

In examining both 'quasi-wages payments for care' and 'carer allowance payments for care', Ungerson (1995) has identified several dilemmas which arise from the commodification process. These dilemmas have particular implications for the status and value of women's caring work. One of these dilemmas arises from the level of payment received by volunteers and care-givers (both directly and indirectly from care-recipients). Ungerson (1995:41) has warned that the low level of payments may result in "...*unregulated and informal 'grey' labour markets*"<sup>91</sup>. Women may be entrapped within low paying positions with poor working conditions, the payments women receive achieving little in terms of increasing the status and value of their caring work. After all, it tends to be predominantly women who provide the bulk of caring work as volunteers or care-givers<sup>92</sup>.

One strategy which could prevent the establishment of 'unregulated and informal grey' labour markets (Ungerson, 1995) and the continuation of poor working conditions and low incomes, is the adherence to three principles put forward by Ungerson (1990:27) for considering payment of caring work per se. Specifically, these principles are: "...*equity of treatment between 'formal' and 'informal' caregiving work, equal pay for equal work, and compensation for unpleasant or difficult working conditions*". As Ungerson has implied, the typology in Table 4 above suggests that 'informal' caring work would receive more financial compensation if these principles were applied in practice. Informal caring work is

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<sup>91</sup> The use of immigrants to undertake caring work for low financial reimbursements is an example of such unregulated and informal grey labour markets (Ungerson, 1995).

<sup>92</sup> Ungerson's (1995) concerns about poor working conditions and low pay levels have been expressed by workers contracted to New Zealand's Sunderland Community Support Services, a Home Support Management Service. Contracted workers have challenged the payments they receive from Sunderland Community Support Services for the work they perform. From the media reports, it appears that Sunderland Community Support Services is providing symbolic rates rather than market rates for some services they contract for (Wanganui Chronicle, 1995f). This challenge has involved contracted workers appointing their union to advocate for them in the Employment Court (Wanganui Chronicle, 1995g).

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characterised by poorer working conditions, less support and more overall responsibility than formal care.

A second strategy for preventing the establishment of 'unregulated and informal grey' labour markets (Ungerson, 1995) has been proposed by the disability community (Morris, 1993a). This strategy relies upon those persons with a disability having benefits adequate enough to ensure that they can purchase their personal assistance and household management from individuals outside of their kinship relationships. It would be less likely that members of the family would be pressured into providing care and support to a family member with a disability for very little financial reimbursement. This point is highlighted by Morris (1993a:48) when talking about those who argue that benefits should be paid directly to the care-giver as opposed to the care-receiver:

*...because they are still focusing on what they see to be an issue concerning women's economic independence: there is no consideration of economic independence being an issue for those who need help with the tasks of daily living, of the way that such economic independence would enable people to influence the quality of their lives, or of the way that it would diminish the vulnerability to abuse. There is no recognition that disabled people may see the right to choose who should provide them with assistance as potentially liberating not only for themselves but also for carers such as family members who feel bound by duty to look after parents, spouses or disabled children.*

Morris (1994:37) has proposed that the commodification of care is one way in which people with disabilities can maintain their dignity and increase both their independence and autonomy:

*It is clear from this study that having the money to pay for personal assistance is the most important factor in enabling disabled people to assert the kind of choices which non-disabled people take for granted.*

These general arguments about payments for care have particular implications when considered in relation to individuals diagnosed with schizophrenia. First, before either 'quasi-wages payments for care' or 'care-allowance payments for

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care' (Ungerson, 1995) are allocated, there must be confirmation that the recipient of care has a proven disability. Discussion of the definition of schizophrenia suggested that receipt of the diagnosis schizophrenia is not a straight forward process. During the time it takes to receive the diagnosis of schizophrenia the individual receiving care may not receive any Government financial assistance for their care needs. Second, it is difficult to distribute payment on the basis of services rendered when the characteristics and complexities of caring work have not first been identified and clearly understood. As already noted, there is a lack of existing detail about the process and interpretation of the care provided to a family member diagnosed with schizophrenia (Atkinson, 1986; Perring et al, 1990; Twigg & Atkin, 1995). Third, the current understanding that care revolves around personal care tasks (Twigg & Atkin, 1995) could lead to other forms of caring work being discounted. Care provided to an individual diagnosed with schizophrenia could be particularly affected by this view of care with the indication that this type of care primarily involves supervision and monitoring tasks (Perring et al, 1990). If this was not to be the case, creative and flexible mechanisms would need to be developed which could accommodate a variety of caring tasks. Fourth, discussion of the care provided to a family member diagnosed with schizophrenia has already highlighted the unpredictability of this form of care. The symptoms of schizophrenia varying over sometimes short periods of time in intensity, frequency and duration suggests that providers of such care may not fit neatly or consistently within the categories of either 'full-time' or 'part-time care-giver'. Innovative and flexible systems would also need to be developed to measure changes in a person's dependency needs over time, and the accompanying level of service provision required. Finally, as a consequence of their symptoms of schizophrenia<sup>93</sup> an individual may not acknowledge their need for assistance even after they have received the diagnosis of schizophrenia from the mental health profession. Symptoms such as paranoia may lead the individual to perceive assistance provided by a care-giver as detrimental to their well being. Under these circumstances, it would be unlikely that care-givers would be paid for any services rendered if payments were made first to the care-recipient.

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<sup>93</sup> Examples of such symptoms are hallucinations, delusions and a lack of insight (American Psychiatric Association, 1987, 1994).

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## The Nature of Care: The Key Themes

The material in this chapter was presented in order to develop an understanding of the unpaid care provided within a family to a member diagnosed with schizophrenia. In developing this understanding, attention was turned first, to the complexities and characteristics of unpaid caring work, second, to the way in which the provision of unpaid care is distributed within 'the family', and finally, to the strategies feminists have proposed to challenge the conceptual public/private split.

Examination of the question 'What is Care?' indicated that the care provided to a family member diagnosed with schizophrenia may challenge the accepted understandings of care. It was noted that the care provided to a family member diagnosed with schizophrenia is likely to: be unpredictable, reflecting the changeability of the symptoms of schizophrenia; involve supervision and monitoring as opposed to personal care tasks; and, involve primarily negative feelings.

The unique characteristics of the care provided to a family member diagnosed with schizophrenia have particular implications for this research. First, the extent to which supervision and monitoring tasks predominate in this care provision needs to be established. It was suggested that the relative invisibility of supervision and monitoring tasks, relative to personal care tasks, could lead to this care being overlooked. This in turn could mean that the needs of informal care-givers of a family member diagnosed with schizophrenia could also be ignored and therefore unmet. It is suggested then that these care-givers not only undertake caring work which is ignored, but are generally unsupported in their care provision.

Second, the changeability of the symptoms of schizophrenia, combined with the relative invisibility of the tasks of supervision and monitoring, suggest that care-givers of a family member diagnosed with schizophrenia may not be able to be categorised easily or consistently as either 'full-time' or 'part-time' care-givers. This research will need to examine whether this is the case.

Third, it was noted that the literature on schizophrenia and caring has focused almost exclusively on the negative emotions experienced by 'the family'. It was

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argued that these emotions are directly linked to the characteristics of schizophrenia. There is a potential conflict between the Expressed Emotion theory (Brown et al, 1962) and the primarily negative emotions experienced by care-givers of a family member diagnosed with schizophrenia. In acknowledging this conflict, this research will examine the range of emotions experienced by those who provide care to the family member diagnosed with schizophrenia. Further, this research will identify whether acknowledgment of the Expressed Emotion theory influences a care-givers' expression of their emotions.

The U-shape of care (Women's Affairs Victoria, 1994) was challenged by the finding that it is primarily adult sons who tend to be the recipients of care (Bulger et al, 1993; Winefield and Harvey, 1994). This research will examine how the continual nature of the care provided to a family member diagnosed with schizophrenia effects the care-giver's quality of life and ability to both 'care for' and 'care about' their family member. This research will need to examine how the gender of care-recipients (typically young adult males) and of care-givers (typically older women) influence the characteristics of this care.

The discussion on rights suggested that the collection and dissemination of the care-recipients' information would be paramount in the caring relationships examined in this thesis (Atkinson, 1989). Further, it was proposed that the tensions surrounding the issue of rights may be magnified by the symptoms of schizophrenia. This research will examine how the informal care-givers of a family member diagnosed with schizophrenia reconcile the tensions between their own rights and the rights of their family member.

Waerness' (1984) assertion that care-giving work can be categorised by either the purpose of 'growth', or 'stagnation', or 'deterioration' was outlined. It was established that the care provided to a family member diagnosed with schizophrenia may not fit neatly and consistently into any of these categories. Waerness' (1984) proposed connection between the purpose of care and the allocation of services and resources was noted. Acknowledgment of the dominant discourses of 'schizophrenia' suggest that New Zealand's mental health services may not be as developed as, for example, New Zealand's general health services.

Examination of the connection between the personal and the political indicated how important it is to determine how micro aspects (the caring relationship) impact upon the macro aspects (policy and service provision) of care and vice versa<sup>94</sup>. The question was raised as to whether the informal care-givers of a family member diagnosed with schizophrenia would willingly participate in making the link between the personal and the political as a consequence of the negative social outcomes associated with publicly identifying yourself as a care-giver of a family member diagnosed with schizophrenia. It was also noted that informal care-givers may not experience much success in changing the dominant understandings of schizophrenia, and therefore, in challenging the current allocation of services and resources to the mental health arena. The dominant discourses of schizophrenia, specifically those of dependence and burden, may mean that little support would be raised for such change and challenge.

Consideration of the question 'What is Care?', suggests that the care provided to a family member diagnosed with schizophrenia challenges existing feminist caring analytical frameworks. Table 5 provides a framework for determining how these feminist conceptualisations of care will need to be extended in order to reflect the particular characteristics and complexities of this caring work.

**Table 5.** The 'what' facets of care.

<b>Intellectual, Physical or Age-Related Disability is most likely to...</b>	<b>Schizophrenia is most likely to...</b>
* be predictable	* be unpredictable
* involve personal care tasks	* involve supervision and monitoring
* involve ambivalent feelings	* involve primarily negative feelings
* be for young children or older adults	* be for young adults
* take a U-shape	* be provided on a continual (flat-line) basis
* be provided to both males and females	* be primarily for males
* involve tension around the issues of rights	* involve tension around the issues of rights
* be consistently either full-time or part-time	* care-giver status needs to be determined
* be for either growth, stagnation or deterioration	* the purpose of care to be determined
* involve reciprocity	* the degree of reciprocity to be determined
* involve linking the personal and the political	* the link between the personal and political to be determined

<sup>94</sup> As already noted, the material presented further on in this thesis identifies and analyses the way in which New Zealand's social, political, cultural, legal and economic context impacts upon the provision of care within individual caring relationships.

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After examining the 'what' aspect of care, attention turned to the question 'Who Cares?' This discussion suggested that the research in this thesis needs to specifically determine the role that women play in the provision of informal care. The time of onset of schizophrenia means that those women who do care are typically older in years and the mother of the family member (Lefley, 1987).

The understanding that it is older women who typically provide the main component of informal care to their family member diagnosed with schizophrenia lead to discussion of WIAG (Lefley, 1987), or who will provide care to the family member in the future. It was noted that research which explores sibling care provided to a family member diagnosed with schizophrenia needs to be undertaken to ascertain how likely it is that siblings will replace their elderly mothers as the main informal care-giver of their family member. Second, questions were raised regarding the effects of the aging process and the level of commitment older mothers are having to make to their family member's care provision.

While noting the over-representation of women within care-giving roles, feminists have argued that women do not intuitively and instinctively know how to care (Needleman & Nelson, 1986; Pitkeathley, 1991). Instead, feminists have proposed that women fill care-giver roles via a process of negotiation, including persuasion, manipulation, and coercion between themselves and their significant others (Finch, 1989). This suggests that the past and current caring responsibilities of these women and their significant others will need to be identified, these responsibilities having influenced the negotiation process of who provides care to the family member diagnosed with schizophrenia.

Differences between the care provision of women and men were also identified. The different ways in which women and men care, as outlined in feminist research are summarised in Table 6. Recent critique of feminist caring research has questioned whether the distinctions feminists have drawn between women's and men's care are as clear and pronounced as feminists suggest (Arber & Gilbert, 1993; Fisher, 1994). This critique, along with the characteristics and complexities of the care provided to a family member diagnosed with schizophrenia, suggests that examination of this informal care needs to extend beyond an exclusive focus upon the care provision of women.

**Table 6.** How women and men care.

<b>Women are more likely to...</b>	<b>Men are more likely to...</b>
* provide care	* not provide care
* 'care for' and 'care about'	* 'care about'
* be denied support services	* receive support services
* care at less convenient times of the life cycle	* care at more convenient times in the life cycle
* provide care to all kin relations	* provide care to a spouse
* undertake personal care tasks	* undertake home and garden maintenance.

Discussion of the 'who' aspect of care noted that feminist analysis has typically neglected the influence of race, class and disability (Graham, 1991, 1993) upon the provision of care. One implication of this critique is that the information in Table 6 should only be utilised as a framework for examining who provides care to a family member diagnosed with schizophrenia. This is particularly the case if the potential differences in the care provision of Maori and *tauiwi* women, as indicated in the material presented in this chapter, are to be examined.

Consideration of the question 'Who Cares?' finished with a discussion about 'the family'. It was argued that the relative lack of information regarding how the care provided to a family member diagnosed with schizophrenia is distributed is, in the main, explained by the attention schizophrenia and care research has directed towards 'the family'. Discussion further on will argue that the capacity of different family forms to meet the welfare needs of their family members needs to be determined (Munford 1995). This is particularly the case when acknowledging the increased responsibility 'the family' has been given, by Government, to be the primary care-giver of its members.

The importance of considering caring work in a way which transcends the public/private split, in order both to acknowledge the value of this work and challenge the over-representation of women engaging in care, was noted. Three mechanisms proposed by feminists to challenge the public/private split were described and discussed. This discussion indicated that the application and implementation of these mechanisms would need to follow careful consideration of how the unique characteristics of schizophrenia impact upon the provision of informal care.

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The first of the mechanisms proposed for considering informal care in a way which transcends the public/private split was to examine the breadth of women's caring work. It was argued that the characteristics of women's paid work participation lead to them being identified as the most obvious care-giver during negotiations (Finch, 1989) about who should care. When acknowledging the competing demands of women's paid and unpaid work, it was noted that it is women's unpaid caring responsibilities which take primary responsibility (Finch & Mason, 1993). This understanding has particular implications for the care-givers of a family member diagnosed with schizophrenia. For example, it was noted that the changeability of the symptoms of schizophrenia may mean that women may be unable to consistently commit themselves to regular paid work. These women may have to increase or decrease the extent to which they engage in their care provision in order to reflect the path of their family member's symptoms.

The second proposed mechanism to transcend the public/private split was an acknowledgment of the differences in the power and autonomy between those persons in caring relationships, regardless of whether the care was provided in the public or private sphere (Waerness, 1984). The changing nature of the symptoms of schizophrenia suggest that shifts in the power and autonomy of care-givers and care-receivers may be intense and frequent. These frequent shifts in power and autonomy will almost certainly have particular implications for the care provided to a family member diagnosed with schizophrenia. For example, the tensions surrounding the rights of care-givers and the rights of care-recipients may be magnified by the process of the family member assuming more or less responsibility for meeting their welfare needs in response to the changes in the type, intensity, duration and frequency of their symptoms of schizophrenia.

Finally, Ungerson's (1995) arguments surrounding the commodification of care and the implications of this process for the conceptual public/private split were outlined. Potential implications, of the symptoms of schizophrenia, for the commodification of care provided to a family member exhibiting these symptoms were identified and discussed. First, it was noted that payments are made to care-givers after confirmation has been provided that the care-recipient has a proven disability. Therefore, the difficulty associated with receiving the diagnosis of schizophrenia could mean that care-givers do not receive any financial reimbursement for their

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care provision for a significant period of time. Second, it was argued that the characteristics and complexities of the care provided to a family member diagnosed with schizophrenia need to be identified and understood if payments are to reflect the care provided. If the care provided to a family member diagnosed with schizophrenia was to be acknowledged, creative and flexible mechanisms, which can accommodate a variety of caring tasks, would need to be developed. Further, it was noted that providers of care to a family member diagnosed with schizophrenia may not fit neatly or consistently within the categories of either 'full-time' or 'part-time' care-giver. Again innovative and flexible systems will need to be developed to measure changes in a person's dependency needs over time, and the accompanying level of service provision required. Finally, it was noted that an individual may not acknowledge their need for assistance, even after they have received the diagnosis of schizophrenia from the mental health profession, as a consequence of some of the symptoms of schizophrenia. This suggests that 'carer allowance payments for care' (Ungerson, 1995) may be more appropriate for caring relationships in which a family member is diagnosed with schizophrenia than 'quasi-wages payments for care' (Ungerson 1995), at least for the care-giver.

The theoretical material and associated arguments presented in this chapter provide a foundation from which further discussion and analysis in this thesis can be considered and critiqued. This material will highlight how closely the understanding of informal care inherent in New Zealand's policy documents reflect actual care provision. Discrepancies arising from this comparison will, in turn, identify the changes required in New Zealand's policy and related service provision. Furthermore, the theoretical material and discussion presented in this chapter, combined with that in the following chapter, will act as a framework for examining the caring experiences of the participants of this research. This examination will facilitate the development of a comprehensive understanding of the care provided to a family member diagnosed with schizophrenia.

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### 3. THE CONTEXT OF CARE

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The chapters 'Schizophrenia Defined' and 'The Nature of Care' have identified how characteristics of individual caring relationships influence and shape the informal care provided to a family member diagnosed with schizophrenia. Examples of these characteristics are the family member's schizophrenia and the profile of both the family members and the women who provide their informal care. This previous discussion proposed that current understandings of care need to be extended in order to reflect the informal care provided to a family member diagnosed with schizophrenia. Discussion in this chapter furthers this examination by focusing on some of the factors external to individual caring relationships which impact upon the care described in this thesis. Specifically, discussion considers how changes to the way in which responsibility for care provision has been distributed between the state, the community and the family impact upon the informal care provided to a family member diagnosed with schizophrenia. These changes are highlighted by examining New Zealand's social policy. The question is raised as to whether the current and proposed future distributions of caring responsibility between the state, community and family, as proposed in New Zealand's social policy, are likely to increase the difficulty women experience in providing informal care to a family member diagnosed with schizophrenia.

After social policy has been defined for the purposes of this thesis, the format of this chapter will be outlined.

#### **Social Policy and Care Provision**

As will be argued in this chapter, New Zealand's social policy influences, amongst other things, the extent to which women are expected to provide informal care to their family member diagnosed with schizophrenia, the type and level of resources which are available to support this informal care and the extent to which the discourses of 'schizophrenia' are supported.

Various debates exist about the nature and purpose of social policy. Reflecting the diversity of these debates is O'Brien's (1995:5) answer to the question "What is social policy?":

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*There is a degree of futility in attempting to answer this question. Certainly it is not a question that can be answered simply and unequivocally....'social policy' is an 'essentially contested' term.*

Nevertheless, in order to reflect and facilitate discussion in this thesis, a description of what is meant here by the term 'social policy' is necessary. In this thesis, social policy will be considered to include both those prescriptions made by Government regarding the type and degree of intervention required by the state, the community, and the family in order to provide support to those persons diagnosed with schizophrenia, and the assumptions which direct this intervention<sup>95</sup>. Discussion in this section will elaborate on this definition of social policy by examining the two components inherent within it. The first component to be discussed is the assumptions held by Government as illustrated by the use of concepts consistently associated with social policy. Particular attention will be directed towards the assumptions associated with 'gender' and 'disability'. This discussion will primarily draw upon the critique of feminist writers and people with a disability. Following this, it will be noted that these assumptions are translated into policy statements and legislation which prescribe the type and degree of intervention to be provided by the state, the community and the family. It is proposed that these prescriptions influence and shape the day-to-day lives of women and the family members diagnosed with schizophrenia they provide informal care to.

Accompanying any discussion of the assumptions or rationale guiding social policy intervention is the consideration of the following concepts: 'rights', 'responsibility', 'citizenship', 'access', 'participation', 'need', 'choice', 'freedom', and 'equality'. Such consideration highlights the contestable nature of the meanings given to these concepts, this contestability arising from the different perspectives people who define these concepts hold. Wilkes and Shirley (1984) have recorded such differences when identifying the assumptions underpinning the following approaches to social policy: monetarist, state functionalist, modified market, socialist, and, Marxist. For example, according to Wilkes and Shirley (1984), a socialist considers 'equality' to be a prerequisite for 'freedom'. Conversely an individual adhering to monetarism would argue that 'freedom' takes priority over its

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<sup>95</sup> Spicker (1995) refers to these assumptions and prescriptions as the theory and practice of social policy.

incompatible rival, 'equality'. The importance of defining what is actually meant by 'rights', 'responsibility', 'citizenship', 'access', 'participation', 'need', 'choice', 'freedom', and 'equality' is illustrated by this comparison as well as Spicker's (1995:14) following comment:

*Many of the expectations or standards which are used to judge social policy conceal important moral judgments. 'Poverty' and 'homelessness' are not simply descriptions of a set of conditions; they are terms which are used to considerable emotive and political effect, and the way they are defined depends strongly on what kind of response is being called for.*

It will be argued that the way in which concepts, such as 'rights' and 'need' are defined primarily determines both the level and type of informal care women are expected to provide their family member diagnosed with schizophrenia and the assistance these women receive with their care provision. Discussion in this thesis will highlight the divergent and often conflicting definitions held by policy makers and the informal care-givers of a family member diagnosed with schizophrenia. This conflict and divergence highlight the different expectations policy makers and informal care-givers hold about the type and level of care the latter are able and willing to provide.

The need to consider the way in which assumptions can direct the development of policy statements and legislation is highlighted by O'Brien (1995:4):

*It is important to emphasise that specific and particular policy decisions are not reached by taking one of the traditions [or approaches to social policy] and then consciously using that tradition to decide on the particular policy measure. While it is certainly true that libertarian thought has provided an important influence on policy development in Aotearoa/New Zealand in the last decade, it is a gross over-simplification to claim that this alone will provide a total explanation of the actual policies put in place. A more sophisticated approach is required in order to make sense of particular and specific policy decisions at any given time.*

In the previous chapter it was noted that, while feminists have consistently uncovered a sexual division of labour in caring work, feminists have challenged the

understanding that caring is a natural activity of women (Baines et al, 1992). In making this challenge that women do not intuitively and instinctively know how to care, feminists have argued that, implicitly, social policy has defined and reinforced the understanding that women are both naturally dependent and the providers of care. As Pascall (1986:3) has explained:

*A unifying theme of these feminist critiques of social policy has been an analysis of the Welfare State in relation to the family: as supporting relations of dependency within families; as putting women into caring roles.*

Feminist writers have analysed the way in which these assumptions are reflected in policy statements and legislation that are of particular concern to women. Specifically, feminist analysis has been directed towards, for example, reproduction, paid and unpaid work, poverty, women's economic dependence, and the provision of care (Baines et al, 1992; Briar, 1992; Finch, 1984; Glendinning, 1992; Maclean & Groves, 1991; Munford, 1995; Opie, 1992; Pascal, 1986; Twigg & Atkin, 1993). While feminists have highlighted how policy statements and legislation have typically reflected the assumptions regarding women being dependent and natural providers of care, some actual social policy has benefited women.

People with a disability have also highlighted the way in which assumptions that have then been translated into policy statements and legislation. This policy has acted to restrict their level of participation in society. It can be argued social policy has incorporated and reinforced a medical definition of disability<sup>96</sup>. A consequence of this is that it is the classification of a person's disability which regulates their access to services and therefore determines the extent of their 'rights', 'responsibility', 'citizenship', 'access', 'participation', 'need', 'choice', 'freedom', and 'equality'. Dalley (1991:4) has described this process:

*...the way in which an individual's impairment is classified has come to be used as a measure for regulating access to income maintenance benefits, employment and personal social services. Thus an individual's capacity to play a part in society*

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<sup>96</sup> The distinction between a social and medical definition of disability has already been made in this thesis.

*is influenced not only by his or her impairment as such, but also by society's methods of classification.*

The medical view of disability is reflected in social policy by the assumption that people with disabilities require care<sup>97</sup>. Increasingly this assumption has been challenged. For example, Wood (1991:199) has asserted that:

*Disabled people have never demanded or asked for care! We have sought independent living which means being able to achieve maximum independence and control over our lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives.*

Attention will now turn to the second component of social policy, namely the prescriptive component of social policy. This component is encompassed in the following definitions of social policy. For Oliver (1988:3), social policy:

*...includes all those things deliberately done by government to promote well-being and to limit the effects of misfortune, primarily in terms of material advantages and disadvantages. Further, because there needs to be losers if there are to be winners, some attention is paid to those at whose cost social policy goals were achieved.'*

Oliver's (1988) attention then is focused upon the role of government in increasing equity amongst the members of its society. While the positive effects of social policy are stressed, Oliver (1988) does acknowledge that there are losers as well as winners. Assumptions about concepts, such as 'need' and 'gender', often mean that those women who provide informal care tend to be the losers. As has been noted previously, feminist analysis of care has identified the physical, emotional and psychological costs of unpaid caring work (Munford, 1989; Opie, 1992; Parker, 1985; Qureshi & Walker, 1989).

For Shirley (1990:133): "*Social policy concerns the way in which society meets its collective responsibilities by enhancing human development and advancing social wellbeing*". Like Oliver (1988), Shirley focuses on the positive outcomes of social

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<sup>97</sup> The assumptions associated with gender typically mean that this care is expected to be provided by women.

policy. Shirley however does not bound social policy purely as the province of Government but instead intimates that responsibility for enhanced human development and increased social wellbeing is the domain of all citizens, as opposed to the representatives of these individuals. This definition of social policy could be utilised to argue that 'care' is the combined responsibility of the state, community and family. However, it will be argued below that, while calls are being made for the merging of state, community and family caring responsibilities (Cass, 1994), current New Zealand social policy is prescribing that 'the family' is primarily responsible for meeting the welfare needs of New Zealanders (Department of Social Welfare, 1995).

As Oliver (1988) and Shirley's (1990) definitions have indicated, 'social policy' tends to prescribe the extent to which resources will be allocated and utilised for the purpose of improving the wellbeing of a society's members. The allocation and utilisation of resources depends primarily upon the assumptions which have directed policy statements or legislation. For example, a socialist understanding of freedom would necessarily lead to the redistribution of services and resources to those disadvantaged. 'Freedom' defined by monetarists would result in the withdrawal of such services and resources in order to provide incentives for the disadvantaged to succeed.

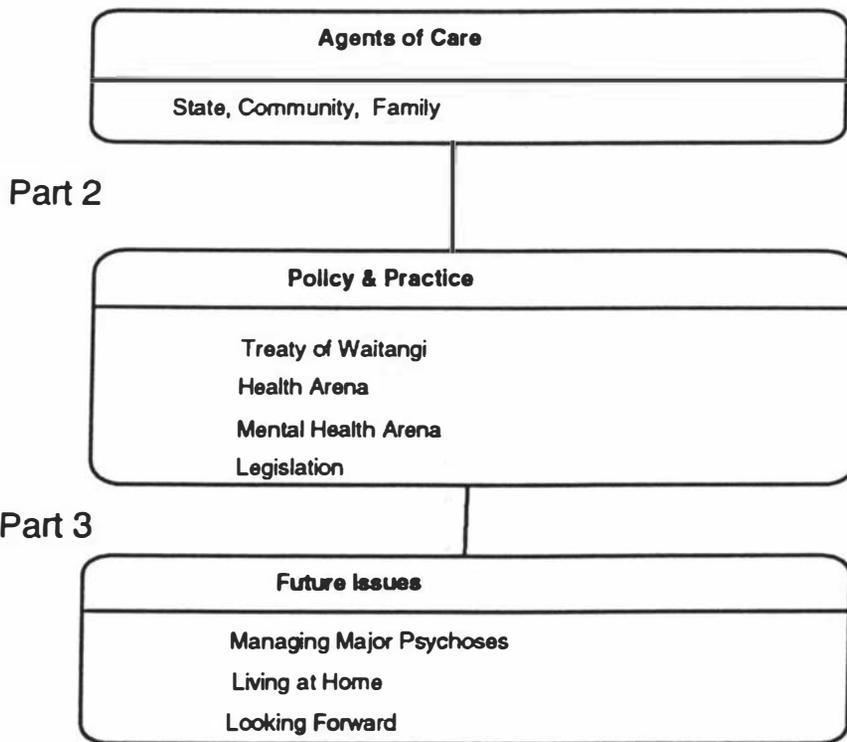
### **The Format of this Chapter**

While it will be argued that all of the traditional policy areas<sup>98</sup> need to be integrated for an holistic approach to health to be achieved, particular attention will be paid in this chapter to the policy and legislation which directly influences the provision of informal care provided to a family member diagnosed with schizophrenia. The diversity and complexity of this connection necessitates that the material in this chapter be divided into three parts as indicated by Figure 1.

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<sup>98</sup> Traditional policy areas include employment, education, housing, health, social security, and personal social services (Cahill, 1994; George & Wilding, 1984; Hill, 1988).

**Figure 1.** Outline for Chapter Three.  
Part 1



Part one of this chapter begins with a description and analysis of the varying combinations of state, community, and family care provision within New Zealand. This discussion notes how these caring agents have been ascribed varying degrees of responsibility for the provision of care to those persons who require support and assistance. The continual redefining of the expectations Government has held over time of the state, the community, and the family's responsibility to care are noted. This redefining is linked with the New Zealand Government advocating either a minimalist or a supportive stance for the state. As a consequence of the state either reducing or increasing its responsibility for providing formal welfare services, the community, and especially the family, have had to either increase or decrease their level of care provision. It is argued that currently 'the family' is being expected, by Government, to increase its informal care provision to its members diagnosed with schizophrenia. The Government's expectations of the family's caring responsibility have been translated into the current configuration of New Zealand's welfare, specifically, mental health services.

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Particular emphasis is placed upon the current configuration of New Zealand's welfare services. It is argued that this configuration has been directed primarily by the New Zealand Government advocating and implementing market liberalism<sup>99</sup>, and the transition from Fordism to Post-Fordism<sup>100</sup>. Briefly, in a climate which emphasises reduced state expenditure and individual responsibility, the state is actively contracting out its responsibility for providing welfare services to an array of providers. These providers are responsible for developing flexible and individualised packages of care. The contradictions and tensions inherent in the current configuration of welfare services are identified and described.

Accompanying the discussion on how the potential or actual caring responsibilities of the state, the community and the family have changed over time is the way in which certain dependency needs have been deemed to be more legitimate than others. They are seen as more legitimate depending on their cause, and the type and degree of dependency involved. Reflecting this redefinition has been the changing criteria of the categories 'deserving' and 'undeserving'. The current emphasis on meeting the needs of the mentally ill, a group traditionally ignored when it comes to resource allocation, is a case in point. It appears that the mentally ill have currently been deemed as deserving of attention from New Zealand's health arena. Reference to how different dependency needs have been legitimated will be made when examining the caring activities of the state, the community, and the family.

Discussion in part one of this chapter provides a framework for the examination undertaken in part two. In part two, attention is directed toward considering how the New Zealand Government's assumptions about who should provide and who should receive care have been translated into policy, specifically in the area of health and mental health. In turn, consideration is then directed to how this policy has influenced and shaped New Zealand's health and mental health services and therefore the provision of care to a family member diagnosed with schizophrenia.

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<sup>99</sup> Market liberalism is defined below.

<sup>100</sup> Post-Fordism is defined below.

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Part two of this chapter begins with describing and identifying the implications of the Treaty of Waitangi, a written agreement between Maori and *tauiwi*, for New Zealand's health services. Acknowledgment of the Treaty of Waitangi in this thesis both highlights and respects the rights and responsibilities that Maori and *tauiwi* hold towards each other as *tangata whenua* and subjects of the Crown respectively. This discussion revolves around acknowledging the different definitions Maori and *tauiwi* have for health. Attention is then directed towards understanding the shape and content of New Zealand's health and mental health services over time. A brief history of New Zealand's health and mental health services is provided. The changing combinations of state, community, and family care are evident in these descriptions. Particular emphasis is placed upon understanding the implications of market liberalism and Post-Fordism for the delivery and receipt of services in these arenas.

It will also be demonstrated how New Zealand's current legislation is influenced by market liberalism and the trend from Fordism to Post-Fordism. This same legislation shapes the level and nature of informal care provided within a family to a member diagnosed with schizophrenia. The legislation examined includes: the Mental Health (Compulsory Assessment and Treatment) Act 1992; the Privacy Act 1993; and, the Human Rights Act 1993.

Part two of this chapter provides an understanding of New Zealand's past and current health and mental health provision. This discussion provides a backdrop for considering the configuration of New Zealand's future mental health services. In part three of this chapter, three of New Zealand's policy documents are examined in order to ascertain the likely shape and content of New Zealand's future mental health services. Two of these documents, entitled 'Managing Major Psychoses' and 'Living At Home', are outcomes of consensus development conferences. The importance of these documents is realised when acknowledging that the Panels of these conferences provide recommendations to the National Advisory Committee on Core Health and Disability Support Services that, after considering these recommendations, advises the Minister of Health. The third document, entitled 'Looking Forward': Strategic directions for the mental health services', outlines the direction that the Minister of Health expects New Zealand's mental health services to proceed over the next three to ten years. Although these documents outline prescriptions for New Zealand's mental health services, the

actual configuration of these services in the future is uncertain. This uncertainty arises from not knowing what is actually meant by the terms 'comprehensive', 'sufficient', 'effective', 'efficient', and 'adequate' in acknowledging the prominence of market liberalism in New Zealand's current context. These terms have been utilised to describe the shape and content of New Zealand's future mental health services. Implications for the future care provision of care-givers providing informal care to a family member diagnosed with schizophrenia are noted.

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## PART ONE: THE AGENTS OF CARE

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Inherent within the definition of social policy provided for the purpose of this thesis, is the understanding that the welfare needs of New Zealanders have been met by different caring agents. It is within this section that these agents are identified, their role in the provision of care being described. Attention will be directed towards examining how the welfare needs of New Zealanders have, over time, been met by differing and fluctuating combinations of state, community, and family intervention (Ellis, 1994; Kelsey, 1993; Oliver, 1988; Tennant, 1989). Inherent within this examination is the understanding that these combinations of state, community, and family care have been primarily influenced by the reigning government's understanding of the terms 'rights', 'responsibility', 'citizenship', 'access', 'participation', 'need', 'freedom', and, 'equality'. Furthermore, it will be argued that the state typically has provided paid caring work referred to in feminist literature as formal care. Formal care is provided predominantly by women who are paid and situated within service delivery positions within the social services (Craig, 1991; Dunn et al, 1992; Munford, 1989, 1992)<sup>101</sup>. While the state typically has provided formal care, the family has been responsible for the informal (unpaid) caring work provided to its members primarily. As noted in the previous chapter, feminist examination of the distribution of informal care within the family has established that it is primarily women who provide this unpaid caring work (Dalley, 1988; Graham, 1983, 1991; Hogan, 1990; Munford, 1989; Opie, 1991; Schultz & Schultz, 1990; Ungerson, 1983). The community has traditionally straddled the caring work of the state (formal) and the family (informal). The community, as defined in this thesis, consists of both voluntary welfare organisations and profit-making agencies with a welfare focus. Voluntary organisations tend to consist of a mixture of paid and unpaid predominantly women staff (Cull, 1992; Malcolm et al, 1993; New Zealand Association of Citizen's Advice Bureaux, 1993). While paid workers are akin to their female counterparts within the paid social services sector, unpaid workers tend to be those women who fill an 'extended caring role' (Traustadottir, 1991). Much less is known about the staff, and their care provision, associated with profit-making agencies or the private sector. The amount of research available on the care provided by the private sector may be explained by

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<sup>101</sup> The specific characteristics of women's paid caring work have already been described.

the tendency to associate welfare provision primarily with the state and voluntary organisations.

Particular attention will be paid to describing the current mix of state, community, and family care provision in New Zealand. It will be argued that the current combination of care providers primarily arose in response to the implementation of monetarist philosophy and principles, the transition from Fordism to Post-Fordism, and the demands from consumers<sup>102</sup> for more responsive services (Barretta-Herman, 1994; Craig et al, 1992; Malcolm et al, 1993; Minister of Health, 1994c; O'Brien & Wilkes, 1993). Throughout this examination of state, community, and family care provision, the changing expectations about who should provide care and who should receive care are noted.

Acknowledgment of the way in which responsibility for care has fluctuated between the state, the community, and the family, will facilitate the development of an understanding of the unpaid care provided within the family to a member diagnosed with schizophrenia. As already argued, the extent to which women are expected to take responsibility for their family member's unpaid care, and the level and range of support they receive while undertaking this work, typically reflects the particular combination of state, community, and family engagement in care provision. After the caring responsibilities of the state, the community and the family have respectively been described, the calls for merging private (family) and social (community and government) responsibilities for care (Cass, 1994) are presented.

## The State

As discussion in this section will highlight, historically the provision of state welfare has been associated with a pattern of extension and retrenchment. These fluctuations in state welfare will be briefly detailed in this section beginning around the time of New Zealand's colonisation by *tau-iwi*<sup>103</sup>. Particular attention is placed upon the type and level of care provided by New Zealand's current state. Those trends which have influenced the current level of state welfare provision are

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<sup>102</sup> The term consumers refers to those individuals who have a direct need for welfare services.

<sup>103</sup> Examination begins at the time of New Zealand's colonisation first, to highlight the different ways Maori and *tau-iwi* structure care provision and second, to acknowledge that the current mix of state, community, and family care has been determined primarily by *tau-iwi*.

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identified and described. The contradictions inherent in the implementation of market liberalism and the transition from Fordism to Post-Fordism are outlined. Throughout this discussion the implications of the current arrangement of state welfare provision for the provision of informal care to a family member diagnosed with schizophrenia are noted.

According to Oliver (1988) early colonial New Zealand Governments concerned themselves primarily with the issue of settlement. In fact, the importance early Governments placed upon the smooth immigration and settlement of Britons meant that "*settlement policy and social policy are almost co-terminous*" (Oliver, 1988:4) at the beginning of New Zealand's colonial history. As a consequence of the attention the early Governments placed upon the acquisition and distribution of land, individuals were expected to have their welfare needs met either via their own actions, via their relatives, or via charitable organisations. In practice, neither the family nor the community were able to meet the dependency needs of those *tauiwi* who had settled in New Zealand (Davidson, 1989; Tennant, 1989). This, combined with the country's geographical location and size, and the small number of gentry who could financially support charitable organisations, led successive New Zealand Governments to increasingly realise the need for state intervention. For example, if the state had not intervened the likelihood of unrest and rebellion from disillusioned settlers was highly probable (Oliver, 1988). Such a response from settlers would have interfered with the successful colonisation of New Zealand.

By the 1890s, a minimalist<sup>104</sup> stance had been taken by the Government towards state and welfare provision. While the state provided some formal care, this care provision was limited to those who were deemed to be deserving. The deserving were those persons whose dependency needs were considered to have arisen as no fault of their own. However, even those individuals who fell within the deserving category were discouraged from drawing upon state welfare provision (Oliver, 1988). Those individuals considered to be undeserving, such as alcoholics and wayward women, were generally left to their own devices.

Oliver (1988) has associated the 1930s and 1940s in New Zealand with an "*...explosion of social policy across the total spectrum from welfare to economic management*". By the mid 1930s, New Zealand had experienced both the

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<sup>104</sup> Minimalist is synonymous with limited.

depression and war. These negative structural conditions were combined with a philosophical change of the incoming Government. In comparison to holding a minimalist stance towards state welfare provision, the first New Zealand Labour Government: *"...considered that assistance to those in need was a right of citizenship"* (Kunowski, 1988:71). Matching the Labour Government's belief about an individual's right to welfare was the development of the 1938 Social Security Act. In essence, the Government took responsibility for the provision of care by developing and implementing, via the state, a comprehensive range of welfare services. *"The Act represented a marked shift in responsibility for several life-cycle crises from the family and/or the community to the state"* (Koopman-Boyden & Scott, 1984:123). Responsibility for welfare provision then had shifted from being individualist to collective in nature. Paralleling the change in expectations about the extent to which the state should be responsible for care provision was a redesignation of persons into the deserving and undeserving categories. The category of deserving was expanded to encompass some groups which previously would have been defined as undeserving, for example the unemployed, and therefore have been denied state support.

In continuing the cyclical pattern of extension and retrenchment of state provision New Zealand Governments, during the 1970s, increasingly indicated they would not be able to continue to expand welfare provision. Explanations for the need to reduce state welfare provision generally referred to financial difficulties:

*As the poor performance of the economy became more obvious after 1975, there were halts to further major innovations in the area of social policy and efforts were made to find ways of reducing public expenditure (Koopman-Boyden & Scott, 1984:120).*

Attempts to reduce state expenditure, and therefore state welfare provision, forewarned of the intention of future Governments to recoil from their care responsibilities established in the late 1930s and 1940s. This reduction of state involvement in the provision of welfare was particularly noticeable following the election of the 1984 Labour Government. This Labour Government initiated *"...massive structural, organisational, and management changes"* (Boston, 1991:1). Two major trends appear to have directed these changes. One of these trends is the adherence and application of monetarist philosophy and principles to social

and public policy. The second trend is the transition from a Fordist to a Post-Fordist state<sup>105</sup>. These trends will be first described and then critiqued below.

The 1984 Labour Government introduced the idea that market liberalism should direct all state activities including its caring work (Moore, 1993). Underpinning market liberalism is the idea that the state's role in welfare provision should be reduced, individual needs and wants should be met via competition in the market place, and, the private sector should be developed and given preference over the public sector (Bunkle & Lynch, 1992; Douglas, 1993; Shannon, 1991; Shirley, 1992; Upton, 1987). In advocating and implementing market liberalism, O'Brien and Wilkes (1993:27) have proposed that the 1984 Labour Government reconstructed the way in which the state was viewed:

*The vision of the progressive 'nanny state' which oversaw a move towards equity and fair play through the post-war consensus was now replaced by a vision of the state as an unwieldy and costly dinosaur which embodied all the worst features of bureaucracy -- inefficiency, obstructiveness and lack of imagination; in short, a burden on the taxpayer and the nation. Labour monetarism argued that New Zealand could not afford its welfare state and would need to trim and reshape it.*

The following comment by Upton<sup>106</sup> (1987:114), from his book entitled 'The Withering of the State', explained what the state would look like after it had been trimmed and reshaped:

*It is remarkable, really, that a monolithic delivery system should be viewed as desirable for some of the most important services which a civilised society requires. In a free, well-educated community, diversity, choice and personal responsibility should be of paramount importance if sclerosis and decay are to be avoided. It does not mean that the state has no role to play: it may well be an appropriate quality controller and provider of information. And it will probably be a crutch of final resort when all else fails. But this residual function is a far cry from the bloated empires presently under its care.*

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<sup>105</sup> Accompanying these two main trends has been the demands by consumers for services to be more flexible and responsive to need.

<sup>106</sup> Upton was the Minister of the National Government which succeeded the 1990 Labour Government.

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Upton's (1987) proposed changes regarding the role of the state in the provision of welfare have been occurring in New Zealand.

As will be confirmed below, while the state was seen as a main provider of care during the late 1930s and early 1940s, the family is now considered to be the agent primarily responsible for meeting the welfare needs of its members. This redefinition is illustrated by Shipley's (1991:1) statement as Minister of Social Welfare:

*The Government's social and economic objective is to provide an environment where New Zealand families are able to take control of their own lives, freed from the dependence on state welfare that currently traps so many of our people. To achieve that objective we must be prepared to make bold changes and strike a new balance between the state's responsibility for their lives and those of their families.*

The Minister (1991:2) went on to explain what this new balance would look like: *"Most importantly, we must take steps now to encourage New Zealanders away from dependence on the state towards personal and family independence"*. The direction announced by Shipley in 1991 towards reduced state involvement in welfare provision was restated by the Department of Social Welfare in its 1995 Corporate Plan. One of the general outcomes stated in this document was *"That people are encouraged to take responsibility for themselves and their families/whanau"* (Department of Social Welfare, 1995:3). Discussion further on in this chapter will propose that identification of the family as the primary care-giver may have particular implications for the care provided to a family member diagnosed with schizophrenia as a consequence of the discourses of 'schizophrenia'.

The criteria for those who are considered eligible for that state assistance which is still available has also changed. Consistent with Upton's (1987:114) description of state welfare provision as a *"crutch of final resort"*, those persons considered by the state to have a legitimate need for its care are those whose dependency needs are so severe that they cannot be met by themselves or their family. This has been evidenced by the 1991 benefit cuts (Craig et al, 1992; Shannon, 1991) and increased housing and health costs (St John, 1994). Not only have criteria for

welfare assistance became more stringent, but the level of assistance received by those who are eligible has also reduced. That the threshold for entry into state-provided welfare services has been raised is confirmed further on in this chapter when discussing the legislation which directly impacts upon the care provided to a family member diagnosed with schizophrenia. For example, it is highlighted that New Zealand's formal mental health services are currently focusing their attention on those individuals in crisis. Consequently, care-givers of a family member diagnosed with schizophrenia are having to manage their family member until the family member becomes a danger to themselves or their community. The characteristics of the acute symptoms of schizophrenia, such as hallucinations and delusions, suggest that managing these symptoms could be a demanding and challenging task.

The prescriptions, regarding the type and degree of intervention to be provided by the state, the community and the family, translated into New Zealand's policy statements and legislation, reflect the assumptions the current Government holds regarding the concepts of 'rights', 'responsibility', 'citizenship', 'access', 'participation', 'need', 'equality', 'freedom', and 'choice'. That the current Government's assumptions are antithetical to the definition of these concepts forwarded by the 1938 Labour Government is further highlighted throughout this chapter. New Zealand's service development documents include terminology such as 'fair', 'adequate', 'effective', and 'value for money', with the 'best outcomes' all under the premise of risk management (National Advisory Committee, 1992, 1992a, 1993, 1993a, 1994; Shipley, 1994; Shipley & Upton, 1992; Upton, 1991)<sup>107</sup>. As Chapman, Goodwin, and Hennelly (1991:12) have argued: "*The language of privatisation, cost-effectiveness and value for money, is replacing notions of needs and rights of individuals*". The tension between services being 'fair' and 'adequate' in an environment which emphasises reduced state expenditure is highlighted below when discussing the implications of Post-Fordism.

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<sup>107</sup> This terminology indicates that the Government is heeding Treasury advice. Treasury, which advocates an individualist/anti-collective view (Williams, 1989), has asserted that the themes of competitiveness, increased trade performance, reduced Government spending, and reduced national debt, should influence all of New Zealand's policy. If this advice is heeded, the Government "...will help the development of a successfully and internationally competitive enterprise culture" (Treasury, 1993:73).

The move from a supportive to minimalist state has been occurring in most industrialised countries worldwide (Bryson, 1994). Bryson (1994) has however noted New Zealand's particular enthusiasm<sup>108</sup> for supporting an individualist/anti-collectivist stance. Kelsey (1993:351) has noted that: "*In less than a decade New Zealand went from a bastion of welfare interventionism to a liberal reformer's paradise*". Shannon (1991:3) has expressed a similar understanding of the social and economic changes which the 1984 Labour Government implemented in New Zealand:

*Somewhat paradoxically, the election in 1984 of a Labour Government, which previously had been responsible for so much of the welfare state, brought about a rapid and major change in direction. New Zealand, once regarded as a 'laboratory for socialism', was transformed in the space of five years almost into its opposite: a 'laboratory' for free market capitalism.*

One of the consequences of market liberalism is that care-givers of a family member have had to increase the level and type of care they provide their family member at the same time that support services and required resources have been reduced. The lack of state-provided welfare services may cause these care-givers particular concern and anxiety. This assertion is made in acknowledging WIAG or *When I Am Home* (Lefley, 1987). No longer can care-givers assume that the state will provide care to their family member when they are unable to continue to perform their caring work. As already noted, WIAG predominates as a consequence of the family members diagnosed with schizophrenia being adult sons (Bulger et al, 1993; Winefield & Harvey, 1994), their care-givers being older women (Lefley, 1987).

Paralleling the implementation of market liberalism is New Zealand's transition from a Fordist to a Post-Fordist state, which also reflects what is occurring internationally (Leira, 1994; Williams, 1994). While O'Brien and Wilkes (1993) have proposed that the move from Fordism to Post-Fordism is not complete in New Zealand, examination of this transition provides a framework for understanding New Zealand's current state welfare provision. Williams (1994:49) has explained

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<sup>108</sup> New Zealand has been accompanied in its enthusiasm by the United States of America, the United Kingdom, and Australia.

that the transition from Fordism to Post-Fordism has been reflected in the welfare arena and involves changes from:

*...mass production to flexible production; mass consumption to diverse patterns of consumption; production-led to consumer-led; from mass, universal needs met by monolithic, bureaucratic/professional-led provision to the diversity of individual needs met by welfare pluralism, quasi-markets, reorganised welfare work and consumer sovereignty.*

Translation of Williams' (1994:49) description of the transition from Fordism to Post-Fordism has the following implications for New Zealand's welfare services: an increased emphasis is placed upon services reflecting and being responsive to individual need as opposed to services being universally applied regardless of individual circumstances; the separation of the provision, purchase, and regulation of welfare services; the replacement of state primacy in the provision of public welfare services, state responsibility being transferred to an array of differing providers; the implementation of various reporting, monitoring, and accountability mechanisms; and, increased competition amongst those who provide welfare services for both funds and clients<sup>109</sup>. As will be seen below, Post-Fordism facilitates the implementation of market liberalism, specifically the reduction of state responsibility for care provision, the meeting of individuals' needs via competition in the market place, and the development of the private sector over the public sector.

While continuing to fund service provision, the state has drastically reduced its involvement in the actual provision of services by developing, offering, and designating state contracts for welfare provision. Effectively then the state has encouraged competition between potential providers by utilising the contracting process. Each contract contains its own service description which is the tool by which contracted providers are monitored. Allen (1992:preface), in speaking of the British context, has explained this process:

*Social service departments are now required to secure a mixed economy of care which meets the care needs of their local communities identified in their community care plans. Departments are also required to develop their ability to draw*

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<sup>109</sup> Specific examples of these implications are provided further on in this chapter.

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*up appropriate contracts for different care services with providers of care...and to ensure that quality standards are specified in contracts and that these are monitored and met.*

Inherent within these contracts is an emphasis upon the development of individualised and flexible packages of care. These packages of care are more in line with the demands of consumers who have called for more flexible and responsive services (Minister of Health, 1994c). The development of individualised and flexible packages of care have the potential to reduce the degree to which women need to engage in the care they provide to their family member diagnosed with schizophrenia. For example, in identifying individual need, these packages of care could reflect more effectively the changing and unpredictable nature of the family member's schizophrenia.

However, while an individual's needs may be more readily identified, the question is raised as to whether individual need will be met in an environment which emphasises the importance of decreasing state expenditure. Munford (1995:24) has spoken about this issue in the New Zealand context:

*In current climates we may see complex systems being devised in order to establish need and ensure that individuals can exercise choice. We must continually ask ourselves why these systems are being established and for whose benefit. If choices are being decided in an environment where resources are seen to be scarce it is likely that entitlements will be based on criteria where notions about determining who is more deserving will be established.*

In the current climate, available resources are likely to determine the extent of 'choice'. New Zealanders O'Brien and Wilkes (1993:181) have argued this point:

*The increased individualisation that is part of the PostFordist framework means more individual choice for some, but much less choice for many. It does not require a miracle of intellectual analysis to realise that choice is massively constrained by economic scarcity.*

Cochrane (1994:132) has expressed similar concerns to O'Brien and Wilkes (1993) about the extent to which clients will be empowered by the current arrangement of welfare provision:

*It is easy and probably right to be cynical about the claims made for 'empowerment', particularly when the terms on which it is to be encouraged are substantially limited by decisions (and strategies) already made elsewhere. The warning that those being 'empowered' need to be aware of resource limitations is usually either stated explicitly or taken for granted as part of the new common sense.*

Evidence has shown that those people who experience increased choice or empowerment will not necessarily be those individuals who exhibit the symptoms of schizophrenia. The review of New Zealand's mental health services, undertaken later in this chapter, indicates that other causes typically have been seen as more worthy of resource allocation than those individuals with a psychiatric disability.

Biehal (1993:444) has questioned the extent to which users of welfare services will be better serviced as a consequence of the increased competition between service providers:

*Service users are seen as consumers who will benefit from competition between a range of providers. Yet welfare users are not equivalent to consumers in the world of commerce. They include some of the most powerless and stigmatized members of society. For some, ill health, frailty or disability may further hamper their ability to 'shop around' and make untrammelled choices in a marketplace of care services. 'Consumers' of social services are rarely in a position to 'take their custom elsewhere'.*

The symptoms of schizophrenia suggest that those individuals who exhibit these symptoms may not necessarily benefit from the increased competition between an array of providers. First, there is the assumption that providers will be willing to compete to provide services to individuals with a psychiatric disability. Discussion on the commodification of care suggested that the various misconceptions regarding schizophrenia (Jones, 1995) would almost certainly mean that potential providers would not identify individuals diagnosed with schizophrenia as the client

group they wish to work with most. In comparison to other areas then, the state may experience some difficulty in inducing potential providers to compete for state contracts for mental health. New Zealand's mental health services may continue to be inadequate and uncoordinated, this situation placing pressure upon informal care-givers to provide care to their family member diagnosed with schizophrenia. Second, as a consequence of services being contracted out to an array of providers, much time can be spent in first, locating and contacting the required service and second, determining the criteria for accessing the service. It has already been noted that the symptoms of schizophrenia can change in type, intensity, frequency and duration in very short periods of time. An individual then may experience a lack of insight, hallucinations or delusions<sup>110</sup>, before they gain access to the service they require. In responding to this, the care-givers of these individuals may need to inform themselves continually as to where specific services are located and the criteria for access. These care-givers may also experience greater difficulty in ensuring that their family member be given access to services as a consequence of their family member advocating that they are not unwell.

While the Government has asserted that current welfare arrangements increase consumer choice, criticism of the trend from a Fordist to a Post-Fordist state has highlighted both the uncertainty clients of welfare services experience and the fragmentation of service provision (Williams, 1992). Client uncertainty is understood when acknowledging the extent of the structural, and organisational change which has occurred in the New Zealand welfare arena since the 1984 Labour Government (Boston, 1991; O'Brien & Wilkes, 1993). The traditional benchmarks, for example universalist policies and the primacy of state care provision, that have previously guided clients through the welfare system have been removed. Clients are unsure about their continued eligibility for services in the near future, the nature of these services itself not being conclusive. The introduction of an array of providers to the welfare arena has increased confusion for clients as to where to go for which services. Increased choice seems to be dependent upon an individual having both the skills to identify and contact the appropriate provider and if necessary the ability to contribute towards the costs of required services. In an environment such as this, care-givers may need to play a

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<sup>110</sup> These symptoms often leading to the individual denying that they require assistance from the mental health profession.

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greater role in first advocating for their family member's access to services while simultaneously increasing the degree to which they engage in their family member's care provision.

The above discussion has described the characteristics of the state's involvement in the provision of New Zealand's welfare over time. The pattern of extension and retrenchment which has characterised the welfare provision of the New Zealand state over time has reflected changing Government definitions of 'rights', 'responsibility', 'citizenship', 'access', 'participation', 'need', 'choice', 'freedom', and 'equality'. These definitions have had particular implications for the extent to which a society's members have been responsible for both meeting their own requirements and providing care directly to those persons with dependency needs. Attention was directed towards detailing the implications of the Government's adherence and implementation of market liberalism and Post-Fordism. As this discussion has highlighted, these implications have particular ramifications for the caring work of those who provide care to a family member diagnosed with schizophrenia.

## **The Community**

Attention will now be directed towards the role that the community has played in assisting those New Zealanders who require care and support. Initially discussion will highlight the ambiguity which surrounds the term 'community'. This ambiguity is further highlighted by discussing the way in which 'community care' has been considered. The term 'community' is then defined for the purpose of this thesis as consisting of both the various voluntary or non profit organisations and profit making organisations which meet the welfare needs of New Zealanders. The role that the community, as just defined, has played in the provision of care and support to New Zealanders is then described. Throughout this discussion the implications, of the current arrangement of community welfare provision, for the provision of care to a family member diagnosed with schizophrenia are noted.

In essence there is no universally accepted, or operative definition of the term 'community' (Brown, 1994). Instead, 'community' is a nebulous term typically associated with differing degrees of locality, territory and collective sentiment (Pearson, 1990; Peters & Marshall, 1988; Shirley, 1979). The term 'community' is

associated with both prescriptive (what should be) and descriptive (what is) components (Jary & Jary, 1991). Prescriptively, definitions of community tend to be value-laden and emotive. Walker (1982:41) has argued that prescriptive definitions of community are: "...connected with the good life, of what kind of life is desirable and what kinds of social arrangements promote intimacy and stability". This understanding of community tends to revolve around the idea that a group of people exist who are both able and willing to collectively pool their resources and work towards meeting the varying needs of its members.

It is often the divergence between the prescriptive and descriptive components of community which creates the impasse between the rhetoric and reality of social policy outcomes. This assertion is supported when considering the current emphasis placed upon community care. The ambiguity surrounding the term 'community care', has repeatedly been highlighted by writers from the United Kingdom, the United States, and from New Zealand (Finch & Groves, 1980; Jones, Brown, & Bradshaw, 1978; Leibrich, 1988; Lentjes & Jonker, 1985; Malin, 1987; Opie, 1992; Parker, 1985; Walker, 1982). Despite the ambiguity surrounding community care, there is some consensus, particularly in feminist quarters, that originally community care referred to 'care in the community'. In effect, care in the community referred to where services would be provided. Responsibility for the funding and provision of welfare services would still rest with the Government. Diverging from this initial concept is care by the community (Abrams, 1977; Finch, 1990; Lewis & Meredith, 1988). Instead of referring to where care would take place, emphasis is directed towards who undertakes caring work, specifically the community<sup>111</sup>.

As noted above, when referring to care by the community, policy makers tend to assume and advocate that caring communities exist. In other words, policy makers refer to the prescriptive components of community. For example, Hawks (1975:277), when speaking about community care and people with a psychiatric disability in the British context, has argued that:

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<sup>111</sup> Walker (1993) has provided a comprehensive description of this development in British community care policy in his article titled 'Community care policy: From consensus to conflict'.

*Basic to the recommendation that the mentally ill should be treated in the community is the assumption that the community is therapeutic or that the community cares...It is assumed, for example, that the community is more than a mere geographic entity, that it is possible to identify it as showing concern, of harbouring those skills and tolerances which previously were the province of the hospital, or else that the community is capable of acquiring these skills. It assumes, too, a community's willingness to tolerate long-term support of non-productive persons visible in the community.*

The assumption that such caring communities exist has been challenged by material which has already been presented in this thesis. First, when discussing the discourses influencing the way in which mental illness and specifically schizophrenia are understood and considered, it was established that psychiatric disability, particularly schizophrenia, is imbued with the themes of fear and violence rather than tolerance and acceptance (Butler, 1993; Miller, 1995)<sup>112</sup>. This understanding implies that a caring community with unified views and purpose towards providing care to persons with schizophrenia is unlikely to exist. Further, the current emphasis placed by the New Zealand Government upon individual responsibility (Shiple, 1991) and managed competition (Fougere 1994) is juxtaposed to the development and existence of such intimate and supportive communities. Peters and Marshall<sup>1</sup>(1988:668-669) have expressed their concern about this contradiction between individual and collective responsibility:

*Our concern is that current social policy discourse, with its talk of community will construct 'communities' thus, in a general sense transforming human beings into 'community objects' who come to perceive themselves as such. But this is maybe an impoverished sense of 'community' with the individualistic and market assumptions leaving the disadvantaged worse off than under the present eroded welfare state. How is it that the traditional liberal framework, emphasising as it does traditional liberal notions of freedom, equality and rights, permits the construction of 'community subjects' who cannot care for the disadvantaged, who cannot see the disadvantaged as in need of some form of welfare state support and who see themselves as members of a 'community'? We are talking about subjects who have views of themselves - 'knowledge' - so that it is not a*

<sup>112</sup> Of course, the existence of such discourse does not totally preclude the existence of persons with supportive views towards persons who exhibit the symptoms of mental illness.

*point of them necessarily being immoral or selfish but, rather, people whose very understanding of themselves and the world is such that the 'true' way to 'care' for the individual is to act in accordance with the free market individualistic beliefs. This then becomes the truth about themselves and the world.*

Inherent within Peters and Marshall's (1988:668-669) comment is the understanding that, in New Zealand, 'community' may encompass less collective sentiment and camaraderie than its prescription implies. Opie (1992:17) has also noted the contradictions which arise from the Government advocating collective responsibility for care while adhering to monetarist philosophies:

*Government is promoting community care on the informal level, so assuming a collective social responsibility, while at the same time actively undermining on the macro level policies implementing that concept. Individuals and local communities are expected to retain a social conscience, but the actual structure or model of society which government policies are defining as desirable emphasises individuation and the loss of a collective responsibility.*

The ambiguity surrounding 'community care' is undoubtedly magnified by the fact that it has been strongly advocated for by various sectors of the New Zealand political spectrum since the 1960s and 1970s, 'community care' having different meanings depending on each sector's political stance. This has been highlighted by Williams (1994:69) speaking of the British context:

*As such, community care in Britain represents an attempt by the new right to generate self help, the traditional role of the family, the introduction of the markets into welfare, the stimulation of the private sector, the residualisation of the state sector, the reduction of local authority powers and of the powers of welfare professionals, and the limitation of state spending within a context of rising needs from older people. At the same time the policies represent pressure from professionals and user-groups for deinstitutionalisation and independent living, pressure also from user-groups for representation and pressure from carers and women's groups about carers' need for support.*

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The different understandings of community care have been reflected in the everyday use of this term. The 'community' component of this form of non-institutional care has encompassed reference to: informal care-givers or specifically women; voluntary welfare organisations; case management; a more holistic approach to care provision; home-based disability support services; non-institutional services; and, more generally, care which is not provided by the state. Indications arising from the implementation of community care overseas suggest that community care will continue to be redefined (Challis, Davies & Traske, 1994). As in New Zealand, this process of redefining is taking place in a context characterised by diversity and change (Challis, Davies & Traske, 1994a; Evers, 1994).

The above discussion has highlighted the importance of clearly defining what is meant by community and therefore community care. This position has consistently been taken by feminists writers and researchers who have argued that in fact it is women who are expected to be both able and prepared to increase their participation in unpaid caring work. Whilst somewhat over-simplifying this argument, Dalley (1988:13) does raise the issues at hand in suggesting that:

*...the whole of community care policies can be seen to be based on the supposition that women are naturally carers, whilst men are naturally providers. And because such policies assume and presume the altruism of women, they reinforce that presumption. If no alternative forms of care or support are available, women will inevitably accept that it must be they who provide it.*

Waerness (1984:68) has also spoken about the assumption that it is women who will care:

*The enthusiasm with which community care or 'informal caring networks' has been taken up in social policy is not matched by much clear thinking, neither about conditions, nor about consequences. It seems to be based on a somewhat nostalgic idea that person's caring for each other in the 'good old days' and at the same time ignoring that the fact that community care hitherto has been fundamentally based on women's unpaid domestic labour.*

The comments by Dalley (1988) and Waerness (1984) confirm the assertion Finch and Groves (1980:494) made early on in the debate about community care, specifically "*...that in practice community care equals care by the family, and in practice care by the family equals care by women*". The importance of this double equation is realised when acknowledging those studies which have calculated that women's unpaid caring labour under community care is "*...at least equivalent to the whole existing statutory input*" (Finch, 1986:21).

The role that women play in the provision of informal care has generally been overlooked in New Zealand by the emphasis placed on the role of 'the community'. Just as in Britain:

*Much of the support for policies of 'community care' is couched in 'naturalist' language...Such language is used to maintain the view that the two (undefined) institutions of 'family' and 'community', and the altruistic relations within them, are 'natural' and therefore inevitable* (Ungerson, 1985:210).

Use of the terms 'community' and 'family' has a more sinister role, these terms veiling the over-representation of women in informal care. As Bowman and Virtue (1993:ii) have said:

*Increasingly, women's responsibility for caring for their children with disabilities (or other relatives) is disguised by bureaucratic jargon. Homogenising terms like 'community care' and 'carers' serve to disguise the fundamental issue of gender in our roles and relationships.*

Most recently, terms such as 'carers' and 'care-givers' have replaced 'the community' and 'the family' within New Zealand's policy documents (CRHA, 1994; Curry & Bascand, 1993; Mental Health Committee, 1986; National Advisory Committee, 1993; Peacock & Burns, 1993). The vital role that care-givers play in the care of dependent persons has been acknowledged (Curry & Bascand, 1993). This trend reflects the increased attention that informal care-givers, both here and overseas, have received within the policy arena (Keith, 1992; Twigg & Atkin, 1995). However, as Bowman and Virtue (1993) highlighted, the use of these terms still neglects to acknowledge the gender issues inherent in caring work. The question needs to be raised as to why these gender issues are not acknowledged within

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policy documents, despite evidence consistently presented by feminist research. Munford (1994:275) has explained the gender neutrality surrounding informal care by the following:

*Policy-makers may have a vested interest in masking the difficulties [in caring relationship]. They do not want to undermine a relationship that is cost-effective and requires minimum funding.*

The fact that women's unpaid caring work has been largely ignored by the New Zealand Government has particular implications for the care provision of women. The politics of creating an environment where women, typically unpaid and untrained, are left to provide care to people who require support should be questioned. This is particularly the case when those people receiving care have complex and changing needs such as those individuals who exhibit the cyclical acute and chronic symptoms of schizophrenia. Discussion already presented in this thesis has highlighted how crucial it is for those who provide care to people diagnosed with schizophrenia to understand this disorder and how it manifests itself.

The above consideration of community and community care provides a backdrop for considering briefly the historical and current contribution the community, defined as consisting of voluntary and profit-making organisations, has made towards meeting the care and support needs of New Zealanders. It is this contribution of the community which is now outlined. The involvement of voluntary organisations and then private organisations in the provision of care and support is discussed.

The level of welfare provided by voluntary agencies has generally oscillated with that provided by the state. When New Zealand's social policy focused solely on issues regarding settlement (Oliver, 1988), it was church and community organisations that provided for the settler's care needs. For example, the Salvation Army which arrived in New Zealand in 1883: "...quickly became involved in social work for those in need – alcoholics, unmarried mothers, prostitutes, orphans, abandoned children, and prison inmates" (Kunowski, 1988:11). Tennant (1989) has proposed, however, that the Salvation Army was one of a few voluntary charities that worked with alcoholics, criminals and other such groups considered undeserving. The majority of voluntary charities chose not to work with these

groups "...referring the expensive long-term cases, or the most troublesome and disreputable among the poor, to the public relief system" once it was established (Tennant, 1989:200). Those community agencies that adhered to the strict distinction between deserving and undeserving supported those beneficiaries considered more acceptable, such as children. In reality, relief from charitable aid was "...all too frequently minimal, condemnatory, and grudgingly given" (Tennant, 1989:199).

It is likely that those persons exhibiting the cyclical symptoms of schizophrenia were defined as troublesome, expensive long-term cases, and therefore were referred to the public relief system. Furthermore, church organisations may not have defined people with schizophrenia as deserving as a consequence of the belief that their symptoms were the sign of spirit possession (Jones, 1995).

One of the reasons for the adherence to the deserving and undeserving criteria was the fact that church and community organisations were often supported to varying degrees by private interests. Private interests were able to translate their views on those deemed deserving and undeserving by targeting which community organisations they would financially support. Those organisations which focused firmly on relief to deserving groups were less likely to lose favour with private interests and therefore jeopardise their funding (Tennant, 1989). However as already noted, support provided by private interests was limited as a consequence of the small number of gentry in early New Zealand society:

*The depression of the 1880s and the early 1890s strained the myth of New Zealand as a land of opportunity with work for all who wanted it. As poverty increased, private benevolence was unable to cope, and the government was forced to become involved to meet the gap (Ehrhardt & Beaglehole, 1993:10).*

The role of voluntary organisations has increased as the state has devolved its responsibility for the provision of care. Baretta-Herman (1994:18) has associated the community's current level of welfare provision with the decisions made by the 1984 Labour Government:

*The reign of the Fourth Labour government came to an end in 1990 but their redirection of social policy remains intact. The*

*main responsibility for caring is now clearly rested in the community. The responsibility of the state for social services in New Zealand continues to fade, overshadowed by the economic struggles of what was once the social laboratory of the South Pacific.*

The expectation that voluntary organisations will increase its capacity to care was identified by one person's submission to the People's Select Committee establishing the affects on beneficiaries of the 1991 benefit cuts:

*The government is shaping our society to being one where concern for the health and welfare of the less advantaged in society is seen as a role for church and other charitable groups and individuals, rather than a state responsibility (Craig et al, 1992:5).*

Voluntary organisations have identified various contradictions surrounding the role they play in replacing the primacy of the state in the provision of welfare. For example, voluntary agencies in all welfare areas have voiced their concern over having to deal with both increasing workloads and what they perceive to be inadequate levels of Government funding (Craig, et al, 1992). Specifically, Malcolm et al (1993:127) have identified the current economic and political climate of New Zealand as having the following implications for organisations in the voluntary sector:

- *increased demands for services;*
- *clients with more complex needs that are harder to meet;*
- *increased level of skill required for working with clients, for management of contracts and their associated obligations;*
- *more competition for scarce funding resources...;*
- *information is more complex and requiring more developed management systems to keep up to date;*
- *advocacy work on behalf of client requirements and the sector needs to be managed within a new environment.*

The increased competition for funding, tighter accountability for funds received, and increased and more complex workloads mean that providers are working under greater pressure. One potential outcome of this pressure is that gaps appear in service provision. Again people who have quite complex needs, such as those

diagnosed with schizophrenia, may find that the services they do receive are not up to standard. It is questionable whether persons diagnosed with schizophrenia will experience more 'choice' and 'flexibility' in their services. The resulting gaps in services place responsibility upon families, more specifically the women within these families, to meet the care and support needs of their members. As already asserted, women are not resourced for their increased care provision. In fact, families of these women are finding their existing resources need to go further as a consequence of for example, benefit cuts, increased housing rentals and health costs.

These same factors, combined with the understanding that providers will operate along business lines (Malcom et al, 1993; Renouf, 1995) has raised concerns regarding the composition of New Zealand's voluntary sector. Ellis (1994:76) has noted the difficulty voluntary agencies may experience in maintaining their unique identity:

*The challenge for voluntary welfare agencies in the present climate is, in my view, to sustain an identity which is distinct and different from statutory agencies and to continue with those activities that have historically made them different and distinct, i.e. by responding to unmet needs, by advocating on behalf of marginal groups in society and by being in the forefront of some innovative, creative and empowering ways of working. This is a tall order in the present economic, political and organisational climate.*

Like Ellis (1994), Walker (1993:220), in speaking about the British context, asserted: *"In a world of competitive tendering it will be difficult for voluntary agencies to maintain their autonomy and act as independent representatives of the groups they serve"*. The reliance voluntary groups have upon state funding, combined with the increased competition for such funding, may mean that voluntary groups jeopardise their funding base if they continue to act as advocates and representatives of the groups they serve. This could mean terminology, such as 'adequate', 'fair', 'effective', and 'value for money', continue to be defined by the proponents of market liberalism.

It has already been noted that it is predominantly women, both paid and unpaid, who work within non-profit organisations (Cull, 1992). As predicted by feminist

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critique, the predominance of women within voluntary agencies means that it is women who are primarily affected by the tensions and contradictions inherent in the current configuration of New Zealand's welfare services. The question is raised however, as to whether women will continue to be able to tolerate these tensions and contradictions along with the changes occurring to the role of women. An example of such changes is the increased participation of women in the paid workforce (Briar, 1994; Statistics New Zealand, 1993).

The above discussion regarding the role of voluntary organisations in the provision of welfare identified that voluntary organisations and the private sector have not had a mutually exclusive relationship. As was noted, those who received support from voluntary organisations during New Zealand's colonial period were typically those individuals considered to be deserving by those private individuals who financially supported voluntary organisations (Tennant, 1989).

As the transition from Fordism to Post-Fordism predicts, the private sector has increasingly been playing a more prominent role in the welfare arena. First, the private sector has received increased public monies via the state contracting with this sector to provide welfare services. Second, the private sector has benefited from New Zealanders purchasing private insurance, primarily for health. Both of these trends will be further described below.

Profit making organisations have been amongst those potential providers competing for state contracts to provide welfare services. It could be argued that profit-making organisations have traditionally operated along business lines. They will have spent less energy and resources in ensuring that their structure and organisation reflects the business-like focus expected within state contracts.

The possible consequences of the profit motive for the distribution of care provision between private and voluntary organisations have been highlighted by Bowie and Shirley (1994:317):

*...the temptation for a profit-driven hospital would be to discharge patients into the community as early as possible, thereby reducing hospital costs, but substantially raising community costs. This strategy can only increase the pressure on voluntary organisations, stretching their resources*

Such circumstances are only likely to increase the pressure and reduce the morale of staff working within these latter organisations (Chapple, 1994).

The entry of New Zealanders into the private arena has not been a recent phenomenon. However, as Oliver's (1988:39) comment regarding the use of private insurance for health care illustrates, the option of private insurance has increasingly become more appealing for those who can afford it:

*Long waiting lists for non-urgent surgery in public hospitals induced those who could afford to do so to join private medical insurance schemes to help finance prompt hospital treatment. By the mid-1970s one sixth of New Zealanders were covered by private insurance, in the later 1980s nearly one-third.*

The more recent statistics provided by Bowie and Shirley (1994:312) illustrate that the trend towards purchasing private health insurance is still continuing: "*Between 1980 and 1992, private health insurance increased from 1.1 per cent of total health expenditure to 4.8 per cent...*". The understanding that 'choice' is determined by an individual's ability to pay, within the current social, political, and economic context, is indicated by Hay (1989:155) who has explained that private health insurance: "... *allows members of that group of consumers who can afford it to circumvent real or imagined difficulties in the public hospital sector...*" (Hay, 1989:155). The process of privatisation has enhanced a dual system of health care, the standard and timeliness of the care a person receives varying significantly on ones income<sup>113</sup>. 'Choice' for the users of private agencies will be regulated primarily by the individual's ability to pay (Taylor, Hoyes, Lart & Means, 1992).

In recognising the importance placed by the private sector upon maximising profit, it is highly probable that the private sphere is going to be primarily interested in those persons who either have the ability to pay or allow the most profit to be gained. Those individuals then who are either unable to pay or have highly intensive and costly care needs could be referred to those residual state services still operating, or to voluntary services. Again, people exhibiting the symptoms of

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<sup>113</sup> As Oliver's (1988:39) comment indicated, this assertion is supported by the waiting lists for surgery within the public health sector (Core Services Committee, 1993).

schizophrenia are likely to predominate amongst those referred to such services. The cyclical and unpredictable nature of the symptoms of schizophrenia mean that a continuum of care needs to be available, the majority of this care is characterised by its expensiveness<sup>114</sup> (Janseen Pharmaceutica, 1993). The prognosis for between forty to sixty percent of those diagnosed with schizophrenia is that they will need access to such care for the rest of their lives (Kaplan & Sadock, 1991).

The above discussion on the role of 'the community' in the provision of welfare described the current mix in New Zealand of voluntary and profit-making welfare providers. It was noted that the current political and economic context has different implications for the non-profit and profit sectors. Specifically the private sector appears to be flourishing as a consequence of both contracting and privatisation. Voluntary organisations however are attempting to maintain their unique identity while responding to the increased demand for their services. The contradictions arising from the Government advocating collective care and individual responsibility were identified and described.

## The Family

Having examined the role of the state and the community in the provision of care, attention will now turn towards establishing the role that 'the family' has played in providing support to its members. In previous discussion, it was established that 'the family' in New Zealand, as in most English-speaking countries, has typically been assumed to be nuclear, that is, consisting of a male breadwinner, a female home-maker, and generally two children (Social Development Council, 1991; Swain, 1990). Challenges to the primacy of the nuclear family were made by acknowledging the variances between family forms recorded by statistical data (NZDS, 1992; Social Development Council, 1991), and by describing the active role that the *whanau*<sup>115</sup> plays in the lives of Maori (Bradley, 1994; Selby, 1994). The following discussion on the family will highlight how social policy has both assumed and reinforced the nuclear family. The need for social policy to acknowledge the variances between families in New Zealand, to amongst other things, correctly assess their caring capacity is noted. After this challenge to the

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<sup>114</sup> Examples of this care are residential respite and the newer neuroleptic medications.

<sup>115</sup> This traditional family form of Maori was defined in chapter two as an extended family consisting of three generations.

traditional nuclear family, the role that the family has played in the provision of informal care, since the colonisation of New Zealand, is outlined.

The term 'family' is not usually explicitly defined in discussions regarding policy. As Van Every (1991/1992:63) has argued, the fact that 'family': "*...is rarely specified assumes that there is something out there called 'family' which is easily identifiable and significantly uniform to allow discussion of it without first defining it*". Authors writing about the family from Australia, America, Britain and New Zealand have consistently highlighted how 'the family' in social policy has been assumed to take a nuclear form (Briar, 1994a; Cox, 1993; Koopman-Boyden & Scott, 1984; Spakes & Nichols-Casebolt, 1994; Swain, 1990; Van Every, 1991/1992). McDonald (1993:44) for example, has described the traditional view of family in Australian social policy: "*...the model of the family that was taken for granted was the nuclear family of mum, dad and the kids with only dad being in the labour force -- the breadwinner model*". When speaking of New Zealand's social policy, Koopman-Boyden and Scott (1984:159) described how the traditional New Zealand family has been perceived by successive Governments:

*The familial system was patriarchal: children and women had few rights in law, and were regarded as the property of the father/husband. Men were the breadwinners and were responsible for the economic support of both women and children, while women cared for husbands, dependent children and destitute relatives.*

Authors have not only noted the consistency by which policy has assumed the nuclear family form but have also argued that policy has reinforced the family form of father, mother and children. St John (1994:94) for example has stated that:

*It would seem that much of the policy which has emerged is based on the notion that regardless of how families are, policy should be made as if they conform to the [breadwinner/home maker] model because that is how they ought to be.*

Challenges have been made to how New Zealand's social policy both assumes and reinforces the nuclear family form. For example, Munford (1995:25) has identified some of the different aspects which need to be incorporated in social policy provision for families:

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*Social policy must acknowledge and incorporate the diversity and difference both between families and within families. Culture and ethnicity, family compositions and functions, geographical location, class, and relationships between immediate family members and extended family members are some of the factors which must be taken into account when formulating social and economic policies for families.*

Acknowledgment of these different aspects is particularly important when considering community care. Different combinations of these aspects could mean that some families would be able to meet their caring responsibilities more easily than others. For example, research on schizophrenia and care has reported that parents providing care to an adult child diagnosed with schizophrenia experience greater burden and need for services than partnered parents (Carpentier, Lesage, Goulet, Lalonde & Renaud, 1992). Munford (1995:26) has provided further examples of how differences between and within families can have particular ramifications for their ability to care:

*Changing roles within the family must also be examined; for example, what impact does the changing work patterns of men and women have on the roles they take on in the household. The profiles and compositions of families with regard to the responsibilities these generate must also be explored. For example, family members may be supporting and caring for young adolescent children at the same time as supporting older parents. In reconstituted families they may be supporting children across two households.*

In attempting to break away from the traditional conceptualisations of 'family', Cass (1994) has referred to families as 'generations of caring'. Cass (1994:22/23) has proposed that this definition "...does not make arbitrary and stigmatising judgements about better or worse family forms". Cass' conceptualisation encompasses the similarities as well as the various, different, and changing forms within a society. Reframing the way families are considered would be particularly advantageous to those families in which a family member is diagnosed with schizophrenia. As already noted, the family has been considered to be a causal factor of schizophrenia (Bateson et al, 1956; Fromm-Reichmann, 1948; Lidz et al, 1957).

In having both outlined the prominent role that the nuclear family has held within the social policy of English speaking countries and noted that challenges have been made to the primacy of the nuclear family, attention will now turn to the role that 'the family' has played in the provision of informal care. When researching the family's role in the provision of care, detail informing the reader about what was meant by 'the family' was typically found to be missing. In considering the primacy of the nuclear family it is assumed that reference to 'the family' in the material drawn on in the following discussion is actually reference to the nuclear family form.

As already noted, around the time of New Zealand's colonisation by *tauiwi*, the state was preoccupied with issues of settlement (Oliver, 1988). Responsibility for welfare provision fell upon both the community and the family. The expectation that the family would care was translated into the 1846 Destitute Person's Ordinance. This Ordinance prescribed that the family was the first port of call for a person in need (Davidson, 1989; Tennant, 1989). The family's ability to comply to policy directives such as those inherent within the 1846 Destitute Person's Ordinance was however questionable. "*In practice, many families were absentee, broken or otherwise incapable*" (Oliver, 1988:14).

As the New Zealand Government increased state care-provision, the expectation that the family was to be the primary provider of care was gradually tempered. By the mid-1930s to the 1950s, the New Zealand Government openly supported the (nuclear) family. The need to stabilise and strengthen the family after the depression and war was translated into the provision of an array of state welfare services (Social Development Council, 1991). These services supported the family which in turn supported its members.

As previously indicated, the family is currently being considered by Government to be a main agent for meeting the informal care needs of its members. For example, one of the recently stated outcomes for social and welfare service policies and practices is that: "*Parents families/whanau and communities take responsibility for the care, protection and control of their children and young persons*" (Department of Social Welfare, 1995:3). However, while families have been given more responsibility for the welfare of their members, many families have reduced

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resources with which to fulfil this responsibility (Craig et al, 1992; Shannon, 1991; St John, 1994).

Discussion on the aetiology and discourses of 'schizophrenia' suggests that identification of 'the family' as the primary care-giver could have particular implications for the care provided to a family member diagnosed with schizophrenia. Although now refuted, the understanding that 'the family' causes schizophrenia has consistently adversely affected 'the family's' provision of informal care to their family member diagnosed with schizophrenia. An illustration of this negative outcome is the traditional poor alliance between families and mental health professionals (Beels and McFarlane, 1982; Bernheim, 1990; Brooker, 1990; Holden & Lewine, 1982; Morris et al, 1989; Willis, 1982). The Government's insistence that the family be the primary caring agent may place 'the family' in a situation where they are required to care but are not supported, even hindered, in their care provision.

The understanding that families are nuclear in form has justified the way in which the family's caring role has been defined over time. The view that the family's main function was that of nurturer and provider, of its members' emotional and physical needs, was supported by the traditional breadwinner/home maker split. The traditional breadwinner/home-maker split also directed what type of care was provided by whom. While the husband was assumed to provide the financial support, it was the wife who was deemed responsible for the physical and emotional needs of both her children and husband (Koopman-Boyden & Scott, 1984). This distinction of responsibility for care within the family was especially apparent in the assumptions of the Plunket Society regarding the vital role of the mother for healthy infant development<sup>116</sup>.

Previous discussion has suggested that the characteristics of the care provided to a family member diagnosed with schizophrenia do not necessarily support the

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<sup>116</sup> The Plunket Society was initiated by Dr Truby King in Dunedin on May 14, 1907. King, the Superintendent of Seacliff Mental Hospital focused the Plunket Society on infant welfare. To achieve the aim of healthy infants King campaigned for the better education of mothers. This is highlighted by the following excerpt from the book entitled 'A Fence at the Top: The First 75 Years of the Plunket Society: *"But how to get his message across? How to reach ignorant mothers who not only had no idea about nutrition, but thought it was harmful to expose babies to the open air, to change their clothes?"* (Parry, 1982:18).

understanding that women need to fill a home-maker or nurturer role within the family. This challenge was made when noting that the informal care provided to a family member diagnosed with schizophrenia primarily consists of supervision and monitoring tasks (Perring et al, 1990) as opposed to personal care tasks.

In talking about Australia, Edgar and Glezer (1992) have indicated that both the attitudes and behaviours of women and men are changing from reflecting the traditional male breadwinner and female home-maker role<sup>117</sup>. Increasingly women and men are sharing paid and unpaid work responsibilities<sup>118</sup>. While noting this shift in attitudes and behaviours, Edgar and Glezer (1992:36) have acknowledged that:

*...since men have more power to lose and prevailing ideologies of home making and parenting are still undervalued, men have less incentive than women to accept a reconstruction of reality [from the breadwinner/home-maker split].*

Edgar and Glezer (1992) have highlighted the need for state, private, and community interests to reflect the challenges made to the bread winner/home-maker split currently occurring within Australian families. If these interests do not accept different distributions of paid and unpaid caring work the changes occurring within families may be fraught with difficulty:

*The real problem is there has been little concomitant change in the structures of work, education, the law and community support services. Until there is, the goals of equal opportunity and shared parenting will remain elusive (Edgar & Glezer, 1992:36).*

Edgar (1992:50) has argued that families cannot meet all of their members' needs on their own: *"No family survives alone, especially not the 'nuclear' family of today. Schools, hospitals, public transport are all there because the so-called*

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<sup>117</sup> The changes to the employment patterns of New Zealand women and men, particularly regarding their involvement in part-time work, suggest that such changes to the bread winner/home maker split may be occurring in New Zealand.

<sup>118</sup> However, as was noted, although men may be spending more of their time engaged in care provision, significant differences still appear to exist in the type and level of care women and men provide (Abel, 1987; Cecil et al, 1987; Dalley, 1988; Game & Pringle, 1983; Ungerson, 1983,1987; Women's Affairs Victoria, 1994).

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*'autonomous' family cannot do it all alone*". Instead of advocating that public assistance should only be provided in extreme cases, or to use Upton's (1987:114) words, act as *"a crutch of final resort"*, Edgar (1992:50) has said: *"It is not being proposed here that public service provision 'take over' from family care; rather that a better balance be struck. Caring is a community responsibility"*.

### **Merging State, Community, And Family Caring Responsibilities**

The above discussion has identified the current role of the state, the community, and the family in the provision of care to New Zealanders who require care and support, respectively. Specifically it has outlined how the state has increasingly devolved its caring responsibilities, theoretically to the family and the community, and in practice to women. Particular consequences, of the current relationship existing between these three caring agents, for the care provided to a family member diagnosed with schizophrenia, were noted. Specifically, discussion identified the increased responsibility women may experience with regard to updating their information about both the various providers of state-contracted services and the criteria for access to these services. The tensions women have to reconcile between the expectation that they will care and the changes occurring to the traditional role of women, specifically the increased participation of women in the paid workforce was noted. The tendency for women to have to manage their family member until crisis point is reached as a consequence of the fragmentation of services and the focus of services upon those individuals in crises. The need for women to respond to the lack of certainty about the state providing care to their family member diagnosed with schizophrenia when they are unable to do so was highlighted. Furthermore, the likelihood that support services will continue to remain inadequate as a consequence of the misconceptions about schizophrenia, this inadequacy placing pressure upon women to meet their family member's needs was acknowledged. Finally, it was noted that while women have increased caring responsibilities the resources they have to meet these caring responsibilities have been reduced. While women are expected to care, this expectation is not necessarily being supported by the characteristics of the care provided to a family member diagnosed with schizophrenia.

In noting the complexity and changing symptoms of schizophrenia, it can be argued that these negative implications for the care provided to a family member

diagnosed with schizophrenia will only be ameliorated by a concerted effort of the state, the community and the family to combine their care provision. This discussion then has reinforced Edgar's (1992:50) call for care to be a community responsibility. Cass' (1994) call for the merging of private (family) and social (community and Government) responsibilities for care is in line with Edgar's (1992:50) demand for a better balance between caring agents. Cass (1994) has proposed that instead of continuing the current fluctuating, fragmented and typically uncoordinated distribution of care between the state, the community, and the family, each of these parties should work together to more effectively meet the welfare needs of a society's members. In other words, Cass (1994:2) has argued that the family, the community and the state should work collaboratively:

*The objective is a better distribution of resources and opportunities to improve living standards and quality of life, strengthening the essential interdependence of families, communities, and government policies, thereby integrating private responsibilities and social responsibilities.*

However, in order to fulfil Cass' (1994) challenge in New Zealand, the current contradictions between individual and collective responsibility (Opie, 1992; Peters & Marshall, 1988) would need to be reconciled. Documents outlining the future directions of, for example, New Zealand's health and mental health services (Minister of Health, 1994b) suggest that the Government is going to continue to simultaneously advocate individual responsibility and collective care. Given the current scenarios, it appears then that it will be unlikely for the state, the community and the family to work collaboratively and combine their caring responsibilities in the near future.

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## PART TWO: POLICY AND PRACTICE

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Part one of this chapter identified and described the various configurations of state, community and family care which have occurred since the colonisation of New Zealand by *tauiwi*. This discussion of how the state, the community, and the family's ability to care has been redefined over time referred to the provision of welfare generally. This generic focus highlighted how the expectations placed upon the community and the family to care changed depending on whether the New Zealand Government proposed that the state should take a supportive or minimalist role in the provision of welfare. Discussion described the current combination of state, community and family care provision. Foremost was the description of how the state is devolving its responsibility for welfare provision by developing and offering state contracts to competing providers, as well as by passing the costs of welfare onto individuals, for example, by cutting benefits and increasing housing and health costs (Craig et al, 1992; Shannon, 1991; St John, 1994). The diverse and changing nature of the welfare arena was noted.

Part two of this chapter highlights the interaction between social policy and practice. Specifically, attention is directed towards understanding how the reigning Government's views, about how the caring responsibility for New Zealanders should be distributed between the state, the community, and the family, have been incorporated into policy statements and legislation, and how this, in turn, has had particular implications for the practices of those individuals working within the formal health and mental health arenas. It will be argued that the dominant discourses of 'mental illness' and 'schizophrenia' have directed the development of New Zealand's health and mental health policy and service provision.

Part two of this chapter then narrows the focus from the provision of welfare generally and provides a more detailed examination of the health and mental health arenas. This examination is required in order to more comprehensively understand the provision of unpaid care provided within a family to a member diagnosed with schizophrenia. It will be argued that the extent to which women are expected to take responsibility for their family member's unpaid care depends on the level and type of assistance provided by formal health and mental health services.

This analysis of the interaction between social policy and practice begins with an acknowledgment of the Treaty of Waitangi, a document unique to New Zealand. After explaining the existence and original purpose of the Treaty of Waitangi, the tensions which exist between the perspectives and beliefs of Maori and *tauiwi* are highlighted by describing how health is understood by these two cultures. The implications of these different definitions of health for the development, implementation, control, and evaluation of the provision and receipt of New Zealand's health services are acknowledged.

A brief historical overview of the development of New Zealand's health services is then outlined, this overview beginning from the time of New Zealand's colonisation by *tauiwi* to the present day. Particular attention is directed towards the health reforms which are currently occurring in New Zealand. The influence upon these health reforms of the implementation of market liberalism and the transition from a Fordist to a Post-Fordist state is identified.

Following this, a review of New Zealand's mental health services is undertaken. Particular emphasis is placed on outlining the trend from institutionalisation to deinstitutionalisation and community care currently occurring in New Zealand's mental health services. The discrepancy between the emphasis placed upon flexible individualised packages of care, and the current level of care provision New Zealanders experiencing mental illness receive are highlighted.

Attention is then turned to how certain legislation has impacted upon the configuration of New Zealand's health and mental health services and therefore upon the provision of care provided within a family to a member diagnosed with schizophrenia. Specifically, the Mental Health (Compulsory Assessment and Treatment) Act 1992, the Privacy Act 1993, and the Human Rights Act 1993 are described and analysed.

## **Treaty of Waitangi**

The Treaty of Waitangi is one of New Zealand's first policy documents. Acknowledgment of the Treaty of Waitangi is relevant to this research for several reasons. First, description of the Treaty of Waitangi provided below will highlight the uniqueness of this document to New Zealand. Second, the status of the Treaty

of Waitangi has been utilised to explain, amongst other things, the poor health and mental health status of Maori, the indigenous people of New Zealand (Ministry of Maori Development, 1993, 1993a). Third, the principles inherent in the Treaty of Waitangi provide a framework for developing, implementing, controlling and evaluating the provision and receipt of welfare services. Fourth, the current emphasis placed upon the Treaty of Waitangi indicates that this document will increasingly influence New Zealand's social policy including health and mental health policy. Acknowledgment of these four reasons highlight that any discussion of New Zealand's health and mental health services must refer to the Treaty of Waitangi.

Before the arrival of *tauiwi*:

*Maori society had its own rules, beliefs and processes which formed the basis of policies governing care of children, the infirm and the elderly, education of the young, the promotion of physical, mental and spiritual health, provisions for redress and restitution where there were grievances, the sharing of resources, the allocation of individuals to their place in the social hierarchy and conservation of the land, forests and fisheries (Briar et al, 1992:2).*

Maori had their own social and economic policies governing their complex social structure<sup>119</sup>.

As the number of *tauiwi* increased with the colonisation of New Zealand, the traditional ways of Maori were threatened. It was soon acknowledged that a mechanism needed to be developed which would both facilitate the peaceful settlement of *tauiwi* in New Zealand and allow Maori to continue to implement their traditional ways of life. The Treaty of Waitangi was developed outlining the rights and responsibilities of both Maori and *tauiwi*. This written agreement, which was signed in 1840 by the Crown's representative William Hobson and five hundred Maori Chiefs, was presented to Maori as a mechanism for securing their cultural identity and way of life, while allowing the continued settlement of *tauiwi* in New Zealand (Orange, 1987).

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<sup>119</sup> The *whanau*, *hapu* and *iwi* have already been examined in this thesis.

Much debate has taken place over the translation and interpretation of the three articles of the Treaty of Waitangi (Orange, 1987)<sup>120</sup>. While there is not the space for detailed discussion of the differences between the English and Maori texts, it is important to acknowledge that the two Treaty texts have different implications for the rights and responsibilities of both Maori and *tauiwi* (Durie, 1994; Royal Commission on Social Policy, 1988). Table 7, taken from Durie's (1994) discussion of the Treaty of Waitangi and its application to health, highlights the main differences inherent within the English and Maori versions of the Treaty.

**Table 7:** Treaty of Waitangi provisions (Durie, 1994:85).

	Article One	Article Two	Article Three
English Text	Crown sovereignty	Tribal property rights	Royal protection and citizenship rights
Maori Text	Crown authority to government	Tribal authority over cultural, social, and economic resources	Royal protection and citizenship rights

The Treaty of Waitangi did not protect Maori sovereignty (Awatere, 1983). Maori were dispossessed of their land and other *taonga* (treasures), primarily by the means of war and legislation (Oliver, 1988; Walker, 1987). As Walker (1990:10) has argued, the consequence of the Treaty of Waitangi not being honoured was the dominance of Maori by *tauiwi*:

*The outcome of colonisation by the turn of the century was impoverishment of the Maori, marginalisation of the elders and chiefly authority and a structural relationship of Pakeha dominance and Maori subjection.*

The values, customs, and structure of *tauiwi* became the status quo:

*The spiritual basis for health was replaced by scientific method; the authority of the tribal elder was challenged by the mental health professional; and the role of the family in community health care was undermined by institutional care for the sick, the homeless and the law breakers (Durie, 1986:2).*

<sup>120</sup> The main premises underpinning these three articles, as translated by Maori and *tau-iwi*, are identified in Table 7 under the headings 'Article One', 'Article Two', and Article Three'.

The effect of Maori losing their sovereignty is demonstrated by the ways in which the New Zealand Maori population features more poorly than the New Zealand European population on each of the following social indicators - health, education, and income levels (NZDS, 1993b; Ministry of Maori Development, 1993a; Statistics New Zealand & Ministry of Health, 1993). Particularly relevant to this thesis is the over-representation of Maori amongst those who are diagnosed with schizophrenia (Ministry of Maori Development, 1993). As will be noted below, this over-representation could be attributed to the different ways in which Maori and *tauiwi* view health.

The undermining of the Treaty of Waitangi has been reinforced by successive New Zealand Governments which have largely ignored the presence of the Treaty (Orange, 1987; Walker, 1990). However, increasing pressure from Maori regarding their grievances culminated in the 1975 Treaty of Waitangi Act which established the Waitangi Tribunal. The purpose of the Waitangi Tribunal was to "*...consider claims relating to the practical application of the Treaty and to determine whether certain matters are inconsistent with the principles of the Treaty*" (New Zealand Government, 1975). In other words, the Waitangi Tribunal first considers whether action has been consistent with the principles of the Treaty of Waitangi and second, makes recommendations to the Crown about what action, if any, needs to be taken in order to compensate any breach with the Treaty principles. This Act was amended in 1985 giving the Waitangi Tribunal the ability to hear claims based upon the principles of the Treaty back to 1840 (Walker, 1987). The Royal Commission on Social Policy (1988) has proposed that the principles of the Treaty of Waitangi incorporate partnership, protection and participation. The Waitangi Tribunal then has been one mechanism Maori have been utilising to re-establish their rights as outlined under the Treaty of Waitangi.

As Beddoe and Randall (1994:22) have argued, honouring the Treaty of Waitangi will have major ramifications for all of New Zealand's social policy including that related to welfare provision:

*A commitment to the Treaty requires not only partnership with Maori but an effort to make good, past breaches of the Treaty, the protection and preservation of the Maori way of life, its language, culture and treasures and a proper sharing of today's resources.*

Some of the ramifications of the Treaty of Waitangi for New Zealand's health and mental health services will now be considered beginning with acknowledging the different ways in which Maori and *tauiwi* view health.

Maori have traditionally adhered to a holistic definition of health, with health being seen as encompassing the following four cornerstones: *te taha wairua* (the soul); *te taha hinengaro* (the mind); *te taha tinana* (the body); and, *te taha whanau* (the family). A person's well-being is also affected by their link with *te whenua* (the land) and *te reo* (language) (Pomare & de Boer, 1988). Maori view health as an all encompassing seamless entity. For Maori then "*Mental health as a separate entity has little traditional meaning...*" (Durie, 1984:2).

As the previous discussion on the *whanau* suggested, the social structure of Maori society is encompassed within the definition of health. Each person within the collectively-based structure of *whanau*, *hapu*, and *iwi* had their own role which was associated with certain rights and responsibilities (Walker, 1990). Individual as opposed to group advancement was frowned upon (Durie, 1986). Maori sought harmony with their physical as well as social, psychological, and spiritual world. Reaching this harmony was supported by the belief that each object in Maori society had its own *mauri* or life force.

According to Cherrington (1994:26): "*Maori explanations of illness and mental disorder centre around spiritual philosophies and supernatural causes*". Sickness in traditional Maori society (*mate Maori*) occurred when the unity between a person and their environment (physical, social, psychological and spiritual) was broken. An example of this is the breaking of *tapu* (Durie, 1977) or taking action that was prohibited by the *whanau*, *hapu* or *iwi* (Potaka-Dewes, 1988). The remedy for this sickness was to re-establish the unity between the person and their social, physical, psychological and spiritual environment.

Durie (1989:284) has argued that New Zealand's health and mental health services have not reflected this Maori definition of health:

*Although knowledge of culture as a basis for health and as a framework for sickness is recognised as an essential*

*requirement for medical training, western and scientific views, often dualistic and mechanical, have so dominated thinking in New Zealand that Maori concepts have been accorded little validity.*

While a *tau-iwi* view of health has traditionally predominated, increasingly New Zealand's health policy and service provision is becoming more responsive to a Maori definition of health (CRHA, 1995). The way in which Maori health initiatives are being supported is outlined when the future of New Zealand's mental health services is described. Attention will now be directed towards briefly explaining what a *tau-iwi* definition of health involves.

The arrival of *tau-iwi* in New Zealand meant the introduction of different philosophies, values and beliefs. Whereas Maori kinship networks were strong, enhanced by the philosophy of collective responsibility and interdependence, *tau-iwi* brought with them the values of individuation and independence (Durie, 1984). These *tau-iwi* values were enhanced in New Zealand by the conditions and requirements of colonisation. Those who traversed the seas to New Zealand were largely transient across the country and relied on their own individual resources for survival.

In comparison to the holistic approach of Maori to health, *tau-iwi* concepts of health<sup>121</sup> encompassed a split between the mind and body, and between individuals and their environment<sup>122</sup>. Within this dualistic framework a hierarchy existed. Ill health which could not be defined as stemming from a visible physical cause was less understood and tolerated. The treatment which the mentally ill received in Britain reflected this hierarchy. Brigham's (1847:11) description of the fate of people with a psychiatric disability describes how 'treatment' fell within the boundaries of persecution and abuse:

*Not to go back to times too remote for abundant and correct historical details, we know that from the fourteenth to the*

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<sup>121</sup> These concepts of health were brought by *tau-iwi* from Britain.

<sup>122</sup> The *tau-iwi* concept of health is inherent in the medical model which is based upon the premise that disease or disorder is caused by some biological malfunction within the person (Vander Zanden & Pace, 1984). This dualistic approach is extensively utilised in the health field today, for example, in the various editions of the Diagnostic and Statistical Manual for Mental Disorders.

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*eighteenth century, very many thousands of insane persons were put to death, and most of them by order of Courts of justice. Some were condemned to death or to imprisonment for life as heretics, some were hung for practicing witchcraft, and vast numbers were burned as sorcerers or for being in league with the devil.*

In reflecting a *tauiwi* definition of health, attention is directed primarily to the presenting problem. This problem is typically assumed to arise from biophysical causes. Consideration of an individual's wider context has traditionally been considered unnecessary. Patients typically have been treated in isolation as opposed to being viewed as part of their wider social structure.

Maori and *tauiwi* definitions of health are in many ways antithetical. Each of these definitions has different implications for the development, implementation, control and evaluation of the provision and receipt of New Zealand's health and mental health services. The Maori definition of health emphasises the importance of viewing an individual within their social, physical, psychological, and, spiritual context. Maintaining a balance between these aspects is vitally important. Adhering to a Maori view of health would ensure that all aspects of a person's needs were met rather than those relating solely to the physical, which are the primary focus of health services based upon the medical model. A holistic approach to health would be particularly beneficial for those individuals diagnosed with schizophrenia. As has already argued, the cyclical acute and chronic symptoms of schizophrenia can affect all aspects of a person's functioning.

The involvement of an individual's social network in the development, implementation, control, and evaluation of strategies to improve an individual's health status would also be required if a Maori view of health was adhered to. The involvement of an individual's social network would have implications for the distribution of funds and resources including: the participation of Maori in the development, implementation, control, and, evaluation of New Zealand's health and mental health services in such a way that Maori social structure and protocols are respected and enhanced; the direct transfer of funds and resources from the Crown to Maori for Maori health initiatives to be developed; and, the incorporation of biculturalism into the practice of mental health staff (National Mental Health Consortium, 1989). Provision of services along these lines and adherence to a

Maori definition of health would increase the options and alternatives for both those persons diagnosed with schizophrenia and their informal care-givers. For example, in respecting Maori social structure and culture, theories such as the 'schizophrenogenic mother' (Fromm-Reichman, 1948), and schismatic or skewed families (Lidz et al, 1957), which see the family/*whanau* as the cause of schizophrenia, would be questioned<sup>123</sup>. The involvement of the family/*whanau* would be seen as imperative for an individual diagnosed with schizophrenia to achieve good health. The traditional poor alliance between the mental health profession and 'the family' of an individual diagnosed with schizophrenia (Beels and McFarlane, 1982; Bernheim, 1990; Brooker, 1990; Fadden et al, 1987; Holden & Lewine, 1982; Morris et al, 1989; Willis, 1982) would be challenged.

If the Treaty principles of partnership, protection and participation are to be implemented, both the Maori and *tauiwi* definitions of health need to be respected and resourced. The importance of incorporating the Treaty principles themselves into New Zealand's health arena has been stressed. For example, although written in 1989, Durie's (p.285) following comment has relevance for today:

*The Treaty of Waitangi was written for the future. At a time when health services are being redeveloped and reorganised, there is a need to consider those Treaty principles and to incorporate them into health philosophies, policies and practices.*

This is particularly so when considering the importance Maori place upon the Treaty of Waitangi:

*The importance of the Treaty as a driving force in contemporary Maori protest cannot be overemphasised. As our people have, in this generation, sought to find a philosophical base for relating to the Pakeha society, the Treaty has become both a symbol and a charter (Ministerial Advisory Committee on a Maori Perspective for the Department of Social Welfare, 1988:13).*

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<sup>123</sup> The damage that these theories have had on the informal care provided within a family to a member diagnosed with schizophrenia has already been highlighted (Mittleman, 1985).

While the Treaty of Waitangi proposes a particular way of planning, implementing, and evaluating New Zealand's health and mental health services, discussion in the following sections will highlight the extent to which this model has traditionally been ignored. The predominance of *tauiwi* understandings of health and mental illness in these respective arenas is highlighted.

## **New Zealand's Health Sector**

This section is devoted to describing the different ways in which New Zealand's health services have been developed and delivered. A brief history of New Zealand's health sector is provided. Many of the themes already discussed in this chapter are further highlighted in this section. For example, particular attention is paid to the implications for the health sector of the implementation of market liberalism and the transition from a Fordist to Post-Fordist state. Also, as already indicated, attention will be directed towards highlighting the relationship between policy and practice. In other words, the way in which policy, imbued with Government assumptions about who should care and who should receive care, influences the practices of those agents who provide care, will be examined. Examination of the changes which have occurred in New Zealand general health services provides a backdrop for considering New Zealand's mental health services.

Before the arrival of *tauiwi* the needs of each person were met within and by the *whanau*. This organisation of care reflected both the Maori view of health and the way Maori society was structured. Separating an individual from the *whanau* would only have worsened *mate Maori*, or in other words, interrupted the unity between the individual and their physical, social, psychological and spiritual environment. In traditional Maori society, care was institutionalised in the sense that it was provided within the established social structure of the *whanau*.

Since the colonisation of New Zealand, health policy has mirrored the fluctuations of the minimalist and supportive stance of successive Governments. The residual nature of welfare provided by early New Zealand states was reflected in hospital provision. As Reinken (1988:44) has explained:

*Hospitals grew and developed against the background of the English experience of the Victorian Poor Laws. The public*

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*hospital system had its provision made for those who could not afford medical attention and nursing care in their own homes, those who had no homes or those whose needs were seen as partly for punishment and partly for healing.*

Fraser (1984:56) has also highlighted the frugality of hospital provision:

*Self-help, and assessments of economic need, based on the then pervasive logic of 'benevolence', which was buttressed by notions of discipline and the deserving poor, rather than explicit ideas about social equality or universalism, were the key to the forms of medical care which developed in the early decades of the colony.*

In the colonial period of New Zealand, Maori health was challenged by *tauiwi* on two fronts. First, the migration of *tauiwi* meant the introduction of various diseases to which Maori had no immunity. "*Tuberculosis, typhoid, venereal disease, measles and other diseases new to Maori exacted a heavy toll*" (Statistics New Zealand, 1994:93). *Mate Pakeha* was experienced by Maori (Sinclair, 1988). Second, the construction of separate institutions for the purposes of health resulted in the deinstitutionalisation of traditional Maori structures. Instead of being cared for within the *whanau*, Maori were isolated within the hospital setting. As Durie (1986:2) explained:

*By the end of the nineteenth century a process of 'deinstitutionalisation' was well advanced, with Maori people becoming separated from the traditional institutions that had nurtured them and maintained standards of health, including mental health.*

The breaking down of traditional Maori kinship structures, coupled with the dispossession of their land and other *taonga* meant that Maori were unable to meet the needs of their people. The *tauiwi* policy of maintaining the unwell within state institutions did little to improve the health status of Maori. As will be argued further on in this discussion, the Maori population is still having to deal with the negative consequences of this colonisation process (Ministry of Maori Development, 1993, 1993a).

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Oliver (1988:13) has proposed that the poor health outcomes for Maori were of limited concern to authorities as a consequence of the belief that the Maori population would not survive the influence of *tauiwi*:

*Successive censuses seemed to point to a solution which precluded the need for policy – that the Maori would die out after contributing a submerged exotic element to a new white race of better Britons.*

Needless to say, the Maori population did survive.

*Tauwi* continued to implement their understanding of health. This implementation was facilitated by the increased role the state played in the provision of health as it moved from a minimalist to a supportive stance. As with other forms of welfare, state health provision was most extensive with the implementation of the 1938 Social Security Act. Access to health care was based more on a person's need rather than their ability to pay for health services (Ashton, 1992; Bowie & Shirley, 1994). This 1938 Act ensured that access to health care was a right of citizenship. For example, hospital services were provided free to all persons.

While the 1930s and 1940s were characterised by comprehensive state-provided health services, the understanding of successive Governments that the state should reduce its involvement in the provision of such services became obvious. As with the provision of welfare generally, in advocating the retrenchment of state health services, successive New Zealand Governments increasingly adhered to monetarist principles and proposed that the delivery of health services should be consistent with Post-Fordism. Increasingly it becomes obvious that terms such as 'afford' and 'adequate' were defined, by Government, consistently with monetarism. It was during the 1970s that the Government reviewed both health expenditure and structure. This review was used by the Government to support its claims that it could not afford<sup>124</sup> to continue to expand New Zealand's welfare provision (Koopman-Boyden & Scott, 1984).

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<sup>124</sup> It is noted below that the need to reduce state health expenditure has been questioned (Bowie, 1992; Bowie & Shirley, 1994).

It was in 1974, in a document entitled 'A Health Service for New Zealand', that the restructuring to Area Health Boards (AHB) was first proposed as a consequence of the inefficiency of the preceding organisational structure. It was however, not until 1983 that the Area Health Board Act was passed.

The Area Health Board Act 1983 not only established the fourteen AHBs, but also defined their functions, powers, and duties. Each AHB was directed by a board, each board consisting of elected representatives. Each board was responsible for ensuring their AHB provided:

*...a full range of hospital, community and preventative services. In addition to providing treatment, they [were] responsible for health protection, health promotion and health education (NZDS, 1992:124).*

Specifically, the AHB's primary objectives were:

- \* *to promote, protect and conserve the public health and to provide health services within their region:*
- \* *to ensure effective co-ordination of the planning, provision and evaluation of health services between the public, private and voluntary sectors within their area; and,*
- \* *to establish and maintain an appropriate balance in the provision and use of resources between health protection, health promotion, health education and treatment services (Department of Health, 1989:4).*

Inherent within the primary objectives of the AHBs was the idea that the AHB structure was developed in an attempt to ensure that health needs within each community could be more easily identified and met. While the AHBs were contracted to the Minister of Health, it was the Department of Health which both funded them via fixed grants and developed the health policy to be implemented by the AHBs.

Reviews of the AHBs increasingly expressed dissatisfaction with their performance. This dissatisfaction was directed at "*...management structures, accountability mechanisms, and the failure to co-ordinate the use of resources to meet the changing needs and priorities of the community*" (NZDS, 1993b:139). Two major problems with the AHB structure as reported in existing literature will now be

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identified. When reading about these problems and the resulting solutions, again note the extent to which the terminology and understandings associated with monetarism and Post-Fordism have directed both the critique of the AHB's performance and structure, and the development of an alternative health structure. It appears that when the AHB structure was reviewed, the reviewers defined concepts such as 'need', 'fair', and 'adequate', consistently from within the philosophy of market liberalism. Further, recommendations from the AHB review emphasised the need to: calculate both inputs and achieved outputs; separate the provision, the purchase, and the regulation of health services; transfer state responsibility for service provision to an array of differing providers; increase competition amongst health service providers for both funds and clients; reduce state expenditure on health services; and, develop flexible, individualised packages of care.

First, AHBs had the dual role of purchasing and providing health services. It was proposed that this dual role meant that the AHBs had conflicting interests (National Interim Provider Board, 1992). For example, AHBs had the responsibility of maintaining the facilities and resources they owned, which in turn limited their ability to purchase services outside their own. AHBs then were not able to adequately purchase services from the private and voluntary sectors in tandem with purchasing their own public services.

Second, as identified above, the Department of Health financed the AHBs via fixed grants. These block grants were provided "*...for an unspecified quantity and quality of services. The focus was on control of inputs. Outputs were taken for granted, or more or less ignored*" (National Interim Provider Board, 1992:24). The focus on inputs has been utilised to explain the lack of information on both the health status of New Zealanders, and on the services aimed at maintaining and improving the health of New Zealanders (New Zealand Health Information Service, 1993).

Reviews of the AHBs finally reached the assessment that this structure was bureaucratic, wasteful, and inflexible (Richardson, 1993). The provision of health services under the AHB structure was becoming increasingly more costly. However, increased expenditure was not ensuring that health needs within the community were being met. The need for the New Zealand Government to reduce its level of health expenditure has been questioned (Bowie, 1992; Bowie & Shirley,

1994). As Bowie (1992:10) has asserted: "*Our health system has been unquestionably successful in containing costs. The alleged blow out in health care expenditure in New Zealand is a myth*". Bowie's assertion is supported when examining the proportion of New Zealand's GDP spent on health. For example, OECD countries on average spend 8.2 percent of their GDP on health expenditure. This is in comparison to New Zealand which spends 7.6 percent of its GDP on health (McKendry & Muthumala, 1993; McKendry & Muthumala, 1994).

Dissatisfaction with the AHB structure and performance led the New Zealand Government to search for alternative ways of ensuring New Zealand's health needs were met. The outcome of this search was the dissolution of the AHBs as directed by the Health Reforms (Transitional Provisions) 1993 Act. In the wake of the AHBs being dissolved, Regional Health Authorities (RHAs) and Crown Health Enterprises<sup>125</sup> (CHEs) were formed as directed by the Health and Disability Services Act 1993. According to Upton (1992:10773), the reforms outlined in the Health and Disability Services Act (1993) encourage: "*...flexibility and innovation in the delivery of those [health and disability support] services to the community*". Attention will now turn to identifying the outcomes of the Health and Disability Services Act (1993) regarding the development of RHAs and CHEs.

As the transition from Fordism to Post-Fordism suggests, the dual role of purchaser and provider has been split within the current health structure. Each of the four independent RHAs<sup>126</sup> is responsible for monitoring the need for health and disability support services, purchasing health and disability support services from competing providers (for example the twenty three CHEs which are responsible for publicly owned health services, private agencies, or voluntary organisations), and monitoring the performance of those providers contracted to provide health and disability support services (New Zealand Government, 1993). The Central Regional Health Authority<sup>127</sup> described the process they undergo to fill their brief,

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<sup>125</sup> The CHEs encompass hospital based services.

<sup>126</sup> Each of the four RHAs is responsible for a different geographical area. The Northern RHA includes Northland and Auckland. The Midland RHA includes Waikato, Bay of Plenty, Tairāwhiti, and Taranaki. The Central RHA includes Hawkes Bay, Manawatu-Wanganui, Wellington, and Nelson-Marlborough. The Southern RHA includes the West Coast, Canterbury, Otago and Southland.

<sup>127</sup> The CRHA covers the geographical region of the participants in this thesis.

this process being similar to that described by Allen (1992:preface) in part one of this chapter:

*...we investigate what services are needed, and consult on both needs and priorities with communities and other interest groups. We formulate a purchasing plan which identifies the direction we are adopting and the way we propose to ensure the availability and development of services for the future. Then we reach agreement with providers (hospitals and other services) on the amount of money we will pay them to provide those services. The agreement is written up in a clear contract, which also sets the standards of quality which must be maintained (Burns & Peacock, 1993:1).*

Each RHA then, enters into contracts with those providers who can most effectively and efficiently<sup>128</sup> meet the health and disability support needs of the individuals in their region. As noted in part one of this chapter, one consequence of the splitting of the state's purchaser and provider roles is the transfer of state responsibility for care provision to an array of providers. Providers from the public, private and voluntary arenas compete to contract with the RHAs. In responding to this competition, providers have had to become more businesslike. The businesslike nature of CHEs is highlighted when noting the make up of CHE management. For example:

*The Auckland region was divided into three CHEs. Of the twenty board members, only two were health professionals. The remaining eighteen were business people, mainly men, including financial consultants, accountants, company directors, managing directors and bankers. A hospital selling health services could apparently be run according to the same management techniques and market disciplines as a grocery shop or a brewery (Kelsey, 1993:33).*

The need for CHEs to run along businesslike lines (Ashton, 1992; Opie, 1995) has supported the view that the transition from AHBs has been financially driven. In fact, the contradictions CHEs face in having to meet health needs with continually reduced budgets has been cited as the main reason for the resignation of seven of the twenty three CHE bosses in eighteen months (Wanganui Chronicle, 1995).

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<sup>128</sup> These terms are typically defined by the ratio of inputs to outputs.

The competition which is an inherent part of the contracting process, makes the monitoring role of the RHAs imperative. As Fougere (1994:115) has argued: *"Competition may encourage providers to skimp on those aspects of quality least visible to purchasers"*.

RHAs are responsible for purchasing and monitoring a wider range of services than previously purchased by the AHBs. Of particular relevance to this thesis is the transfer of disability support services<sup>129</sup> to the RHAs, these services being previously funded and provided via both the Department of Health and the Department of Social Welfare. The decision to transfer disability support services to RHAs is said to have arisen out of the consultation process described and furthered in the policy documents 'Support for Independence for People with Disabilities' (Shipley & Upton, 1992) and 'Support for Independence for People With Disabilities: A New Deal' (Shipley & Upton, 1992a).

From this consultation process, the Government developed its goals for disability support services. As listed in the document 'The New Zealand Framework For Service Delivery' (Minister of Health, 1994c:11) these goals are to ensure that:

- *people with disabilities have access to appropriate services of acceptable quality*
- *services provided are responsive to the needs of people with disabilities*
- *there are incentives to promote rehabilitation*
- *the system is sensitive to the needs and preferences of Maori and other groups*
- *policies reflect the importance and needs of caregivers, voluntary agencies and other providers*
- *services provided give value for money*
- *changes are implemented in a way which minimises disruption to the lives of people with disabilities and their caregivers.*

Again, the emphasis placed upon 'value for money' and the development of flexible and individualised packages of care inherent in the above goals highlights the influence monetarist philosophy and Post-Fordism has had on New Zealand's

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<sup>129</sup> Disability support services include mental health services.

current health structure. The influence of the latter is highlighted further by the development of Home Support Management Services in New Zealand. The CRHA Disability Services Manager has been quoted in 'Central News'<sup>130</sup> (CRHA 1995a:3) as saying: *"The purpose of the Home Support Management Service will be to develop a home support plan tailored to match the needs of people with the right services"*. While the theory behind the development of Home Support Management Services appears to be consistent with the call from consumer groups for tailored and flexible care plans, Taylor et al (1992) have questioned whether the development of such services actually increases the 'choice' exercised by service users. There is still the possibility that decisions will be made at the management level rather than by the users themselves: *"...devolving decisions to intermediaries such as care managers or general practitioners is not the same as devolving decisions to users themselves"* (Taylor et al, 1992:19).

Implementing the changes just described has not been an easy or simple process. As the CRHA has identified, the RHAs have had to overcome several difficulties in carrying out their brief. The CRHA had:

*...the clear goal of achieving a better health status for the people of the central region. We were well aware of the seriousness and degree of difficulty of the task ahead. The public health system had severe financial problems, service providers were worried and unsure of the future, and public cynicism about the health system had reached unprecedented levels (Peacock & Burns, 1994:4).*

One of the major criticisms of the transition to RHAs and CHEs is that these changes have been implemented in response to the New Zealand's adherence and implementation of monetarist philosophy and principles. In other words, the health reforms have been viewed primarily as a cost-saving mechanism. While acknowledging that market liberalism has, to some extent, directed the formulation of New Zealand's current health structure, the funding the Government has directed towards New Zealand's health and disability support services must be acknowledged. According to the Minister of Health (1995:1) the Government has approved:

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<sup>130</sup> Central News is the newsletter of the CRHA.

*\$7 million from 1 July 1994 for RHA initiatives aimed at allowing more people to remain in their own homes and to establish new needs assessment processes throughout New Zealand.*

*\$17 million from September 1994 for policy changes to income and asset testing for older people covering increases in the allowable thresholds from \$20,000 to \$40,000 for married couple where one is living in the community and the other in residential care.*

*\$9.2 million to for RHAs to put in place new community and home based support service initiatives.*

Proposed funding levels for disability support services in future years include:

*1994/1995 - \$17.9 million*

*1995/1996 - \$43 million*

*1996/1997 - \$45.7 million*

*1997/1998 - \$46.3 million - this figure will be ongoing*

The failure of recent Governments to follow through on promises regarding the redirection of resources to the mental health arena (Chapple, 1994) has led to doubt about whether these approved funds will be released when proposed.

The above discussion has identified and examined the changes which have occurred over time to New Zealand's health services. These changes have reflected Government views about first, whether the state, the community, or the family should be primarily responsible for the provision of care and second, who is entitled to receive this care. Particular attention was paid to the current configuration of New Zealand's health services, and how this has been influenced by the implementation of market liberalism and the transition from Fordism to Post-Fordism and the demands of consumer groups via the process of consultation. The above discussion has provided a backdrop for the consideration of New Zealand's mental health services.

## **New Zealand's Mental Health Services**

Reflecting the *tauiwi* definition of health, the mental health needs of New Zealanders have traditionally been met separately from those needs arising from general health concerns. This section describes the structure and characteristics

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of New Zealand's mental health services. These are examined and described while briefly presenting their history. The configuration of these services has historically had, and continues to have, particular ramifications for the type and level of care provided within a family to a member diagnosed with schizophrenia. These ramifications are identified when examining the trend from institutionalisation to deinstitutionalisation and community care.

### **Institutionalisation**

As already noted, the arrival of *tauiwi* in New Zealand introduced amongst other things, both a different conceptualisation of health and illness and a different organisation of society. In comparison to Maori, *tauiwi* expected a healthy individual to be responsible for meeting her/his own needs and to be able to direct her/his own course in life. *Tauwi*, in drawing upon their British origins, initially advocated that the (nuclear) family and benevolent societies should provide for those who were defined, by *tauiwi*, as mentally ill (Holmes & Hawke, 1988). As well as the family or benevolent societies providing care to the mentally ill, a further option was to contain these persons within the ill-equipped jails that were existent at the time (Brunton, 1986). The level and type of care provided either by families, benevolent societies or within the justice system was not adequate enough to meet the needs of those persons experiencing mental illness. In order to deal more effectively with the 'lunatic' problem, provincial lunatic asylums were established. This was the beginning of institutionalisation or the process whereby people are cared for custodially within institutions removed from their community.

Asylums were quickly established, the first of these institutions being built in Wellington and Auckland in 1844 (Abbott, 1987a). Lunatic asylums had become the answer to the initial attempt by *tauiwi* at care by the community which according to Abbott (1987b) had become 'community neglect'. A consequence of the establishment of asylums was that responsibility for the care of the mentally ill transferred from the individual themselves, or their family and benevolent societies, to provincial authorities, who funded and administered these institutions.

In 1876, the state relieved provincial authorities from funding and administering the eight established asylums. The transfer of responsibility of these asylums from provincial authorities to the state was in effect the development of the first social service department (Oliver, 1977). At this time, the rate of institutionalisation for the New Zealand population was 193 per 100,000 (Abbott, 1987a). The rapid increase in institutionalisation of those persons diagnosed as mentally ill meant that the provision of mental health services became:

*...the third most expensive state welfare activity (excluding education) after pensions and health, and employed (again excluding education) by far the greater number of state employees (Oliver, 1977:11).*

Oliver has noted that by 1914, over 650 people were employed in mental health services. At this time psychiatric institutions cost the state over 160,000 pounds. The subsequent increase in the rate of institutionalisation in New Zealand is illustrated by Dowland and McKinlay's (1985) inventory which established that in 1984, New Zealand had one private psychiatric hospital and nine public psychiatric hospitals. New Zealand's fifteen psychiatric units also provided some residential care.

While discussion in part one of this chapter emphasised the reluctance of colonial Governments to become involved in the funding and provision of welfare services, Tennant (1989:13) has argued that: "*...government responsibility for mental illness prompted relatively little debate...*". The degree of consensus regarding the primacy of state caring responsibility for those persons defined, by *tauiwi*, as mentally ill reflected the discourses influencing the way mental illness is defined. As already noted, mental illness has traditionally been perceived to be a threat to public order and was therefore seen as a legitimate focus for state intervention. Intervention then was in response to the "*feeling that society must be protected from people with mental handicaps or illness*" (Manning, 1987:322). Coupled with this was the belief that "*...people with mental problems must be cared for in a safe and secure environment for their own good*" (Manning, 1987:322). This belief is reflected in the title given to the first psychiatric institutions, 'lunatic asylums'. The word 'asylum' is synonymous with the terms refuge or sanctuary. Psychiatric institutions were initially meant to be places where the mentally ill could be cared for and treated in sedate surroundings.

While containment of persons diagnosed as mentally ill was deemed as appropriate by and for *tauiwi*, for Maori this action was disastrous. As noted above, Maori achieved good health by maintaining and nurturing the unity between themselves and their physical, social, psychological and spiritual environment. The isolation of Maori from their physical, social, psychological and spiritual environment did little to improve their health status.

The reality of residing within one of New Zealand's psychiatric institutions has been acknowledged in the book titled 'Out of Mind, Out of Sight: The Story of Porirua Hospital' (Williams, 1987)<sup>131</sup>. The following material taken from 'Out of Sight' not only highlights the experiences of those individuals who resided in Porirua Hospital, but also highlights some of the reasons for the trend towards deinstitutionalisation which is discussed next.

Overcrowding and the inadequacy of available accommodation was a recurrent theme throughout the history of Porirua Hospital. Williams (1987:175) cited part of a report of an Official Visitor to Porirua:

*...the absolute inadequacy of the accommodation in no.3 day room. Between 90 and 100 patients are in this room measuring approximately 42 feet x 22 feet. There is of course standing room only...Today the question of money cannot to my mind be made the excuse as suffering humanity has I imagine a first call on the Government purse which is by no means empty.*

The difference in quality between the admission wards whose decor had a more homely feel to them and the back wards resided in by long stay chronic patients was not public knowledge. Several mechanisms were put in place to ensure that little contact with the outside world was made:

*From the beginning access to the hospital or its grounds by visitors or community groups had been limited, official visitors screened and the staff bound by rules and regulations which prevented the disclosure of any information about hospital life (Williams, 1987:175).*

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<sup>131</sup> Porirua Hospital, a 'lunatic asylum' situated north of Wellington, was authorised in 1887 (CRHA, 1994a).

It can be assumed, from this description of the attempts that were made to reduce contact with the outside world, that institutionalisation relieved informal care-givers of their caring responsibilities. Those family members who consistently exhibited a cyclical pattern of acute and chronic symptoms of schizophrenia would undoubtedly have spent considerable periods of time in institutional care. During this time, informal care-givers would have been able to disengage from their care provision. This assertion is supported in the following comment presented in the document entitled 'Mental Health Strategy: 1996/97:

*...deinstitutionalisation has, in some ways, made life for families of the chronically mentally ill more difficult than it was for my mother-in-law back in the days when lifelong hospitalisation was the fate of most of the mentally ill (CHRA, 1996:16).*

The mechanisms utilised to ensure residents had limited contact with the outside world undoubtedly reinforced the understanding that people exhibiting the symptoms of mental illness need to be both contained and feared. The living conditions of the residents of Porirua described below seemed to propose the view that the residents were somehow less than human reflecting the 'model of animality' described by Foucault (1967:72).

By the mid-1960s little had been done to rectify the poor conditions within Porirua Hospital noted in 1939, especially within the older blocks. In 1966, the Public Service Association highlighted the following inadequacies:

- 1) *Overcrowding of sleeping quarters and day rooms*
- 2) *Bathing and ablution facilities can only be described as primitive.*
- 3) *Outdated insanitary toilet blocks, which cannot be adequately and effectively cleaned.*
- 4) *General defective plumbing and drainage installations and defects.*
- 5) *Inadequate and unhygienic dining facilities.*
- 6) *Non-existent heating and sleeping dormitories where aged and young children are accommodated.*
- 7) *Housekeeping, particularly around the kitchen at M.6 is not good (Williams, 1987:236).*

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These inadequacies of Porirua Hospital were almost certainly evidenced in New Zealand's other psychiatric institutions.

Despite the initial sincere attempts at providing humane and appropriate care and treatment for those persons with a psychiatric disability, institutional care began to be questioned from several quarters. The Committee of Inquiry (1988) forwarded several explanations for the rejection of institutionalisation policy including the introduction of new treatment methods, specifically antipsychotic drugs, which meant that for many persons containment was no longer necessary. A further reason was the civil rights movement that questioned the ethics of containing persons within institutions, for some on a life long basis. The unpleasant conditions in institutions and the effects from living within an institution for any length of time<sup>132</sup> were identified. Improved pay, training and working conditions of staff meant increased expectations were transferred to patient care. Finally, there was an awareness of international trends towards care of the persons with a psychiatric disability in the community. Economic considerations also accompanied these factors identified by the Committee of Inquiry. The New Zealand Government proposed, as it did with other health expenditure, that it would be unable to cover the projected financial costs to be incurred by continuing to take primary responsibility for the care of those persons with a psychiatric disability.

In response to the tighter restrictions successive New Zealand Governments placed upon state expenditure, the use of neuroleptic medications<sup>133</sup>, and the acknowledgment of the inadequacies with institutional care, alternative models of mental health care began to be formally considered. The New Zealand Government furthered the trend whereby people with a psychiatric disability were residing out of New Zealand's psychiatric institutions by advocating and implementing the twin policies of deinstitutionalisation and community care which are defined and discussed separately in the sections below<sup>134</sup>. As will be explained, the implementation of these policies drastically altered the configuration

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<sup>132</sup> Goffman's (1961) work has been extremely influential in this area.

<sup>133</sup> As the Committee of Inquiry (1988) identified, the relative effectiveness of neuroleptic medications meant that people with a psychiatric disability did not need to be restrained long-term within an institutional setting.

<sup>134</sup> In choosing this option, New Zealand again followed Britain, as well as other Western countries such as America and Italy.

of state, community and family caring responsibilities. The primacy of state care was replaced by the expectation that the community, and particularly the family, would increase their care provision.

### **Deinstitutionalisation**

Deinstitutionalisation is the dual process of releasing patients from institutional care, and not admitting persons as long-term patients unless absolutely necessary<sup>135</sup>. The implementation of deinstitutionalisation has quickened the reduction in inpatient numbers which began with the utilisation of neuroleptic medications :

*For the first 20 years from 1945 to 1965, inpatient numbers reduced from approximately 500 to 400 per 100,000. During the past 20 years however, they have dropped more dramatically, to approximately 200 per 100,000 in 1984 (Committee of Inquiry, 1988:136).*

It appears that deinstitutionalisation has been successful in its first aim of reducing inpatient numbers. Inpatient numbers have reduced to the point where several of New Zealand's psychiatric institutions have been closed, for example, Lake Alice near Marton<sup>136</sup>. People with a psychiatric disability are currently expected to receive the support, treatment, and rehabilitation they require by accessing community-based mental health services<sup>137</sup>. The implications, for the provision of informal care to a family member diagnosed with schizophrenia, of closing New Zealand's psychiatric institutions while mental illness is still feared and misunderstood (Miller, 1995) and community-based mental health services are not adequately developed are noted below. As frequent reports in the media suggest (Wanganui Chronicle, 1995a:1995b), the New Zealand public is witnessing mental illness, specifically schizophrenia, without the restrictions previously present with institutional care. The general public's experiences with some individuals who are severely affected by the symptoms of schizophrenia are being used to support the understanding advocated by some factions of the New Zealand public that all

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<sup>135</sup> The prescriptions within the Mental Health (Compulsory Assessment and Treatment) Act 1992, which is examined further on in this chapter, suggest that 'absolutely necessary' is considered when an individual is a danger to themselves or members of their community.

<sup>136</sup> Marton is a rural town in the central area of the North Island.

<sup>137</sup> The status of these community-based mental health services is detailed below.

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people diagnosed with this disorder should be institutionalised (Wanganui Midweek, 1995).

As the following discussion will confirm, Maori are more likely to be involved in the process of reducing the inpatient numbers of New Zealand's psychiatric institutions. Maori experiencing mental ill health have fared worse than their *tauiwi* counterparts. The appalling state of Maori mental health in New Zealand has been highlighted in the document '*Nga ia o te Oranga Hinengaro Maori, Trends in Maori mental health: A discussion document*' (Ministry of Maori Development, 1993). The findings within this document, for example highlight that while first admission rates of *tauiwi* have remained stable, first admission rates of Maori have dramatically increased over the last thirty years as is indicated by the following statement:

*Maori rates of admission are increasing in both public and psychiatric hospitals, but the increase in the rate of Maori admitted to psychiatric hospitals and wards is enormous and has gone from about 400 per 100,000 to 600 per 100,000 Maori in the space of 10 years (Ministry of Maori Development, 1993:11).*

Maori men are more likely than *tauiwi* to be admitted to a psychiatric hospital because of serious psychoses, particularly schizophrenia. The Ministry of Maori Development (1993) when discussing the pattern of admission to New Zealand's psychiatric and hospital wards has demonstrated that Maori men are twice as likely to have the diagnosis of schizophrenia as their *tauiwi* counterparts. The poorer outcome for Maori mental health has raised a number of questions about for example, the cultural appropriateness of current mental health services and the compatibility of Maori and *tauiwi* conceptions of mental illness (Cherrington, 1994; Ministry of Maori Development, 1993). The utilisation of Treaty of Waitangi as the foundation for the redevelopment and reorganisation of New Zealand's future mental health services Durie (1989) is one way of ensuring that these services are culturally appropriate and therefore do not misrepresent either Maori or *tauiwi*.

Research is also required to determine the nature and shape of the care provided to Maori who previously would have entered New Zealand's institutionally-based mental health services. As already argued, it cannot be assumed that the care provision of Maori is the same as that of their *tauiwi* counterparts. For example,

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care provision may be distributed differently within the family/*whanau*. Furthermore, in reflecting the differences between Maori and *tauiwi* definitions of health, Maori and *tauiwi* care-givers may perceive and define their family member's schizophrenia differently, this difference impacting upon the care-giver experience.

The second aim of deinstitutionalisation is to reduce or prevent the admission of persons long-term. This aim is also being accomplished. Statistics show that when requiring mental health care, persons increasingly have been treated via short stays in hospitals or by non-hospital-based services (New Zealand Health Information Service, 1993). This pattern of care has been labelled the revolving-door syndrome (Lamb & Shaner, 1993). As Butler (1993:43) has explained, the revolving-door syndrome means: "*...that the total numbers of hospital patients was reduced but the new population is made up of a significant number of people who pass through the system time and time again*". Those individuals experiencing schizophrenia are likely to predominate amongst those involved in the revolving door syndrome<sup>138</sup>. Again it appears that Maori will be more affected by the second aim of deinstitutionalisation than their *tauiwi* counterparts: "*Once admitted, Maori are 40% more likely to be re-admitted than Pakeha, Maori readmission rates have risen 40% in the decade from 1981-1990, while Pakeha rates have fallen by 25%*" (Ministry of Maori Development, 1993:29).

The revolving-door syndrome may have particular implications for the informal care provided to a family member diagnosed with schizophrenia. In reflecting the cyclical nature of their family member's symptoms, care-givers may experience a cyclical pattern of increasing and decreasing their level of engagement in their family member's care. When their family member gains access to institutionally-based mental health services, care-givers may be able to disengage in part from their care provision, this care provision being increased when their family member returns to 'the community'. Consideration of the revolving-door syndrome suggests that informal care-givers and formal mental health staff will need to work collaboratively in order to plan and arrange for the family member's entry and exit from formal mental health services. This collaboration challenges the poor working relationship between informal care-givers and formal mental health staff

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<sup>138</sup> As already highlighted, the prognosis of schizophrenia is characterised by a cyclical pattern of acute and chronic episodes.

consistently reported in schizophrenia and care literature (Bernheim, 1990; Brooker, 1990; Holden & Lewine, 1982; Morris et al, 1989; Willis, 1982).

The two stated aims of deinstitutionalisation within New Zealand have not gone unquestioned. Release from a psychiatric institution has not always equated with an improvement in quality of life:

*If the process of deinstitutionalisation was about getting people out of hospitals, then it was successful. However, if it was about empowering people, improving the mental health status of the community, and improving the quality of life of people with mental illness, then we must admit that the results of deinstitutionalisation were mixed (Burns et al, 1994:2).*

The concerns of Burns et al (1994) have also been expressed by Chapple (1994), a writer for the New Zealand magazine 'Metro'. Chapple has vividly described the situations that some mentally ill individuals experience in Auckland. 'Peter' for example was "...found late last year living on the streets, underweight, wearing recycled clothes and crawling with scabies and lice" (Chapple, 1994:74). Further on, Chapple (1994:78) described a boarding house in Auckland:

*The damp stench of urine soaks the air of the boarding house in View Road, Mt Eden. There are no staff around. In the lounge a woman sits in the back of several rows of padded chairs arranged like in a classroom in front of the television. In the dining room, silver painted pine cones are almost the only embellishments. A young man with his name scrawled across the back of his T-shirt stares at himself in a large mirror.*

This represents the reality of deinstitutionalisation for many persons with a mental illness. It stands in direct opposition to the Government's claim that current health and disability support services provide choices for consumers via the delivery of services in the form of flexible packages of care. The scaling down and closure of New Zealand's institutionally-based mental health services, without the development of comprehensive and assessable community-based mental health services<sup>139</sup>, effectively means that people with a psychiatric disability are

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<sup>139</sup> Discussion further on in this chapter will highlight the inadequacies which consistently characterise New Zealand's community-based mental health services on a national basis.

generally left to fend for themselves or rely on friends, family, or voluntary agencies for support. The cyclical and unpredictable nature of the symptoms of schizophrenia mean that forty to sixty percent of people diagnosed with this disorder are in this position as a consequence of requiring support on an ongoing basis for the rest of their lives (Kaplan & Sadock, 1991). As Taylor et al (1992) have suggested, people exhibiting cyclical acute and chronic symptoms of schizophrenia are often 'enforced users', or individuals who have no choice about when and where they receive treatment. The current predicament is that these 'enforced users' do not have comprehensive, coordinated, or accessible services.

The contradictions which exist between how deinstitutionalisation has been proposed to occur, and how deinstitutionalisation is in reality being implemented is highlighted when comparing the findings of Chapple with the following statement made by the CRHA (1994a:19), presented in the document 'Planning For Health':

*Central RHA agrees that the process of deinstitutionalisation needs to be carefully managed, and we have no intention of inappropriately moving people into the community, or moving anyone without adequate support. Different individuals have different needs, so each client will be assessed to ensure that services are provided to meet those needs. We are not rushing to close institutions, but rather wanting to make sure that services are being provided in communities before clients leave an institution.*

Evidence from the United Kingdom and the United States has shown that deinstitutionalisation needs to be coupled with proactive, not passive, community care (Leibrich, 1988; Mental Health Committee, 1986) if we are not to return to what Abbot (1987b) termed 'community neglect'. Mechanic (1979:120) has clearly illustrated this point:

*Community life is no panacea unless the patient's suffering is alleviated and social functioning improved. We have learned that community life without adequate services and supports, could be as dehumanising and debilitating as the poor mental hospital.*

## Community Care

The ambiguity surrounding the defining of community care (Finch & Groves, 1980; Jones et al, 1978; Leibrich, 1988; Lentjes & Jonker, 1985; Malin, 1987; Parker, 1985; Walker, 1982) has already been identified. Specific reference was made to the differences between care in the community and care by the community. The former referred to where services would be provided, whereas the latter referred to who would undertake the caring work (Abrams, 1977; Finch, 1990; Lewis & Meredith, 1988). This section will highlight the extent to which care in the community and care by the community have been implemented with regard to New Zealand's mental health services.

While the policy of deinstitutionalisation has been translated into specific steps, for example regarding the time span in which the country's psychiatric hospitals will be closed, community care has not received the same treatment. In New Zealand, community care has largely been passive in nature. The lack of coordinated direction within New Zealand's social policy regarding community care, is mirrored in the configuration of New Zealand's mental health services. For example, In 1988, the Committee of Inquiry, found that, overall, community mental health services were inadequate, partial, and uncoordinated, in the areas of Auckland, Waikato, Wanganui, Nelson, Canterbury, the West Coast, and Otago. The Committee of Inquiry (1988:147) went on to say that: "*Nowhere in New Zealand has the development of community services kept pace with the growing need that has resulted from deinstitutionalisation*". In their recent document 'Core Services for 1994/95', the National Advisory Committee (1993) restated the Committee of Inquiry's concerns in assessing that New Zealand's mental health services were not comprehensive, integrated or coordinated.

Specific problems with New Zealand's mental health services were identified by a recent survey on the quality of services for people with psychiatric illnesses undertaken by Schizophrenia Fellowship (NZ) Inc (1995). The 'Regional Survey of Services for People With Psychiatric Illnesses' consisted of a questionnaire on the quality of mental health services being sent to all of the branches of Schizophrenia Fellowship in New Zealand. Twelve regions were represented by those branches which responded to this questionnaire including: Auckland; Hawkes Bay; New Plymouth; Southland; Wairarapa; Wellington; Canterbury; Manawatu; Otago; Waikato; Wanganui; and, West Coast. The problems collectively identified by the branches included: the continuing reductions in inpatient bed numbers which

contributes to the difficulty people experience in receiving voluntary assessment<sup>140</sup> and the revolving-door syndrome; the high caseload numbers apportioned to mental health staff; the lack of trained mental health staff; the lack of developed and coordinated community-based mental health services, particularly supported accommodation options; and, the emphasis the mental health system places on patients' rights at the expense of the rights of care-givers and the community<sup>141</sup>.

Problems inherent in New Zealand's mental health services, when considering the needs of those persons experiencing serious psychoses, are increasingly being highlighted by events such as Eric Gellatly's death. Gellatly was shot by police after he left the Invercargill<sup>142</sup> sports store that he had holed himself up in for twenty one hours, shooting indiscriminately during that time. In explaining Gellatly's behaviour, the media informed the public that "*Gellatly had a 20-year history of psychiatric problems and drug abuse.... He was on medication to combat schizophrenia*" (Wanganui Chronicle 1995a:1). As more of Gellatly's biography became known, Gellatly was defined as a victim of New Zealand's mental health services. As Mr Peck, MP for Invercargill was quoted as saying: "*Eric Gellatly's case is a symptom of where our health services are going wrong. This issue is not restricted to Invercargill*" (Wanganui Chronicle, 1995b:3).

Peck's assertion that the problems with Invercargill's health services were indicative of those across New Zealand were supported by a further incident which was cited in the media about two weeks later. On October 7th 1995, a woman with a history of depression was found to have given birth on a Waitangirua<sup>143</sup> street around 4:15am (The Dominion, 1995a). When talking about this incident Graham Kelly, MP for Porirua, was reported to say that it was "*...an indictment on the country's health system*" (Evening Post, 1995:1).

The problems with New Zealand's mental health services as highlighted by Gellatly's death are also being identified overseas. Inadequacies with community care services are being drawn upon to explain the violence and crime being

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<sup>140</sup> This difficulty is further explained when the Mental Health (Compulsory Assessment and Treatment) Act 1992 is discussed.

<sup>141</sup> The tensions surrounding patient's rights are highlighted when the Privacy Act 1993 is discussed.

<sup>142</sup> Invercargill is a city in the South Island of New Zealand.

<sup>143</sup> Waitangirua is found in the North Island of New Zealand.

exhibited by individuals exhibiting the symptoms of mental illness (The Times, 1995, 1995a). One such crime was the death of Bryan Bennett who was stabbed eighty two times and killed by Stephen Laudat who had been diagnosed as a paranoid schizophrenic (The Times, 1995). The question now being asked is how many people have to commit such acts before the Government reviews and finances its policy of community care:

*How many corpses does it take to convince a government minister that his policy is a failure?*

*According to official figures, two people are being murdered every month by mentally ill people who should be in secure hospitals. Approximately every six months there is a public inquiry into one of those murders, and each time the murder has been blamed on the policy of 'care in the community' (The Spectator, 1995:5).*

Mullen (1992) has proposed that episodes of violence such as these reported by the media, occur in response to an individual not receiving the care and support they require. Instead of reverting back to containing people with schizophrenia within psychiatric institutions, Mullen (1992:155) has argued that:

*The message is clear, that more adequate community care and support for those at risk and a policy of active follow-up of patients with schizophrenic disorders are required. The response to the knowledge that schizophrenia may bring with it an increased of criminal behavior is not to abandon community care, but to make it a reality, particularly for the most disabled and disadvantaged amongst those with schizophrenia.*

Specific factors preventing the development of comprehensive, integrated and coordinated mental health services in New Zealand have been identified including a the lack of coordination between the different Government departments which provide welfare services (Committee of Inquiry, 1988; National Advisory Committee, 1992, 1993) and the lack of consultation with users of services (Committee of Inquiry, 1988; National Advisory Committee, 1993). There has been a bias towards existing institutionally-based services as opposed to community-based services (Opie, 1992; Shipley & Upton, 1992). Another factor has been the lack of liaison and cooperation between hospital-based and community-based services (Abbott, 1987b; Committee of Inquiry, 1988; Dowland & Mckinlay, 1985)

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which leads to a difficulty in allocating resources between institutional-based and community-based services (National Advisory Committee, 1992; Shipley & Upton, 1992). Mental health services have been developed unevenly throughout New Zealand (Barwick, 1994). Finally, there has been a lack of data or information on both the health status of individuals and on the use of health and disability support services (New Zealand Health Information Service, 1993; Peacock & Burns, 1993; Shipley & Upton, 1992a).

While all of the factors identified above have contributed towards the poor state of New Zealand's current mental health system, the lack of funding available for its development has consistently been identified as a major influential factor. Historically, funding for mental health services has been lower than that provided to other disability areas. Of the disability support services funding, people with psychiatric disabilities utilised about sixteen percent (Bascand, 1993; Minister of Health, 1994). The Hospital and Related Services Taskforce (1988) explained the funding shortage for community mental health services by the bias of regional policy towards institutional care. Out of the total mental health budget of \$5.6 billion (to June 1991), \$3 billion was spent on institutional care with just under \$2 billion being spent on community health care services (National Advisory Committee, 1992). The difficulty involved in redirecting funds from institutionally based services to community based services is highlighted by the statistics provided in the document titled 'Strong Links' (CRHA, 1994b). When examining the reason for admission to hospital in Southern Porirua during 1991, it was found that mental disorders predominated. In fact, persons being admitted for mental disorders, while only being four percent of all admissions, utilised forty four percent of all bed days. Schizophrenia was the main cause of mental health admissions<sup>144</sup>. These statistics support the assertion made by Janseen Pharmaceutica (1993:4) that hospitalisation and residential care figure most highly amongst the financial costs of mental illness.

The CRHA has implemented strategies aimed at ensuring that the mental health needs of those in its region are met. One of these strategies has been a review of

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<sup>144</sup> The next highest percentage (eleven) of all bed days was utilised by persons with circulatory disease.

general adult mental health services within the greater Wellington region<sup>145</sup>, as described within the document 'A Better Life' (CRHA, 1994). This review established that the current expenditure on Porirua Hospital (in excess of sixteen million dollars), was not the most beneficial use of funds. The proposed outcome of this review was a *"...change in focus from the present dominance of inpatient services to one which responds to people in the community and uses inpatient services as a back up..."* (CRHA, 1994:39). In financial terms, the proposed reconfiguration of mental health services in the greater Wellington region will mean that expenditure will change from sixty-four percent inpatient mental health services and thirty-six percent community mental health services, to thirty percent inpatient mental health services and seventy percent community mental health services<sup>146</sup>. According to the CRHA (1994) inpatient services provided at Ngawhatu within the Marlborough region of the South Island, and those that were provided at Lake Alice near Marton in the North Island will also be redeveloped to reflect recommendations within the document titled 'A Better Life'.

A further question that needs to be answered is why those factors that have prevented the development of comprehensive, integrated and coordinated mental health services have not been overcome. In answering this question, the link Waerness (1984) has made between the purpose of care and service provision is useful. As already explained, Waerness defines care-giving work as the care provided to a person who requires care and support. In noting the different outcomes of care-giving work, Waerness (1984) has questioned whether the purpose of care is linked to the distribution of services and resources to those in the caring relationship. For example, Waerness (1984) has asserted that caring work associated with 'growth' is both the most attractive to professionals and commands the majority of available resources. The assignment of resources to growth-oriented care has been justified by the fact that in the short- or long-term, the recipients of care no longer have a need for this form of care. This exit of the care-recipient from the caring relationship is a form of effectiveness measure. In comparison, Waerness (1984:812) has proposed that:

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<sup>145</sup> The greater Wellington region includes Wellington, Porirua, Kapiti Coast, Hutt Valley and Wairarapa.

<sup>146</sup> As will be confirmed in part three of this chapter, the change in focus from institutionally-based to community-based mental health services is consistent with the national directions provided by the Minister of Health (1994b).

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*It is difficult for public care-giving services connected with stagnation and deterioration to justify for greater resources on the basis of any kind of criteria of 'effectiveness'. Rather, they have to appeal to more general humane values.*

Waerness' proposition has particular implications for the distribution of resources to persons diagnosed with schizophrenia. As was noted in chapter one, the prognosis of schizophrenia is predominantly characterised by cyclical acute and chronic episodes. Waerness' proposition suggests that this care-giving work would receive fewer resources than care-giving work associated with growth.

The public's reluctance to acknowledge and combat mental illness, specifically schizophrenia, was highlighted by Walsh (1985:171) when talking about the American context:

*What do we do for schizophrenia? Although it occupies more hospital beds than cancer, heart disease, diabetes and arthritis combined, the answer is: almost nothing. The public's heart is closed to schizophrenia...Look hard for the schizophrenic poster child, a national fund-raising campaign, the celebrity sponsor, or the holiday telethon. You won't find them.*

Miller (1995) has highlighted the intersection between the prevailing discourses of mental illness and the provision of services. Specifically, the fear and misunderstanding associated with mental illness has meant that:

*...psychiatry does not receive the resources that it deserves, or would be made available for any other branch of medicine of such importance. For instance, international guidelines suggest that there should be one psychiatrist for every 10,000 of the population. In New Zealand the average figure is only one for every 19,000, and in some parts of the country the ratio is very much lower than this. The shortage of mental health professionals in turn means that they are invariably overloaded with work. This sometimes means that there are major inadequacies in the service they can provide; and this further reinforces the low esteem in which mental health professionals are held by the public (Miller, 1995:8).*

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Attempts to establish ways in which available resources can be more effectively utilised to manage schizophrenia are also limited in comparison to other conditions. In making this point Miller has noted that:

*...the major funder of medical research in New Zealand, the Medical Research Council, granted \$25,000 for schizophrenia research between 1976 and 1985 but more than \$4 million to heart disease over the same period (Miller quoted in Mahey, 1995:90).*

The limited research undertaken on schizophrenia in New Zealand is surprising considering the cost of this disorder both personally to those persons directly affected by it and financially to the country as a whole (Mahey, 1995).

The identification of both the reported experiences of people with a psychiatric disability (Burns et al, 1994; Chapple, 1994; Christchurch Press, 1995; Wanganui Chronicle, 1995, 1995a, 1995b, 1995c) and those factors which have contributed to the poor state of New Zealand's mental health system, including inadequate funding, suggests that care *by* the community rather than care *in* the community primarily characterises New Zealand's mental health services. Whether 'the community' is able and willing to meet the care and support needs of those persons with a psychiatric disability is however another question that needs to be raised.

It seems trite to argue that New Zealand's community-based mental health services need to be improved. However, this is exactly what needs to happen if the experiences of informal care-givers of a family member diagnosed with schizophrenia are to improve. These care-givers are having to manage their family member who is experiencing the symptoms of a complex and changeable disorder. As already noted the symptoms of schizophrenia differ not only between but also within a person in type, intensity, duration and frequency. Persons diagnosed with schizophrenia require more or less support depending on whether their symptoms are acute or chronic. The absence of readily accessible and comprehensive community-based and institutionally-based mental health services raises the question as to the extent to which informal care-givers are having to increase their level of care provision. Consideration also needs to be given to the difficulty informal care-givers are experiencing as a consequence of their care provision to

their family member diagnosed with schizophrenia not being supported. These questions will continue to be considered when discussing how New Zealand's legislation has impacted upon the provision of this informal care.

## **Legislation**

'Social policy' was defined at the beginning of this chapter as including both those prescriptions made by Government regarding the type and degree of intervention required by the state, the community, and the family in order to provide support to those persons diagnosed with schizophrenia, and the assumptions which direct this intervention. These prescriptions have become increasingly evident within New Zealand's legislation. Amidst the restructuring of the wider health and more specifically mental health arena, pieces of legislation related to health and disability have been passed and implemented. This section will focus on that legislation which has particular implications for the provision of care provided within a family to a member diagnosed with schizophrenia. Specifically, then, the following legislation will be examined: the Mental Health (Compulsory Assessment and Treatment) Act 1992; the Privacy Act 1993; and, the Human Rights Act 1993.

### **The Mental Health (Compulsory Assessment and Treatment) Act 1992**

The Mental Health (Compulsory Assessment and Treatment) Act 1992 has dramatically redefined the criteria for both who is eligible to access New Zealand's inpatient mental health services, and who should provide care to those persons experiencing mental illness. The way in which this redefinition has occurred will be highlighted below by noting the differences between this 1992 legislation and its predecessor, the Mental Health Act 1969. The implications of these changes for those caring relationships in which a family member is diagnosed with schizophrenia will also be identified.

According to the 'User's guide to the Mental Health (Compulsory Assessment and Treatment) Act 1992' (Bailey, 1993), this current legislation has introduced several changes. First, a narrower definition of 'mental disorder' is proposed. The Mental Health Act 1992 states that the term 'mental disorder' can only be applied if there is:

*...an abnormal state of mind (whether of a continuous or an intermittent nature), characterised by delusions, or by disorders*

*of mood or perception or volition or cognition, of such a degree that it*

- (a) *poses a serious danger to the health or safety of the person or of others; or*
- (b) *seriously diminishes the capacity of that person to take care of himself or herself (New Zealand Government, 1992:4).*

A person may not be defined as mentally disordered because of their: political, cultural or religious beliefs; sexual preferences; criminal or delinquent behaviour; substance abuse; or, intellectual handicap (Bell, 1992).

Concern has been expressed from several quarters about the need for individuals to be defined as a 'serious danger' before they come under the brief of the Mental Health Act 1992. As the Ministry of Health (1993:2) has said: "*Concern has been expressed that the definition of mental disorder is being applied too narrowly, and that people who are quite clearly unwell, are not receiving treatment*". This concern has been heightened by the number of cases, noted in the media, which involve persons with a psychiatric disability harming themselves or others after being turned away from mental health services. Mike Moore, MP for Christchurch North, has spoken of those cases he has become aware of:

*Take for example, the recent case of a man who asked for help and was sent home, picked up naked in a city centre, again sent home by hospital staff, and ignored by the police. He went on to kill his father and then himself. Another man tried to kill himself in his car, went to hospital, was sent home after five days, and then killed himself. The family was not advised he was on the streets. During a period of six weeks, six patients from one hospital alone committed suicide. The system is bursting apart and the current public cases are only the tip of the iceberg (Christchurch Press, 1995:11).*

These cases illustrate that people are often not able to receive treatment until they are acutely unwell, if then. This assertion is supported by the following statement

from the report of the inquiry into Matthew Innes' death<sup>147</sup>. In accordance with the definition of mental disorder:

*It is not enough that a person is mentally ill, they must also be dangerous. This requirement has effectively raised the threshold for entry into the system.*

*As a result people, such as DAOs [Duly Authorised Officers], who are involved in dealing with those people who are potentially mentally disordered often wait until those people are very unwell before interviewing (Mason, 1994: 139).*

Those persons who require access to mental health services themselves have questioned the applicability of the Mental Health Act 1992. As Dave, who identifies as an ex-psychiatric patient, said: *"I think the system's gone to the other extreme. It's just as hard to get in now as it was to get out, unless you become violent or come to the attention of the police"* (O'Hare, 1994:22). With the emphasis on 'mental disorder' (as defined by the 1992 Act) and compulsory assessment and treatment, (discussed below), mental health services are focusing on those who are acutely unwell (Author Unknown, 1992; Ross, 1995). This focus reflects the current inadequate level of mental health services -- primarily crisis, as opposed to preventative or rehabilitative, work is being undertaken (Chapple, 1994).

The definition of 'mentally disordered' within the Mental Health Act 1992 has restricted the extent to which early intervention can be achieved. This was clearly demonstrated in the findings of the survey undertaken by Schizophrenia Fellowship (NZ) Inc (1995:2) on the state of New Zealand's services for people with psychiatric illnesses:

*The Mental Health Act is not being used effectively. Indeed, it is widely perceived as being detrimental to the early treatment of mentally ill people. Because a person has to be "a serious danger to himself or others" before compulsory treatment, early warning signs are ignored. The same criteria are widely*

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<sup>147</sup> Members of Innes' family, in becoming concerned about Innes' erratic behaviour, had rung the local psychiatric hospital (Kingseat) in Auckland for advice. The police were sent to the family home in response to this call. Innes was forcibly restrained and transported to Kingseat Hospital by police who were acting under the Mental Health Act 1992. Innes died on 10 January 1994 in Middlemore hospital directly after he had been transported by the police. An inquiry was held to establish amongst other things the events leading to his death (Mason, 1994).

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*imposed on people who seek voluntary admission or treatment: they are not treated until they are acutely unwell. The entry and exit thresholds for treatment work against patients getting well.*

In acknowledging the implications of the current definition of 'mentally disordered', Health Minister Jenny Shipley has introduced a bill which changes the criteria of 'serious danger' to 'danger' (Wanganui Chronicle, 1995c). This proposed change will not alleviate those problems in New Zealand's mental health services which arise from resource constraints. Widening the criteria for those deemed to need mental health services will only deepen these problems.

Until New Zealand's institutionally-based mental health services are more accessible and New Zealand's community-based mental health services are developed and coordinated, responsibility for the care and support of persons exhibiting the symptoms of schizophrenia falls upon the individuals themselves or their family, friends, or voluntary organisations. Discussion already presented in this chapter has demonstrated that, in New Zealand, these care-givers are likely to be women. The implications of placing this responsibility on women have been noted above and will be revisited further on in this chapter.

A second difference from the Mental Health Act 1969 is that voluntary assessment and treatment is not legislated for in the Mental Health Act 1992. Instead, compulsory assessment and treatment is the 1992 Act's focus. Those persons who receive mental health services under the jurisdiction of the Mental Health Act 1992 fit Taylor et al's (1992:9) concept of 'enforced users', these persons have no choice about receiving assessment and treatment. Emphasis is, however, placed on ensuring that treatment is provided in the least restrictive manner possible. A legal framework for community treatment orders has been developed which allows a person to be treated at home or within their community. As a consequence of persons not being admitted as easily to institutional care, informal carers may increasingly have to manage more overtly psychotic behaviour than previously.

Third, the importance of recognising the cultural identity and beliefs of each person for their well-being is acknowledged within the 1992 Act. Persons should have their cultural identity, language and beliefs respected, these persons being treated in a culturally appropriate manner. This requirement is consistent with the Treaty of Waitangi and the calls which have been made to incorporate the principles of

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this Treaty into health practices (Durie, 1989). The implementation of this requirement could however be difficult to fulfil. For example, New Zealand's mental health system predominantly reflects *tauiwi* understandings of health and mental health (Minister of Health, 1994b).

Fourth, procedures have been established which clearly outline the process for the review and appeal of decisions about a person's mental health and legal status. This process ensures that timely decisions are made, these decisions being open to review. While 'patients' have gained from this process (in comparison with the Mental Health Act 1969), the role of care-givers has not been given the same degree of attention. For example, care-givers are not as of right present at any hearings. Instead: "*Families may be represented at reviews or hearings at the discretion of the judge, but have no legal aid if they need a lawyer, or any help with travel or accommodation expenses*" (Wood, 1994:13). This is ironic as Wood (1994:13) continues to highlight: "*Families are experts in the long-term behaviour of the patient in the community, and often the burden of caring for a difficult and non-coping family member falls upon them*".

A further concern about the various legal hearings directed by the Mental Health Act 1992, is their "*adversarial nature*" (Ministry of Health, 1993:6). This is despite hearings being heard, if possible, within the Family Court. The focus on compulsory assessment and treatment can mean that the onus is on care-givers<sup>148</sup> to initiate the process for their family member to be committed for assessment and treatment. The legal framework within the Mental Health Act 1992, then, could result in care-givers and family members taking opposing sides -- the care-giver advocating for a Compulsory Assessment and Treatment Order, the family member opposing this same order. The shifts in the degree of power and autonomy held by a family member diagnosed with schizophrenia and their care-giver (Atkinson & Coia, 1995; Waerness, 1984) will almost certainly be highlighted during this public assessment of the family member's mental state. The focus of the 1992 Act upon compulsory assessment and treatment suggests that struggles between care-giver and care-receiver to either increase or decrease their power and autonomy will be

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<sup>148</sup> As already noted, 'care-givers' in the Mental Health Act 1992 is defined as: "*...the friend of the patient or the member of the patient's family group or whanau who is most evidently and directly concerned with the oversight of the patient's care and welfare*" (New Zealand Government, 1992).

a frequent occurrence. The care-givers and their family member's taking opposing sides can be extremely damaging to the care-giver and family member's rapport (O'Hare, 1994) which can, for example, as demonstrated below, result in the family member refusing to allow information to be passed on to the care-giver.

Finally, the rights of the person who is subject to compulsory assessment and treatment are specified, along with procedures for investigation and rectification of any breaches of these rights. Specific patient's rights which are mentioned in the Mental Health Act 1992 are: the right to information about their assessment and treatment; the right to independent advice; the right to company; the right to call for a review of their mental health and legal status; the right to treatment; and, the right to send and receive mail.

Care-givers of family members diagnosed with schizophrenia have spoken about the irony of the Mental Health Act's 1992 focus on patients' rights. Two of the symptoms of schizophrenia are lack of insight and lack of judgement. While a patient's rights are now acknowledged and advocated for, the right to refuse treatment, for example, care-givers are concerned that not every patient has the ability to assess their mental health status or make judgements which best serve the patients' interests (for example, seek support and/or treatment when the initial symptoms are exhibited). Similar concerns are expressed outside of New Zealand with regard to providing care to a family member diagnosed with schizophrenia. Leggatt (1994:2), an Australian researcher, has explained that:

*Mental illness can cause regression to dependent childlike behaviour, but the law views the mentally ill person as an adult able to make mature decisions about his or her own welfare. Doctors have to abide by this law.*

*The result is that families have to deal with an adult mentally ill person who a) has little or no insight and will not seek help and b) has adult independent status, but behaves with childlike dependency.*

The issue of rights has already been raised in this thesis when describing Ungerson's (1993) depiction of the complexity of developing established sets of rights for carers and the cared-for in the United Kingdom. The Associate Minister of Health, Katherine O'Regan (1992:6860) has also noted the tension between

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patient's rights and care-giver's rights in stating: "*Attempting to strike the balance of the rights of patients and the rights of those who care for them is indeed the central dilemma of any mental health legislation*". While the rights of both parties within the caring relationship would be acknowledged and respected, this duality of focus (Twigg & Atkin, 1995) is extremely difficult to translate into policy and service provision.

On a regional level in New Zealand, attempts have been made to construct a set of protocols which encompass this duality of focus. The Wellington Branch of Schizophrenia Fellowship (WSF) has combined with the Wellington Mental Health Consumers Union (WMHCU), with the aim of establishing protocols which acknowledge the right of care-givers and the right of consumers to privacy. WSF and WMHCU are hoping that these protocols, once developed, will be adopted by mental health services within the Wellington region. A range of issues have been identified by WSF and WMHCU when considering the rights and needs of care-givers. Some of these issues revolve around: the value judgements mental health professionals make about 'the family' regarding its level of functioning; the need for care-givers to know basic information regarding their family member's health status; the decision as to what information should be considered confidential; and, who makes decisions for a family member if they are unable to make decisions for themselves (Wood, 1995).

The issue of rights has also been considered at the national level. In response to the Health and Disability Commissioner Act 1994, a Health and Disability Commissioner was appointed whose brief it is to "*...promote and protect the rights of consumers of health and disability services*" (Health and Disability Commissioner, 1995:1) The Health and Disability Commissioner has called for submissions regarding a code of consumer rights. The development of such a code will hopefully provide a forum whereby tensions such as those identified by Atkinson (1989) and WSF and WMHCU can be identified and discussed<sup>149</sup>. Work that has been undertaken on a regional level might be integrated to construct this code of consumer rights.

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<sup>149</sup> The proposed draft of this national code of rights was distributed at the time of writing this thesis (Health and Disability Commissioner, 1995).

In summary, then, in comparison to the previous Mental Health Act 1969, the current mental health legislation has ensured that the wishes and interests of a person who is experiencing mental ill health, (up to the point where the term 'mentally disordered' can be applied), are taken into account and advocated for if they are consistent with the best interests of the person. The Mental Health Act 1992 acknowledges that a person does not stop being a person because they have become a patient. Those persons who do experience mental disorder can be more assured that their dignity and person status will remain intact, by, for example, the emphasis on patient's rights. While the intentions behind the Mental Health Act 1992 should be applauded, acknowledgment of the implications, of this Act for the informal care-givers of those individuals diagnosed with schizophrenia, suggest that more thought needs to be directed towards how the 1992 Act can maintain a duality of focus. For example, the tightening of the criteria for access, which has been achieved via the narrower definition of 'mentally disordered', has placed considerable pressure upon informal care-givers to increase the level of informal care they provide to their family member diagnosed with schizophrenia. This increased care provision is by default, including care that previously would have been provided by formal mental health staff. Therefore, informal care-givers may face increased stress and strain as they develop the skills and knowledge which will allow them to more effectively provide care to a family member exhibiting the psychotic symptoms of schizophrenia. Furthermore, despite the expectation that informal care-givers will increase their engagement in their care provision, the Mental Health Act 1992 is characterised by the primacy of patients rights. In other words, while the Act focuses upon 'enforced users' (Taylor et al, 1992) or those persons who are violent and require compulsory assessment and treatment, it is the patients who, for example determine which information is provided to their informal care-givers. Care-givers are being expected to provide care without knowledge about their family member's diagnosis, prognosis or treatment.

### **The Privacy Act 1993**

Shortly after the Mental Health (Compulsory Assessment and Treatment) Act 1992 was passed, the Privacy Act 1993 came into force. The apparent contradictions inherent between these two pieces of legislation were quickly identified by those in a care-giver role. For example, of primary concern was the tension between the Mental Health Act 1992, which transferred more responsibility for care provision to

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informal carers, and the Privacy Act 1993, which tightened the conditions under which information, for example about a person's health status, could be disclosed.

Briefly, the function of the Privacy Act 1993 is to promote and protect individual privacy. The 1993 Act legislates procedures for when and how an individual's personal information can be collected, stored, utilised and disseminated (Woodd & Hobson, 1993). Primarily, only personal information which is relevant and necessary should be collected. This information should also be utilised only for the initial purpose it was collected. Information cannot be utilised for a secondary purpose or be disseminated (without the individual's consent) to other agencies which did not initially collect the information. Information which is collected should be stored securely.

The Privacy Act 1993 focuses on privacy in relation to information, excluding privacy with regard to the routines and activities of everyday life. According to Montague (1993), emphasis is placed on the different types of privacy depending on a person's disability. For example, privacy to do with information is of primary concern to those persons with a psychiatric disability just as daily life privacy issues are of major concern to persons with a physical disability. Both of these aspects of privacy are of concern to persons with an intellectual disability. The Privacy Act 1993 and the informational privacy procedures inherent within it, then, are particularly relevant to persons diagnosed with schizophrenia.

So how does the Privacy Act 1993 impact upon the caring relationship in which a family member is diagnosed with schizophrenia? According to the Privacy Act 1993, those persons who are defined as mentally disordered<sup>150</sup> are assured that their personal information will not be utilised or disseminated in ways they have not consented to. In essence, a patient's request that information related to their mental health status not be released should be respected. Again, in following the Mental Health Act 1992, the rights of the 'patient' are protected.

Care-givers, however, have identified the Privacy Act 1993 as an obstacle to their provision of informal care (Morton, 1994). Historically, those persons who provide care to a family member diagnosed with schizophrenia have had difficulty in

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<sup>150</sup> 'Mentally disordered' is defined by the Mental Health (Compulsory Assessment and Treatment) Act 1992.

receiving information about their family member's health status from mental health professionals. This difficulty resulted first from the confidentiality which is part of a professional relationship between a family member and the mental health professionals working with that family member, and second, theories espousing family causation for a family member's psychiatric disability<sup>151</sup>. However, before the Privacy Act 1993, care-givers were often able to receive general information about their family member, such as whether their family member was in hospital. Implementation of the current privacy legislation has reportedly meant that even this information is sometimes being withheld from care-givers (The Press, 1994). The following quotation taken from the Regional Survey of Mental Illness Services highlights the extent to which some mental health professionals are incorrectly utilising the Privacy Act 1993 to protect the privacy of the family member despite the implications this response may have for the family member's safety: *The week before our daughter took her own life, I phoned the psychiatrist to say that she had put up a "noose". The psychiatrist asked if I had my daughter's permission to call* (Schizophrenia Fellowship [NZ] Inc, 1995:3).

The following comment of Jim Crowe (1995:2), President of Schizophrenia Fellowship (NZ) Inc, highlights the need for mental health professionals to receive training about how to use the Privacy Act 1993 appropriately:

*The New Zealand Privacy Act 1993 has caused a wall of silence between the family and the psychiatric system. It appears to me that staff who are not completely sure of the Act usually respond with a "NO, we cannot discuss your family member without his or her consent.*

Care-givers of persons with schizophrenia hold concerns about the licence given to patients to withhold information from them. Often as a result of their paranoia and/or hallucinations and/or delusions, a person diagnosed with schizophrenia can perceive their care-giver as a threat to their well-being. A family member's ill feeling towards their care-giver can also result from the care-giver's role in instigating Compulsory Assessment and Treatment Orders. Care-givers are acknowledging that with rights come responsibilities, and are therefore questioning whether family members have the ability to decide who should receive information

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<sup>151</sup> These theories on family causation of schizophrenia were discussed in Chapter One.

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about their health status when it has been assessed they need to be committed. As one care-giver eloquently stated:

*If a person is in need of psychiatric treatment, it is often because that person is not fully responsible for his/her actions or mental outlook at that time. Yet that same person is expected to answer perfectly sanely who will be told what. Caregivers have no rights whatsoever. I feel this is very undesirable and unfair to those who have to pick up the pieces and offer support when things are not going too smoothly (Workhorse, 1994:11).*

The CRHA has noted the potential and actual conflicts between those who receive and provide care when it comes to the receipt of information. In response to this conflict the CRHA (1994a:29) proposed that a:

*...protocol be developed for involvement of carers and information sharing with carers. This protocol should be developed jointly by consumers, carers, CHEs, clinical and other relevant staff (CRHA, 1994a:29).*

A similar assurance about the development of such protocols was again given in 1996 in the document entitled 'Mental Health Strategy: 1996-97': "*Protocols are currently being developed to govern referrals, and issues of confidentiality and information sharing*" (CRHA, 1996:16). The importance placed by care-givers upon the development of these protocols suggests that a concerted effort should be made to ensure that they are developed before another two years go by.

The consequence then of the Privacy Act 1993 for some care-givers of family members diagnosed with schizophrenia is that, although they are primarily responsible for their family member's care, they are being refused access to information about their family member's care if the family member demands this. The rationale of withholding this information, from a care-giver's point of view, needs to be questioned. This is especially the case with the trend towards community care. The rights of family members need to be balanced with the rights of care-givers, particularly when care-givers are also increasingly being given greater responsibility for the provision of their family member's care.

## The Human Rights Act 1993

The Human Rights Act 1993 also has potential ramifications for the informal care provided to a family member diagnosed with schizophrenia. The Human Rights Act 1993 makes specific reference to the fact that people with a psychiatric disability or their associates cannot legally be discriminated against. This legal recognition is particularly important in the context of the dominant discourses which influence the way in which mental illness, and particularly schizophrenia, is defined. The ignorance and fear associated with mental illness (Miller, 1995) typically leads to discrimination, rejection and isolation (National Mental Health Consortium, 1989). Such discrimination, rejection and isolation will undoubtedly reduce the likelihood that community care has positive outcomes for persons diagnosed with schizophrenia.

The Human Rights Act 1993 is the successor of the Human Rights Commission Act and the Race Relations Act, and took effect from 1st February 1994. The purpose of the Human Rights Act 1993 is to provide *"...greater protection for people facing discrimination. Its intention is to help ensure people are treated fairly in a number of areas of public life and commerce"* (Human Rights Commission, 1993:5).

Before 1st February 1994, the date at which the new Act took effect, it was unlawful to discriminate on the grounds of: marital status; sex; race and colour; religion or ethical belief; ethnic or national origins; and, age (Lewis, 1994). The Human Rights Act 1993 has extended the basis upon which discrimination is unlawful including: sex, marital status; disability; age; political opinion; employment status; family status; religious belief; race; colour; and sexual orientation. While all of these components are important additions, the recognition of disability is particularly relevant to this thesis. For legislative purposes, disability has been defined as:

*...physical disability or impairment; physical illness; psychiatric illness; intellectual or psychological disability or impairment; any other loss or abnormality of a body or mind function; reliance on a guide dog, wheelchair or other remedial means; the presence in the body of organisms capable of causing illness* (Human Rights Commission, 1993:6).

Psychiatric illness, which encompasses schizophrenia, is included in this term disability. When examining the extent to which people with a disability are

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protected by the 1993 Act, it is noted that people who have either had a disability in the past, may presently have a disability, may have a disability in the future, or are believed to have a disability cannot be lawfully discriminated against (Human Rights Commission, 1993). This condition is particularly relevant for persons diagnosed with schizophrenia. As already noted, forty to sixty percent of persons diagnosed with schizophrenia experience cyclical patterns of acute and chronic episodes on an ongoing basis (Kaplan & Sadock, 1991). In drawing upon the above condition, it could be argued that while a person is not exhibiting the acute symptoms of schizophrenia, they should not be prevented from engaging in public life and commerce.

The power of the Act extends beyond protecting the person with a disability from discrimination. *"It is also unlawful to discriminate against relatives or associates of people with a disability, because of that disability - e.g., a spouse, carer or business partner"* (Human Rights Commission, 1993:10). The protection against discrimination for spouses and care-givers of persons diagnosed with schizophrenia is also a positive condition of the 1993 Act. This is particularly the case when considering the blame care-givers<sup>152</sup> have received for causing schizophrenia in the first place. Furthermore, it would be naive to assume that the stigma and misunderstanding surrounding schizophrenia does not transfer to the spouses and care-givers of those persons diagnosed with schizophrenia.

The introduction of the Human Rights Act 1993 has been timely. Discussion in this chapter has highlighted the extent to which deinstitutionalisation and community care are currently being implemented in New Zealand's mental health arena. If the process of deinstitutionalisation and community care is to be successful for people diagnosed with schizophrenia and their care-givers, these people need to be able to participate in, amongst other things, employment, recreational, and educational pursuits. While the existence of the Human Rights Act 1993 will not automatically prevent the discrimination directed towards people diagnosed with schizophrenia and their care-givers, the Act does provide a process for challenging that discrimination which falls within its brief.

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<sup>152</sup> These care-givers are typically middle aged mothers (Lefley, 1987; Warren, 1994/1995)

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Whether the Human Rights Act 1993 will actually reduce the discrimination experienced by persons diagnosed with schizophrenia, or their care-givers, is uncertain. For example:

*People with disabilities are protected from discrimination in: employment; business partnerships; vocational and qualification authorities; access to public places; provision of accommodation; educational establishments; provision of goods and services. Services include banking, insurance and superannuation; grants; loans, credit or finance; services provided by any profession or trade (Human Rights Commission, 1993:10-11).*

However it is unlikely, in the current political environment, that the Human Rights Act 1993 will be financed sufficiently to enforce its own directions. The Accessible Bus Campaign is a case in point. The expense and organisation required for ensuring that New Zealand's buses are wheelchair accessible has been cited as reasons for not ensuring that buses are purpose-built for people with disabilities (NZPA, 1995; Taylor, 1995). Also, proving and processing discrimination which occurs in any one of these areas for any particular type of disability would be extremely time and resource intensive.

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## **PART THREE: FUTURE ISSUES**

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Discussion in part two of this chapter provided an analysis of the structure and characteristics of New Zealand's past and current health and mental health services. This analysis highlighted the various contradictions evident in these services, these contradictions widening the divergence between the prescriptions in social policy and the lived experiences of those persons who provide and require health and mental health services. Attention will now turn to identifying and analysing those strategies which have been proposed specifically to improve New Zealand's mental health services.

Two consensus development documents, which have major implications for the care provided within a family to a member diagnosed with schizophrenia, are initially examined in this section. Consensus development conference documents provide advice to the National Advisory Committee on Core Health and Disability Support Services which, after considering this advice, makes recommendations to the Minister of Health. The material contained within 'Management of Major Psychoses' (McGeorge & Fernando, 1993) and 'Living At Home' (Naylor & Lardner, 1994) is particularly relevant to the topic of this research. The recommendations outlined within these documents could quite conceivably become the foundation upon which future national policy is constructed. It is important, then, that these proposals are examined in terms of their implications for both those persons receiving and those persons providing informal care.

Information regarding the characteristics of schizophrenia, as outlined in Chapter One, and the material describing the components of care, as outlined in Chapter Two, will be utilised to analysis those proposals within the consensus development conference documents 'Management of Major Psychoses' and 'Living at Home'. This analysis will highlight how these proposals will influence and shape the informal care provided within a family to a member diagnosed with schizophrenia. As already noted, these proposals could underpin New Zealand's future social policy.

After the focus of these documents has been identified, attention will be paid to: how these documents view health; the implications of their recommendations for both expenditure and resource allocation; and, how these documents resolve the

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potential and actual tensions between those who provide and those who receive care.

Following the discussion on the documents 'Management of Major Psychoses' and 'Living at Home', the strategies proposed by the current Minister of Health for improving New Zealand's mental health services are identified and described. These strategies have been outlined in the document entitled 'Looking Forward: Strategic directions for the mental health services' (Minister of Health, 1994b).

### **Shaping Mental Health Services: Consensus Development Conference Documents**

The consensus conference discussion on the 'Management of Major Psychoses' focused purely on the outcomes, treatment and consumer issues associated with patients experiencing schizophrenia and bipolar disorder. The construction of schizophrenia within this document was similar to that described in Chapter One. Specifically, the changing nature of schizophrenia was highlighted:

*It was pointed out by the panel, that any discussion of the psychoses must take into account a range of disorders that vary in their severity from one person to another, and in the individual over time, sometimes with normal functioning interrupted by episodic deteriorations of mental state. In other words, a person suffering from such a disorder may not always be in a psychotic state and, with appropriate care and support, can experience a good quality of life (McGeorge & Fernando, 1993:10).*

The focus of the document 'Living at Home' was much broader. Specifically, the document 'Living at Home' is the outcome of a consensus development conference held to:

1. *Identify the most important factors that enable people with disabilities to live in, or close to, their own homes and communities.*
2. *Identify, in general terms, the situations in which it is appropriate for people with disabilities to live in or close to their own homes, and contrast these with situations where it may not be appropriate or practical.*

3. *Make recommendations on how to develop services that enable people to live in, or close to, their own homes and communities (Naylor & Lardner, 1994:29).*

Persons with disabilities were defined within 'Living At Home' as those individuals with a physical, sensory, psychiatric, neurological, psychological, developmental, or learning disability. Wider aspects of a person were also taken into account such as their age, and their economic, cultural, historical, environmental, social, and political background. Living at home referred to "*...affordable accommodation where the individual chooses to be and calls home*" (Naylor & Lardner, 1994:28).

Reflecting the documents' foci was the emphasis placed upon moving beyond the medical model of health. It was the range and variety of outcomes of the diagnosis schizophrenia which led the Panel<sup>153</sup> to call for both a holistic approach to care and a comprehensive range of services. According to the Panel, a holistic approach to care would take:

*...into account patients symptoms, the unique course of their illness, the periods of wellness, their social and cultural background, their living conditions, their strengths, their rights and their personhood (McGeorge & Fernando, 1993:6).*

This call for a holistic approach to care was mirrored by the emphasis placed upon an integrated social policy within the document 'Living at Home'. An integrated social policy was defined as one which incorporates:

*...housing, income support, cultural aspects, home support and health care services, transport, recreational opportunities and access to the built or constructed environment, which is also sensitive to the needs of people with sensory disabilities. Policy must ensure equality of access to services, economic independence and effective participation in decision-making, as inherent in the Treaty of Waitangi and Ottawa Charter. Choice and flexibility are identified as the underlying key principles within an integrated social policy, ensuring success in the living at home process (Naylor & Lardner, 1994:8).*

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That Panel discussing the management of major psychoses.

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Further, the Panel proposed that an integrated policy should encompass the principles of equality of access to services and economic independence.

The call for both an holistic approach to care and an integrated social policy is consistent with calls from consumers to utilise a social, as opposed to a medical, definition of disability. As explained earlier, a social definition of disability acknowledges the way in which societal structures further prevent people with a disability from participating in their society (Ballard, 1994; Morris, 1993a). For example, within the consensus development conference document 'Disability Support Services: Priorities', it was argued that:

*Eligibility for disability support services should be based on a person's total need for services, taking into account the barriers the individual experiences to participation in society, the person's relationship with family and caregivers, learning needs, and cultural and social needs. The need for services strongly relates to the degree to which the person's physical and social environment is supportive (Curry & Bascand, 1993:6).*

The Minister of Health incorporated this latter recommendation into a needs assessment process for both people with a disability and older people. This assessment process is outlined in the 1994 document 'Standards For Needs Assessment For People With Disabilities' (Ministry of Health, 1994a).

The call for both an holistic approach to care and an integrated social policy has particular ramifications for the allocation of available resources. In acknowledging this the Panel discussing the management of major psychoses clarified that calculating the costs related to implementing the Panel's recommendations was beyond their brief. However in terms of costing it was asserted that:

*...the recommendations of the panel should not be seen as simply a 'wish list'. While the pattern of care suggested by the panel is capable of being costed, it is important to recognise that modern psychiatric treatment is now highly sophisticated and multi-faceted (McGeorge & Fernando, 1993:29).*

In the current environment it seems more likely that the recommendations proposed in both consensus conference documents will be considered as a wish list. The cuts to benefits, rises in state housing rentals, and increasing health costs (Barker,

1992; Bowie, 1992; Craig et al, 1992; Kelsey, 1993) are in direct opposition with the Panels' proposals. The implementation by the New Zealand Government of market liberalism suggests that resource restrictions will continue to determine policy and service development. The tension between needs and resources (Lewis, Bernstock, & Bovell, 1995:75) is likely to continue.

Both 'Managing Major Psychoses' and 'Living at Home' paid particular attention to those persons with a disability. Advocacy for the wellbeing, empowerment and participation of persons with a disability was particularly evident within the 'Living at Home' document, as is illustrated by the following statement:

*Whatever the chosen lifestyle, it is recognised that various characteristics are vital to create wellbeing. Individuals must feel valued and able to participate in and contribute to their own, their family's and their community's growth and development. This is achieved when individuals are empowered to take control and exercise choice to determine their own destiny (Naylor & Lardner, 1994:8).*

The 'Living At Home' document is accompanied by other consensus conference documents which focus on the empowerment and participation of individuals with a disability. In the document titled 'Disability Services: Client Orientation', the following message was articulated: "*Nothing about us without us*" (Bennie & Maniapoto, 1993:7). People with disabilities called for their involvement at all levels of service development and implementation, including evaluation, during the consensus development conference on 'Self Help And Empowerment: People With Disabilities Challenging Power, Promoting Change' (Gates & Hunt, 1993). The Core Services Committee (1994) forwarded the proposal that consumer participation be a priority to the Minister of Health. Consumer participation has not been supported purely for altruistic reasons. The presence of economic reasons which justify the emphasis being placed upon consumer participation in the planning, implementing and evaluating mental health policies and programmes is highlighted in the following comment:

*Increased consumer input, if carried out effectively, should lead to services that are more responsive to consumer needs. As a flow on effect consumer involvement may diminish the costs of service operation by "getting it right first time" for consumers*

*and by promoting consumer health through participation. It would also improve outreach and encourage development of more co-operative and less paternalistic treatment regimes (Ministry of Health, 1995:4).*

However, as already explained, the degree to which people with disabilities are 'empowered' or able to exercise 'choice' will also undoubtedly be determined by the limitations placed upon resources made available to implement their decisions (Cochrane, 1994; O'Brien & Wilkes, 1993), and the extent to which they are 'enforced users' (Taylor et al, 1992).

In being consistent with the document 'Managing Major Psychoses' the Panel<sup>154</sup> noted how people's needs differ as a consequence of the nature of their disability. For example, when discussing the need for a diversity of accommodation options the Panel explained that: "*This diversity is brought about by the type and extent of disability, how it is acquired, the age of onset, and the experience and attitudes of the individual and/or the family, etc*" (Naylor & Lardner, 1994:8). Such a stance would ensure that the specific needs of persons diagnosed with schizophrenia are met.

While focusing upon the needs of those persons exhibiting the symptoms of either schizophrenia or bipolar disorder, the document 'Managing Major Psychoses' gave care-givers and the implications of their caring work limited consideration<sup>155</sup>. However, the document 'Living at Home', did differ from this stance. For example, in discussing the role of family/informal care-givers, it was noted that:

*Family caregivers are predominantly women. They may have sacrificed a career or left paid employment to care; they may be influenced by society's 'expectation' that they will take on the caring role; they may be consumed with guilt if they want to relinquish that role.*

*The caring role can go on for years in the case of chronic disability, requiring an increase in physical and emotional commitment due to ageing and increased incapacity of both the caregiver and the person with a disability in many instances.*

<sup>154</sup> The Panel discussing the issues of living at home.

<sup>155</sup> As previously noted, this is the level of consideration usually given to the personal characteristics of care-givers and the costs associated with their care provision within policy documents (Bowman & Virtue, 1993; Munford, 1994).

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*The stress of long term caring with no end in sight can be debilitating and demoralising (Naylor & Lardner, 1994:21).*

While acknowledging first that it is typically women who provide informal care, and second some of the conditions in which this care is undertaken, the Panel did not challenge this division of labour. Instead, emphasis is placed upon the requirement to maintain and improve the care of care-givers, rather than explore how their responsibility for care could be shared. This is highlighted in the following quotation:

*Major issues that need to be addressed for family caregivers are the support, recognition and relief necessary to manage what is often a demanding and protracted commitment (Naylor & Lardner, 1994:9).*

The Panel suggested various services which would support these predominantly women care-givers in their provision of care. Examples of these suggestions were: access to counselling services; regular and appropriate respite care; and, the receipt of support, information, and training. Supporting the predominance of women in the provision of informal care is consistent with the state's aim to reduce its involvement in the delivery of care.

While the Panel seemed to assume the primacy of family care-givers, the above quotation (Naylor & Lardner, 1994:9) could be utilised to support the merging of state, community and family care (Cass, 1994; Edgar, 1992). It is disconcerting to acknowledge that the caring work of women is known to be a "...*demanding and protracted commitment*" (Naylor & Lardner, 1994:9) without effectual attempts being made to reduce the level of commitment involved. The provision of support, information and training, access to counselling services, and regular and appropriate respite care will not adequately reduce the extent to which family care-givers engage in this "...*demanding and protracted commitment*" (Naylor & Lardner, 1994:9). In other words, the current caring arrangement needs more than fine tuning. Instead this arrangement needs to be fundamentally changed.

The wellbeing, participation, and especially empowerment of care-givers did not receive the same degree of attention within the 'Living At Home' document, as that attention paid to people with a disability, despite initial acknowledgment of both the characteristics of care-givers and the costs associated with their caring work.

Instead, the care-giver was referred to only in relation to the person they provided care to, to ensure the latter's quality of life. As with other policy documents, care-givers were primarily considered as part of the cared-for's social context (Bennie & Maniapoto, 1993). For example, when identifying who should be consulted regarding housing policy for people with disabilities, the input of care-givers was not seen as an integral part of the consultation process, that is, unless care-givers come under the heading of 'other interested parties'. This disregard for care-giver input occurs despite overseas research which has established that over half of persons diagnosed with schizophrenia return to live with their families after hospitalisation (Anderson et al, 1986; Kuipers, 1993; Smith & Birchwood, 1987; Staznickas et al, 1993). It seems that care-givers in New Zealand receive the same attention as British carers when it comes to service provision. Twigg and Atkin (1995:7) have noted:

*...the uncertain and ambiguous position that carers occupy within service provision. They are not clients, yet they are increasingly part of the concern of welfare agencies. They exist as it were off centre to service provision rarely themselves the direct focus of an intervention, yet often significant in the determination of provision.*

Taylor et al (1992:20) have argued that participation and empowerment of users and carers within the social services need to be considered differently:

*The distinction between users and carers must be made explicit because their needs are different, because the basis of their relationship with formal service providers is different and because their participation in service development, delivery and evaluation requires different frameworks.*

It appears that those who construct New Zealand's policy have yet to acknowledge the need to distinguish between users and care-givers when considering and endeavouring to actualise the participation and empowerment of these two groups.

While not acknowledging the potentially different needs of care-givers, the Panel discussing the issue of living at home did note the conflict which can occur in meeting the needs of both the care-giver and the person cared-for. Like Ungerson (1993), the panel utilised the example of respite care: "*In dementia, the classic*

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*issue is the person who does not want to go to a home to allow the carer to have a break*" (Naylor & Lardner, 1994:11). The Panel, however, did not offer any specific strategies as to how the potential and actual antagonism between those (typically women) who provide care and those persons who receive care can be resolved, except for noting that: "*Policies and practices have to be evolved which do not differentiate unduly against one person in the [caring] relationship*" (Naylor & Lardner, 1994:11)<sup>156</sup>.

The connection between the particular complexities of different caring relationships, and the differing needs of those who provide care, were briefly acknowledged. For example: "*...those [needs] of a family caring for a member with Alheimers disease will be very different from those looking after a teenager with head injury*" (Naylor & Lardner, 1994:10). Apart from this comment, reference to the differing needs amongst care-givers remained generalised. The brevity of the above statement gives no indication as to whether the needs of carers in different caring relationships have been examined, and if so, how these needs will be translated into policy and service provision. The material presented, when discussing the nature of caring work, highlighted the importance of first identifying and then understanding how the complexities and characteristics of caring work differ amongst care-givers depending on the abilities of the person receiving care. The particular implications of the symptoms of schizophrenia for the development and implementation of service provision have been indicated throughout the material presented in this chapter.

In summary then, the above discussion examined two consensus development conference documents, entitled 'Managing Major Psychoses' and 'Living at Home'. As these titles suggest, the first document discussed those issues surrounding the outcomes, treatment, and consumer issues associated with people experiencing either schizophrenia or bipolar affective disorder. The second document explored what was required for persons with a disability to live at home with dignity. Both of these documents acknowledged the importance of moving beyond those health needs associated with a particular diagnosis. The recommendations forwarded in both of these documents were consistent with a social definition of disability.

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<sup>156</sup> Discussion of the Mental Health Act 1992 highlighted how important it is to construct policies which are not detrimental to either those providing or receiving care.

Both 'Managing Major Psychosis' and 'Living at Home' focused their attention primarily upon the wellbeing, empowerment and participation of those persons with a disability. In reflecting this focus, the Panels' recommendations reflected the optimal course of action to meet the needs of persons with a disability. Tensions exist however between these recommendations and the extent to which available resources will allow people with a disability to be empowered to exercise choice. The continuum of care, required by individuals exhibiting a cyclical pattern of acute and chronic symptoms of schizophrenia, suggests that these individuals will continue to experience limited choice. The informal care-givers of these individuals will continue to take primary responsibility for providing the care and assistance they require.

While the 'Living At Home' document covered issues usually neglected within policy documents, specifically those issues surrounding the role of women in the provision of care, these issues still need to be clarified, expanded, and rethought if a duality of focus (Twigg & Atkin, 1995) in caring relationships is to be taken. Particular thought needs to be paid to how the potential and actual antagonism between those who provide and those who receive care can be resolved. Furthermore, strategies need to be developed to ensure that policy and related service provision is flexible enough to reflect the complexities and characteristics of differing caring relationships. Challenges need to be made about the assumption that women will continue to undertake their caring work, despite this work being a "*...demanding and protracted commitment*" (Naylor & Lardner, 1994:9).

## Looking Forward

The task of looking forward into the future continues in this section. The document 'Looking forward: Strategic directions for the mental health services' (Minister of Health, 1994b) will provide the framework for this examination. As the title of this document suggests, attention will be directed towards the proposed configuration of New Zealand's future mental health services.

The Minister of Health Jenny Shipley has acknowledged the current problems and gaps inherent in New Zealand's mental health services -- problems and gaps

already identified in this chapter. Shipley's solution to these "*serious and deepseated problems*" (Minister of Health, 1994b:5) are the following five strategic directions which are to be implemented in New Zealand over the next three to ten years:

- *implementing community-based and comprehensive mental health services*
- *encouraging Maori involvement in planning, developing and delivering mental health services*
- *improving the quality of care*
- *balancing personal rights with protection of the public*
- *developing a national alcohol and drugs policy* (Minister of Health, 1994b:13).

According to Shipley, the result of the completion of these strategic directions over the next ten years, will be a comprehensive and cost-effective mental health system<sup>157</sup>. Clarification needs to be provided as to what Shipley means by 'comprehensive and cost-effective'. The emphasis the current New Zealand Government is placing upon reduced state expenditure and increased individual responsibility suggests that contradiction and difficulties may arise from this pairing. Just as with the terms 'choice', 'rights', 'citizenship', 'access', 'participation', 'need', 'freedom', and 'equality', the terms 'comprehensive' and 'cost-effective' need to be understood in the context of the current political, social, and economic environment.

The first strategic direction, implementing community-based and comprehensive mental health services, indicates the continued shift away from providing mental health services within psychiatric hospitals. As the Minister of Health (1994b:27) has noted:

*Community mental health services will become the linchpin for the mental health services. They will be the primary focus for care, providing services to all members of the community. Use will still be made for residential services with consumers moving back and forth between community and residential care depending on their needs.*

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<sup>157</sup> The possible contradiction and difficulties associated with uniting the terms 'comprehensive' and 'cost-effective' have already been noted in this chapter.

Adequate provision of community mental health services will be vital if the movement between community and residential care is not to be unduly characterised by the revolving door syndrome (Butler, 1993; Lamb & Shaner, 1993). In order for consumers to move *"...back and forth between the community and residential care depending on their needs"* (Minister of Health 1994b:27), those contradictions which exist between the aim to implement community-based and comprehensive mental health services and the Government's wider social and economic policy need to be addressed. An example of such contradictions has been provided by Campbell Roberts, Salvation Army Social Services National Director, when talking about why the Lower Hutt Salvation Army closed its emergency housing: *"...trying to keep emergency houses going had been a nightmare. This has all come about since market rents became government policy"* (The Dominion, 1995:1).

The Lower Hutt Salvation Army emergency accommodation was receiving around five referrals a week for psychiatric *"patients"* being discharged from residential care and *"disturbed people"* the police had found on the streets (The Dominion, 1995:1). The erratic behaviour of these persons, the difficulty experienced in trying to collect rent from them, and the higher maintenance costs because of the misuse of the house meant that the house could no longer continue to operate. Concern was expressed by Mr Christoffersen, from the Lower Hutt Salvation Army, about the care *"discharged patients"* and *"disturbed people"* (The Dominion, 1995:1) receive. Mr Christoffersen was quoted as saying: *"...the real tragedy was that such people were victims who needed help, but that help had to come from professionals equipped to cope"* (The Dominion, 1995:1).

A benchmark of three percent has been established as the percentage of the general adult population and their families, and of youth and their families, who will require mental health services. The benchmark for these two groups has been adapted for New Zealand from work which has been undertaken in New South Wales, Australia. Table 8 outlines what the three percent benchmark means in practical terms by indicating the number of beds which will be available in both inpatient and community residential services. The number and type of mental health staff which will be available is also noted in Table 8.

**Table 8.** Number of available beds and mental health staff (Barwick, 1994:12).

	New Zealand Overall	Per 200,000
* inpatient beds (acute 525; medium/longstay 424)	949	56 (31,25)
*community residential services (level I 654; level II and III 1,780)	2,434	144 (39, 105)
* community mental health services (psychiatrists 203; nurses 678; other clinical 678; non-clinical 311)	1,870	110 (12,40,40,18)

The adequacy of this three percent benchmark has however been questioned. Burns et al (1994:9) have proposed that:

*The [3 percent] benchmark reflects levels of use of a narrow range of services and narrow definitions of mental illness. It takes no account of*

- *Historic levels of unmet need.*
- *Changes in the social and economic environment which might reduce or increase mental health needs.*

Examples of such social and economic changes already identified in this thesis are: the 1991 benefit cuts, the rises in state housing rentals and increasing health costs. Disley (1991:21) has spoken of the potential implications of the 1991 benefit cuts for those persons with a psychiatric disability:

*It is acknowledged that already people who suffer from a psychiatric disability often do not have their basic needs for food, clothing and shelter adequately met. To further decrease their ability to meet these needs would have major implications for their wellbeing. The additional stress due to financial pressures could lead to a deterioration in mental health and readmissions to acute health services.*

The recommendations within the documents 'Managing Major Psychoses' and 'Living at Home' that services need to be comprehensive and social policy integrated are again implied by Disley's (1991:21) comment.

When setting the benchmark for mental health services, attention needs to be paid to the particular characteristics of mental disorders. Schizophrenia is a case in point. As already noted, schizophrenia, for those forty to sixty percent who regularly utilise mental health services (Kaplan & Sadock, 1991), is characterised

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by a cyclical pattern of chronic and acute episodes. The need to acknowledge the recurrent nature of mental disorders was noted in the document 'Looking Forward' by focusing on the prevalence of mental disorders as opposed to solely their incidence.

*Prevalence describes the number of people who are 'ill' at any one time. For many people, their mental disorder is recurrent and long-standing. Even if there were no new cases of mental disorders, mental health services will still have to deal with people with existing mental illness or disability (Minister of Health, 1994b:9).*

Several implications arise from focusing on the prevalence of mental disorders. Foremost of these implications is the need for a continuum of services and acknowledgment that resources are being allocated to an area not associated with 'growth' (Waerness, 1984). Both of these issues will be briefly discussed below.

In order to deal with the changing nature of the symptoms of schizophrenia, New Zealand's mental health services need to be provided on a continuum from the least restrictive community-based services to the more restrictive institutionally-based services. Such a continuum would ensure that services are able to meet the care and support needs of people diagnosed with schizophrenia during their periods of wellness and then follow the course of their illness. Developing and maintaining such a continuum of care is going to be resource intensive. Influencing the decision to allocate the level of resources required will be the acknowledgment that mental illness is not associated with 'growth' (Waerness, 1984). As was argued earlier in this chapter, those causes associated with either 'stagnation' or 'deterioration' tend to receive fewer resources than those associated with 'growth'. The question is raised as to whether decision makers will challenge accepted ways of deciding who will and who will not receive funds. Mental health services, that traditionally have been perceived as less fashionable than other services will need to be given renewed priority. While it is true that mental health services will not be improved dramatically over night, the question is raised as to how committed the New Zealand Government is to fixing those gaps which currently exist in these services and when significant changes will occur.

Improving access to mental health services is one of the principles guiding the first strategic direction (Minister of Health, 1994b). The importance of this principle was highlighted in the consensus development conference document 'Management of Major Psychosis'. The conference Panel acknowledged the vital importance of persons having easy access to services in order to ensure that symptoms had limited impact upon both the individual's functioning, and those people in the individual's social network:

- \* *...early intervention in a first episode of illness or a relapse may avert the development of symptoms that would be more difficult to settle if left untreated*
- \* *delayed access to treatment may result in increased risk to self or others.*
- \* *early and rapid access to treatment may facilitate a less complex intervention which is less stigmatising and disruptive of a person's life and social network (Fernando & McGeorge, 1993:18).*

In order to ensure easy access, the Panel suggested amongst other things that: *"...services should be provided that extend beyond normal working hours to provide 24 hour/7 day a week rapid and direct access to care"* (McGeorge & Fernando, 1993:19).

The discussion above suggested that the aim of improving people's access to New Zealand's mental health services is often prevented by the Mental Health Act's 1992 focus upon both those individual's defined as 'mentally disordered' and compulsory assessment and treatment. The examples provided by Mike Moore, MP for Christchurch North, indicated that people often have to be acutely unwell before they gain access to New Zealand's formal mental health services. Second, early intervention may be hindered by the distribution of state contracts for welfare services amongst an array of providers. Whereas services for mental health have typically revolved around one of the main psychiatric institutions, this is no longer the case. Bronwyn Rogers, the chairperson of the Wanganui Committee on Community Care highlighted the fragmentation associated with the mental health services in her area:

*In Wanganui's case we've ended up not with one large institution (Lake Alice) but with fragmented services and several*

*locations and several organisations. So there's fragmented accountability. You end up with this fragmented service which makes communication very difficult* (Wanganui Chronicle, 1995d:3).

The above discussion on early intervention and the fragmentation of services highlighted the pressure informal care-givers face to increase their level of care provision to their family member diagnosed with schizophrenia. Specifically, the restricted access to New Zealand's mental health services means that these informal (typically women) care-givers are having to provide care which previously would have been delivered by formal mental health staff. The difficulty these care-givers experience in providing this care is magnified by the severity of their family member's symptoms before formal mental health services will assist. The politics of placing untrained and unsupported informal care-givers in this position has already been questioned.

The second strategic direction is encouraging Maori involvement in planning, developing, and delivering mental health services. The need for such a strategic principle is required not only by the Treaty of Waitangi, but also by the state of Maori mental health in comparison to *tauiwi* (Ministry of Maori Development, 1993). Particular factors need to be taken into account when encouraging the involvement of Maori in the formal mental health arena. Some of these factors are the aims that Maori have set for themselves regarding their health. While acknowledging the diverse needs of Maori, Durie (1994) has identified three broad aims for Maori health development. Specifically, within the bounds of *tinu rangatiratanga* or tribal authority and self determination, these aims include: *"...the elimination of disparities between Maori and non-Maori, the health and safety of future generations, and active Maori participation"* (Durie, 1994:189).

Another factor is the inverse age distribution between Maori and *tauiwi* (NZDS, 1993c). The New Zealand Maori population has been noted particularly for its youthfulness (Statistics New Zealand, 1994). In 1991 *"...almost half of New Zealand Maori were under 20, while only 5 percent were aged 60 years and over"* (Statistics New Zealand, 1994:32). In comparison, the New Zealand *tauiwi* population is recognised as being an aging one (Statistics New Zealand, 1994). In the 1991 census, persons identifying as solely European (including New Zealand European) counted for 19.5 percent of the New Zealand population. *"Less than*

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*one-third of New Zealand Europeans were aged under 20 years, while 18 percent were aged 60 years and over* (Statistics New Zealand, 1994:32). Services then need to acknowledge that the health needs of elderly *tauiwi* could be in direct competition with the health needs of young Maori.

The age structure of the New Zealand Maori population raises the question of who provides informal care to young adult Maori diagnosed with schizophrenia. Previously it was noted that the schizophrenia and care literature has identified older mothers as the primary informal care-giver of a family member diagnosed with schizophrenia. These mothers have generally been found to be in their mid-fifties to mid-sixties (Lefley 1987). The youthfulness of the New Zealand Maori population (Statistics New Zealand, 1994), however, suggests that there may not be a contingent of older mothers available to fill an informal care-giver role for those young adult Maori diagnosed with schizophrenia. Again, the importance of not generalising the caring experiences of white, middle-class and heterosexual women, is emphasised (Graham, 1991).

The greater involvement of Maori in delivering mental health services appears to have been enacted by the RHAs directly contracting with Maori to provide health and disability support services. The extent to which the CRHA has contracted Maori initiatives was highlighted in 'Central News' (CRHA, 1995). The CRHA has confirmed twenty-three contracts with Maori providers, this number exceeding the CRHA's initial expectations. Further, the CRHA has ring fenced further funding for purchasing services for Maori. Specifically, *"The RHA has earmarked \$2.8 million for specialist Maori mental health services and \$1.7 million for Maori providers"* (CRHA, 1995b:5).

Improving the quality of care is the third strategic direction outlined in the 'Looking Forward' document. While 'care' was not clearly defined, discussion of this third strategic direction revolved around New Zealand's formal mental health services. According to the document 'Looking Forward', New Zealand's formal mental health services are being overhauled in order to improve the quality of care, particularly to those people with severe psychiatric disabilities. This overhaul includes: the development of data collection and analysis systems; the coordination of services; the establishment and revision of monitoring mechanisms; and, an increase in the number of community mental health workers. The material presented in this thesis

suggests that quality care will be achieved only when informal care is simultaneously addressed with formal care provision. Discussion in this thesis has highlighted the need for more to be known about the complexities and characteristics of the informal care provided within a family to a member diagnosed with schizophrenia. Furthermore, it was argued that a resolution needs to be made to reduce the tensions between those who provide care and those who receive care. In other words, a duality of focus is required (Twigg & Atkin, 1995). The understanding that women are willing and able to continue to be the main informal care-givers and undertake what has been defined as a "*...demanding and protracted commitment*" (Naylor & Lardner, 1994:9) needs to be challenged.

Understanding the characteristics and complexities of both formal and informal care, and addressing the inadequacies in this care provision will facilitate the merging of state, community, and family care provision. The highest quality of care is likely to be provided only when state, community and family care is coordinated and comprehensive (Cass, 1994). Again, whether a commitment will be made to achieve this merging is questionable. The merging of state, community and family care seems unlikely to happen in New Zealand's current political, social and economic environment.

The fourth strategic direction is balancing personal rights with protection of the public. The Mental Health Act 1992 has determined this balance to a large extent. Unless an individual is defined as 'mentally disordered', they are entitled to make their own decisions regarding their treatment and living arrangements. Not surprisingly, when considering the discourses which influence the way in which mental illness is understood and the number of events reported in the media which have involved persons with a psychiatric disability<sup>158</sup>, much debate has surfaced regarding the adequacy of the balance between personal rights and the protection of the public as defined within the Mental Health Act 1992 (Bridgman, 1994). As already noted, moves are being made to alter the current balance of rights by changing the criteria of 'serious danger' to 'danger' (Wanganui Chronicle, 1995c).

Discussion to establish a more appropriate balance between personal rights and the protection of the public has reportedly been restricted (Crowe, 1995). The

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<sup>158</sup> Such an event is the death of Eric Gellatly.

public has been withheld information about circumstances surrounding some incidents involving people with a psychiatric disability as a consequence of the Privacy Act 1993. Both the Minister of Health and the Capital Coast<sup>159</sup> spokeswoman declined to talk about the psychiatric patient giving birth on a Waitangirua street as a consequence of the Privacy Act (The Dominion, 1995a). Jim Crowe, President of Schizophrenia Fellowship (NZ) Inc, spoke, at the World Federation Mental Health Congress at Dublin earlier this year, about how the Privacy Act 1993 has been used as a tool for preventing change :

*As far as I am concerned the Privacy Act condones bad practice. It shields the psychiatric system and government almost totally. When incidents happen, they cannot be discussed. For example, in a recent case in New Zealand when a person with a mental illness made a number of attempts to access treatment, but was refused on all occasions, the unfortunate result was a murder-suicide. When attempts were made by community groups to obtain information on the situation with the intention of preventing similar future occurrences the Privacy Act was invoked, which meant no one would discuss anything. This shows how powerless the community is in causing change to prevent further such incidents (Crowe, 1995:2).*

The issue of early intervention is particularly relevant when discussing rights and protection with regard to people exhibiting schizophrenia. The acute symptoms of schizophrenia, such as lack of insight, hallucinations, and delusions, mean that it is often extremely difficult to convince a person exhibiting these symptoms that they require professional assistance. The difficult task of determining when this person can be defined as 'mentally disordered' then begins. Until this definition can be applied, an individual continues to have the right to go without treatment. As demonstrated by the material presented in this chapter, the issue of protection versus rights frequently arises while consideration is being made about whether a person is 'mentally disordered'. The current state of New Zealand's mental health services means that even if changes are made to the definition of 'mentally disordered' early intervention will be difficult.

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<sup>159</sup> Capital Coast is the name of one of the CHEs.

The fifth and final strategic direction identified in the document 'Looking Forward' is developing a national alcohol and drugs policy. This policy should reduce the difficulty that people with existing mental disorders have in accessing services for alcohol or drug addiction (Minister of Health, 1994b). Previously mental health services and drug and alcohol services have worked independently.

As already intimated within the above discussion, funding is going to be a major factor determining the implementation of the above five strategic directions for New Zealand's mental health services. This was identified by the Minister of Health (1994:4):

*Adequate mental health services will require better utilisation of existing mental health expenditure and, through recognition of mental health as a health gain priority area, the shifting of health resources to mental health. The Government also recognises mental health as a priority area for new health funding.*

In acknowledging the funding problems inherent in New Zealand's mental health services, the Government in its 1994 budget announcement<sup>160</sup>, indicated its intention to allocate additional funds to mental health over the next three years. Specifically an additional \$20 million will be spent on mental health services in the 1994/95 financial year, with \$25 million being spent in each of the following two financial years. This money will be targeted towards "higher-quality services in the community to assist people in need of care, and especially those who have come from institutions" (Birch, 1994:8). However, the question is raised as to whether these additional funds will translate into higher-quality services. As Mahey (1995:95) has argued:

*...'mental health' includes a huge raft of complaints and conditions, taking in not only the major psychoses like schizophrenia and manic depression, but also some treatments for drug and alcohol abuse, anxiety disorders, mood disorders including depression, eating disorders, Maori mental health - the list goes on. Seen from this perspective Jenny Shipley's Budget-night hand-out of just less than \$1 million per CHE<sup>161</sup>*

<sup>160</sup> This announcement was made on June 30, 1994.

<sup>161</sup> As was noted in part two of Chapter Three, there are twenty three CHEs throughout the country.

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*does not herald dramatic improvements for our 20,000 people with severe, long-term schizophrenia.*

Although the five strategic directions, which will direct the development of New Zealand's mental health services over the next three to four years, have been outlined, a level of uncertainty exists as to the final characteristics and shape of New Zealand's mental health services. Examination of the terminology utilised within the document 'Looking Forward' explains some of this uncertainty. Terms such as 'cost-effective', 'sufficient', 'effective', 'efficient' bound the discussion of New Zealand's mental health services. This terminology is consistent with that utilised by Shipley (1991) and Upton (1987), these policy makers advocating market liberalism. Again, the need for such terms to be understood within the current social, political and economic environment is stressed. Although one has certain suspicions about the future configuration of New Zealand's mental health services, it is the future which will inform us of the outcomes of Shipley's (1994b) strategic directions.

It appears that implementation of the directions outlined in the document 'Looking Forward' (Minister of Health, 1994b) will come under close scrutiny. For example, the concerns which have consistently been raised about the adequacy of New Zealand's formal mental health services (Christchurch Press, 1995; Evening Post, 1995; Wanganui Chronicle, 1995b) have led to yet another inquiry of these services. This inquiry, also led by Judge Mason, is to focus upon those services provided to individuals with acute and semi-acute mental disorders which will include consideration of the rights of members of the family. (The Dominion, 1995c).

### **The Context of Care - The Key Themes**

Discussion in this chapter has extended the understanding of the care examined in this thesis by focusing on how factors external to individual caring relationships impact upon the care provided to a family member diagnosed with schizophrenia. Guiding this discussion was the consideration of social policy as defined for the purpose of this thesis. Social policy was considered to include both those prescriptions made by Government regarding the type and degree of intervention required by the state, the community, and the family in order to provide support to those persons diagnosed with schizophrenia, and the assumptions which direct this

intervention. Examination of the two components of social policy occurred in the three parts of this chapter.

It was argued that the state has been primarily responsible for the paid care undertaken by women in service delivery positions within the social services. The community, consisting of voluntary and profit making organisations, was noted for the way it straddled the formal caring work of the state and the informal caring work of the family. Finally, the family was identified as being primarily responsible for the unpaid caring work, typically provided by women, to family members with a need for care. It was argued that the various combinations of state, community, and family care have reflected the changing definitions successive New Zealand Governments have associated with the terms 'rights', 'responsibilities', 'citizenship', 'participation', 'access', 'need', 'choice', 'freedom', and 'equality'. It was argued that the current Government's consideration of the terms 'rights', 'responsibilities', 'citizenship', 'participation', 'access', 'need', 'choice', 'freedom', and 'equality' has been guided by an adherence to market liberalism and coupled with the transition from a Fordist to a Post-Fordist state.

As expected, the state has been following the Government's directions to increasingly devolve its responsibility for care provision to the community and the family. The schizophrenia and caring literature has established that it is generally mothers in their mid-fifties to mid-sixties (Lefley, 1987), rather than 'the community' or 'the family', who provide the majority of their family member's informal care. These women will undoubtedly feel anxious about the current emphasis being placed upon individual responsibility and 'the family' for care provision. These women can no longer assume that the state will provide for their family member when they themselves are no longer able to do so as a consequence of death or ill health.

Welfare services as a whole are characterised by uncertainty and fragmentation as state contracts are being won by an array of providers. The particular difficulties people diagnosed with schizophrenia may experience in accessing New Zealand's welfare services were noted, these difficulties arising as a consequence of the symptoms of schizophrenia. It was argued that the informal care-givers of these individuals may need to assume responsibility for establishing first, who has welfare contracts, second, where these providers are situated, and third, the

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criteria for accessing these services. Once care-givers have established this knowledge base, they may then need to advocate that their family member needs professional assistance. Care-givers are expected to have the resources, energy, knowledge and skill to provide care to a family member whose symptoms of schizophrenia invariably change in type, frequency, intensity and duration, and are also expected to remain informed about how to access formal service provision which has been disseminated amongst various service providers. The practicality of this expectation may mean that family members do not receive the formal services they require.

Consideration of the contracting process for welfare services, combined with an acknowledgment of the dominant discourses of schizophrenia, suggested that the state may experience difficulty in finding potential providers who are experienced and willing to compete for state contracts for mental health services. Mental health has traditionally been less fashionable than other areas of health and disability and has therefore received fewer resources (Bascand, 1993; Minister of Health, 1994). Insufficient interest from providers may mean that the quality of those providers who do compete for the provision of mental health services may not be as high as in other welfare arenas. This unwillingness could translate into a lack of innovation in the mental health arena relative to general health services. Therefore, those women who provide informal care to a family member diagnosed with schizophrenia may need to continue to assume increasing amounts of responsibility for their family member's care provision.

The state's devolvement of its caring responsibilities has also been achieved by the focus of current legislation, such as the Mental Health Act 1992. As was illustrated when discussing the narrow definition of 'mentally disordered' (Ministry of Health, 1993), the Mental Health Act 1992 has raised the threshold of entry to New Zealand's formal mental health services. By default, then, women are being expected to increase their care provision to attend to the welfare needs of their family member when their family member is not defined as 'mentally disordered'. In the light of discussion such as this, it was proposed that informal care-givers are having to take responsibility for the care which formal mental health services would previously have provided to their family member. Care-givers then, are joining the general public in witnessing schizophrenia without the restrictions previously

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provided via New Zealand's formal mental health services, for example, institutionalisation.

The policy of deinstitutionalisation has challenged the dominant discourses that proposed that the public needs to be protected from those individuals exhibiting the symptoms of mental illness. This challenge provided an opportunity for competing discourses of mental illness to be accepted as 'truths'. However, the opportunity for challenging the dominant discourses of schizophrenia has been reduced as a consequence of the inadequacies inherent in New Zealand's community-based mental health services. Indeed, discussion of events, such as Eric Gellatly's death (Wanganui Chronicle, 1995a:1995b), indicated how these events have supported the belief that people diagnosed with schizophrenia are dangerous and violent.

New Zealand then, has not taken the opportunity to rectify the problems traditionally and currently inherent in its formal mental health services during the transition from institutionalisation to deinstitutionalisation and community care. One possible explanation for this lost opportunity is the assumptions the New Zealand Government appears to have held about the availability and appropriateness of women as informal care-givers of their psychiatrically disabled family members. Even if women are willing and able to increase their informal care provision, the assumption that women will automatically be able to provide care previously the responsibility of New Zealand's formal mental health staff appears to be flawed. While discussing the complexity and heterogeneity of schizophrenia, it was proposed that no matter how much a woman loves her family member, women may not intuitively or instinctively know how to provide care. Such an assumption about the natural ability of women to care would undoubtedly place undue strain and stress upon those women who are expected to provide care to a family member diagnosed with schizophrenia.

Despite the emphasis social policy, and its accompanying service provision, has placed upon the increased role these care-givers should play, these women are still not considered as part of the mental health team. For example, discussion of the Mental Health Act 1992 and the Privacy Act 1993 highlighted the contradictions which surround the pressure informal care-givers experience as they increase their care provision to include that care previously provided by formal mental health

staff, these informal care-givers are often not provided with information about the family member's diagnosis, prognosis or treatment.

Acknowledgment of the difficulty informal care-givers experience as a consequence of their care provision, suggests that state, community and family care provision needs to be combined if the quality of life of these informal care-givers is to be improved. This combining of social and private caring responsibilities (Cass, 1994) would more effectively ensure the continuum of care required by those individuals who exhibit the cyclical positive and negative symptoms of schizophrenia (McGeorge & Fernando, 1993). Consideration of the symptoms of schizophrenia suggest that a continuum of care would need to include early intervention services, community-based mental health services, and institutionally-based mental health services. It was acknowledged that it is unlikely that the current Government will support the merging of social and private caring responsibilities. Such a merger would be antithetical to increased individual responsibility and reduced state expenditure.

In the following chapter, a framework for the analysis of care is developed. The understandings about care presented in this and the previous two chapters provide the foundation from which this framework is developed. This framework will show the relationship between theoretical perspectives on care, the development of policy and its implementation, and the experiences of those who provide care to a family member diagnosed with schizophrenia.

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## 4. A FRAMEWORK FOR ANALYSIS

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In this chapter 'the framework for analysis of care' is developed. The framework will act as a conceptual tool for developing an understanding of the informal care examined in this thesis. The framework will act as a guide for making sense of the participants' experiences of providing informal care to a family member experiencing the cyclical acute and chronic symptoms of schizophrenia.

The development of 'the framework for analysis of care' involves an amalgamation of the themes identified in the previous three chapters. In Chapter One, an understanding of schizophrenia was developed. This discussion highlighted the complexity of this heterogenous disorder and identified some of the ways in which schizophrenia could influence the provision of informal care. In order to further understand the lived experiences of those persons diagnosed with schizophrenia and their informal care-givers, the dominant discourses of 'disability', 'mental illness', and 'schizophrenia' were identified and discussed. Attention was then turned, in Chapter Two, towards establishing the characteristics and complexities of the unpaid care provided to a family member diagnosed with schizophrenia. Discussion identified the similarities and differences between this form of care and the care provided to a family member with an intellectual, physical, or age-related disability. In continuing to consider the nature of the care provided to a family member diagnosed with schizophrenia, the question of who provides this caring work was considered. Foremost amongst this consideration was an acknowledgment of the over-representation of women amongst those who provide informal care. In having considered how factors, internal to the caring relationship, impact upon the provision of informal care provided to a family member diagnosed with schizophrenia, attention was then turned to consider the impact of external factors. In Chapter Three, an understanding of how New Zealand's social, cultural, political, legal, and economic context impacts upon the informal care provided to a family member diagnosed with schizophrenia was developed by examining how New Zealand's social policy, both directs and reflects the way in which caring responsibilities are divided between the state, the community and the family. It was argued that current and proposed future distributions of caring responsibility between these three caring agents are likely to increase the difficulty women will

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experience in providing informal care to a family member diagnosed with schizophrenia.

'The framework for analysis of care' consists of three main components. The first of these components to be considered is the 'what' facet of care, or in other words, what does the informal care provided to a family member diagnosed with schizophrenia consist of? When considering the question 'what is care?', various feminist conceptualisations of care were presented including: 'caring for' and 'caring about'; the persons receiving care; the rights of care-givers and the rights of care-recipients; the purpose of care; and, the personal is political. Material from the schizophrenia and care literature both complemented and extended the discussion of these feminist conceptualisations of care. This examination raised several main points. Foremost amongst these points was first, that 'care' is a complex and demanding form of work, and second, that existing feminist understandings of care need to be extended in order for these understandings to reflect the informal care provided to a family member diagnosed with schizophrenia. Both of these points are confirmed by the material presented in Table 5<sup>162</sup>. Utilising Table 5 as a guide when considering the care examined in this research should highlight the extent to which existing feminist understandings of care could be extended in order to reflect the informal care provided to a family member diagnosed with schizophrenia.

The second component of 'the framework for analysis of care' is the 'who' facet of care. The insights feminists have contributed on the question of 'who cares?' have been useful for examining the care provided to people with schizophrenia. Table 6<sup>163</sup>, both highlighted the greater involvement of women in the provision of informal care and some distinct differences which exist between the care provision of women and men. The degree to which Table 6 reflects the 'who' facet of care provided to a family member diagnosed with schizophrenia will be examined in this research.

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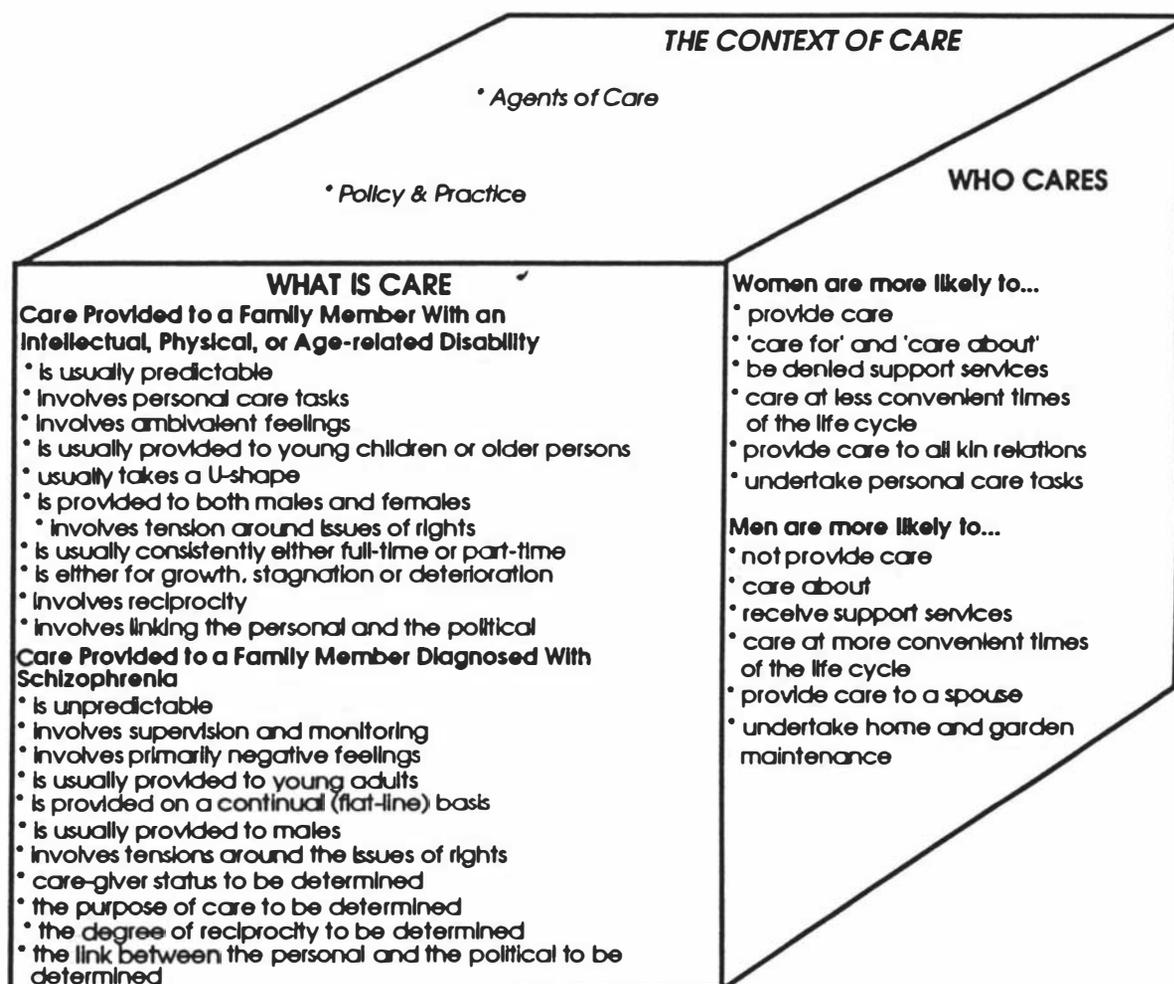
<sup>162</sup> Table 5 was presented when identifying the key themes present in the chapter entitled 'The Nature of Care'.

<sup>163</sup> Table 6 was also presented when identifying the key themes present in the chapter entitled 'The Nature of Care'.

The third and final component of the framework for analysis is 'the context of care'. The understanding that informal care provided within individual caring relationships does not occur within a vacuum was confirmed. This discussion proposed that when examining the unpaid care provided to a family member diagnosed with schizophrenia, consideration needs to be given first, to the way in which caring responsibilities are divided between the state, the community and family and second, to how this division both reflects and directs social policy and its accompanying service provision.

The 'what' and 'who' facets of care and the 'context of care' have been incorporated into what I have termed, 'the framework for analysis of care' presented in Figure 2. This framework reflects the interrelatedness of these three facets of care.

**Figure 2.** 'The framework for analysis of care'.



As was noted above, the framework will act as a conceptual tool for developing an understanding of the informal care examined in this thesis. As will be more fully explained in the following chapter, the fieldwork component consists of interviews during which the participants told their stories about providing informal care to a family member diagnosed with schizophrenia, and three group meetings which the participants attended. In the final chapter, 'the framework for analysis of care' will be redeveloped in order to reflect the characteristics and complexities of the participants' care provision to their family member. 'The framework for analysis of informal care provided within a family to a member diagnosed with schizophrenia', presented later in this thesis, is constructed from this dialogue.

## **S**ection Two:

# **M**ethodological

# **I**ssues

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## 5. THE RESEARCH PROCESS

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This research examines the characteristics and complexities of the informal care provided within a family to a member diagnosed with schizophrenia, in New Zealand. The research question consists of two components. First, what are the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia? And second, how is this care provision influenced by the social, political, cultural, and economic context of New Zealand? The research question had particular implications for the methodological framework utilised in this research, implications that are set out below.

Initially, attention is directed towards acknowledging the theoretical underpinnings of the methodology. First, the premises underlying the positivist, interpretive and participatory research paradigms are identified. Incorporated within this discussion is an acknowledgment of the various methods and procedures which arise from the premises of each research paradigm. In the discussion on the positivist research paradigm, the utilisation of the structured questionnaire is detailed. The use of stories is covered when the interpretive research paradigm is examined. Encompassed within the discussion of the participatory research paradigm is a description of 'member checking', 'feedback loops' and 'triangulation'. The tendency to dichotomise research as either quantitative or qualitative is then challenged. Following this discussion of research paradigms is an identification of the feminist principles which guide this research. This discussion of feminist principles identifies the important role that groups can play in the research process.

Following the consideration of research paradigms, attention is then directed at the extent to which values, ethics and politics influence the research process. This discussion, highlights that the research findings and resulting conclusions are directly influenced by how the researcher resolves these issues. The final part of this chapter will discuss the specific procedures utilised in this research.

## Research Paradigms and Feminist Principles

Just as there are different ways of thinking about or conceptualising care, there are also different ways of studying or researching care. A researcher typically chooses a research paradigm by matching their own experiences and view of the world with the premises and philosophy underpinning a particular research paradigm. This is reflected in Munford's (1992a:162) following statement: "*Our methodological orientation must of necessity match the value stance we adopt*". However, this process is bi-directional. The research paradigm we choose acts as a lens we use to filter our view of the world around us. Our view of the world directs our actions as we move within it. Each research paradigm:

*...shapes what we look at, how we look at things, what we label as problems, what problems we consider worth investigating and solving, and what methods are preferred for investigation and action. Likewise a paradigm influences what we choose not to attend to, what we do not see (Maguire, 1987:11).*

As Maguire's (1987) explanation implies, the choice of a research paradigm is an important decision, for each research paradigm has different consequences not only for the research results, but also for the research participants and the quality of their lives.

The following discussion will illustrate that positivist, interpretive, and participatory research paradigms have their own strengths and weaknesses. It was the acknowledgment of this which led me to incorporate each of these research paradigms, along with feminist principles, when gathering, processing, and analysing the findings of this research.

### The Positivist Research Paradigm

Positivism is, in recent history at least, the most frequently utilised research paradigm. An underpinning assumption of positivism is that phenomena can be logically explained, these phenomena interacting in consistent and predictable patterns. The success of positivist research in describing the realm of the natural sciences saw positivism being utilised for examining people and their interactions with others. As Neuman (1994:58) has explained:

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*Positivism defines social science as an organised method for combining deductive logic with precise empirical observations of individual behaviour in order to discover and confirm a set of probabilistic causal laws that can be used to predict general patterns of human activity.*

Positivism then is utilised to identify those causal relationships which direct the predictable interaction between people and their environment.

The premise that phenomena are predictable as a consequence of various causal relationships directs the way in which positivist researchers view and define knowledge. According to Carr & Kemmis (1986:61) positivism proposes that: "*the label 'knowledge' can only be ascribed to that which is founded in 'reality' as apprehended by the senses*". In short, positivism states that there is only one predictive truth. This truth is objective (external), parsimonious (simply explained), predictive, and explanatory of observed phenomena (Conrad & Maul, 1981). Great emphasis is placed by positivist researchers upon findings being valid (meaningful) and reliable (replicable).

To ensure that 'the truth' is found, research guided by positivism often takes an experimental form. The most common methodologies utilised by positivist researchers include experiments and self-report structured questionnaires. One major benefit of these methodologies is their ability to be utilised with large (100 to 1000 plus) sample sizes with relatively limited resource expenditure. The data of this research paradigm is then collated and categorised into quantified dependent variables which can be examined via statistical analysis. From these analyses, inferences from the sample to the population the sample purportedly represents are then advanced, along with the levels of confidence that the researcher hold for these inferences.

The 'truth' is also ensured by positivist research through the strict adherence to principles of what constitutes 'proper' research -- distance, control, hierarchy, and being non-emotive. As Neuman (1994:61) has proposed, the positivist "*...researcher remains detached, neutral, and objective as he measures aspects of social life, examines evidence, and replicates the research of others*".

While positivist research has provided us with general principles which help us to explain our world, the premises underpinning positivism have been critiqued. For example, feminists have argued that in searching for one correct truth, the experiences, views and lives of women have been disregarded:

*Such research again takes as the norm the androcentric view of the world in which the circumstances of women's (and other oppressed 'groups') lives are seen as aberrations from this norm: 'deviant', 'other', 'the exception' (Duelli Klein, 1983:2; see also de Beauvoir, 1972; Smith & Noble-Spruell, 1986).*

In summarising positivist research, feminists have concluded that this form of research is simply:

*...another agent of authoritarian social control. Knowledge and power are all on the side of the researchers and their political masters, and none is on the side of those who provide the data and are subject to its subsequent application (Heron, 1981:34).*

It has been argued that positivist researchers consider people to be subjects which respond in predictable ways to their environment. In examining the responses of individuals in isolated situations, little attention is paid by positivist researchers to the way in which these responses are influenced by the wider context in which their subjects reside. Instead, problems are seen as inherent in the person, social change is virtually non-existent (Oliver, 1992).

### *The Structured Questionnaire*

I initially gained access to the participants of the research for this thesis by utilising a structured questionnaire. A sociology student, who knew I was about to embark on the research for this thesis, asked me to help develop the questionnaire for a study he was undertaking. It was during this process that I saw the questionnaire as an opportunity for accessing potential participants. The last question of this questionnaire invited the respondents to participate in the research for this thesis. While the questionnaire was the main mechanism by which the participants were contacted, the message was given via Schizophrenia Fellowship that I was inviting care-givers to take part in the research.

The structured questionnaire was developed in order to determine the 'needs of care providers of people with schizophrenia'. A care provider was defined as that person who was a friend of the care-receiver or a member of the care-receiver's family group or whanau, and who was most evidently and directly concerned with the oversight of the care-receiver's care and welfare<sup>164</sup>. The care-receiver was the person diagnosed with schizophrenia. The questionnaire was sent out to care-givers who were members of Schizophrenia Fellowship in two lower North Island cities. Twelve of the fifty respondents of this questionnaire (ten women and two men) indicated that they were interested in participating in the research for this thesis.

While the questionnaire provided me with an opportunity to indicate to potential participants that the research for this thesis was being undertaken, feedback from the respondents of this questionnaire (both those who did and did not offer to participate in this research) indicated that the questionnaire was difficult to answer. Each question asked the respondent to circle a number on a five point scale which most reflected their experiences or circumstances. The five point scales did not capture the fluid and changing nature of the respondents' experiences of their care provision. On reflection I considered whether more of the fifty questionnaire respondents might have offered to participate in this research if initial contact with them was more in line with the participatory research paradigm. One possible alternative to utilising the questionnaire to recruit participants would have been a public meeting for those persons who provide care to family members diagnosed with schizophrenia to discuss relevant issues.

### **The Interpretive Research Paradigm**

While the positivist research paradigm facilitates the establishment of various principles to both explore and predict interaction between individuals, this paradigm does not facilitate an exploration of what certain events, feelings and views mean to those persons experiencing them (Conrad & Maul, 1981; Neuman, 1994). One response to this is the interpretive research paradigm. When utilising an interpretive research paradigm, the focus moves to the experiences and

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<sup>164</sup> This definition was derived from the Mental Health Compulsory Assessment and Treatment Act's 1992 definition of a 'Principal Caregiver'.

perceived realities of the respondent, expressed in the person's own words and concepts:

*...the 'interpretive' tradition of social inquiry seek[s] to replace the scientific notions of explanation, prediction, and control, with the interpretive notions of understanding, meaning and action (Carr & Kemmis, 1986:83).*

Interpretive research then does not aim to find 'the truth' but allows expression of multiple experiences (Denzin & Lincoln, 1994; Oliver, 1992). In order to gain an understanding of a respondent's experiences, interaction with each respondent should be more concentrated. Research based on an interpretive research paradigm usually involves considerably smaller participant numbers than research based on a positivist paradigm. Questioning of the validity of interpretive research has been one of the consequences of the need for smaller respondent numbers. However, Blumer's (1969:141) statement responds to such questioning:

*One should sedulously seek participants in the sphere of life who are acute observers and who are well informed. One such person is worth a hundred others who are merely unobservant participants. A small number of such individuals brought together as a discussion and resource group is more valuable many times over than any representative sample.*

Those who utilise the interpretive paradigm are clear about their aim to break down the hierarchical researcher/subject relationship inherent within positivist research. The 'value-free' assumption of positivist research is shed as is the belief that interactions in the social world are predictable and sterile. Instead, researchers adhering to an interpretive research paradigm *"...emphasise the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning"* (Denzin & Lincoln, 1994:15).

Criticism of the interpretive research paradigm revolves around the idea *"...that while the interpretive paradigm has changed the rules, in reality it has not changed the game"* (Oliver, 1992:106). The researcher is still typically considered to be 'the expert'. The researcher chooses the research topic, develops the interview questions without consulting those participating in the research, and analyses and

interprets the results. It is the researcher who also determines when and how the research results will be utilised.

### *The Use Of Stories*

In order to allow the participants to describe their own experiences, interactions, and thoughts, I suggested to the participants that the research methodology incorporate the opportunity for them to tell their stories about their informal care provision. In making this suggestion, I was acutely aware of feminist critique of previous research which had failed to capture the experiences of women. Feminist writers have argued that women and their experiences have predominantly been filtered and defined by men (Anderson, Armitage, Jack & Wittner, 1990; de Beauvoir, 1972; Figs, 1986; Harding, 1987; Lewis, 1981; Thiele, 1986). This viewpoint is succinctly stated by Lerner (1986:14):

*What women have done and experienced has been left unrecorded, neglected, and ignored in interpretation. Historical scholarship, up to the most recent past, has seen women as marginal to the making of civilisation and as unessential to those pursuits defined as having significance.*

*Thus, the recorded and interpreted record of the past of the human race is only a partial record, in that it omits the past of half humankind, and it is distorted, in that it tells the story from the viewpoint of the male half of humanity only.*

The challenge from feminist writers such as Lerner (1986) confirmed my aim to ensure that the women in the research would be able to tell their stories openly and that these stories should be recorded, acknowledged and validated. My methodology needed to be flexible enough to accommodate both the similarity and diversity in the participants' experiences. My intention then was to hear the 'women's experiences' as opposed to hearing the 'woman's experience' (Harding, 1987) of providing care to a family member diagnosed with schizophrenia. Research techniques based upon the positivist research paradigm would not facilitate the hearing of the 'women's experiences'. As Barnes (1992:116) has explained:

*...methodologically, statistical logic and an experimental approach are no longer considered appropriate for studying the meanings of the everyday life world in which we all live.*

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*Surveys, random sampling techniques, and the use of control groups are not necessarily applicable to the quest for understanding.*

The method of stories was attractive for many reasons, one of which was that through stories, people reveal not only themselves, but also the power that orients their lives (Christ, 1980). Second, the storyteller has more control over what aspects of their lives are identified for investigation in comparison to traditional data collection methods (Graham, 1984). Third, stories, in comparison for example to a survey or traditional question-answer interview, allow cohesiveness in the way the storyteller constructs and reports their experiences (Graham, 1984). Via their stories, the storyteller situates their experiences within the social, cultural, political and economic context of their society. Fourth, within the storyteller's story, one also receives a degree of their interpretation of their experiences (Graham, 1984). Finally, "*There is a dialectic between stories and experience, stories give shape to experience, experiences give rise to stories*" (Christ, 1980:5).

In considering the use of stories as a form of data collection, several issues came to the fore. First, discussion on the nature of care emphasised the lack of detail which exists regarding the process and interpretation of the care provided to a family member diagnosed with schizophrenia (Atkinson & Coia, 1995; Perring et al, 1990; Twigg & Atkin, 1995). Utilising the method of stories provided an opportunity to determine not only the characteristics and complexities of this care provision, but also to establish the meaning associated with these characteristics and complexities by the women who provided this informal care.

Second, although I was not expecting the participants to be skilled in the art of storytelling (Sawyer, 1970; Shedlock, 1951), I acknowledged that via their involvement in their local branch of Schizophrenia Fellowship the women had a good grasp on their own and the experiences other women had had in their caring relationships. The women were used to talking about and sharing with others in a similar situation, their stories about their caring situation.

Third, when telling a story, events and experiences are often detailed and comprehensive. I felt it was important that the participants be given the opportunity to edit their stories. The process of 'member-checking' proposed by

Lather (1986) and Reason and Rowan's (1981) similar process of 'feedback loops'<sup>165</sup> answered this problem.

Third, when expressing my intention to use stories, some of my peers challenged me with issues of validity (meaningfulness). I also had some concerns about these issues. This concern stemmed from my awareness of the privileged position of quantitative as opposed to more qualitative research methods within the academic setting. In answer to the challenges of validity, I instigated the process of 'triangulation'<sup>166</sup> utilised in conjunction with the methods of member checking and feedback loops. Graham's (1984:120) point also helped to decrease my concern about issues of validity with regard to the use of stories: *"The opportunity for fabrication, for 'telling tales' in a perjorative sense, is present in stories as it is in conventional question-and-answer techniques"*.

The information collected via the method of storytelling<sup>167</sup> provides the reader with a window through which to view and comprehend the perceived realities of the research participants as expressed in their own words and concepts.

### **The Participatory Research Paradigm**

A third way of undertaking research is within the framework of a participatory research paradigm. This research paradigm has, as its focus, political action and social change. When utilising a participatory research paradigm, unquestioned assumptions, for example, about the nature and role of those involved in the research, about who has the right to create knowledge and about who owns the research results, are challenged. A consequence of this challenge is that past prescribed rules and boundaries are not adhered to (Lather, 1986). The position of people is not examined, noted, and generalised to establish 'social facts'. Focus is on how power shapes and influences these persons' positions legitimating them as truth.

Political action and social change is achieved through the empowerment of the research participants (Barndt, 1989; Reason, 1994). A research participant is no longer seen as a 'thing' being acted upon by the world, but as a participant *"...who acts upon and transforms his [sic] world, and in so doing moves towards ever new*

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<sup>165</sup> Both 'member checking' and 'feedback loops' are discussed below.

<sup>166</sup> The process of 'triangulation' is also discussed below.

<sup>167</sup> This information is presented in the following three chapters.

*possibilities of fuller and richer life individually and collectively*" (Freire, 1986:12). A research participant is seen to have the potential to "...gradually perceive his [sic] personal and social reality as well as the contradictions in it, become conscious of his [sic] own perception of that reality and deal critically with it" (Freire, 1986:12), if they have access to the appropriate tools.

Instead of simply capturing the respondents' understandings of the world in which they live<sup>168</sup>, a researcher drawing upon a participatory research paradigm acts as the medium or vehicle for this change, working in collaboration with the research participants, contributing their skills and knowledge to be utilised by the participants. The research participants have an equitable role in the production and utilisation of the knowledge established during the research (Maguire, 1987).

This focus upon political action and change was relevant to the topic of this thesis for several reasons. First, discussion on the nature of care highlighted the predominant place that burden held within the schizophrenia and care literature (Arieti, 1984; Atkinson, 1986; Beels & McFarlane, 1982; Bernheim, 1990; Brooker, 1990; Dearth et al, 1986; Deveson, 1985; Doll, 1976; Falloon et al, 1984; Hatfield, 1978, 1979; Holden & Lewine, 1982; Howe, 1991; Lamb & Oliphant, 1978; Lefley, 1987; Mittleman, 1985; Morris et al, 1989; Wahl & Harman, 1989; Walsh, 1985; Willis, 1982). The participatory<sup>7</sup> research paradigm provided a potential mechanism whereby the burden 'the family' provides could be challenged. This is especially the case when acknowledging the expectation that the family will increase its level of welfare provision to its members. Challenge could also be provided to the over-representation of women amongst those who provide care to a family member diagnosed with schizophrenia. Lefley's (1987) and Warren's (1994/1995) arguments have questioned the expectation that women, typically in their mid fifties to mid sixties will continue take primary responsibility for their family member diagnosed with schizophrenia.

The first step towards this radical transformation of the research participants' perceived reality, is the exploration of their experiences, feelings, and thoughts. The expression of these aspects of the research participants' realities are

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<sup>168</sup> Simply capturing the respondents' understandings is usually the focus of the interpretive research paradigm.

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acknowledged as legitimate forms of truth. It is at this time that participants 'name the moment' or identify what is taking place so that strategies for change can be developed and implemented (Barndt, 1989). Research can be a mechanism by which research participants can identify and change the 'status quo', transforming structures which were previously accepted as natural and unchangeable. 'Naming the moment' (Barndt, 1989) not only helps to empower the research participants, but also allows the researcher to work towards both understanding and positioning her/himself in the lives of the participants (Kondo, 1990).

The third step in participatory research involves the researcher, in collaboration with the research participants, utilising this understanding of the participants' perceived realities to challenge the existing power relations at every level (Reason, 1994). A space is created where participants are acknowledged as experts of their own experience, defining what for them is truth. Participants are given the space to voice their own opinions (Lather, 1991). Research becomes relevant to the participants' lives not only in the validation and affirmation of their reality, but by instigating political action to positively alter their position and experiences in their society.

Participatory research provides the space needed for the participants to share their stories with others. However, the particular characteristic which drew me towards a participatory research paradigm was the possibility of moving beyond acknowledging, representing, and validating the participants' experiences, feelings and views which is primarily the premise underpinning the interpretive research paradigm. A participatory research paradigm provided the potential for the participants, in collaboration with myself, to implement some positive change in their everyday experiences. It was this latter outcome which gave me the incentive to continue and complete the research described in this thesis.

While noting the benefits of drawing upon the participatory research paradigm, I had to actually implement a method which would enable the premises underpinning this paradigm to be realised. It is to this method which attention will now turn. First, description will be provided on how the women participated in developing the interview guide utilised in this research. Following this, the

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strategies of member checking, feedback loops, and triangulation, will be discussed.

### *The Interview Guide*

To each interview, I took along with me a guide consisting of seven main themes. These themes were identified by both the women and myself when the question of the focus of this research was discussed at the women's first group meeting. In other words, at this initial group meeting the women and myself identified issues which we thought were needed to be explained within this research. The seven themes were to act as departure points for the women's stories (see Appendix Three). Under each of these seven themes, I had listed questions which could act as prompts if needed. The prompts acted as a guide to ensure that these issues were covered by each of the participants. The interview guide had one primary purpose. It ensured that there was continuity between the interviews, this being important later for organising and analysing the women's stories.

### *Member Checking*

In being consistent with the premises underpinning the participatory research paradigm, the participants needed to not only 'name the moment' (Barndt, 1989), or acknowledge and articulate their own experiences, understandings, and ideas, but also needed to have control over the use and interpretation of the information they had provided. This was particularly important as a consequence of the method of storytelling potentially collecting extremely personal information. I therefore searched for a mechanism whereby the participants could maintain as much control as possible over the information they shared. During this search, I found the method of 'member checking' (Lather, 1991). A 'member check' involves taking the data/results provided by the research participants, back to them, to receive and incorporate their critique/feedback. The interpretations of the participants' information that I myself as a researcher hold, and the participants hold are discussed, compared and contrasted. Together, myself and the participants can work by negotiation towards an understanding of each others interpretations. In implementing this negotiation process, the participants were sent written copies of any of their information which had been taped in order to critique and censor it as they felt fit. The draft chapters of the thesis were also sent to the participants for comment.

### *Feedback Loop*

Lather's (1986) member checking is similar to Reason and Rowan's (1981) feedback loop in which issues are revisited or identified and discussed several times. In this research, the themes and issues identified by the women at their initial group meeting were incorporated into their stories and again at the group meeting where the results were fed back to the women. The men revisited the issues they had identified during their storytelling at their group meeting where the results were fed back. Again all of the participants received draft chapters of the thesis for comment.

### *Triangulation*

A possible consequence of increasing the control the participants had over the production and utilisation of their knowledge was the critique that this research is not valid. As already noted, I had been challenged by my peers about issues of validity when discussing using storytelling as a mechanism for data collection with them. In order to better address the issue of validity, I utilised the process of triangulation (Lather, 1991). Triangulation involves utilising several different methods of data collection. First, I undertook a review of the existing literature on providing care to a family member diagnosed with schizophrenia. Second, New Zealand's policy documents, particularly those related to mental health, were examined to establish the implications of such policy for the care provided to a family member diagnosed with schizophrenia. Third, information was obtained via the structured questionnaire on needs of care providers of people diagnosed with schizophrenia<sup>169</sup>. Fourth, I drew upon my own knowledge of providing care to a family member diagnosed with schizophrenia. This knowledge was developed via both acknowledging my mother's experiences of caring and my involvement in Schizophrenia Fellowship. Fifth, the method of storytelling was utilised during both a one-to-one interview with the women, and then with those men who undertook a secondary supporting role. This process highlighted the similarities and differences between the experiences of the women and their husbands. Finally, as well as meeting the participants individually, the women and the men met separately in groups.

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<sup>169</sup> As already noted, this questionnaire was utilised as a method primarily to recruit participants for the research outlined in this thesis.

## **Combining Research Paradigms**

The methodological framework developed for this research combined positivist, interpretive, and participatory research paradigms. This process is contrary to one stream of thought which dichotomises the use and value of the various research paradigms. This stream of thought has assigned research processes and techniques to either category of masculinity (quantitative/positivist) or femininity (qualitative/interpretive). As a researcher, I agree with Smith and Noble-Spruell (1986) who state:

*In scholarship, there has been an over-validation of hard data over soft, and an artificial splitting of these characteristics falsely ascribed to the two sexes. This has led to dichotomous ways of thinking and to the separating out of different approaches, which then are placed in false opposition to each other.*

It is important to challenge this dichotomous way of thinking. A researcher who is aware of the strengths and weaknesses of each paradigm, and has a good ethical base, can enhance their research by developing a methodological framework which draws on a combination of research paradigms. This assumption is supported by the methodological framework utilised in this research. Combining the various research paradigms was required in order to examine how the internal and external factors of a caring relationship impact upon the informal care provided to a family member diagnosed with schizophrenia.

## **Feminist Principles**

Feminist principles also informed this research. As was noted above, feminist researchers are particularly interested in understanding the perceived realities of women. The feminist perception of the world is that men and their experiences, views and needs are acknowledged as if they are the experiences, views and needs of all humankind (Anderson et al, 1990; de Beauvoir, 1972; Figs, 1986; Harding, 1987; Lerner, 1986; Lewis, 1981; Thiele, 1986). The specific experiences, views, and needs of women and children are generally ignored. Feminist researchers are primarily concerned with addressing this imbalance by ensuring that the experiences, feelings, and views of women are acknowledged, represented, and validated within wider society. In holding this perspective,

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feminist researchers have directed their research at areas which have particular concern and/or relevance for women. Some of these areas have been, for example, housework, child care and the interaction between women's unpaid and paid work commitments (Briar, 1992; Easting, 1992; Horsfield & Evans, 1988; Novitz, 1987; Women's Affairs Victoria, 1994). In order to ensure that the experiences, feelings and views of women are acknowledged, represented, and validated, feminist researchers have utilised a variety of research paradigms, their feminism either directing their use of an existing method or instigating the development of new research methods (Reinharz, 1992).

Just as there are several types of feminism, there is no formalised way of undertaking feminist research. However, several principles have been identified in the feminist research literature as guides for the feminist researcher's use of various research methods. Six of these principles have guided the research in this thesis. These principles are listed below:

- To keep in the forefront the identification and examination of gender issues with the intention of developing strategies to positively alter them for women, and ultimately men (Cook & Fonow, 1990; Finch, 1984; Lerner, 1986; Maguire, 1987). This principle can be drawn upon in acknowledging first, that care is primarily provided by women, and second, is associated with reduced life opportunities and poor physical and psychological health (Hicks, 1988; Parker, 1985; Qureshi & Walker, 1989).
- The belief that each person has their own basket of knowledge and skills which should be acknowledged and respected (Heron, 1981). While undertaking this research, I was acutely aware of the vital role the participant's played in guiding this research. The importance of the participants' experiences and knowledge is noted when again acknowledging the dearth of information regarding the process and interpretation of the care provided to a family member diagnosed with schizophrenia (Twigg & Atkin, 1995).
- To utilise a collaborative approach in working towards the feminist ideal of a non-hierarchical relationship with participants - this relationship involving the establishment of reciprocity (Lather, 1991; Oakley, 1981; Reinharz, 1992). This principle encouraged me to find ways of undertaking research which would allow the participants and myself to work in a collaborative

and non-hierarchical manner. Inviting the women to establish, with myself, those issues to be examined in this research was one way I adhered to this principle.

- To acknowledge 'women's experiences' as opposed to 'woman's experience' (Grant, 1987; Harding, 1987; Kondo, 1990; Plaskow & Christ, 1989). It is important to remember that the term 'women' is not a homogenous category. Diversity is celebrated in feminist research. This principle reminded me that I needed to note both the similarities and the differences in the participants' experiences. For example, while all of the women were providing care to a family member diagnosed with schizophrenia, it was important to acknowledge how their care provision was affected for example by their economic circumstances and the support they received from others.
- To create a space where the participants can draw on their experiences and can voice their own opinions to challenge existing 'truths' (Anderson et al, 1990; Christ, 1980; Graham, 1984; Lather, 1991; Lerner, 1986; Lewis, 1981).

This principle reminded me of the importance of bringing people together to share their experiences and to establish how these experiences are similar and different from the accepted truths. It is via this process that the personal can be transformed into the political. Apart from their involvement in Schizophrenia Fellowship, many of the participants had had little opportunity to openly share their stories.

- To present research in a form that enhances the participants' position and is accessible to them and facilitates their taking action to effect change (Lather, 1991). If information is not accessible to those involved in the research, it cannot be utilised by them to positively alter their circumstances. Utilising the process of member-checking and feedback loops increased the participants' access to the results.

### *The Use Of Groups*

In drawing on feminist principles I acknowledged the importance of bringing together individuals with similar experiences to acknowledge and articulate their experiences, feelings and thoughts. The power of collectively identifying the group's experiences allows the personal to become political. Individual group members have the opportunity to acknowledge the structural constraints and

solutions to their individual situations. This process of consciousness raising is more likely to result in action within the support and collective power of a group. The processes of making the personal political and of consciousness raising were consistent with the premises and philosophy underpinning the participatory research paradigm.

The group meetings were consistent with the data collection method of focus groups. A focus group is: "6 to 12 individuals who are similar in some way and come together to discuss an issue of specific interest to the researcher" (Asbury, 1995:415). The information collected through the use of focus groups is characterised by its richness. As Krueger (1995:530) has explained:

*Focus groups allow participants to hear ideas and use those concepts in formulating their options. Focus groups capture the complexity of the human experience and provide valuable information to decision makers.*

## **Values, Ethics and Politics Guiding This Research**

Regardless of which research paradigm is being utilised, the researcher needs to consider the role of values, ethics, and politics and how each of these impact upon the research. The role and influence of values, ethics and politics are inextricably linked in this research. Each of these issues will be discussed below, with the inter-relationship between values, ethics, and politics being identified.

### **Values**

Much debate has occurred over the role and place of values within the research process. This debate was alluded to when the positivist, interpretive, and participatory research paradigms were discussed above. Traditionally, research (positivist in nature) has been viewed as being value free and objective (Denzin & Lincoln, 1994; Neuman, 1994) and therefore has been regarded as proper research. The advent of other research paradigms (for example interpretive or participatory) has challenged the traditional view that proper research needs to be viewed as value free. Finch (1984a) has argued for example that researchers utilising more recent research paradigms have simply been more honest in acknowledging the impact their values have had on the research process.

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May (1993) has indicated the extent to which values influence all research, from the research topic, to the choice of the research paradigm, to how and what questions are asked, to how the results are interpreted, to how the results of the research will be utilised. Scrutiny of the various components of this research identifies the values that both myself as a researcher and the participants, the women in particular<sup>170</sup>, held. The following discussion will illustrate the influence that values have had on this research by focussing upon the research topic. As already noted, the research question consists of two parts. First, what are the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia? And second, how is this care provision influenced by the social, political, cultural, and economic context of New Zealand?

By its very existence, this research question implies that the unpaid care provided to a family member diagnosed with schizophrenia is worthy of examination. Further, this research question proposes that unpaid care is work. Challenges are automatically made then to the understanding that work consists simply of those paid activities undertaken in the public sphere (Waring, 1988). The next major component of the research question identifies the recipient of care, a family member diagnosed with schizophrenia. As was clearly highlighted in previous discussion, people with schizophrenia have typically been feared and discriminated against (Miller, 1995) and consequently left to endure social isolation (National Mental Health Consortium, 1989). This research question implies that instead of continuing to ignore people diagnosed with schizophrenia, research needs to be undertaken to ascertain how the disorder schizophrenia uniquely impacts upon the provision of informal care these people receive. This influence needs to be examined and detailed not only to understand but also to improve the lives of these family members and their care-givers.

## **Ethics**

Ethics in the research sense refer to determining whether research is being conducted appropriately with due regard for the rights and responsibilities of both researchers and participants. One way of making this determination is to ask

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<sup>170</sup> As will be detailed more fully later in this chapter, the women participated in developing the methodology of this research.

whether the ends or findings a researcher gains justify the means or methodological process the researcher involves their participants in. Providing an answer to this question may in itself be a difficult task. As Neuman (1994:428) has explained:

*Ethics define what is or is not legitimate to do, or what "moral" research procedure involves. These are few ethical absolutes. Most issues involve trade-offs between competing values and depend on the specific situation.*

While there are few ethical absolutes, there are certain established ethical principles that every researcher needs to consider. These principles are primarily concerned with the treatment and safety of the participants involved in the research. Specifically, as a researcher I needed to consider the issues of: informed consent; confidentiality; minimising of harm, truthfulness and social sensitivity (Massey University Human Ethics Committee, 1994). Just as was the case with values, ethics affect all stages of the methodological process from the choosing of the research topic, to the recruitment of the research participants, to the choice of research paradigm, to the use, distribution and storage of raw data, to the presentation of the research findings.

While all of the above ethical principles were adhered to, I was particularly concerned about three issues. The first issue was informed consent. The participants' involvement in this research was both discussed with them, their rights and responsibilities being further outlined in a written consent form (See Appendix 2). After having answered any of the participants' questions about their participation in this research, they signed the consent form. The second of these issues was that of confidentiality. For example, the participants needed to be able to return to their home knowing that they would not be further discriminated against as a consequence of the personal information they had shared about their care provision. Use of the strategy 'member checking' provided the participants the opportunity to delete information which could have personally identified them. The third issue was closely related. The results of this research needed to be presented in a such a way that they could not be utilised to reinforce the incorrect, but dominant discourses surrounding schizophrenia. For example, supporting the understanding that all people diagnosed with schizophrenia are necessarily violent individuals would do little to improve the lives of either persons diagnosed with schizophrenia or their informal care-givers. Particular care was taken when

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writing this thesis to challenge the dominant discourses of schizophrenia. Discussion of time, for example, when the family members did exhibit anger or aggression clearly indicated the precursors to this behaviour. While these issues were related to the ethical principles of confidentiality and the minimising of harm, the need to consider such issues arose from the political environment in which the research was situated. The political nature of mental illness is highlighted below.

## Politics

Historically, both the researcher's role and the research undertaken have been conceived as objective and neutral. I begin this discussion on politics and research by stepping outside this conception, openly acknowledging the political nature of this research. I will now draw on several aspects of this research to illuminate this assertion.

First, I acknowledge that issues related to mental illness have been firmly situated in the arena of public debate, thus helping form it into a political topic. As already indicated, I was especially aware of how results of this research could be utilised in this debate to either improve or worsen the quality of life of both those individuals who experience schizophrenia and those women (and men) who provide informal care to these individuals. In researching the experiences of these women and men, I needed to be aware of the implications of studying down or researching the less powerful. Bryson (1979:100) argues that studying down provides *"...information that can lead to more effective control of the less powerful"*.

Second, in researching with the primary and secondary providers of informal care<sup>171</sup> for a family member diagnosed with schizophrenia, I politically aligned myself with the interests and concerns associated with those persons who fill such a role. I chose to provide these persons with the opportunity to 'name the moment' (Barndt, 1989) and have their voices heard. My aim is that the interests and viewpoints (Bryson, 1979) of these women and men will be furthered.

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<sup>171</sup> In the following discussion it will be explained that whereas the women provided the majority of their family member's care, the men tended to fill a secondary supporting role. The specific characteristics of this supporting role are detailed below.

Third, I need to acknowledge how my own personal characteristics and structural position influenced the methodological process. The participants knew of the journey I was travelling in establishing first what the provision of care to a family member diagnosed with schizophrenia involved and second, deciding whether I would be prepared to provide this care in the future. The similarity of experiences between myself and participants not only provided "*an entree into the interview situation*" (Finch, 1984a) but also enhanced the flow of information from the participants.

Also, in identifying the political nature of this research, I needed to acknowledge the discrepancy between the gains from this research obtained by the participants and myself as researcher. Although my aim was to facilitate the enhancement of the position of those persons who provide informal care to a family member diagnosed with schizophrenia, I am aware that for me this research is, in part, a means to acquire a Ph.D.

### **Gathering the Data**

After having clearly identified both the theoretical underpinnings of this research and the way in which values, ethics and politics would influence this research, I then turned to the task of gathering the data. The process of gathering the data for this research began with my reading of the existing literature about the care provided to a family member diagnosed with schizophrenia and those policy documents related to this care provision. As has been noted in the previous discussion, various gaps existed regarding first, how this care was distributed within the family, the particular characteristics and complexities of this care provision, and how this care was influenced by the context in which it was situated. The discussion which follows outlines the strategies taken to gather the information needed to fill these gaps. Specifically, discussion will be presented under the following headings: 'Recruiting and selecting the participants'; 'The participants'; 'Contacting the women and arranging for the first group meeting'; 'The women's first group meeting'; 'The women's one-to-one interview'; 'Contacting the women's husbands'; and, 'Interviewing the men'.

## Recruiting And Selecting The Participants

Ten women and two men who completed the structured questionnaire offered to participate in this research. My first step was to decide whether it would be productive for all of these people to participate. This process was highlighted by a number of factors. First, my mother was one of those individuals willing to participate in this research. I felt that if my mother was to participate, she needed to have the opportunity to openly articulate her understandings about her care provision. In being both 'the researcher' and my 'mother's daughter', I was unsure as to whether I would allow her voice to be heard. After discussing this issue with my mother, we decided that she would not participate in this research. Second, a woman who had not initially offered to participate in the research indicated that she would be willing to participate around the time I was contacting the other participants. I accepted this woman's offer. Third, from the time that I had received the replies from the structured questionnaire, to the time when I was to begin this research, eight months had passed by. During this time the personal circumstances of one of the men who originally offered to participate as a care-giver had altered to the extent that it was not viable for him to participate in this research.

Finally, in utilising the methodological framework I had chosen, I felt it would not be appropriate to have one man in a group of women, especially when it came to issues of power. This decision was a difficult one to make in the light of the challenges which have been made about acknowledging and examining the caring work of men (Arber & Gilbert, 1993). In being consistent with existing research on care (Arber and Gilbert, 1993; Finch, 1986) both of these men were primary care-givers to their spouse.

As a result of this process, the participants consisted of ten women. My potential participant size was a maximum of twenty persons, ten women and their partners<sup>172</sup>. In recalling Blumer's (1969) statement, I was not concerned about undertaking research with a participant number which could be considered inadequate by traditional positivist researchers. The women especially were 'acute observers' illustrated through the action they took in their caring

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<sup>172</sup> As will be explained further on in this chapter, ten women and four of their husbands participated in this research. The women made it clear they preferred that the men were called their 'husbands' rather than, for example, their partners which was the terminology I had initially utilised.

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relationship, and their involvement in their local branch of Schizophrenia Fellowship.

The fact that the Schizophrenia Fellowship was established in the geographical areas the research took place, was a major help at this stage of the research. The Fellowship consisted of an already self identified population of persons, who were ideal participants for this research. Those individuals who did participate in this research will now be introduced.

### **The Participants**

The stigma and discrimination associated with schizophrenia means that it is imperative that the anonymity of the participants stays intact. As will be highlighted in the following chapters, the women and men who participated in this research had been discriminated against simply for acknowledging to others, such as neighbours and work peers, that their family member had been diagnosed with schizophrenia. The potential ramifications for these women and men could be much greater if they were linked to the personal and detailed information presented in the following chapters. Initially, the women who participated in this research will be identified as a group to ensure their anonymity. Then, each of the women will be introduced individually by the pseudonym they chose for themselves<sup>173</sup>. The same process will then be followed when introducing the four men.

#### *The Women*

All of the women who participated in this research identified themselves as primary care providers<sup>174</sup> for a family member diagnosed with schizophrenia. The women were most evidently and directly concerned with the oversight of their family member's care and welfare. As Table 9 indicates, for eight of the women it was their adult child who was diagnosed with schizophrenia. The predominance of young adult male children was consistent with the findings presented in the research on schizophrenia and care (Bulger et al, 1993; Winefield & Harvey, 1994). All but one of these women had more than one child.

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<sup>173</sup> The women also chose the pseudonym for the family member they provided care to.

<sup>174</sup> This definition was derived from the Mental Health (Compulsory Assessment and Treatment) Act 1992.

**Table 9.** Gender and generation of persons receiving care.

Generation	Gender	
	Male	Female
Offspring	6	2
Partner	1	--
Parent	--	1

All of the women were *tauiwi*, three of the women were born overseas. As with the men, the majority of the women preferred to call themselves European. Although the women's ages ranged from late thirties to mid-sixties, seven of the women's ages were between the late fifties to mid-sixties. This finding was again consistent with the schizophrenia and care research (Lefley, 1987; Warren, 1994/1995). All of the women had been married. One woman was divorced, another was widowed, and a third woman was remarried. For seven of the ten women, nursing was the career they had chosen for their past or current paid employment. The way the women combined their unpaid and paid work varied. One of the women undertook full-time paid work as well providing informal care. Three of the women combined their informal caring responsibilities with part-time paid work. The rest of the women primarily undertook their informal caring work within their homes. Five of the women who were not involved in full-time paid work were actively involved in their local branch of Schizophrenia Fellowship. These women then filled an 'extended caring role' (Traustadottir, 1991). Their own personal caring experiences, and their community work within their local branch of Schizophrenia Fellowship meant that these women were well informed about issues surrounding schizophrenia care.

While all of the women identified as the family member's main provider of informal care, each of the woman defined her care-giver role differently, their particular definition being presented in inverted commas below. The particular characteristics of the women's individual caring relationships are also identified:

**Sonya** who was in her early sixties, had been a 'carer' for her son Paul for the past eleven years. Paul lived at home with Sonya.

**Mary** had been her husband's 'care-giver' for the past seven years, during which time Michael lived at home. Mary was in her early forties.

**Helen** was 'responsible for' her mother Lidia. Helen, who was in her late thirties, had undertaken this role for the past three years. Lidia lived in a granny flat which was attached to Helen and her husband's house.

**Pat** was in her mid sixties. Her daughter Rebecca had primarily been living away from home in institutional care from the time she received the diagnosis of schizophrenia twenty years ago.

**Jill** who was in her sixties 'supported' her son Joshua, who had been exhibiting the symptoms of schizophrenia for the past sixteen years. Joshua had just moved into semi-supervised accommodation when the practical component of this research began.

**Margaret** also identified as a 'supporter' for her son Daniel who was living at home. Margaret who was in her early sixties had undertaken this role for the past thirteen years. Margaret had experienced mental ill health herself.

**Anne** had been in what she called a 'mother role' for her son Patrick for the past eight years. Patrick was in institutional care after killing his father whilst delusional. Anne was in her late fifties.

**Jackie** who was in her late forties, identified with the role of 'supporter' which began two years ago when her son Luke began exhibiting the symptoms of schizophrenia. Luke was living at home. Schizophrenia was present in the families of both of Luke's parents. In the past, Jackie had taken up a primary role for other family members, especially her mother. Jackie said that she had experienced periods of mental ill health herself.

**Harriet** had been her daughter's 'care-giver/supporter' for the past seven years. Harriet was in her late fifties. Rachael was living at home.

**Joy** had been her son's 'care-giver' for the past eighteen years. Bill was living away from home in semi-supervised accommodation. Joy was in her mid sixties.

In acknowledging the individual circumstances of each woman, it is important to remember that the complexity and changing nature of each caring relationship has not been captured by the above descriptions. These individual depictions of the various caring relationships will, however, provide a base upon which information identified in the following pages can be placed.

Throughout this thesis, the women will be referred to individually by the pseudonym they chose for themselves, or collectively as 'the women'.

### *The Men*

While the women were their family member's primary informal care-giver, the men filled a secondary supporter role. The main function of the men's supporter role was to act as a buffer to reduce the anxiety and hurt the women experienced as a consequence of the care they provided. The four men (by pseudonym) were **Ben, James, Ralph** and **Trevor**. Joy was married to Ben, as was Jill to James. Pat was married to Ralph and Trevor was Jackie's husband.

Three of the men were in their late sixties and seventies, and were either retired or semi-retired from professional occupations. The fourth man was in his early forties and was still in full-time paid employment. All of the men were *tauiwi*, one man was born overseas. Ben, James and Trevor had sons who were diagnosed with schizophrenia. Trevor was actually Luke's stepfather. Ralph's daughter was diagnosed with schizophrenia. All but one of these adult children were living away from home.

Throughout the thesis, these men will be referred to either individually by the pseudonym of their choice, or collectively as 'the men'.

### **Contacting The Women And Arranging For Their First Group Meeting**

I contacted the ten women who had indicated their interest in participating in the future research by letter. Along with an invitation to participate in this research, I sent an information sheet and consent form (see Appendix One and Two). When I later contacted the women by telephone as a follow up to the posted material, all of the women were still willing to be involved in this research. I thanked them for their interest and informed them that I would recontact them when I had a time and a venue for their first group meeting. When I had finalised these arrangements I posted each woman an invitation and then again followed this invitation with a telephone call to check each woman's availability.

During this telephone contact, I checked with each of the women whether they needed transport to and from the group meeting, and/or child care to ensure that the women would not be prevented from participating because of financial reasons. Several of the women offered to transport other women to the group meeting if needed. For example, Mary, when realising that she knew the other

women participants from her area, actually organised and transported three of these women in her own vehicle. The women who used their own transport were reimbursed for this travel in proportion to the distance they travelled. Because of previous commitments, two of the ten women could not attend the first group meeting. A third woman stated she would not come to the meeting as she did not feel comfortable in group situations.

### **The Women's First Group Meeting**

Sonya, Mary, Harriet, Helen, Pat, Jill and Joy came to the first group meeting which took place in mid-May, 1993. To begin with, each woman present introduced herself and described her particular caring relationship. The women also identified the reason(s) they had decided to participate in this research. A common response was that the women had a commitment towards the development of knowledge about the issues related to schizophrenia. The women wanted to be involved in 'something' that would contribute towards helping others whose lives had been affected by schizophrenia. Next, I explained the various research paradigms identified above, clarifying the implications of each paradigm for the role of the researcher and those involved in the research. After answering the questions the women asked, I proposed that a participatory research paradigm be utilised during the practical part of this research. The women agreed to this suggestion stating their eagerness to 'participate' in the research<sup>175</sup>. The information sheet and consent form were discussed, after which the consent form was signed by the women.

According to literature about participatory research, the ideal situation was for the research question to come from the participants:

*— The research process should involve the community in the entire research project, from the formulation of the problem and the interpretation of the findings to planning corrective action based upon them" (Hall, 1982:22).*

At first I was concerned that I was not following this ideal. After considering this concern I realised that if I had waited for this 'ideal' to occur this research would probably never have been initiated. Providing care to a family member with

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<sup>175</sup> The women had previously been involved in research projects where filling in a questionnaire was the only role they had in the research.

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schizophrenia was a major part of many women's lives. These women were busy dealing with that part of their life on a day-to-day basis. It was unlikely that these women would have stood back and started searching for someone to research their specific experience. I learnt then that the ideal paradigm is not always realistic in terms of its implementation. Utilising a research paradigm is only useful so long as it fits the particular situation under study.

The women asked if no men were invited because I thought men did not care. I explained to the women that by the time the meeting had been arranged, only one man was able to attend. I then expressed my concerns about the potential implications of this man's attendance upon the group process. The women also spoke of the potentially different (power) dynamics when men were present in a group of women. The absence of any men meant that the women felt they could express ideas and thoughts which they would not be able to if men were present.

The women were then invited to identify issues surrounding the provision of their care which they thought needed to be researched. The women drew from their own experience of schizophrenia when identifying issues or themes to be examined. In other words, in line with the first step towards the goal of participatory research, social transformation, the women 'named the moment' (Barndt, 1989). The women shared and discussed their experiences, feelings and thoughts about providing informal care to their family member diagnosed with schizophrenia. Working with the women to identify issues related to their caring relationship ensured that the research was focused on meaningful and relevant, as opposed to artificial, problems (Blumer, 1969).

The feedback I received from the women during their initial group meeting and their one-to-one 'interview' with myself heavily influenced the focus of this research. It was during this meeting that the women and I identified themes and issues which we thought needed to be studied in this research. As already noted, these themes and issues were translated by myself into an interview guide. The focus of this research became an examination of the informal care provided to a family member diagnosed with schizophrenia within the social, political, cultural, legal and economic context in which this caring relationship is situated.

I was impressed with the way the group seemed to 'gel'. Although my role was directive at the beginning of the group when, for example, discussing the various research paradigms and their implications for our respective roles, the women quickly became active members of the group. On reflection, I put this cohesion down to the women being a subgroup of Schizophrenia Fellowship. After the results had been collated, I understood this phenomenon even more. The women distinguished between their 'schizophrenia friends' and their 'other friends'<sup>176</sup>.

Another factor which I felt added to the active role taking of the women, was my own personal experience of the illness. I had shared with the women that the decisions I would make about whether to provide care in the future to my family member diagnosed with schizophrenia, would be guided by the findings of this research. I had informed the group that I acknowledged their experience and knowledge on the research question as more comprehensive than my own. On reflection, I had actually situated myself more within a 'student' role than the 'expert researcher' role. My personal need to learn about providing care to a family member diagnosed with schizophrenia was consonant with the need of many of the women to be involved in something that would contribute towards helping others whose lives have been affected by schizophrenia. The way in which the first group meeting had been organised was conducive to these needs being met. Also, my ability to fill a 'student' role in relation to the women was helped in part by the age difference between myself and the women<sup>177</sup>. This age difference which could have acted as a barrier between myself and the women, actually helped the transfer of information.

In deciding stories would be an effective, valid, and ethical method of data collection, I introduced this idea to each of the women. Again, in drawing on feminist principles (Grant, 1987; Harding, 1987; Heron, 1981; Kondo, 1990; Plaskow & Christ, 1989), I reinforced the idea that the women's knowledge, drawn from their own experiences, was legitimate. Stories were one mechanism by which this knowledge could be expressed. I explained that it was over to the women to talk about the issues or themes identified at the group meeting in the

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<sup>176</sup> This distinction is detailed later in this thesis.

<sup>177</sup> At the time of the first group meeting I was aged twenty-three years.

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way they wanted. They knew what information was relevant and important to their situation. All of the women responded positively to this proposal.

Before the group meeting, I was aware that, although I wanted the research to move in one direction, there was the possibility that the women might have wanted to follow another alternative. Utilising participatory research meant being open to negotiation about what should be researched and how it should be researched, right throughout the research process. Receiving a Scholarship to undertake this research meant that this negotiation with the participants could take place.

The group discussion was dynamic and reflected a stream of consciousness with interjection, and moving from topic to topic, being indicative of the group meeting. The complexity involved in providing care to a family member diagnosed with schizophrenia was highlighted at the group meeting. The meeting, which was tape-recorded, closed with the women expecting me to contact them to arrange a time for a one-to-one interview with myself.

### **The Women's One-To-One Interview**

All of the women participated in a one-to-one interview with myself. The interviews began at the end of May 1993 and finished in early July 1993. The date, time and place of the interviews were determined by each woman individually. Most of the interviews took place in the woman's own home, two of the women deciding to come to my own home so they were not interrupted or overheard. The time the interviews took varied with some women's stories taking longer than others. Besides the tape recorded material, which ranged from two and a half hours to four and a half hours, I spent an extra hour or two with many of the women talking about personal issues which either they indicated they did not want to be taped, or I did not feel comfortable taping. In undertaking the interviews myself, I was able to achieve a valuable overview of the women's experiences.

Before the interviews, I ensured that I was familiar with the content of the interview guide, so I could follow on from where the women ended. Part of this process was pre-testing the guide with my peers. The relevance of the guide for persons who have experienced schizophrenia was soon highlighted. All of my

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peers had had a wide range of life experiences. However, none of my peers' experiences provided them with a base upon which they could discuss the seven themes. Needless to say, I utilised all of the prompts provided.

On reflection, I think that the term interview is misleading in describing the process that occurred with the women. A more appropriate description of this process is that of a storytelling session, with dialogue interspersed between stories for clarification or beginning a new story. Without utilising this process the richness, complexity and continuity that was present in the transcriptions would not have been captured. To note the difference between the positivist concept of interview and the process involved in the interviews undertaken in this research, the latter will be referred to as an 'interview' in the rest of this thesis.

I feel that the interactions between myself as researcher and the women as participants during the group meeting were important for establishing a rapport for the 'interviews'. I do not feel that the women would have taken control over telling their stories to the extent that they did, if, as the researcher, I had explained participatory research without having begun practising it as well. As the content of the following chapters confirms, all of the women shared information that was personal and heartfelt. The women described what was involved in being primarily responsible for providing care to a family member diagnosed with schizophrenia. They identified their past expectations of a 'normal' life for themselves and their family member. The women also shared the revised expectations they held, and described the day-to-day existence they currently lived. The women identified how the social, political, cultural, legal and economic context of New Zealand, impacted upon the care they provided. In particular, the women referred to legislation, such as the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Privacy Act 1993, and the adequacy of New Zealand's mental health services.

All of the women at some point during the 'interview' asked for feedback on their story telling. The comments of **"Oh you don't want to hear about all this"** and **"Am I still on the topic?"<sup>178</sup>** were common. As alluded to above, I found all of the

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<sup>178</sup> Words spoken by a participant or the participants collectively will from now on be presented in bold.

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women's information to be interesting and relevant. I was aware, however, that the women did not just have one story, but many stories. The stories the women shared seemed to depend on a number of factors. These factors included first, the events that had happened over the last few days, weeks, or months. For example, medication was a major issue if their family member was due for their injection. Certain symptoms of schizophrenia were more prominent than others depending on the wellness or 'the space their family member was in' at the time. Second, the women adapted their stories according to their perception of my own personal experiences. Initially the women were less likely to explain in detail happenings they knew I had experienced with my own family member. The women did however talk more fully about situations I had yet to experience, for example, comparing the caring relationship at times with the responsibility of looking after a toddler for twenty four hours a day. Third, when talking about issues and experiences which could be considered controversial, some of the women assessed my reactions to these while considering how much they should say and whether to continue.

The women's stories helped me become more aware not only of the contradictions within each caring relationship and the social, political, cultural, legal and economic context of New Zealand, but also of the contradictions within myself. When I heard of the situations the women faced, a part of me stated that I would never put up with such an arrangement. Another part of me knew all too well that if I was in a similar situation as these women, I would most likely follow in the women's footsteps.

In comparison to the group meeting, the 'interviews' with the women were more focused and easier to follow. The women took the time they needed to describe their experiences in detail. The women tended to finish talking about one theme before they went onto another. The latter was easier to do without others contributing to this process as was the case in the group meeting.

### **Contacting The Women's Husbands**

Because some of the women had identified some tension between themselves and their husband with regard to their family member and the care they provided, I felt it was important that I checked with the women whether they felt comfortable about involving their husbands in this research. At the end of each 'interview', I

asked the women if they were agreeable with this proposal. Two of the women I approached felt uncomfortable about this proposition. These women explained that they had always been responsible for the main component of their family member's care and therefore did not want to involve or interrupt their husbands with this research<sup>179</sup>. I did not 'interview' a third man because of his busy work schedule. This left me with four men to 'interview'. I asked the women who were agreeable to my proposal if they would invite their husbands to participate in this research. If the men said 'yes', I contacted them by telephone and arranged a time and place to meet. Consequently, I contacted all of the four men.

### **'Interviewing' The Men**

I decided to initiate my contact with the men via a one-to-one 'interview' with myself as opposed to a group meeting. This decision was based on several factors. First, the men were not used to meeting as a group to share their experiences of schizophrenia. It was their wives who were primarily the members of Schizophrenia Fellowship. Second, I held the assumption that men generally feel uncomfortable about participating in a support group environment. When talking later with the men about the possibility of starting their involvement in this research with a group meeting, the men acknowledged that they preferred the initial contact with myself to be a one-to-one 'interview'. The men expressed their reluctance towards coming together with others they did not know to discuss such personal issues.

Ben, James, Trevor and Ralph were 'interviewed' in their own homes in the latter part of July, 1993. I took with me the 'interview' guide I had utilised in the women's 'interviews'. This original interview guide was changed slightly to ensure that it was applicable to the men (see Appendix Four). For example, I added prompts which asked the men to specifically talk about the women's care provision.

Initially I discussed with the men the focus of the research by identifying both the aims of the research and the research paradigms which were being utilised as a framework for this research. I explained how the aims and focus for this research

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<sup>179</sup> It seemed that these women were concerned that their husband's involvement in this research would raise issues that they did not want to, or could not deal with.

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had been chosen in negotiation with the women. While explaining this, I informed the men, just as I had the women, that they were able to raise issues or themes not covered the interview guide. As with the women, I also talked briefly about the method of storytelling.

I expected that the men's 'interviews' would be qualitatively different from those of the women. I thought that the men may not have been as comfortable as the women were about discussing their experiences and thoughts related to their family member's schizophrenia. However, my assumption was generally unfounded. My first request, for the men to tell me about themselves, did initially pose some difficulty. Despite this initial difficulty, the men openly invited me into their lives. They shared their own personal experiences of schizophrenia. Often their feelings were clearly visible. In comparison to the women, however, I did need to utilise the prompts more frequently. This was not surprising considering that the men had not participated in the group meeting where the information for the interview guide was identified.

Whereas the women's stories were from the perspective of being primarily responsible for their family member's care, the men spoke of filling a secondary supporting role. As already noted, the men primarily likened themselves to a buffer, working to reduce the level of harm and stress experienced by the women as a consequence of their caring work. In comparison with the women, the men spoke of being not as emotionally involved in the caring relationship. This was reflected in the tasks the men undertook in their supporting role, these tasks lacking interaction with their family member on a personal and/or emotional level<sup>180</sup>.

## **Processing the 'Interview' Material**

The above discussion described the process through which the research findings were collected. This collection process left me with over forty three hours of taped material. In order for some detailed analysis to be undertaken, this material needed to be processed. This section describes how the taped material was transcribed and then handed back to the participants for comment.

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<sup>180</sup> Further characteristics of both the women's and the men's care provision are identified and described in the following chapters.

### **Transcribing The 'Interviews'**

I transcribed each 'interview' myself word for word. When saying to others that I was transcribing the 'interviews' myself, I was often provided with reassuring responses that this task would soon be completed if I spent the time on it that it required. Transcribing the completed 'interviews' literally took months and there were times when, if I had had the money available, I would have happily paid someone else to do it. However, the benefits of spending this time soon surfaced. First, I knew each of the 'interviews' intimately. This familiarity quickened the process of comparing the various issues within and between the 'interviews' and finding representative quotations. Second, transcribing the whole 'interview' allowed the participants to easily identify which information they did and did not want to be utilised in this thesis.

### **Giving Back The Transcribed 'Interviews'**

Each of the participants received an unedited copy of their own transcribed 'interview', for the purpose of being able to delete or clarify any of their information. In acknowledging the opportunity the participants would have to delete information that could be considered controversial and/or embarrassing, I initially felt this was a risky practice. However, on the whole only names and other personally identifying information were deleted. More concern was expressed by the participants over whether I was going to leave in the 'ums', 'you knows' and unfinished sentences. All of the participants commented about the level of their verbal articulation, some stating jokingly that they would not be tape-recorded again. The participants were agreeable about their information being utilised for this research and any future publications. This was especially true when the possibility that this information could be used to help others whose lives have been affected by schizophrenia was mooted.

The participants returned the edited transcribed interviews to myself. Four of the participants took up the offer of receiving their own unedited copy of the transcripts which they could keep. One woman also asked for an edited copy of her interview which I sent to her. Several of the participants had mentioned that the transcribed 'interview' had provided them with a copy of the events and the

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sequence in which these events had occurred leading up to and following the diagnosis of their family member with schizophrenia. The transcribed interview would be kept as part of their own records.

### **Analysing the Participants' Stories**

As described above, analysis of the material provided by the participants occurred continually throughout the fieldwork component of this research, both collectively as the participants met in their groups and individually by the participants and myself as researcher. After the one-to-one 'interviews' had been transcribed, I initially examined each 'interview' individually, noting any consistent and inconsistent themes and issues that emerged. I then compared each theme/issue between the 'interviews' using the process of filing and coding (Lofland & Lofland, 1984). This involved physically cutting up the 'interviews' and collecting material on each theme/issue in a separate folder for further analysis. One of the findings of this analysis was a high level of consistency between the women's and the men's transcripts. At the next group meeting, I asked the women whether they had talked to their husbands about their 'interview', informing the men of their answers. The women clearly stated that the men had told their own stories and had not been influenced by themselves.

Analysis of the 'interview' material continued while this material was both being fed back to the participants and written into prose. This process is described in the following sections.

### **Feeding Back The Results To The Women**

I invited all the women to meet again as a group at the end of August, 1993. Sonya, Mary, Harriet, Helen, Pat, Joy, Jackie and Anne came to this second group meeting. One of the two women who did not attend had a prior arrangement. The second woman, who also did not come to the first meeting, again acknowledged that she did not feel comfortable in group situations.

Several topics during this tape recorded group meeting were discussed. The meeting was informal with discussion and clarification taking place throughout the

meeting<sup>181</sup>. My first task after welcoming the women was to feed back to the women the collective results of their 'interviews'. In feeding back the results, the themes and issues identified by the women were organised under three headings: a conundrum; assuming responsibility; and, being on call<sup>182</sup>. The results were generalised by ensuring that no identifiable personal information was given. The only exception to this was when examples of the results were identified and shared by the women themselves.

I then turned the group's attention towards those factors the women had identified as needing some change in order to improve the conditions under which they provided their care. Each identified need was explored further by the women after which discussion turned to whether and how these needs could be met. In acknowledging the power base of a group, as opposed to that of individuals, the women decided that they would utilise their respective branches of Schizophrenia Fellowship to work towards meeting the needs they had identified. For example, Mary and Joy said the following:

**Mary Well, we want to do something. We just don't want to talk about it, do we? If the needs are there we need to meet them...Do we go to the Fellowship?**

**Joy Well the Fellowship is the better way, as I see it, in that they are a national body.**

As a researcher drawing primarily upon a participatory research paradigm, I was initially despondent at the avenue the women had decided to take in meeting their needs as identified in this research. My expectations about the action we as a group could take were much 'greater' than going through an already established organisation. While hearing the women's consensus about utilising the Schizophrenia Fellowship to meet their needs, I was cognisant of Maguire's (1987,28) description of participatory research as being "*...not merely to describe and interpret social reality, but to radically change it*". The temptation to try and push the women into considering more radical action which would make this research a 'success', according to the ideal participatory research paradigm, increased. In response to my despondency, I re-learned that being a researcher

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<sup>181</sup> The informal nature of the meeting was enhanced by a pot luck lunch.

<sup>182</sup> The origin and significance of these three headings is noted in the next three chapters.

utilising a participatory research paradigm can mean that the research does not always go in the direction you have predicted.

The third task undertaken at this group meeting was to feed back the results from the men's interviews<sup>183</sup>. Again this information was generalised. From initially establishing the meeting agenda, to actually reporting the men's results, the women voiced their interest in what the men had to say. After hearing the results, some of the women were surprised by the themes and issues identified by the men. This surprise sparked the following discussion as to why the men had been open about the information covered in their 'interviews', for example, the feelings they associated with their family member diagnosed with schizophrenia.

**Sonya It's rather interesting to hear that from a man though. They wouldn't normally say that to you.**

**Joy But do you think that was because it was a one-on-one interview?**

**Jackie It might be because you were interviewing the other side too.**

My final task at the group meeting was to discuss with the women their experience of being part of the research. The women identified several outcomes from this research which they defined as positive. First, the women found listening to other women's stories during the group meeting very useful. The women were reaffirmed that they were not the only ones in which schizophrenia had had such an impact on their lives. As Joy shared:

**I think it's been excellent. And I think I'd like to share our experiences with other people that have suffered in the same way as we have if you like. I think every one here is very sympathetic and understanding.**

Second, some of the women had said that via the sharing at the group meeting they had been able to establish a standard from which they could assess their

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<sup>183</sup> The women at their initial group meeting and the men during their 'interviews' gave consent for their generalised information to be presented at the women's second group meeting and men's first group meeting.

own unpaid work. Mary for example said the following: **"I think too, that being able to talk about our role as care-givers I've learnt about myself more. That maybe I've learnt that I'm not so bad after all".**

Third, the group meeting had facilitated the sharing of information about available resources and recent research. The group meeting provided a forum where information from the two geographical locations from which the women came could be shared. For example, Anne said: **"Yes and hearing about good news is great. I think that you've done an excellent job Leigh".**

Fourth, some of the women were pleased about making new contacts and/or re-establishing past contacts via the group meeting. This was highlighted by Sonya: **"Nice to have met other people too".**

Finally, through participating in the 'interviews', some of the women commented that they had gained some self awareness, and were able to understand their own caring relationship better in a wider context. Coupled with this, the women were pleased to be involved in research which could help not only themselves, but others whose lives have been affected by schizophrenia. Again Sonya contributed her opinion: **"I think when there is no cure for something, and there is research going on, its neat to be part of helping people".**

The increased awareness the women had about the care they provided and the caring relationships of others, was a benefit clearly expressed by the women. The women also appreciated the support they had provided to each other at the group meetings. The truth of Reason and Rowan's (1981:491) following statement shone through

*Don't assume that you have to aim at some social action. The very fact of mutual exploration and common learning will provide action and change. One important change is that all the people involved will tend towards becoming more aware, realised, self-directing: new paradigm research enhances the development of persons in important ways.*

Rowan and Reason's statement challenged me to acknowledge the importance of the women becoming more aware of the role they played in meeting their family member's care needs. While defining the successfulness of this research by

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resulting structural and political change, I had minimised the importance of the change which had occurred in each of the women's lives.

### **Feeding Back The Results To The Men**

The men were invited to come to meet as a group at the beginning of September 1993. Ben and Trevor attended this meeting. One of the two men who did not attend the meeting had a prior arrangement, the second man did not want to come to the group meeting. The men's group meeting was held in one of their homes<sup>184</sup>.

A similar format to the women's meeting was followed: the results of the men's interviews were presented; the needs identified by the men were acknowledged and discussed; the women's results from their interviews were presented; and, finally, there was discussion about the men's experience of being part of this research. The men's group was also informal in nature. Discussion of the results continued throughout the meeting. As with the women, I fed back the results of the research under the framework of the three headings of a conundrum, assuming responsibility, and, being on call. The discussion of the results was enhanced with Ben's son having exhibited the symptoms of schizophrenia for eighteen years, compared to Trevor's two year involvement with these issues with regard to his step-son. Ben tended to talk about where his caring relationship was currently situated, as well as where it had been. In comparison, Trevor tended to talk about where his caring relationship was currently situated as well as what direction it was taking. Both Ben and Trevor utilised the meeting to find answers to some of their questions. Undirected by myself, the men offered further support and advice to each other outside of the research process if required. As with the women, Ben and Trevor identified Schizophrenia Fellowship as the vehicle to met their expressed needs.

In terms of their involvement in the research, Trevor and Ben expressed similar comments about the research process. Trevor's following quotation is an example of what they had to say:

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<sup>184</sup> I was much appreciative of this offer as it reduced the organising I would have had to have undertaken to secure another venue.

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For me personally, the process you've used has been spot on. I probably wouldn't have contributed very freely to an initial group situation of strangers. So for me being interviewed on a one-to-one basis, I was comfortable with that. And then from that to review or revise the ideas. And I think you've done an excellent job in summarising a huge diversity of information. I've been quite watchful of your techniques in terms of whether or not you had preconceived concepts and sort of shaping the information towards something which you'd already settled as an outcome. I think that your methodology does stand up. You've kept an openness and objectivity to what people are saying. I congratulate you on your research.

### **Reflecting on the Research Process**

From the time I initially decided to undertake this research, I had held certain expectations about how this research would unfold and what it would achieve. However, in utilising the methodological framework described in this thesis, I quickly learnt that I needed to be flexible and open to change. I had to constantly utilise the process of action/reflection. As the 'researcher', I found myself participating in a bi-directional process in which I adapted to the research process and vice versa. This process meant increased uncertainty for myself as researcher but also increased rewards when a new stage of the research evolved and was completed.

When returning their copy of the draft chapters, the majority of the participants enclosed letters or cards which thanked me for the way I had involved them in the research, and the way that they had been kept informed. This along with the feedback they provided me about the draft chapters made it, worth the extra time and cost involved in drawing primarily upon a participatory research paradigm.

The effectiveness of the methodological framework for answering the research question can be assessed by the information presented in the following three chapters. The use of storytelling and group meetings allowed in-depth analysis to be undertaken. The participants' understandings and interpretations of their care provision were collected. Specific detail is provided about the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia. Distinctions which existed between the women and their

husband's care provision are outlined. Further the connection is made between this care provision and how it is influenced by the social, political, cultural, legal and economic context of New Zealand.

## **S**ection Three:

**T**he

**L**ived

**E**xperiences

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## INTRODUCING 'THE LIVED EXPERIENCES'

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As already noted, 'the framework for analysis of care' provides a platform from which the participants' experiences of informal care provision can be considered. It is the participants' experiences of care which will influence how this framework will be developed in order to reflect the informal care provided to a family member diagnosed with schizophrenia. In this section the care-giving experiences of the women and their husbands are identified and described. While the participants' stories primarily present the care-giver perspective, the participants' stories also provide indications of their family member's perspective of the care they receive. Furthermore, while their own experiences and circumstances take centre stage, the participants highlight how their own caring relationships are similar to or different from other caring relationships they know of. The participants also make connections between their own caring relationship, and the social, political, cultural, legal and economic context in which it is situated.

The discussion presented in the previous chapters has indicated that it is timely that the participants' voices are heard. Foremost was the New Zealand Government's advocacy and implementation community care. The implementation of community care without the development and integration of community-based mental health services, has placed increased caring responsibilities upon 'the family'. The politics of expecting usually untrained and under-resourced women to increase their level of care provision, to a family member diagnosed with schizophrenia, was questioned. Furthermore, a balance needs to be achieved between the needs and rights of those individuals exhibiting the symptoms of schizophrenia and the needs and rights of those individuals who provide their informal care. This assertion is supported given some of the changes implemented in the Mental Health (Compulsory Assessment and Treatment) Act 1992.

Certain consistent and regular patterns and themes repeatedly arose in the participants' stories. Regulating this consistency between the participants' stories was the path of the family members' schizophrenia. It was the family members' schizophrenia which accounted for the consistency between the participants' stories. As existing research on schizophrenia has suggested, the family members became increasingly unwell, eventually experiencing cyclical acute and chronic episodes of schizophrenia. The path of the family members'

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schizophrenia, as reported by the participants, is the thread which links the three chapters entitled: 'A Conundrum', 'Assuming Responsibility', and 'Being on Call'. As is detailed below, each of these three chapters describes and analyses a part of the participants' stories.

Words synonymous with 'conundrum' are puzzle or mystery. 'Conundrum' is a term which several of the participants utilised when referring to the issues and events they described at the beginning of their stories. These issues and events revolved around the women's attempts to understand their family member's behaviours and thoughts before the diagnosis of schizophrenia was provided, by the mental health profession. On average the participants experienced these distressing and harrowing events for six years. Discussion of these early experiences identifies some of the unique characteristics of the care the participants provided. Particular attention is directed towards noting how the women's care provision was influenced by the unpredictability and changeability of the family members' symptoms. The impact of the dominant discourses of schizophrenia upon the women's care provision is also highlighted.

In the chapter entitled 'Assuming Responsibility', attention turns to outlining the way in which the process and interpretation of the participants' caring work was altered by the receipt of the diagnosis schizophrenia. As the title of this chapter<sup>185</sup> suggests, the women assumed responsibility for their family member's ongoing informal care and support needs after the diagnosis of schizophrenia had been given to them by the mental health profession. The internal and external factors which impacted upon the women's decision are identified and discussed. Receipt of this diagnosis both legitimated the family members need for care and the women's care provision. It is noted that while the women assumed responsibility for their family member's care, the men decided to fill a secondary supporting role. The main function of the men's supporting role was to reduce the hurt and harm the women experienced as a consequence of their care provision. Distinct differences in the way in which the women and men 'cared for' their family member will be identified in this chapter.

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<sup>185</sup> This title was chosen by myself.

The third chapter 'Being On Call' identifies those events which allowed the women to reduce their involvement in their provision of care. I chose this title to acknowledge that while the women were able to reduce their involvement in their provision of care, they were unable to completely disengage from their provision of care. The women remained 'on call' prepared to increase the level of their care provision when the need arose. One of the events which allowed the women to reduce their care provision was when their family member began assuming responsibility for monitoring and meeting their own health and medication needs. The second event was when their family member entered New Zealand's institutionally-based mental health services. While the women were on call, the men were also able to reduce their involvement in their supporting role. The men did not have to spend as much time acting as a buffer between their family member and the women. Those differences in the women's and men's care provision continue to be highlighted.

It is important to note that the views, understandings, and perspectives of the participants may not reflect all of those persons in New Zealand providing informal care to a family member diagnosed with schizophrenia. First, the participants all identified as *tauiwi*. As a consequence of, for example, the different ways that Maori and *tauiwi* view health and illness (Durie, 1984; Pomare & de Boer, 1988), it would be unwise to generalise the issues and events contained in the participants' stories to people other than those who identify as *tauiwi*.

Second, the majority of the participants were providing care to an adult son or daughter diagnosed with schizophrenia. As highlighted in the following chapters, caring relationships are associated with their own characteristics depending on the kinship relationships contained within them. That kinship influences the exchange of care has been highlighted by feminist researchers, such as Finch (1989). As was noted, Finch (1989) has proposed, for example, that the care provided by siblings is different from the care provided by parents.

Third, the majority of the participants had formed a nuclear family. In reflecting this bread winner/home maker split, it was the women who provided the majority of their family member's care. Furthermore, the women typically received support from their husbands who also filled a secondary caring role. This bread winner/home maker split may not predominate amongst the various family

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formations which exist in New Zealand (NZDS, 1992; Social Development Council, 1991).

Finally, there are various outcomes to the receipt of the diagnosis schizophrenia. Previous discussion in this thesis proposed that twenty to thirty percent of people diagnosed with schizophrenia are able to live relatively normal lives, twenty to thirty percent continue to experience moderate symptoms, and forty to sixty percent are significantly impaired by the symptoms of schizophrenia for the rest of their lives (Kaplan & Sadock, 1991). The participants' stories suggest that the majority of the family members would fit the latter category. The process and interpretation of the care described in the following three chapters would almost certainly be different from the care provided to those persons who live relatively 'normal' lives.

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## 6. A CONUNDRUM

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This chapter describes the experiences which the participants associated with their family member increasingly exhibiting unusual behaviours and thoughts. Emphasis is placed upon the steps the women in particular took to develop explanations for and respond to their family member's behaviours and thoughts, up until the diagnosis of schizophrenia was provided by the mental health profession. As the title of this chapter suggests, the participants referred to this period in their care-giving experiences as a conundrum. The participants' non-existent, incorrect, or limited knowledge about mental illness, specifically schizophrenia, restricted the participants' explanations of their family member's behaviours and thoughts. Initially, the participants' explanations referred to either drug use or what they termed a 'teenage phenomenon'. Similarly, the fact that their family members' behaviours and thoughts were outside the women's previous caring experiences meant that the women were not able to automatically respond to their family member's care needs. It is important to note that the experiences, issues and themes condensed in this chapter occurred over an extended period of time, specifically for an average of six years.

The participants explained how the women's 'mother' role was extended in meeting the needs of their predominantly young adult son or daughter, at a time when their family member would typically have been striving for independence. The participants had to battle with the tensions arising from the increasing need for the women to provide higher levels of care to their family member and the participants' expectations that their family member should be increasing their independence.

In trying to manage their family member's behaviours and thoughts, the women tended to utilise the method of 'trial and error'. The women continually altered the way in which they interacted with their family member in the hope that their actions would encourage their family member to respond more appropriately according to their age and culture. The fact that the women had to utilise the method of trial and error in order to respond to their family member raises the question of why it was the women, and not their husbands, who responded to their family member's need for assistance.

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Typically, it was the women who initially realised that their family member's behaviours and thoughts could not simply be explained as either a teenage phenomenon or as a consequence of drug use. In realising that something was wrong with their family member, the women began to search for answers. This initial search ended when their family member was given the diagnosis 'schizophrenia' by the mental health profession.

During these initial experiences, the women had not decided to fill an ongoing care-giver role. In thinking that their family member was exhibiting behaviour concomitant with the teenage years or drug use, the women understood their care provision as simply a response to the expressed needs of a member of their family. As explained in the following chapter, the women did not decide to assume responsibility for their family member's ongoing care provision until the mental health profession had provided the diagnosis of schizophrenia as an explanation for their family member's behaviours and thoughts.

The participants agreed that the men did not actively support the women in dealing with the conundrum their family member's schizophrenia had become. In adhering to some of the dominant discourses of schizophrenia, the men usually thought that the women were over-reacting in their assessment that something more was wrong with their family member than a teenage phenomenon or drug use. The men were also slower to accept the diagnosis of schizophrenia and its implications.

### **The Family Members' Unusual and Socially Inappropriate Behaviours and Thoughts**

As existing research has predicted (American Psychiatric Association, 1994a; Kaplan & Sadock, 1991), the symptoms of schizophrenia usually began to be exhibited by the family members when they were in their late teens to late twenties. Instead of actively establishing their own life and career path<sup>186</sup>, the family members' behaviours and thoughts became increasingly unusual and socially inappropriate. Joy provided examples of Bill's behaviour:

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<sup>186</sup> Both of these activities are associated with the early adult years (Berger, 1986) and are consistent with the *tauiwi* values of individuation and independence (Durie, 1984).

But then he just gradually got worse and worse. He wasn't looking after himself. He wasn't washing himself, he was grubby, and his clothes were grubby. And he wasn't eating properly, he became very thin. He'd come home at times and things were rather odd. Getting worse and worse, gradually. He'd be sitting like we are now and the neighbour would walk across and he'd just giggle, and think it was hysterically funny...He'd walk up to an open door, and he'd put his foot out and pull it back. It took him forever to decide whether to walk through a doorway. And he was definitely very up key.

The deterioration in the functioning of the family members indicated that they were in the prodromal (initial) phase of schizophrenia. Symptoms associated with the prodromal phase are:

*1) marked social isolation or withdrawal; 2) marked impairment in role functioning...; 3) markedly peculiar behaviour; 4) marked impairment in personal hygiene and grooming; blunted or inappropriate affect; 5) digressive, vague, overelaborative, or circumstantial speech, or poverty of speech, or poverty of content of speech; 6) odd beliefs or magical thinking influencing behaviour and inconsistent with cultural norms; 7) unusual perceptual experiences; 8) marked lack of initiative, interest or energy (Kaplan & Sadock, 1991:333).*

A person may exhibit these prodromal symptoms for months, even years, before they move into the active phase of schizophrenia. The progression of this disorder itself, combined with the multiple conditions which must be met before the diagnosis of schizophrenia can be applied<sup>167</sup>, added to the difficulty experienced by the participants in receiving an accurate and timely diagnosis of schizophrenia. As will be highlighted in the discussion below, the absence of a diagnosis had several implications for the women's care provision. For example, the women were uncertain about why their family member continued to think and act so unusually. This uncertainty led to the participants explaining their family

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<sup>167</sup> One such criteria is that the symptoms of schizophrenia must be exhibited continuously for at least six months.

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member's thoughts and behaviours as either a teenage phenomenon or drug use. Furthermore, the women were generally unsupported in their provision of care to their family member. Without a diagnosis, the women and their family member experienced great difficulty in accessing both New Zealand's formal and informal resources and support.

### **Teenage Phenomenon or Drugs?**

Initially, the women and their husbands rationalised the behaviours and thoughts of their family member with two explanations. First the participants proposed that their family member was going through a phase of experimentation associated with the teenage years. As the title suggests, the participants explained their family member's behaviours and thoughts as a consequence of a teenage phenomenon. For example, Jill stated that: **"At that stage we didn't really expect anything other than that it was the sort of phenomenon that belonged to the teenage years"**. The family members' behaviours were viewed as simply a consequence of them being irresponsible. Margaret's following comment about Daniel's use of money is a case in point: **"And he had five thousand dollars in his bank account Leigh. Five thousand cause he never spent money. And when he took sick, he blew it just like that"**. As Ben's comment illustrates, Daniel was not the only family member who disposed of their savings when unwell: **"He'd saved up six thousand dollars. But he managed to give most of that away by standing on the street and then handing it out"**.

Second, the participants explained the symptoms of schizophrenia as the consequence of drug use. As Margaret said: **"It is sort of very hard to explain those early days cause I thought it was drugs doing to Daniel what was happening to him"**. Thinking that their family member's symptoms were drug-related was supported by the fact that the majority, although not all, of the individuals receiving care had actually been experimenting with drugs, including alcohol, at the time. Some of the symptoms of schizophrenia, for example hallucinations and delusions, can be associated with drug use (Kaplan & Sadock, 1991).

Research on non-prescription drug use and schizophrenia has focused predominantly on drug abuse (Drake, Osher & Wallach, 1989; Pristach & Smith,

1990). Mueser, Bellack, and Blanchard (1992) have acknowledged the difficulty in establishing the prevalence of substance abuse among people diagnosed with schizophrenia. Differences in the definition of substance abuse, the demographic characteristics of people diagnosed with this disorder, and assessment techniques, have resulted in quite varied results. Despite this, Mueser et al (1992) have listed the demographic and clinical predictors of substance abuse in schizophrenia as: being male; being young; having a low level of education; having good premorbid social-sexual adjustment; being of an early age at first hospitalisation; having poor treatment compliance; high relapse rates; and, a higher level of suicidality. Mueser et al's (1992:846) review of the literature established: *"...that substance abuse in schizophrenic patients is a common clinical problem"*. This was especially the case with alcohol abuse. Although the dual diagnosis of drug abuse and schizophrenia is common, research has indicated that more study needs to be directed towards understanding how drug abuse impacts upon schizophrenia and its treatment (Mueser et al, 1992).

The co-morbidity of schizophrenia and drug abuse has important implications for New Zealand's mental health services. As previously explained, historically New Zealand's mental health and alcohol and drug services have worked independently. Research such as Mueser et al's (1992) challenges this arrangement, suggesting that services need to be integrated to be most effective. The proposal to develop a national alcohol and drugs policy, as outlined in the document 'Looking Forward' (Minister of Health, 1994b), is in line with the recommendations of Mueser et al's research in that it acknowledges the relationship between mental illness and non-prescription drug use.

The participants expected that once their predominantly adult son or daughter had found some direction in their life, or reduced or stopped their drug use, their unusual behaviours and thoughts would disappear. Margaret expressed her thoughts on this: **"I always thought it would actually go away. I think I felt, if he didn't take drugs, Daniel would be Daniel"**. Falloon et al (1984) have spoken of families who have provided these same explanations for their family member's prodromal symptoms.

Helen who provided care to her mother Lidia, differed from the other participants in her explanation of Lidia's behaviours and thoughts. This response is not

surprising in that Lidia initially exhibited the acute symptoms of schizophrenia when she was thirty-nine years of age. Furthermore, whereas the majority of the other participants were parents of the men and women receiving care, Helen was Lidia's daughter. For Helen, the answer for her mother's unusual behaviours and thoughts lay with herself:

**I blamed myself a lot of the time. I used to think, because I was a bit of a handful as a teenager, "Oh no, I've pushed her over the limit again!" I used to think it was me that had done it.**

Helen's explanation for her mother's symptoms highlights the guilt members of the family can experience in response to thinking that they have caused their family member's symptoms of schizophrenia (Mittleman, 1985).

The participants' reluctance to link their family member's behaviours and thoughts with a psychological explanation is not unusual. For example, Kreisman and Joy (1974:38) found that when persons were defining 'deviant' behaviour of a family member, they: *"...were slow, first, to view their sick member as deviant, and second, to view him as a deviant because of psychological aberrations"*. This response is understandable when acknowledging the dominant discourses of 'mental illness' and 'schizophrenia' (Atkinson and Coia, 1995; Jones, 1995; Miller, 1995). For example, it would be hurtful, if not devastating, to think that a family member was the 'nutter' spoken of in the sonnet quoted in the Wanganui Midweek (1995:7).

### **The Family Members' Unsettled Behaviour**

The participants' family members were often very mobile, moving from job to job. Anne spoke of Patrick's work history: **"So then he got a job...Same thing, lasted two days, off"**. The family members also travelled widely within and outside of New Zealand. Joy spoke of Bill's transient behaviour: **"And then he took funny jobs, and went to Wellington and went to Auckland, and just seemed very unsettled"**. Harriet described how Rachael would move from one geographical area to another:

**She rang a fortnight later, said "I'm at Lorn, I'm on my bicycle. I've lost my passport. I've run out of money, and**

**I've no food. But I don't need any. I'm going to Western Australia on my bike" and hung up. And I said, "Oh my God. What do we do?"**

These periods of geographical distance between the family members and the women, added to the difficulty the women experienced in determining the extent to which their family member was unwell. The transient behaviour of the family members had further implications. First, their unsettled behaviour initially supported the participants' understanding that they were just not acting responsibly. Second, the participants talked about spending substantial amounts of money on travel to enable their family member to come back to the family home after they had found themselves stranded either within or outside New Zealand<sup>188</sup>. Finally, when acknowledging that something more was wrong with their family member than either a teenage phenomenon or drug use, the participants would direct their family member to access medical services, generally their family practitioner. The family members' unsettled behaviour often meant they were untraceable and unwilling to keep any appointments the participants had made.

### **Contact With Police**

Early on in their stories, the participants spoke of their family member's contact with the police. Many of the family members were either the victims of assaultive behaviour, or were picked up by the police and/or charged with minor offences, such as disturbing the peace, as a consequence of their behaviour. It was via the police that many of the women were notified of their family member's antics. Pat described her experience of the police with regard to Rebecca: **"Then she got worse and worse. The police would be at the front door, and she'd be out the back. And that went on for weeks and weeks"**. As Pat explained, it was the police who eventually committed Rebecca: **"In the end the police came to us, 'For God's sake, get this girl committed because she's wasting so much time and manpower'. So they committed her"**.

The importance of the police receiving training on how to understand and respond appropriately to persons with a psychiatric disability was highlighted by the inquiry into Matthew Innes' death (Mason, 1994). Recent events such as

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<sup>188</sup> The extent to which the participants' financial circumstances impacted upon their care provision is discussed later in this chapter.

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Eric Gelately's death (Wanganui Chronicle 1995a, 1995b) and the press releases such as the following one, made by the Police Association president Steve Hinds, highlight the importance of the police being adequately trained to respond to individuals exhibiting the symptoms of mental illness. When talking about the extent to which the police are being asked to deal with people with psychiatric disabilities, Hinds (Sunday Star Times, 1995:1) was quoted as saying:

*Certainly I can confirm our workload has significantly increased. We have become the only 24-hour social agency around...What this really highlights is that police are not the best people to deal with these situations. These people aren't criminals and in some cases the last thing they need is to see a couple of cops coming up the driveway... Unfortunately, because of the downsizing in psychiatric hospitals, there is no one else out there for them. We are picking up the pieces.*

### **'Trial and Error' as a Management Strategy**

Consistent with the research on the employment patterns of women (NZDS, 1993; Statistics New Zealand, 1993), seven of the women participants had a nursing or nurse-aid background. The women explained this similarity in occupation by focusing on their caring nature and their commitment towards their caring responsibilities. For example, Helen explained the women's involvement in nursing by stating that: **"We are prepared to take up our responsibilities"**. Mary on the other hand, said that it: **"Shows you we care"**. Ben however explained this commonality of the women's careers, by acknowledging that when the majority of these women were younger, nursing was one of the few accepted career options for women.

The nursing training of six of the seven women did not cover mental illness within its curriculum. For these women, their professional training did not help them to respond specifically to their family member's experiences of mental illness. However, the women explained that their nursing careers did help them care and support their family member, by having provided them with a framework for working with persons who are sick. For example, Joy said the following about her nursing training: **"I know how to look after sick people, and I suppose that's something you use"**.

Two of the women had personally experienced mental ill health during their life time. These women drew primarily upon their own personal experiences when dealing with their family member's behaviours and thoughts. Margaret acknowledged that: **"...what helped me more was my own breakdown"**. Jackie explained how her own experience of mental ill health helped her to understand Luke's experiences of schizophrenia:

**Because I do understand more than he realises. I do understand what it's like to have another reality, interwoven with the here and now everyday world. And to be coping with it. It's like different channels coming through the T.V. at once, and switching all the time. I know what it's like.**

In not being able to draw on any particular knowledge or training about mental illness, specifically schizophrenia, the women utilised 'trial and error' as a primary strategy for dealing with their family member's behaviours and thoughts. Helen admitted that the strategies she used to manage her mother's symptoms were developed:

**...over years of trial and error. And that was the hard part, because we didn't know how to be responsible for her...we didn't know what the diagnosis was, what we were dealing with.**

Those women who had experienced mental ill health themselves also utilised a certain amount of trial and error. These women acknowledged that every person and caring relationship is unique in its character as a consequence of the symptoms of schizophrenia varying between and within individuals<sup>189</sup>.

These initial experiences were often associated with feelings of frustration, guilt and regret. The women talked about the emotional, psychological and sometimes physical harm they and their family member experienced as a consequence of utilising trial and error. This harm resulted from the women not knowing what they

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<sup>189</sup> The variance in the symptoms of schizophrenia between and within the family members is discussed in detail in the following chapter.

were dealing with or how to respond appropriately. The frustration expressed by the women was highlighted by Helen who said:

**I just wish that years ago, we had known just simple things like not to reinforce the delusion, and not to get angry...You didn't know how to deal with it. You'd try to yell at her, you'd try to cry. You'd try all these sorts of things and nothing seemed to work.**

Trial and error continued to be a main strategy utilised by the women even after the diagnosis of schizophrenia had been provided to explain their family member's behaviours and thoughts. Mental health professionals typically refused to inform the participants about their family member's schizophrenia as a consequence of patient confidentiality<sup>190</sup>. Without this information, the participants were unable to fully understand or respond to changes in their family member's symptoms. For example, were changes in their family member's symptoms due to their family member's prognosis or due to prescribed changes made to their family member's neuroleptic medications? Second, the women explained that information about how they could respond effectively to the men and women receiving care remained non-existent. Some of the mental health professionals the participants had contact with adhered to theories about family causation of schizophrenia (Bateson et al, 1956; Fromm-Reichmann, 1948; Lidz et al, 1957). These mental health professionals were not prepared to consider the participants as part of the mental health team. As already noted, the schizophrenia and care literature has consistently noted the extent to which 'the family' has to deal with uncooperative mental health professionals (Bernheim, 1990; Brooker, 1990; Holden & Lewine, 1982; Morris et al, 1989; Willis, 1982),

The need for the women to develop the strategy of trial and error raised several issues. First, although all of the women had previously provided ongoing care to their children and older parents, the women did not intuitively or instinctively know how to provide the care their family member required. The characteristics of their family member's symptoms of schizophrenia were outside of the women's previous caring experiences. The use of trial and error was the primary

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<sup>190</sup> As was noted this has particularly been the case in response to the Privacy Act 1993 and the Mental Health Act 1992 (Crowe, 1995; Morton, 1994; The Press, 1994; Wood, 1995).

mechanism the women utilised to increase their understanding of their family member's care needs. When considering the nature of care, it was proposed that the care provided to a family member diagnosed with schizophrenia may challenge the accepted understandings of 'care', these understandings being based upon the care provided to a family member with an intellectual, physical or age-related disability (Twigg & Atkin, 1995). The women's unfamiliarity and lack of awareness of the nature of the care provided to an individual diagnosed with schizophrenia suggests that the accepted understandings of care do indeed need to be extended.

The use of trial and error highlights the importance of care-givers, whether they be male or female, receiving formal training on the complexities and characteristics of the care provided to a family member diagnosed with schizophrenia. As the women's previous and future comments will indicate, this formal training would need to include: the aetiology, course, and treatment of schizophrenia; appropriate strategies for dealing with those men and women exhibiting the symptoms of schizophrenia; an explanation of the current Mental Health Act 1992 and how it can be utilised; a guide to how to negotiate the mental health system; and, identification of relevant social support agencies.

The need for those women and men who provide care to a family member diagnosed with schizophrenia to receive formal training has become imperative with changes to New Zealand's mental health legislation. For example, as a consequence of both the narrower definition of 'mentally disordered' (Ministry of Health, 1993) and the advent of Community Treatment Orders, specified under the Mental Health Act 1992 (New Zealand Government, 1992), care-givers may find themselves having to deal with more overtly psychotic behaviour. As has been argued, one consequence of the increase of the threshold for entry to New Zealand's formal mental health services is that individuals now have to be acutely unwell before they will be admitted to these services (Mason, 1994; Ministry of Health, 1993).

### **Economic Circumstances of the Participants**

Discussion of the family members' unsettled behaviour suggested that the participants' economic circumstances influenced the nature of their care. It was

noted that the participants spent considerable amounts of money to pay for their family member's travel home from destinations both within and outside New Zealand. The following discussion will continue to illustrate how the participants' economic circumstances directly affected the type and level of the care they provided to their family member during these early experiences.

The participants' economic circumstances were primarily dictated by the men's income. In mirroring other women in their cohort group (Davies & Jackson, 1994) the majority of the women had left paid work at the birth of their first child and therefore had been financially dependent for the majority of their married lives upon their husband's income.

Those couples in which the men had been in a high income bracket before retirement were more able, for example, to subsidise their family member financially to return home from geographical locations inside and outside New Zealand. These same participants were also able to provide their family member with money for basics, such as for food, accommodation and clothes. Ben said the following about Joy and Bill:

**She'd say, "Oh where are those trousers?" "Oh I've lent them to somebody". Course they've gone. He only had the clothes he stood up in almost at times. So she would have to go and organise clothes for him. To which I said to her all the time, "Don't worry about it. It's only a little bit of money. We're lucky we can afford it. It doesn't matter. If he loses twenty or fifty dollars worth of trousers, it's okay".**

The economic circumstances of the participants continued to influence their care provision after the diagnosis of schizophrenia had been provided by the mental health profession. For example, those couples in which the husband had been in a higher income bracket had the options of, for example, sending the family member to a private psychiatrist, taking the family member away on overseas holidays, and buying alternative accommodation for the family member when the need arose.

In comparison, those participants from a lower income bracket did not have the same range of options available to them. Women who received a state benefit were more restricted in their care provision as a consequence of their economic

circumstances. For example, Sonya found that taking even small steps towards helping Paul become more independent were too costly. As Sonya explained:

**You try to make them more responsible, and to take more on. I've made him go and do the grocery shopping. And he comes back with all the wrong things. And, I can't afford that. That comes down to money. You just can't afford to have all the things he got. And he has had a list.**

Competing with the need of these women to provide care to their family member, was their own need to live within the constraints of their limited income. Not surprisingly, those women who received a state benefit reportedly had a lower standard of living than their married counterparts. The link that Glendinning (1992) and Graham (1987) have made between caring and poverty rang true for the women in Sonya's position.

Some of the participants did note that the predominantly adult sons and daughters did not seem to appreciate the extent to which they were financially subsidised. This was also difficult for some of the participants to understand. For example, Jackie said: **"I was subsidising him, by fifty dollars a week and he wasn't even co-operating with the programme!"**<sup>191</sup>

In drawing upon research from Australia (Andrews et al, 1985), the United States of America (Rice, Kelman, Miller & Dunmeyer, 1990), and specifically Massachusetts (Franks, 1987), Souetre (1994) has noted the significant contribution that 'the family' makes to the care of a family member diagnosed with schizophrenia. For example, Franks (1987) invited members of the Massachusetts National Alliance for the Mentally Ill to participate in a sixteen page questionnaire. This questionnaire covered background data on the ill

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<sup>191</sup> The lack of reciprocity between the participants and their family member is highlighted in discussion later in this thesis.

family member and the family, the time and money contributed by the family, and the use of the formal care system. Analysis of this data established that *"On average, these families spend [US] \$3,539 per year (direct costs) on their ill members and devote 798 hours per year to their care"* (Souetre, 1994:4)<sup>192</sup>. In highlighting the contribution made by 'the family' Souetre (1994) proposed that more research is required to ascertain the structure of the costs of schizophrenia. For example, *"...what is the relationship between direct and indirect costs. What parts of total cost are financed by the health insurance and what parts by the patient or his family?"* (Souetre, 1994:8).

Those persons exhibiting the symptoms of schizophrenia will almost certainly continue to rely upon their 'family' for financial assistance as a consequence of the government's adherence to market liberalism. The benefit cuts, increased housing rentals and health costs (Barker, 1992; Bowie, 1992; Craig et al, 1992; Kelsey, 1993) mean that people with care and support needs are going to have less resources to meet their own requirements (Disley, 1991). Receipt of the newer neuroleptic medications, such as risperdal, is also likely to be determined, in part, by the economic circumstances of a family member's informal care-giver. As already noted, recently introduced neuroleptic medications are typically expensive (Janseen Pharmaceutica, 1993).

After acknowledging the costs incurred by 'the family' with regard to their care provision, it seems pertinent now to turn to the work which Ungerson (1995) has undertaken on the commodification of care. As was explained, Ungerson (1995) has made the distinction between 'quasi-wages payments for care' and 'carer allowance payments for care'. Examination of the women's initial experiences of their family member exhibiting the prodromal symptoms of schizophrenia raise

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<sup>192</sup> The research in this thesis highlights the importance of defining the term 'care'. In order to obtain an accurate estimate, any study of the costs of schizophrenia should take into account the unique characteristics and complexities of the informal care provided to a family member diagnosed with schizophrenia. Previous discussion indicated that this informal care may extend feminist caring literature. The material presented in the following two chapters will confirm whether this is the case. Furthermore, consideration of the costs of schizophrenia needs to acknowledge the extent to which the family member is impaired by their symptoms. The prognosis of schizophrenia, which is variable (Kaplan & Sadock, 1991; Miller, 1995), will almost certainly affect the costs associated with this disorder.

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certain problems with both of these types of payments. These problems will be identified below.

'Carer allowance payments for care' are those unconditional payments made to the care-giver of an individual who has been assessed as having a proven disability, typically by a medical practitioner. Discussion in this chapter is concerned with the women's care provision before the diagnosis of schizophrenia was provided by the mental health profession to explain their family member's unusual and inappropriate behaviours and thoughts. For an average of six years, the women provided increasing levels of care which was not legitimated by a diagnosis. In the following section it is explained how even the women's husbands and other siblings thought the women were simply over-reacting to their family member's behaviours and thoughts. Given Ungerson's (1995) definition of 'carer allowance payments for care', it is clear that the women would not have been eligible for such payments during these early experiences. Dependency upon their husband's income, for many of the women, would continue to be their means of financial support.

The women's eligibility for 'carer allowance payments for care' (Ungerson, 1995) will continue to be considered in the following chapter. As was argued previously, it is highly probable that the way in which 'care' has been traditionally considered will need to be re-evaluated. This reconsideration is particularly related to the understanding that care revolves around personal care tasks and that carers neatly and consistently fit within the categories of full-time or part-time carers.

'Quasi-wages payments for care' (Ungerson, 1995) include conditional payments made to volunteers and payments made to care-recipients. Just as with the women's payments, the family member would need to receive their formal diagnosis before payments would be provided. Even after the diagnosis was given by the mental health profession, 'quasi-wages payments for care' made to care-recipients may be associated with difficulties. First, the family member would need to acknowledge that they do in fact have a disability. As is noted when the process of committal is discussed later in this chapter, individuals exhibiting the symptoms of schizophrenia do not always acknowledge that they are in fact doing so. This lack of insight could mean that

'quasi-wages payments for care' would not be spent on purchasing their own care provision. Related to this is the difficulty some people diagnosed with schizophrenia have experienced with money, when unwell. Margaret and Ben's comments are examples of this difficulty. Again, quasi-wages payments to the family member would not necessarily ensure that they receive the care they require when unwell.

### **Something Is 'Not Quite Right'**

Over time, the women became convinced that something more was wrong with the predominantly adult sons and daughters than just a teenage phenomenon or drug use. The participants utilised the terminology 'something's not quite right'<sup>193</sup> to describe their family member when acknowledging that their previous explanations of drug use or a teenage phenomenon were not adequate. For example, Harriet described when she first realised that Rachael's behaviours and thoughts were not the product of drug use: **"We were doing this painting and we were aware that there was something really, really strange. That if it had been drugs it would have worn off by then"**.

The women argued that their husbands were much slower to acknowledge and articulate that there was something wrong with their family member, something which was not going to magically disappear. As Joy said about Ben: **"I knew there was something wrong when Bill was eighteen. But Ben wouldn't believe it. He said 'Oh let him go. He's just like all these kids today, like his friends'"**. The men agreed with the women that they were much slower to acknowledge that the behaviours and thoughts of their family member were not appropriate for their age or culture. Ben, for example, admitted that: **"Going back, I suppose Joy was more doubtful of it...I was more forgiving say...But she was more strongly suspicious. And I made excuses for him for longer"**.

One of the consequences of the men not realising and accepting that something was wrong with their son or daughter, was their lack of support for the women in their provision of care. When expressing their opinion that something was wrong with their family member, the women were often told by their husbands that they

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<sup>193</sup> The term 'something's not quite right' is frequently utilised by members of Schizophrenia Fellowship.

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were over-reacting, or, that in time, their family member would come right. James described his reaction to Jill's concerns:

**I always sort of held Jill back a little bit and said "Leave the boy alone, he'll wake up"...I thought that he was in a dormant phase of his development, and one day he'd bloom out. But he didn't.**

One strategy the men utilised to cope with the different opinions they and the women held about their family member's behaviours and thoughts, was to increase their participation in paid work. The consequence of this for the women was increased isolation. As Margaret said, she found this:

**Very hard. I mean that just didn't go on for a week or two. This went on for years...I mean I felt I was being torn with my husband. I sort of felt he didn't really want to know. That Daniel should be able to pull himself together.**

The men's increased participation in their paid work, in order to remove themselves from the site of caring, is consistent with Ungerson's (1987) findings. As was explained when discussing the differences between the care provision of women and men, men tend to use their paid work to buffer themselves from their potential or actual caring responsibilities. The men's increased involvement in their paid work meant they were unavailable to assist in their family member's care provision.

The women's husbands were not the only members of the family who discounted the women's provision of care. Joy spoke of the reactions of her other children regarding her care-giver role:

**They left home when they were about eighteen or seventeen. They've been to university and so on, and they've been overseas for years. They're only just back in New Zealand. But, they really didn't see all the high drama with Bill. So they're learning. But they don't. I think to begin with they just didn't believe. They just thought "Oh she's just exaggerating".**

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Instead of the women's immediate family acknowledging that there was something 'not quite right' with their family member, the family developed and maintained the understanding that the women were being over-protective or were over-reacting to their family member's behaviours and thoughts. In other words, the immediate family supported the dominant discourses of 'schizophrenia' regarding a mother's domineering and possessive nature (Fromm-Reichmann, 1948). Understandably then, this time in the women's care provision was associated with frustration and isolation.

### **The Participants' Knowledge of Schizophrenia**

Eventually the participants began to wrestle with the question: "If the changes in their family member were not due to the use of illegal drugs, or to teenage years, what else might explain their behaviours and thoughts?" The difficulty the participants experienced in answering this question was considerably increased by their lack of knowledge about mental illness per se, let alone schizophrenia specifically. Anne admitted that she knew: **"Oh nothing, nothing about mental illness whatsoever. And [I had] never had any contact with anyone with mental illness. It was absolutely a field unknown".** Anne's degree of knowledge was similar to Ralph's who stated: **"So what did we know about it? Sweet nothing. Well we knew something was wrong, but what, we didn't have a clue".**

For those participants who had some idea about schizophrenia, their information was often gleaned from the realm of fiction. For example, Margaret thought schizophrenia was, **"...a split personality".** While Helen acknowledged that she knew, **"...nothing really. Only just what you see at the movies".** Mary had also constructed her definition of schizophrenia from what she had seen on the television:

**I can really truthfully say that all I knew about schizophrenia was what I'd seen on television. Institutions of people walking with funny movements. Swinging their arms, funny facial expressions. And knowing possibly that they can't come out into the community. That they've been in institutions and that's where they stay for the rest of their lives.**

The participants noted, then, that as well as being the subject of academic research, especially that of medicine and psychiatry, schizophrenia has had a life of its own in the realm of fiction and in the media. Within these realms of fiction and the media, schizophrenia is often misrepresented as a 'Jeckyl and Hyde' condition characterised by uncontrollable violence (Jones, 1995), schizophrenia is a culmination of society's monsters and demons<sup>194</sup>. As was noted when discussing the dominant discourses which influence the way mental illness is understood, an element of fear and mystery veils mental illness (Miller, 1995; Mullen, 1992; National Mental Health Consortium, 1989). Such visual imagery is more memorable for its audience and therefore harder to combat, than the theoretical academic arguments about the aetiology, prognosis, and treatment of schizophrenia. The lack of a consistent, agreed and easily understood answer to the question "What is schizophrenia?", from the academic and other spheres, and the visual imagery from the realm of fiction and media, reflect and reinforce the dominant discourses of 'schizophrenia'.

### Finding Answers

In trying to explain the changes in the behaviours and thoughts of their family member, health services, usually in the form of a general practitioner, were contacted by the participants. According to the participants, health professionals at this initial contact focused on finding a physical cause for these changes. As Helen explained: **"They did all sorts of physical tests. And they sort of said that she had problems with corpuscles or something...she wasn't psychiatrically referred anyway"**. Sonya's experience with Paul was similar: **"So I rushed him to the doctor. And the doctor said he'd have to have a scan. He thought there was something wrong...a brain tumour or something"**. Initially establishing whether symptoms are the consequence of a physical ailment before moving on to consider a psychological explanation, is common practice amongst the health profession.

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<sup>194</sup> The way in which the New Zealand media negatively portrays schizophrenia and those individuals exhibiting its symptoms was illustrated when acknowledging how the newspapers reported the events involving Eric Gelately (Wanganui Chronicle 1995a, 1995b).

When services with a specific mental health focus were contacted by the women and their husbands, two main responses to this action predominated. Often the behaviours and thoughts of their family member were considered by mental health professionals to be a response or coping mechanism to problems within the family. The participants reported that these explanations appeared to support those theories relating family influences to the causation of schizophrenia, for example, the 'schizophrenogenic mother' (Fromm-Reichmann, 1948) or schismatic and skewed families (Lidz et al, 1957). Anne shared her response to a mental health professional's assessment of Patrick's behaviours and thoughts:

**Any rate, she [mental health professional] said there was nothing wrong with him. We should let him make his own decisions. I mean he'd been at university and boarding school and everything, it was just so ridiculous.**

When talking about her early experiences with mental health professionals, Sonya explained that all she wanted to be able to do was: **"Get help when help's needed. And not being treated like an over emotional, dramatic mother"**. The view that mental health professionals are uncooperative when dealing with the carers of family members diagnosed with schizophrenia is not unusual. As noted above, this situation is a recurring theme within the schizophrenia and care literature (Anderson, et al, 1986; Bernheim, 1990; Brooker, 1990; Holden & Lewine, 1982; Morris, et al, 1989; Willis, 1982).

The other predominant response of mental health professionals was to actually turn the participants and their family member away. The participants offered two major explanations for this particular response by mental health professionals. First, the participants noted a lack of comprehensive and coordinated mental health services in their regions. Access to mental health services was primarily during the working hours of 8:00am to 5:00pm, Monday to Friday<sup>195</sup>. An example of this was provided by Harriet who described her experience of trying to receive help for Rachael before crisis point: **"We rang up [the local acute unit] and they said, "Well it's Friday. We're terribly sorry you'll have to wait till Monday"**. In

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<sup>195</sup> The participants' assessments of the state of New Zealand's mental health services is consistent with the findings of various reviews of these services (Committee of Inquiry, 1988; National Advisory Committee, 1993).

acknowledging the difficulty that Harriet experienced in gaining access to formal mental health services, the content of her following comment should not be surprising: **"My initial experiences with the hospital were really ones of agony. We just didn't get any help for ages and ages and ages"**. Harriet's comments suggests that Mike Moore's examples of individuals being turned away from New Zealand's formal mental health services (Christchurch Press, 1995:11) may not be isolated cases.

According to the participants, mental health professionals made value judgements about whether help was needed and whether it would be provided. In talking about this Sonya said: **"But when you do ring up [the local acute unit], depending whose on, and whose idea it is, a lot of people are blocked at that stage"**. Being blocked from accessing formal mental health services often placed the women in very vulnerable positions. As Jackie explained:

**Because people who haven't been in that situation. I don't think they have any idea about how scary it is to be with a person, who however good and nice and trustworthy is normally...when they're having hallucinations or delusions, they're completely unpredictable.**

As has been suggested previously, the increased threshold for entry to New Zealand's formal mental health services means that women, such as Jackie, are being expected to assume responsibility for care provision previously provided by formal mental health staff. These women are now having to deal with the more psychotic symptoms their family member exhibits when unwell.

The importance of ensuring easy access to New Zealand's mental health services is highlighted by the women's comments. As was noted in the document 'Management of Major Psychosis', easy access facilitates early intervention which in turn allows treatment to be received. The more acute symptoms of schizophrenia tend to be controlled more quickly, which in turn, both reduces the risk of harm to self and others, and means less disruption to an individual's life and social network (Fernando & McGeorge, 1993:18).

The second reason for mental health professionals turning away the participants and their family member, was related both to the unpredictable nature of

schizophrenia (Hatfield, 1978; Torrey, 1983; Laffey, 1978), and the difficulty in accurately diagnosing the symptoms of schizophrenia. The participants spoke about how their family member would **"pull themselves together"** for the duration of a visit to a psychiatrist, their symptoms again worsening on the way home. Brett (1992:98) has spoken about this process:

*People suffering from schizophrenia frequently retain the ability to pull themselves into something approaching a rational state for limited periods even when in an acute phase. This is especially so when confronted with authority figures like doctors or police, a fact which further confounds those trying to convince the medical profession of a family member's need for help.*

This aspect of the family members' schizophrenia increased the stress experienced by the participants and added to the invisibility of their care. Instead of the family members being defined as legitimately requiring care, the women were often considered by mental health professionals to be over-reacting. The efforts that the participants had made both to establish the cause of the symptoms of schizophrenia, and receive help for the family members, were often unrecognised or ignored by mental health professionals. An example of this was provided by Ben who described the following experience:

**And I remember [the psychiatrist] saying specifically, "Oh you should have brought him along a lot earlier, we could have treated him far better". Which was his mistake. He shouldn't have said that, cause that was a bit of a nail in our coffin.**

The ability of people exhibiting the symptoms of schizophrenia to **"pull themselves together"** adds further to the concern surrounding the current definition of 'mentally disordered' in the Mental Health (Compulsory Assessment and Treatment) 1992 Act. It is unlikely people exhibiting the symptoms of schizophrenia will come under the jurisdiction of the Mental Health Act 1992 if they are able to **"pull themselves together"** at the time of assessment. As already noted, often an individual has to be severely unwell before the mental health profession will define them as 'mentally disordered' as defined by the

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Mental Health (Compulsory Assessment and Treatment) Act 1992 (Author Unknown, 1992; Christchurch Press, 1995; Mason, 1994; Ross, 1995).

Discussion in this chapter has repeatedly highlighted the difficulty the women experienced when trying to determine why their family member was exhibiting such unusual behaviours and thoughts. This difficulty is concerning when acknowledging that the majority of these women had worked in the health sector. Their knowledge of hospital systems and protocols would have assisted them in their search.

### **Varying Diagnoses**

During their contact with mental health services, the family members often received varying diagnoses before the label of schizophrenia was given. Helen explained the confusion over her mother's diagnosis:

**I think she's actually paranoid schizophrenic, but...I think they [mental health professionals] must have been thinking that she might have been slightly manic-depressive to...Like it's changed a lot over the years.**

This variation in diagnosis can often be attributed both to the difficulty associated with categorising the exhibited symptoms of schizophrenia and to the multiple conditions which need to exist before the diagnosis of schizophrenia can be applied. As was explained, all of the symptoms of schizophrenia are associated with other psychiatric illnesses. Multiple conditions must be met before the diagnosis of schizophrenia is given.

At the time of Pat's one-to-one 'interview', Rebecca's diagnosis was again being questioned by mental health professionals. Rebecca had been diagnosed with schizophrenia at the age of eleven. Now, with Rebecca in her early thirties, mental health professionals were proposing that Rebecca, over the years, had been exhibiting behavioural problems as opposed to schizophrenia. Pat explained the following:

**It was not until [Rebecca] went to [the long term stay unit] that we knew she had schizophrenia. But mind you, she's**

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**not schizophrenic now...[mental health professionals] think she's got behavioural problems.**

The difficulty in receiving an accurate and timely diagnosis led the participants to search for their own answers to explain the behaviours and thoughts of their family member. However, without the professional diagnosis, this search was often unsuccessful. Helen shared her experience of searching for answers before a diagnosis was provided:

**I contacted the Schizophrenia Fellowship at one stage. I said "I think my mum is schizophrenic". They actually said to me, "Well unless you know that your mother's schizophrenic you can't come here".**

This response illustrates how the women's access to formal and informal support services was facilitated by the diagnosis of schizophrenia<sup>196</sup>.

Even when mental health professionals had decided upon a diagnosis, both the family member and the participants were not always informed of this. According to the literature, this occurs quite regularly (Howe, 1991). An example of this situation is shared by Margaret. Margaret thought Daniel was going to the long term care unit because of drug use:

**And my mind was really reeling, it really was. And as we were walking out he [doctor] turned to me and said, "Of course you realise there is another problem". I just heard this, but it wasn't until Daniel was admitted, that I sat down and I thought, what problem? What was the other problem?**

Margaret was later informed that this other problem was schizophrenia. Sonya also explained that Paul's diagnosis of schizophrenia had been withheld from him:

**He said "I want to know what is wrong with me". And really Paul had read all his girlfriend's notes on schizophrenia.**

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<sup>196</sup> Such a response should no longer be given with Schizophrenia Fellowship now providing information, support, education and advocacy for persons affected by schizophrenia *and related disorders*. This change in focus means that the diagnosis of schizophrenia does not necessarily have to be given before assistance is provided.

**He said to his social worker, "I've got schizophrenia haven't I". And he said "Yes, yes I think you have Paul. But the doctor will talk with you about it". And that was three months after...the first attack.**

The diagnosis of schizophrenia is withheld for reasons other than ensuring it is being correctly applied. The diagnosis may be withheld first, because of either the increased anxiety or despair a person might experience in receiving the diagnosis, second, because of the negative reactions a person might receive from the public as a result of their diagnosis, or third, because of the risk to the doctor-patient relationship with the person not believing the diagnosis is correct as a consequence of their lack of insight (Atkinson, 1989a; McGorry, 1991).

An important difference between a psychiatric disability and, for example, a physical disability, is highlighted by the caution exercised by psychiatrists when considering if an individual should be informed of his or her diagnosis. For example, it would be extremely rare, and even considered negligent if an individual was not informed that they had broken their leg or had high blood pressure. In comparison, withholding of the diagnosis schizophrenia, for the reasons just provided, is considered by some to be an acceptable practice. This is despite the uncertainty, confusion, and stress experienced by both those who exhibit the symptoms of schizophrenia and those who provide their care, and despite the importance of taking medication for symptom control (Kaplan & Sadock, 1991).

Not surprisingly, even when the diagnosis of schizophrenia was provided, it often took time before this term was reliably applied by the mental health profession. Harriet provided an example of this situation with regard to Rachael:

**She had several relapses before the diagnosis. Then they gave her the diagnosis [of schizophrenia]. And then the time before last [the long stay unit] changed their mind. But [the local acute unit] have decided to stay with schizophrenia.**

## **Committal**

By the time the women had realised that something more was wrong with their family member than drug use or a teenage phenomenon, their family member's symptoms had usually become acute. The family members' delusions and

hallucinations often led the family members to consider their behaviours and thoughts as reasonable, and most importantly, normal. The family members then saw no reason for them to consult mental health professionals about their behaviours and thoughts. As a consequence of the family member refusing to have contact with mental health services, the process of committal was typically the only way a diagnosis and professional follow-up help could be gained. Committal involved securing the family member within New Zealand's formal mental health services where they were monitored and treated as necessary. According to the participants, acknowledgment of patients' rights meant that the committal process could only be initiated when the family members became a danger to themselves or others. Ben's comment highlights some of the frustration the participants, as care-givers, associated with this situation:

**This day after Bill was not committed, that time we just had to wait till he did something and the police picked him up. And we just sat and waited. And we wondered whether it would happen.**

The instigation of the committal process is a distinctive feature of the participants' care provision. The participants committed their family member against their will knowing that their family member would remain in institutional care for an unspecified length of time<sup>197</sup>. While committal can be viewed as a severe response, the participants believed this action was warranted as a consequence of their family member's lack of insight. As was noted above, the family members thought they themselves were not the ones who were sick, everyone else was. Joy explained that this was the case with Bill:

**Well, we could see then there was something wrong. So we tried to persuade him to seek medical attention, or go and see somebody. But of course he said that we were odd, and he was all right. He said that we were all funny.**

The participants' discussion of the committal process highlighted the shifts of power and autonomy (Atkinson & Coia, 1995; Waerness, 1984), between

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<sup>197</sup> This was under the Mental Health Act 1969, the predecessor of the Mental Health Act 1992. The latter encompasses specific timeliness standards regarding the containment and release of 'patients'.

themselves and their family member. While the participants had the task of convincing the mental health system that their family member was unwell, to the point that they were a danger to themselves or others, the family members typically remained steadfast to the understanding that their thoughts and behaviours were a response to a reality which everyone shared, everyone except the members of their family. According to the participants, both themselves and the family members experienced great difficulty adjusting to the changes in their relative roles as the committal process proceeded. For example, as it became increasingly obvious to mental health professionals that the family members were unwell, the credibility of the women as care-givers increased. The committal process challenged the understanding that the women were simply dramatic, over-reacting mothers. Consequently, the family members' status changed, if not in their own, at least in the eyes of others, from that of a 'normal' individual to a person who needed to be contained as a consequence of their mental illness. Discussion further on in this thesis will highlight the constant struggle arising from the changing degrees of power and autonomy held by the women and the family members. As was suggested above, the frequent changes in the relative power and autonomy of the women and the family members arose in response to the changing nature of the family members' symptoms.

While the committal process ensured their family member entered New Zealand's formal mental health services and confirmed their assessments that something was 'not quite right' with their family member, the participants proposed that the committal process was not a solely positive experience. The struggles between the participants and their family member to increase or retain their power and autonomy suggested that this would be the case. In fact, the women and their husbands associated the committal process with dread, guilt, disappointment and heartbreak. Joy, for example, spoke of how the committal process had been poorly implemented in relation to Bill :

**However the next thing is that the psychiatrist here said to us that Bill must start his medication forcibly cause he was getting into bother. And that we must arrange for committal...And then the next bizarre performance was the fact that he was let off. That he wasn't committed. There was a bungle.**

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Harriet, who also spoke about complications with committal procedures she had initiated, explained that: **"I've had to commit her at one stage of it. Was one of the most horrific things that I've done"**. Helen's thoughts about committal were similar to Harriet's: **"...the hardest thing is if I have to commit her for treatment...To actually do it, it's pretty hard. You're thinking, 'Am I doing the right thing?"**

The committal process also highlighted the extent to which the family members were 'enforced users' (Taylor et al, 1992). When it was confirmed that the family members were experiencing an acute episode of schizophrenia, the family members had little, if any, choice about both entering New Zealand's formal mental health services and the type and level of care they received. Margaret's comment highlights the helplessness the family members' experienced as a consequence of their 'enforced user' status: **"The day we had him committed there was such misery in Daniel's eyes. It was almost as if his eyes were screaming 'Help me"**.

The lack of choice the family members experienced and the struggles which occurred between the participants and their family member typically generated ill-feeling and mistrust within the caring relationship. A common consequence of the committal process was for the family members to blame the participants, especially the women, for their stay in institutionally-based mental health services. This ill-feeling, mistrust and blame, combined with the symptoms of schizophrenia<sup>198</sup> reduced the likelihood that the caring relationship would be characterised by collaboration, reciprocity and trust.

Many of the participants had to initiate the committal process after the diagnosis of schizophrenia had been received from the mental health profession. This task often arose in response to their family member entering an acute episode of schizophrenia after ceasing their neuroleptic medication. Initiating the committal process after the diagnosis of schizophrenia had been received was associated by the participants with considerable amounts of frustration and concern. First, by this time the participants had learnt of the importance of early intervention. The participants acknowledged that the acute symptoms of schizophrenia could be

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<sup>198</sup> Examples of these symptoms are a lack of insight, delusions and hallucinations.

reduced if mental health professionals responded promptly. As Joy explained: **"I mean the sooner you go on to medication the better it is for coping with the illness. And the longer you wait, the worst it is"**. Consideration of the research on the neuroleptic treatment for schizophrenia has confirmed this understanding about the importance of receiving treatment. As Kissling (1994:10) has explained:

*A summary of the methodologically superior studies, with a uniform follow-up of one year, shows that if schizophrenic patients are not treated, a 74% relapse rate can be expected within the first year, compared with a relapse rate of only 16% on prophylactic neuroleptic treatment (mainly depot).*

The difficulty experienced in trying to convince mental health professionals that committal was required typically meant that prompt responses were not achieved. Acknowledgment of the importance of early intervention often led the women to feel more comfortable about initiating committal procedures for their family member. For example, after reflecting back on her past experiences of initiating the committal process, Margaret said: **"I felt personally I'd done the right thing [in committing Daniel]"**.

Second, the participants also understood that each acute episode of schizophrenia further reduced their family member's general level of functioning (Reed Healthcare Australia, no date). Harriet said the following about Rachael:

**We just didn't get any help for ages and ages... If she got help early she might be back at university or she might be back at art school. She might be coping...if she'd been got onto proper medication right at the beginning.**

The family members not only experienced the acute symptoms of schizophrenia, but had to deal with the ongoing detrimental effects to their overall functioning.

The committal process highlights the tensions between the rights of the women as care-givers and the rights of their family members as care-recipients. On the one hand, the family members reportedly did not want to be admitted to a form of care which in the first instance they did not see a need for and in the second instance, disliked. On the other hand, the women did not feel that they should be put in a

position where they were expected to take the brunt of the family members' positive symptoms<sup>199</sup> for which they had had no formal training. Sonya spoke of the potential outcome for herself as care-giver of Paul not being admitted:

**At that stage I wasn't coping. And they put him on heavier drugs, and said that it's not a nice time to be in hospital over Christmas. And okay I'll go along with that. But that convinced me you see, to take him home again. But I wasn't coping. It was a matter of whether they want two patients really. And that's what it often amounts to really when a person is at that stage.**

The women's experiences of committal raises several implications for New Zealand's mental health services. First, the above discussion highlighted the trauma that both the participants and their family member experienced as a consequence of the committal process. This trauma suggests that mental health professionals need to acknowledge the importance of their practice encompassing a duality of focus (Twigg & Atkin, 1995). Not only do those individuals exhibiting the symptoms of schizophrenia require treatment and care, their informal care-givers also require support and must be considered more than simply a part of the cared-for's social context (Bennie & Maniapoto, 1993).

Second, the women's experiences of committal demonstrate the importance of early intervention rather than focusing primarily upon those individuals in crises<sup>200</sup>. In order for early intervention to be achieved, New Zealand's mental health services need to be both adequate and accessible (Fernando & McGeorge, 1993). Early intervention would not only reduce the human costs associated with committal but also the direct and indirect financial costs which arise from costly institutional care and the poor general functioning of some individuals diagnosed with schizophrenia (Miller, 1995).

Third, until community-based mental health services are adequately developed, the newer more effective medication is easily accessible, and early intervention

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<sup>199</sup> Positive symptoms were defined earlier as behavioural excesses, such as delusions and hallucinations.

<sup>200</sup> New Zealand's mental health services currently focus on those individuals in crises as a consequence of the threshold for entry set by the Mental Health Act 1992.

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is more readily enacted, there will continue to be a need for institutionally-based residential respite. In saying this it is important to note that residential respite does not have to mirror the institutional care traditionally provided in New Zealand (Williams, 1987). Institutionally-based residential respite can perform more than a containment function.

## **The Diagnosis of Schizophrenia**

The women felt that their persistence in trying to find some answers to explain their family member's behaviours and thoughts had been worthwhile, when the diagnosis of schizophrenia was eventually provided by the mental health profession. This occurred through their family member either going themselves, usually reluctantly, to mental health services, or being committed. The women explained that the relief they experienced when health professionals officially acknowledged what was wrong with their family member, was juxtaposed with a sense of foreboding as the women struggled to understand the implications of the diagnosis schizophrenia. Jackie shared the concern she held about her son's diagnosis:

**I'm hesitant really to label him as schizophrenic. Even though I recognise that's what it is. But I still think of it as an acute psychotic episode that was drug induced because he's got the hereditary tendency. And I guess I don't really want to think that it's going to impinge on his whole life. To put a label on him like that at the age of twenty one.**

As Wheeler's (1992) interviews with four New Zealand women care-givers found, receiving the diagnosis of schizophrenia for a family member can be associated with trauma, distress, uncertainty, fear, disruption, relief, and powerlessness. For Wheeler's (1992) care-givers, the impact of receiving the diagnosis of schizophrenia depended upon the degree of education, support and availability of relevant information the women had access to.

Any relief the women felt about being provided with an explanation for the behaviours and thoughts exhibited by the family members was often not shared by the family members themselves. Even though the diagnosis of schizophrenia had come from the health profession, some of the participants reported that the family

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members still refused to accept their diagnosis. Joy spoke specifically about this: **"And of course he suggested medication and so on. And Bill of course said that it was drivel"**. These participants realised that even though a diagnosis had been provided, it was not going to be smooth sailing. Joy provided some justification to explain Bill's unwillingness to accept the diagnosis of schizophrenia: **"...if somebody tells you you've got a disease, that you're mad, you wouldn't like that much either would you?"**. Again the dominant discourses which influence how mental illness and schizophrenia are understood and interpreted had a negative impact upon the caring relationships examined in this thesis.

The time it took to receive the diagnosis of schizophrenia, beginning from when the women knew there was 'something not quite right' with their family member, ranged from a couple of months to ten years, averaging around six years. From the women's stories, it was clear that the variation in time taken for the family members to receive the diagnosis depended on: the severity and frequency of their symptoms; the time it took for the family members to be acknowledged by the mental health system; and, the willingness and ability of psychiatrists to apply the diagnosis of schizophrenia to the family members' behaviours and thoughts.

The participants believed that the frustration, guilt and regret the women experienced as a result of utilising the strategy of trial and error, could have been reduced had the diagnosis of schizophrenia been provided earlier. In acknowledging this, James identified the need for an accurate and timely diagnostic service:

**A good diagnostic service in the first place would have been helpful. I mean, for a good many years we didn't really know what was going on. This label five or six years ago was put on him. Which in some ways helped to explain why our effect on John was so minimal.**

The participants' call for an accurate and timely diagnostic service does not seem to be an unreasonable one. The National Advisory Committee (1992:16) has recommended that persons with schizophrenia (and manic depressive disorders) *"...should be provided with an accurate early assessment of their condition"*.

## **A 'Conundrum': The Key Themes**

The care the women were required to provide to their family member was outside their previous caring experiences. In reflecting this, the women utilised the strategy of trial and error. The women's use of this strategy highlighted the importance of informal care-givers, whether they be male or female, receiving training about schizophrenia and the implications of this disorder for their care provision. If the women had received training about how to provide care to a family member diagnosed with schizophrenia, the frustration, guilt and regret they experienced as a consequence of utilising trial and error, to the degree they did, would probably have been reduced.

The family members in this research were principally young adults, which is explained by the time of onset of schizophrenia. The majority of the family members exhibited the symptoms of schizophrenia in their late teens. This meant that the women had constantly provided care to their family member since their family member's birth. Moreover, the family members in this research were predominantly males. The women's care provision was provided on a continual (flat-line) basis rather than reflecting a U-shape as is reported in the caring literature (Women's Affairs Victoria, 1994). One would assume that providing care on a continual (flat-line) basis would place considerable stress and pressure upon the women. This is particularly the case when acknowledging the age of these women. This will be considered in the following chapters. Furthermore, the finding that the majority of the family members were young adult males, combined with the finding that their informal care-givers were women, suggests that gender issues will need to be acknowledged when further considering the participants' experiences of care provision.

It was noted that at the onset of schizophrenia the women increased their provision of care to their family member despite their input being questioned by their immediate family and mental health professionals. The women were often perceived by others outside the caring relationship as over-protective and over-reactive mothers. In reflecting this, the women's caring work was typically ignored and devalued. The questioning of the women's care-giver role continued until the diagnosis of schizophrenia was provided by the mental health profession to explain their family member's unusual behaviours and thoughts. The diagnosis of

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schizophrenia legitimated the level of care the women provided to their family member. A consequence of this legitimation was the women's access to other agents of care, such as their local mental health services, and their local branch of Schizophrenia Fellowship. Prior to the receipt of the diagnosis, the women had received limited, if any, assistance with their care provision. The diagnosis also typically led to the women's husbands filling a secondary supporting role<sup>201</sup>.

The difficulty the participants experienced in receiving the diagnosis of schizophrenia raised several implications for New Zealand's mental health services. Foremost amongst these implications was a challenge to the current focus upon those individuals in crises (Author Unknown, 1992; Christchurch Press, 1995; Ross, 1995). The importance placed upon early intervention in New Zealand's policy documents (Fernando & McGeorge, 1993; Minister of Health, 1994b) needs to be translated into mental health services which are adequate and easily accessible. While noting this, the question is raised as to whether New Zealand's mental health services will be developed to meet this standard in the current political and economic context.

The importance of early intervention for the treatment and prognosis of persons diagnosed with schizophrenia was also acknowledged in this chapter when the process of committal was discussed. This process is a distinctive feature of the care provided to a family member diagnosed with schizophrenia. The committal process highlighted the difficulty the women experienced in dealing with a family member whose view of reality was significantly incompatible with their own.

The committal process highlighted the shifts of power and autonomy (Atkinson & Coia, 1995; Waerness, 1984), between the women and their family member. It was proposed that these shifts would occur frequently in reflecting the cyclical nature of the symptoms of schizophrenia. The frequency of these shifts would undoubtedly place pressure upon the women, and their family member, as they adjusted to new tasks and responsibilities concomitant with the level of power and autonomy they hold (Atkinson and Coia, 1995).

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<sup>201</sup> The characteristics of this secondary supporting role are described later in this thesis.

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Discussion of the committal process provided a classic example of when a duality of focus (Twigg & Atkin, 1995) is required. The discussion about the rights of the women and the rights of their family member during these early experiences highlighted the need for a balance to be achieved between the rights of these two stakeholders. The discussion on the process of committal asserted that the women need to be considered in their own right, as more than simply a part of the cared-for's social context (Bennie & Maniapoto, 1993).

The full implications of the onset of schizophrenia for the provision of informal care have been hidden, to a certain extent, by the personal circumstances of the women who participated in this research. Whilst not undertaking paid work and being supported financially by their husbands, the majority of the women were able to increase the amount of care they provided to their family member as their family member's prodromal symptoms became more acute. Demographic changes however (Briar, 1994; Statistics New Zealand, 1993) may limit the ability of women in younger generations to gradually increase the care they provide to a family member diagnosed with schizophrenia.

The theme of unpredictability consistently arose in the participants' statements. Discussion in this chapter indicated that this unpredictability has particular implications for the provision of care. For example, the unpredictability of the family member's symptoms, coupled with their transient behaviour, increased the difficulty the participants experienced in defining what was wrong with their adult son or daughter. The material presented in the following chapters will continue to highlight how the unpredictability and changeability of the family members' symptoms impacted upon the participants' care provision.

The participants' early experiences regarding their family member's schizophrenia were shaped considerably by the discourses which influence the way in which 'mental illness' and specifically 'schizophrenia' are defined and understood (Anderson et al, 1986; Butler, 1993; Foucault, 1967; Jones, 1995; Miller, 1995). First, that knowledge which the participants did hold about schizophrenia incorporated the various myths and stereotypes which exist about this disorder. According to the participants, the family member's acceptance of the diagnosis schizophrenia was also influenced by such myths. The importance of accurate and accessible information regarding the aetiology, course, and treatment of

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schizophrenia was highlighted by the participants and their family member's working knowledge about this disorder. Second, the women were often perceived by mental health professionals, as domineering, controlling, and over-reactive. Third, the stigma and discrimination associated with schizophrenia was sometimes utilised as a justification for not assigning the diagnosis of schizophrenia, and not informing the family members or the participants of this diagnosis. The seriousness of this action is highlighted when acknowledging the role that neuroleptic medication plays in controlling the symptoms of schizophrenia, particularly the positive symptoms (Chouinard et al, 1993; Janseen Cilag, no datea, no dateb; Taylor, 1989). Access to neuroleptic medication, particularly the newer medications such as clozapine and risperdal, is associated with improved prognosis (Janseen Pharmaceutica, 1993). Again, it is questioned whether people experiencing other health conditions which also depend on medication use, such as high blood pressure, would have their diagnosis withheld.

The women's strategies for dealing with their family member and their prodromal symptoms were influenced by their financial circumstances, in practice their husband's income. Those couples in which the men had been in a high income bracket before retirement were more able, for example, to subsidise their family member financially. In comparison, those participants from a lower income bracket did not have the same range of options available to them. Their care provision was more restricted as a consequence of their economic circumstances. It was proposed that informal care-givers, such as the participants, may experience more pressure to financially support their family member as a consequence of the action taken by the state to reduce its expenditure on New Zealand's social services (Barker, 1992; Bowie, 1992; Craig et al, 1992; Kelsey, 1993).

The likelihood of the women and their family member receiving payments for care (Ungerson, 1995) was then discussed. It was acknowledged that neither the women nor their family member would be eligible for such payments until the diagnosis of schizophrenia had been formally given. The family member's symptoms of schizophrenia, especially hallucinations and delusions, were such that 'quasi-wages payments for care' (Ungerson, 1995) would not necessarily ensure the family member received the care they required when unwell.

Furthermore, it was asserted that the way care has been traditionally considered would almost certainly need to be challenged if the women were to receive 'carer allowance payments for care' (Ungerson, 1995). This assertion will be revisited in the following discussion.

The care described in this chapter equates with Waerness' (1984) category of 'deterioration'. The women provided increasing amounts of care to their family member in order to prevent the prodromal symptoms of schizophrenia from becoming more acute. However, despite the care the women provided, their family member became increasingly unwell. Experiencing the consequences of their family member entering the prodromal or initial phase of schizophrenia was a distressing and harrowing process for the participants, especially the women. This process typically extended over a long period of time. As already noted, the time it took for the diagnosis of schizophrenia to be provided varied from participant to participant but averaged around six years.

Discussion in this chapter has revolved around the participants' responses to their family member's behaviours and thoughts becoming increasingly unusual and socially inappropriate. Emphasis was placed upon the steps the women, in particular, took to develop explanations for, and respond to, their family member's behaviours and thoughts, until the diagnosis of schizophrenia was provided by the mental health profession. Discussion in the next chapter indicates that new events and issues arose in response to the receipt of the diagnosis schizophrenia.

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## 7. ASSUMING RESPONSIBILITY

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This chapter begins with describing the participants' initial responses to receiving the diagnosis schizophrenia from the mental health profession. The participants were given this diagnosis as an explanation for their family member's unusual behaviours and thoughts. Discussion in this chapter will emphasise the importance of the participants receiving the diagnosis schizophrenia. The diagnosis provided the participants with a legitimate reason for their family member's need for care at a level generally not analogous to their age. Second, in response to the diagnosis the women assumed responsibility for the provision of their family member's informal care. Third, the women's husbands tended to fill a secondary supporting role after the diagnosis of schizophrenia had been provided. Fourth, the diagnosis facilitated the participants' access into New Zealand's formal and informal mental health services.

When analysing the participants' stories, it soon became clear that the participants had spoken most comprehensively about both the events associated with, and the implications of, the women assuming responsibility. This chapter has been divided into three parts because of the large amount of material linked to the women assuming responsibility. The discussion below will briefly identify the main themes and events encompassed within each of these three parts.

Part one is titled 'Naming the Moment'. As the title suggests, part one identifies and describes the process the participants underwent in order to first, define the diagnosis schizophrenia and second, translate this diagnosis into their own lived experiences of their family member's symptoms. It is noted that the participants contacted health professionals, read relevant literature, and, fellowshipped<sup>202</sup> with

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<sup>202</sup> 'Fellowship' was a term the participants utilised when talking about how they met with other members of their local branch of Schizophrenia Fellowship to share their experiences and knowledge of schizophrenia.

others in order to develop a reliable and valid definition of schizophrenia. Attention is then turned to identifying those symptoms of schizophrenia the family members collectively exhibited. An aspect of this process involves acknowledging the degree to which the symptoms of schizophrenia vary in type, intensity, duration, and frequency both between and within an individual.

In part two of this chapter, entitled "Choosing' to Care', discussion revolves around the women's decision to provide their family member's ongoing informal care. The word choosing is in inverted commas to denote that the women's decisions to assume responsibility for providing their family member's ongoing informal care were influenced by various factors. The following factors are noted for the way in which they influenced the women's decision: the extent to which care was encompassed in the women's identity; the women's economic dependence upon their husband or the state; and, the dominant discourses which influence the way schizophrenia is understood. Furthermore, the men's decision to fill a secondary supporting role as a response to the women assuming responsibility is described. Attention is briefly paid to the decision of some women, not participating in this research, not to assume responsibility for their family member's care provision. This discussion is important as it proposes that women are not predestined to provide care to their family member diagnosed with schizophrenia. The functions and tasks of the women's care-giver role and the men's supporting role are respectively described.

Part three of this chapter is entitled 'Responding to the Decision to Care'. Discussion continues to examine the themes, issues and events the participants associated specifically with the women assuming responsibility. The material presented identifies the ways in which the participants adjusted to both their family member's diagnosis and their decision to care. Discussion in part three continues to highlight the extent to which the unique characteristics of schizophrenia influenced the informal care the participants provided.

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## PART ONE - NAMING THE MOMENT

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As the title 'Naming The Moment' suggests, attention will be directed towards describing the process the participants enacted in order to define and understand what the diagnosis schizophrenia meant for both their family member and their provision of care. Previous discussion has highlighted some of the reasons for the participants having to enact such a process. One of these reasons was the participants' lack of an accurate knowledge about mental illness generally and schizophrenia specifically. Ralph's statement that he knew "**Sweet nothing**" about schizophrenia was indicative of the participants' understanding of this disorder. Another reason for the participants having to establish the implications of their family member's schizophrenia for their provision of care is related to the fact that the women did not naturally know how to care. This was highlighted by the women's reliance upon the strategy of trial and error in order to respond to their family member's care needs.

The title 'Naming the Moment' also indicates the political implications (Barndt, 1989) of the participants identifying and understanding first, the reason for their family member's unusual behaviours and thoughts, and second, the implications of their family member's schizophrenia for their care provision. For example, before the diagnosis had been provided by the mental health profession, the women were generally isolated and unsupported in their care provision. Discussion in the previous chapter described how even members of the women's immediate family perceived the women to be over-acting and the women's care provision to be a means of 'mollycoddling' their family member. Understanding the diagnosis of schizophrenia and translating this understanding into their lived experiences was usually the first step the participants took before joining with others to make the personal political.

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Discussion in this chapter begins with outlining the steps the participants took in order to develop a reliable and valid definition of schizophrenia. Specifically, these steps included contacting health professionals, reading relevant literature, and fellowshiping with others. Following this, the symptoms which the family members collectively exhibited are identified and described. Acknowledgment of these symptoms helps to translate the diagnosis of schizophrenia into the every day experiences of the participants and their family member.

## Learning About Schizophrenia

When considering the nature of schizophrenia, it was asserted that the informal care-givers of a family member diagnosed with schizophrenia need to have a comprehensive understanding of this disorder. Discussion in the previous chapter confirmed that without such an understanding, informal care-givers are unable to effectively meet their family member's need for assistance and experience copious amounts of frustration, guilt and regret as a consequence of their utilisation of trial and error.

As already explained, the knowledge participants did have about schizophrenia came predominantly from the realm of fiction. Learning about schizophrenia then meant challenging the dominant discourses of 'schizophrenia'. For example, the participants had to understand that individuals diagnosed with schizophrenia did not have **"...a split personality"**<sup>203</sup> and did not walk **"with funny movements. Swinging their arms [and making] funny facial expressions"**<sup>204</sup>.

On receiving the diagnosis of schizophrenia, the participants automatically began to define its meaning. The urgency associated with this task is highlighted by Pat's reaction after she had been given the term 'schizophrenia' to explain Rebecca's behaviours and thoughts: **"All I could think of....was I must think of**

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<sup>203</sup> To use Margaret's words.

<sup>204</sup> To use Mary's words.

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that word. I'm dying to see what's going on. I must think of that word. Get home. Dive for the dictionary...". Information about schizophrenia was reported by the participants to be a vital factor in helping them to understand the characteristics and implications of the care they would need to provide their family member. In this regard, the participants' assessment was consistent with existing research on schizophrenia and care, which reports the importance of family caregivers receiving such information (Falloon, et al, 1984; Hatfield, 1979; Howe, 1991; Kuipers, 1991, 1993).

The three main avenues identified by the participants in their quest for finding information on schizophrenia were: contacting local health professionals; reading relevant literature; and, 'fellowshipping'. Each of these avenues will be discussed respectively below.

### **Contacting Health Professionals**

When searching for information about the diagnosis of schizophrenia, the family general practitioner was usually the first port of call for the participants. As material in the previous chapter has already demonstrated, the participants found that these health professionals were generally unhelpful, even obstructive. Anne's comment was indicative of the participants' responses when talking about receiving information from their general practitioner: **"But you've got to go out and ask for [information]. I don't think the doctors tell you. Ours certainly didn't"**. The lack of relevant information provided by health professionals to 'the family' on providing care to a family member diagnosed with schizophrenia, has also been reported in the literature consistently (Fadden et al, 1987; Hyde & Goldman, 1993; Seeman et al, 1982; Winefield & Harvey, 1994).

Just as with the diagnosis of schizophrenia, the reluctance of health professionals to inform 'the family' about schizophrenia has reportedly stemmed from either the belief that such information would only upset and discourage 'the family'

(Anderson et al, 1986), or adherence to theories espousing family causation of this disorder<sup>205</sup> (Beels & McFarlane, 1982; Brooker, 1990; Laffey, 1978). Another explanation for general practitioners not disseminating relevant information is their own lack of knowledge about mental illness and mental health services (Mason, 1994). The difficulty general practitioners reportedly experience in guiding care-givers of individuals diagnosed with schizophrenia to the correct mental health services is likely to continue, if not increase, as a consequence of the split between the purchase, provision and regulation of such services (Burns & Peacock, 1993). In response to the devolution of state responsibility for service provision amongst an array of competing providers, general practitioners will need to continually update their knowledge about how to access services. General practitioners may play a pivotal role in guiding informal care-givers to the correct mental health services. As already noted, the state contracting process may not only fragment services (Wanganui Chronicle, 1995d; Williams, 1992) but also increase the uncertainty experienced by service users (Boston, 1991; O'Brien & Wilkes, 1993; Williams, 1992) and continue to restrict the extent to which service users experience choice (Munford, 1995; O'Brien & Wilkes, 1993) and empowerment (Cochrane, 1994). Discussion of the participants' experiences highlights how blocking the access of informal care-givers to New Zealand's formal mental health services places pressure upon these informal care-givers as a consequence of the lack of assistance they receive with their care provision.

In noting the participants' descriptions of health professionals as obstructive, it is important to remember that some participants are describing the attitudes and actions of health professionals ten to fifteen years ago. Since then, the understandings regarding 'the family' as the cause of schizophrenia have changed. This change has occurred as a consequence of theories such as the

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<sup>205</sup> As already noted, 'the family' being seen as a causative agent for a person's schizophrenia, has reduced the quality of the informal care this person receives (Beels & McFarlane, 1982).

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'schizophrenogenic mother' (Fromm-Reichmann, 1948) being refuted. Health professionals have also become more informed on the issues of mental illness. For example, Anne acknowledged that: **"I think doctors are getting more alert to mental illness, because they are getting more training in it"**. Both Joy and Ben expressed similar thoughts to Anne when speaking about mental health professionals:

Joy **"I think we were treated like twits to begin with. And I don't think [mental health professionals] took much notice of me. But I think that's changed"**.

Ben **"I think the mental health professionals are getting better. Starting to realise that carers have a very vital role to play"**.

Acknowledgment of the vital role that family care-givers play in relation to the well-being of a person diagnosed with schizophrenia, is reflected in calls to involve 'the family' as part of the mental health team (Atkinson, 1986; Bernheim, 1990; Broker, 1992; Hatfield, 1979, Willis, 1982). However, despite New Zealand's policy documents increasingly noting the valuable role of informal care-givers (Naylor & Lardner, 1994), discussion of the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Privacy Act 1993, suggested that such a merger, between informal care-givers and formal mental health staff, is being blocked. Furthermore, it was noted that this legislation is reducing the ability of care-givers to provide quality care (Crowe, 1995; O'Hare, 1994; Schizophrenia Fellowship [NZ] Inc, 1995; The Press, 1994). It appears that the emphasis placed on patients' rights may actually be reducing the standard of both the formal and informal care individuals diagnosed with schizophrenia receive.

One positive outcome arose from the participants contacting health professionals in order to learn what the diagnosis of schizophrenia meant. In response to the health professional's inadequate knowledge of the mental health system, the women themselves had to develop their own map of their local mental health

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services. In developing this map, the women also learnt the various procedures and systems utilised within these services. This knowledge helped the women become a more confident and effective advocate for their family member. As Pat stated: **"One thing about it. After all the years you get to know the right people to ring"**. However, as Joy's comment illustrates, information regarding the mental health system was not collected or assimilated overnight: **"So we've had a lot of bad experiences in a way. I'm all right now, but we were so new at the game then. It wasn't easy"**. The ongoing organisation and structural changes which are occurring, for example the splitting of the purchase, provision and regulation of New Zealand's welfare services, almost certainly mean that informal care-givers, such as the women, will need to continually update their knowledge about the procedures and systems utilised in New Zealand's mental health services. As already argued, this knowledge base will need to be up-dated at the same time that the women are expected to provide care to a family member whose symptoms of schizophrenia invariably and frequently change in type, frequency, intensity and duration.

### **Reading Relevant Literature**

The participants also turned to relevant literature in order to establish what the diagnosis of schizophrenia meant, for both themselves and their family member. Reading was identified as the primary method utilised by the women in their search for information, the women's level of reading surpassing that of their husbands. The men often only read the material the women brought home, for example, from their local branch of Schizophrenia Fellowship. Throughout the practical component of this research, the participants expressed their willingness to learn about any material recently published on the topic of schizophrenia. The significance of reading, especially for the women, again confirmed the importance of care-givers receiving reliable, accessible and up-to-date information about schizophrenia and related issues (Abramowitz & Coursey, 1989; Hatfield, 1978, 1979; Walsh, 1985).

### **'Fellowshipping'**

The term 'fellowshipping' in this thesis does not have the religious or spiritual connotations which are usually assigned to it. Instead, fellowshipping is defined as coming together with other persons who provide care to a family member diagnosed with schizophrenia, both to share stories of your own particular caring relationship and to provide support for others in a similar situation. The term fellowshipping was extrapolated from the women's stories. The women consistently used the word 'fellowshipping' when describing how they came together with others who also provided care to a family member diagnosed with schizophrenia.

Toseland, Rossiter, Peak, and Smith (1990) have investigated the similarities and differences of individual and group interventions for family care-givers. They found that bringing care-givers together as a group enables care-givers to share their feelings and experiences of care-giving, and have them affirmed and validated. Care-givers were able to utilise this feedback to positively reassess their role as a care-giver. Care-givers also gained information on available community resources and information which helped them to prepare for events which might happen in the future with regard to their care-giver role. Care-givers who met as a group reported "*...positive changes in social support, both formal and informal*" (Toseland et al, 1990:215).

All of the women who participated in the research were members of their local branch of Schizophrenia Fellowship. The Fellowship was the only social service organisation from which the women acknowledged they drew support regarding their informal provision of care. The women reported that the Fellowship was the main vehicle through which they both found others to talk to about their experiences of schizophrenia, and received and gave support. For example, Jill explained that: **"The Fellowship is a good thing. Especially in the beginning.**

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It was great to go and find out that there were other people having the same kind of problems". Harriet identified that: "Once you actually find the right people, who suffer from it, who have had family members, you learn quite a bit from them". The women supported Toseland et al's (1990) research by speaking about themselves and their caring being affirmed and validated through their membership in Schizophrenia Fellowship. Furthermore, it was via their involvement in Schizophrenia Fellowship that the women considered how changes to the mental health system could ease and improve and their care-giver role<sup>206</sup>.

The men proposed that talking to others in a similar situation was the primary way they learnt about schizophrenia. As Ben explained: "I probably learnt more from speaking with people. I think Joy got more from reading. Well at least she got more than I". The men identified the benefits of joining Schizophrenia Fellowship. For example, Trevor shared:

**But it's really just knowing that you're not alone. You know that there are other people there that have already gone down that road. You can look to them for guidance and assistance, and a shoulder to lean on.**

The activity of fellowshipping encompassed many of the feminist principles which guided the methodology of this research. First, in coming together to share their experiences it was assumed that each person has their own basket of knowledge and skills which should be acknowledged and respected (Heron, 1981). The sharing of this knowledge and skill led to the participants and their care provision being affirmed and validated. Second, the activity of fellowshipping provided a space where each person could draw on their experiences and voice their own opinions to challenge the existing 'truths' (Anderson et al, 1990; Christ, 1980;

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<sup>206</sup> How the participants acted as change agents is discussed later in this thesis.

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Graham, 1984; Lather, 1991; Lerner, 1986; Lewis, 1981). As will be demonstrated below the challenging of these existing 'truths' led to strategies for change being implemented.

The value of fellowshipping with others in a similar situation was highlighted by the distinction the women made between what they called their 'schizophrenia friends' who they had met through their local branch of Schizophrenia Fellowship, and their 'other friends'. This distinction between friends was particularly drawn by Joy:

**We're very lucky. We've got some wonderful friends, and I don't think I could have survived without them. But they don't really understand, deep down. But my schizophrenia friends, they all know.**

Distinguishing between those who have experienced schizophrenia in the family and those who have not, drew attention to a caring culture. For example, the women and their 'schizophrenia friends' held similar meanings and interpretations for: the neuroleptic drugs prescribed for schizophrenia and their effects; the procedures used within mental health services; the subjective meaning of having a family member experiencing delusions or hallucinations; and, the unpredictability associated with schizophrenia. In comparison, the women's 'other friends' had no personal knowledge or experience in relation to these issues.

The distinction the women made between their 'schizophrenia friends' and their 'other friends' supports the understanding that the care provided to a family member diagnosed with schizophrenia has its own distinct characteristics and complexities. As the previous discussion on the nature of care highlighted, this distinctness suggests that the understanding of 'care', based upon feminist research, needs to be extended in order to reflect the care provided to a family member diagnosed with schizophrenia. The efficacy of this suggestion will

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continue to be established as the participants' care-giving experiences are described.

The participants were clear that they only knew about schizophrenia now, because they had been affected by it. If their family member had not been diagnosed with schizophrenia, the participants thought that they would still only know "sweet nothing"<sup>207</sup> about this topic. For example, Anne stated: **"I mean, would I know anything about mental illness now if it weren't for Patrick? No...it's when you get affected you get interested"**. Wiltshire, Lazarus, and Brooker (1991:24) have noted how common it is for people not to inform themselves about mental illness until they themselves are faced with dealing with it in their own lives. Specifically, Wiltshire et al (1991:24) have said that mental illness:

*...tends to be something which the majority of people are likely to ignore, that is until they come face to face with it, either in terms of a personal direct encounter or when someone who is close to them has a 'breakdown' of some kind.*

Sonya acknowledged that most of the people she had come across were not interested in understanding what schizophrenia was. Instead: **"They really want to know if [Paul's] dangerous. That's really what they want to know"**. It can be assumed that such concern about the perceived dangerous behaviour of the family members arose in response to the dominant discourses of schizophrenia. As already noted, 'mental illness' and 'schizophrenia' have been linked with fear (CRHA, 1995c; Miller, 1995; National Mental Health Consortium, 1989; Wanganui Midweek, 1995). The dominant discourses of schizophrenia again increased the difficulty the women experienced in their care provision - the women often had to reassure others that their family member would not spontaneously exhibit violent behaviours.

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<sup>207</sup> To use Ralph's words.

Increasingly, interest has been focused on evaluating the effects of providing information about schizophrenia, not only to the family member diagnosed with schizophrenia, but also to the family member's relatives. The results of providing educational material have on the whole been positive. For example, researchers found that: "*Both psychiatric patients and their relatives benefit from learning about mental illness and how to cope with it*" (Mueser, Bellack, Wade, Sayers, & Rosenthal, 1992:674). Specifically, Smith and Birchwood's (1987:645) study found that: "*Education led to considerable knowledge gains and to reductions in relative's reported stress symptoms and fear of the patient*". Anderson et al (1986) stated that information about schizophrenia allows the 'family' to develop a sense of mastery over their particular situation and to develop realistic expectations and strategies for the future.

Research has also been undertaken to establish the most productive way of presenting educational material to a person diagnosed with schizophrenia and their family (Barrowclough, Tarrier, Watts, Vaughn, Bamrah, & Freeman, 1987; Birchwood, Smith & Cochrane, 1992; McGill, Falloon, Boyd, & Wood-Siveno, 1983; Mueser et al, 1992; Tarrier & Barrowclough, 1986). From this research it has been found that the relevance of information may vary for different groups of persons. For example, Mueser et al (1992) undertook a survey of the educational needs of persons with schizophrenia or schizoaffective disorder, persons with a major affective disorder, and their relatives. Their survey emphasised the need to assess:

*...the specific needs of different diagnostic groups, as well as the value of distinguishing between the needs of patients and family members and between persons who are/are not members of self-help organisations (Mueser et al, 1992:670).*

This finding supports the need for support services to acknowledge and reflect the particular characteristics and complexities of different caring relationships (Twigg & Atkin, 1995). Meuser et al (1992) have also established that educational material should be presented on a continual basis if the benefits of education programmes are to be maintained.

The task of searching for information about schizophrenia had not stopped for the women after their initial search for a definition of this illness. Keeping informed about new developments was an important part of their care provision. The women's enthusiasm at being involved in this research, in most cases, stemmed from the importance they placed on both the receipt and development of knowledge pertaining to schizophrenia.

Having knowledge about schizophrenia and an understanding of their family member's symptoms will be vital for the informal care-givers of these family members in the current environment. For example, previous discussion has argued that legislation, such as the Mental Health (Compulsory Assessment and Treatment) Act 1992, is placing increased responsibility on such care-givers to meet a wider range of their family member's care and support needs. One way in which this responsibility is being exerted is by the introduction of community treatment orders (New Zealand Government, 1992) which allow a person to be treated at home. One possible consequence of community treatment orders is that those women who provide their family member's informal care could have to deal with the more psychotic symptoms of schizophrenia. As already argued, the boundaries which have previously restricted the expression of schizophrenia, for example institutionalisation, no longer predominate.

While in practice informal care-givers will need information and education in order to manage a wider range of their family member's symptoms of schizophrenia, the politics of placing this responsibility on women, who are typically both under-

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resourced and untrained in the area of mental illness, needs to be questioned. One of Jackie's previous comments indicated how scary it is to have to deal with their family member's symptoms when their family member is unwell. As Jackie said:

**I don't think they have any idea about how scary it is to be with a person, who however good and nice and trustworthy is normally...when they're having hallucinations or delusions, they're completely unpredictable.**

The complexity, changeability, and unpredictability of the symptoms of schizophrenia is highlighted in the following section in which the symptoms the family members collectively exhibited are identified.

### **Symptoms of Schizophrenia Exhibited by the Family Member**

By the time of their 'interview', the majority of the participants had spent a considerable amount of their time informing themselves about the aetiology, course, and treatment of schizophrenia. The participants referred to either a biochemical or cognitive explanation of this disorder, or, the diathesis-stress model<sup>208</sup>, to explain the incidence of their family member's schizophrenia. For example, Mary defined schizophrenia as: **"...a disordered thinking process"**. Harriet spoke of schizophrenia arising from both a: **"...genetic link..and a chemical imbalance"**.

Having an established knowledge base about schizophrenia upon which they could draw, allowed the participants to begin to understand and explain the behaviours and thoughts of their family member. As already identified, the Diagnostic and Statistical Manual of Mental Disorders (revised third edition: DSM-III-R)<sup>208</sup> was the criteria most likely utilised by mental health professionals at the time

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<sup>208</sup> Both biochemical and cognitive theories and the diathesis-stress model were described when discussing the aetiology of schizophrenia.

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many of the participants' family members were diagnosed with schizophrenia. DSM-III-R defined schizophrenia by the following symptoms: hallucinations; delusions; incoherence or marked loosening of associations; catatonic behaviour; flat or grossly inappropriate affect; and, impairment in social functioning (American Psychiatric Association, 1987). The material presented below will highlight what these symptoms meant in real terms for the participants and their care provision.

When reading the following material it is important to remember several points. First, as already explained, the family members experienced cyclical acute and chronic episodes of schizophrenia. All aspects of the family members' functioning were affected by their symptoms of schizophrenia. Those individuals diagnosed with schizophrenia with a different prognosis (Kaplan & Sadock, 1991) may not exhibit the symptoms of schizophrenia with such intensity and therefore require different levels of care provision. Second, although the family members' symptoms of schizophrenia affected the care provision of both the women and their husbands<sup>209</sup>, it was the women's care provision which was primarily affected. This is not surprising considering that the women were the primary informal caregivers of the family members. In reflecting this, it is the women's explanations and understandings of their family members' symptoms which predominate amongst the material presented below.

The symptoms the participants identified varied significantly between their family members in type, intensity, duration and frequency. The uniqueness of the experience of schizophrenia for each person, was highlighted by the participants defining schizophrenia as a continuum. In speaking about the continuum of schizophrenia, Harriet acknowledged the different prognoses of this disorder (Miller, 1995; Kaplan & Sadock, 1991):

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<sup>209</sup> This assertion is supported when describing the respective caring roles of the women and their husbands.

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**It's an illness that has a range of levels... And so there are people who have got severely handicapped and are more at risk than others...So they have to be treated differently to those who have recovered and have never had another breakdown.**

The type, intensity, duration, and frequency of symptoms also varied within the family member. Ralph for example, talked about the changes that had occurred in Rebecca:

**I'd have to say that she's not as violent as she used to be. We couldn't talk to her. She'd throw a tantrum. Throw more than one tantrum. You just couldn't cope with it. But she will listen now.**

Helen spoke about similar changes in Lidia's behaviour:

**Over the years she's mellowed. Absolutely. I don't know if I could handle her if she was like she was a few years ago. I don't think I could have taken her on really. She scared the hell out of me really when she was like that.**

Attention will now be turned to identifying and describing the symptoms of schizophrenia the family members collectively exhibited.

### **Negative Symptoms**

The symptoms described below are referred to as the negative symptoms of schizophrenia or those symptoms which involve a behavioural deficit (Davison & Neale, 1986; Johnstone, 1989; Wing, 1992). Behaviour which is generally present, such as the ability to communicate is missing. One of these symptoms was a lack of motivation. For example, James described Joshua as: **"Completely devoid of any motivation"**. Sonya described Paul's lack of motivation around the time when Paul had received the diagnosis of schizophrenia:

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**Pretty much that whole year he spent in bed. He used to sleep all night right up to lunch time. I'd come home at lunch time and get him up. Make sure he'd got up and had a shower. He'd be up until the afternoon.**

While the family members' lack of motivation may well be a symptoms of schizophrenia, the family members' lack of motivation is understandable when considering the dominant discourses of 'schizophrenia'. Being unmotivated could be considered a 'normal' response to being informed, in Joy's words, that **"...you've got a disease, that you're mad..."**. Furthermore, the family member's lack of motivation is consistent with the dominant discourses of schizophrenia which propose that people diagnosed with this disorder will be dependent and a burden to those who provide care to them (Atkinson & Coia, 1995).

The participants voiced their frustration and disappointment in their family member lying on their bed with the curtains drawn all day or loitering around the house. Some of the participants also spoke about their family member's frustration in not being able to engage in paid employment or find the energy to do day-to-day tasks, such as prepare a meal or tidy their living area. In noting the opportunities their family member missed in having low levels of motivation, the participants expressed their wish for there to be some way they could give their family member some enthusiasm for life.

Another symptom identified by the participants was their family member's lack of personal grooming. The women in particular spoke of reminding, sometimes forcing, their family member to shower, comb their hair, and change their clothes. Sonya spoke of Paul's personal grooming:

**I know he wouldn't wash his clothes, iron them unless I stood over him. He wouldn't eat properly...he seems to keep himself fairly clean although the shower bit and the**

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**washing hair would be every three days rather than every day.**

The women expressed their frustration at their family member failing to take care of their personal hygiene. As Jill stated, **"...if he washed himself he wouldn't smell quite as bad probably...if you haven't washed yourself for quite a while you do smell"**. In neglecting their personal grooming, the family member was often stared at or avoided by the wider public. The family member's lack of personal care signalled to others that they were unwell. The participants acknowledged that such public reactions often fed their family member's symptoms of schizophrenia, especially paranoia<sup>210</sup>.

Some of the family members also found it hard to concentrate for any length of time. Tasks such as reading the newspaper or listening to someone talk could only be undertaken for short periods of time if at all. Some of the side-effects of the various neuroleptic drugs<sup>211</sup> lowered the family members' level of concentration. This lack of concentration could explain the family members' tendency to withdraw socially, this being another symptom the participants associated with their family member's schizophrenia.

The women reported that in social situations, their family member would withdraw to another space where they could be alone. As Jill stated, members of the family: **"...say 'hello' to Joshua and sit and talk for a while until Joshua disappears, because he doesn't stay and talk to you"**. This occurred whether visitors were strangers, close friends, or family members. Times such as Christmas, birthdays, and even meal times, were recognised by most of the participants as stressful and tension filled. Trevor spoke about the tension during meal times resulting from Luke's behaviour:

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<sup>210</sup> The symptom paranoia is described further on in this discussion.

<sup>211</sup> Neuroleptic medications will be further discussed later in this chapter.

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**He sort of eats his meals as fast as possible and heads back to his room. He seems to want to avoid being present with us...instead of there being a sense of relaxed sharing of a meal together, it's quite tense.**

One of the consequences of the family members' social withdrawal was that they developed and maintained few personal relationships. This resulted in the predominantly adult sons and daughters being isolated. Margaret spoke of Daniel: **"Schizophrenics are loners...ok, he has friends that he might go to, but he never rings up anybody, nor will he go out"**.

Poverty of speech, or a reduction in the family members' ability to converse, was another symptom often exhibited by the family members. Margaret, for example, identified that since Daniel's first acute episode of schizophrenia: **"His conversation lets him down"**. While speaking about Joshua, Jill acknowledged that Joshua, **"...finds it really hard to communicate with people"**. The participants spoke of the tendency of their family member to communicate only to receive the personal services they required, such as food or money.

The participants proposed that their family member's negative symptoms of schizophrenia were the most difficult to live with day-to-day. For example, the family members' lack of motivation drained the participants of their energy and enthusiasm. As previously explained, neuroleptic (antipsychotic) medication traditionally available has not significantly affected the expression of negative symptoms (Choulnard et al, 1993). The participants found this ineffectiveness of neuroleptic medication on the negative symptoms of schizophrenia frustrating. Harriet was the only participant who found the positive symptoms of her family member's schizophrenia more difficult to manage. For example, Harriet said: **"Although most people say it is difficult to deal with the negative symptoms, I found it's the acute symptoms I couldn't come to terms with"**.

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Previous discussion on the treatment of schizophrenia suggested that informal care-givers would advocate for the accessibility of the newer neuroleptic medications, such as risperdal. Access to these medications, which control both the negative and positive symptoms of schizophrenia, could reduce the frustration experienced by the participants, and could improve their family member's quality of life (Janseen Pharmaceutica, 1993). The need for the newer neuroleptic medications to be more accessible in New Zealand has been advocated by Schizophrenia Fellowship New Zealand Inc. Schizophrenia Fellowship New Zealand Inc has encouraged its members to engage in a letter-writing campaign to Parliament. It has suggested that the writers:

*Ask why people with physical illness can get modern drugs, but people with psychiatric illness must make do with drugs developed in the 1950s [and] Why is mental illness being penalised? How can a person hope to become really well if optimal treatment is not employed? (Schizophrenia Fellowship New Zealand Inc, 1995a:2).*

The request by Schizophrenia Fellowship New Zealand Inc., for its members to engage in a letter-writing campaign suggests that the participants, at least via their membership in Schizophrenia Fellowship, do act as agents for change. This is despite the negative consequences which can be encountered by informal care-givers of a family member diagnosed with schizophrenia while making the personal political. As already noted in previous discussion, the participants could face negative social outcomes as a consequence of publicly identifying themselves as a care-giver of a family member diagnosed with schizophrenia.

### **Positive Symptoms**

As well as the negative symptoms described above, the participants also collectively identified those positive symptoms of schizophrenia which were exhibited by their family member. As already explained, positive symptoms refer

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to behavioural excesses or behaviour which would not typically be exhibited by a person. Again it is important to note that all of the following symptoms were not exhibited by all of the family members, all of the time. While the participants found their family member's negative symptoms most difficult to deal with on a day-to-day basis, the participants also found their family member's positive symptoms to be significantly challenging<sup>212</sup>.

All of the participants spoke about their family member experiencing hallucinations and/or delusions. As already noted, hallucinations involve a person experiencing sensory perceptions such as sights, sounds, smells and tastes which are not actually present. Delusions are false and persistent beliefs not substantiated by a person's culture or environment. Mary spoke about Michael's experience of these symptoms:

**...he brought the Listener, and there on the front page, was a picture of a little girl, a ballerina. And he says, "This is Patricia, our daughter, why is she in the Listener?" And I said "No, that's not Patricia". He said, "Yes it is". And then he said, "Why am I getting messages from the radio?". He said "I'm getting messages from the radio telling me things".**

The family members' belief in their hallucinations and/or delusions, illustrates that the process of committal was not the only time that the participants, and their family member, experienced difficulty relating to each other. At times, the participants and their family member's perception and understanding of the world were completely different. The family members' hallucinations and/or delusions meant that there were times when the family members did not provide any reciprocity in their caring relationship<sup>213</sup>. Jackie compared this situation to caring for someone with a physical disability:

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<sup>212</sup> The participants varied in their reports as to whether their family member found the negative or positive symptoms of their schizophrenia more difficult to live with.  
<sup>213</sup> The degree of dependency within the caring relationships examined in this thesis is further discussed below.

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**It's completely different from a physical disability, because if the person's mentally capable, you're working as a team...If they're quadriplegic and you come in on the raw, they will be able to tell you how to lift them safely. They know their limits, and they know their abilities. And they can guide you, and it's team work.**

The participants reported that perceiving the world differently from their family member was particularly challenging and at times terrifying. Jackie who was in the unique position of both personally experiencing schizophrenia and filling a care-giver role in relation to Luke, effectively illustrated this point. From the perspective of a care-giver, Jackie said:

**He wants me to accept his paranoia is true, and I can't. And I have to confront him about those things...like he's telling me his doctor took his eyeballs out and cleaned behind them. Tells you this in quite a matter of fact way.**

Later in drawing from her own experience of schizophrenia Jackie shared the following:

**It's very scary being psychotic. Your perceptual filter which filters out the relevant and irrelevant breaks down. And you hear the clock ticking as loudly as you hear someone talking to you. And that little hiss in the gas heater would be unbearable. And the conversation in the next room would all be impinging with equal strength.**

Paranoia, a delusional disorder, was a common symptom identified by the participants. As Sonya's quotation illustrates, the family members often believed that someone was trying to hurt either themselves or someone else they knew: **"He thinks that always there's a conspiracy against him"**. The women described situations where their family member thought the neighbours were plotting to harm them. They also described situations where their family member

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had accused the women of poisoning their food, or wanting to do harm to them by other means. Again Sonya provided an illustration of this: **"...when he's having a breakdown, he's very suspicious of me, and thinks I'm getting at him"**. Activities that the women undertook in their provision of care were sometimes defined by their family member as strategies devised to hurt them. This symptom in particular added to the women's perception that their family member did not acknowledge or value the care they received. Paranoia also meant that the family members did not always contribute to this long-term caring relationship. As Harriet identified:

**[My supporting role in relation to Rachael] is a different sort of supportive role than it is to other members of the family where there's a sort of reciprocal thing. I s'pose...cause [with Rachael] I have to accept either not getting any response at all or having to take responsibility for some of the things she might do.**

Winefield and Harvey (1994:556) in their study on the needs of family care-givers in chronic schizophrenia, found that: *"The psychological rewards of caring seem to be minimal for many caregivers, with little reciprocity that characterises mutually supportive relationships"*. However, even, when the predominantly adult sons and daughters exhibited hallucinations, delusions or paranoia, the women reported that they still continued to provide care to them.

The fact that there were times when the family members did not reciprocate the participants' care provision is another distinct characteristic of the care examined in this thesis. While family members with an intellectual, physical, or age-related disability are not always pleased about having to receive assistance (Morris, 1993a, 1994), the family members responses went further than acknowledging their disdain at having to receive care from the women and their husbands. Their hallucinations, delusions and paranoia led the family members to perceive the

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participants' care provision as detrimental to their wellbeing, sometimes to their survival.

The participants noted a lack of reciprocity existed between themselves and their family member while their family member exhibited both the positive and negative symptoms of schizophrenia. Sonya, for example, explained that Paul would not even take responsibility for mowing the lawns by himself, a task which Sonya was finding harder to do as a consequence of her age:

**I'll say to him day after day, "What about the lawns today? What about the lawns? After about two or three days I go out and start the mower. Well he comes out and does it. But then I have to be out there with him. Like when he's mowing the lawns, I empty all the grass.**

It appears then that caring relationships, in which a family member experiences cyclical acute and chronic episodes of schizophrenia, may not contain as much reciprocity as other caring relationships.

The theme of religion or spirituality was strongly associated, by the women in particular, with their family member's hallucinations and delusions. Harriet provided an example of how Rachael's spirituality influenced her symptoms:

**And when she came back she said the house she'd been in was haunted, or that she was possessed by Maori spirits...she insisted on it. And she was terrified, absolutely terrified.**

Margaret noted Daniel's past fixation with religion: **"He did go through a terrible stage of religion, which I think most of them do. You know, the bible and stuff".** Sonya's comment illustrates how common the theme of religion or spirituality is: **"...Paul said that the minister loves going to [the local acute unit] because everyone's talking about God".**

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The women explained this predominance of religion or spirituality in the symptoms of their family members by the following. First, the hallucinations and delusions the family members experienced, impacted upon them to such a degree that a supernatural power was the only thing that could explain them. As Helen said: **"I actually found with mum that the voices in her head were so powerful that it had to be God talking to her. That was her explanation"**. Second, the participants thought that various religious institutions reinforced the family members' symptoms by paying attention to their family member when they expressed religious or spiritual ideas. When describing the role religious institutions played in reinforcing their family member's symptoms, the women noted how historically the association between religion or spirituality and schizophrenia had led schizophrenia to be considered a form of spirit possession (Jones, 1995). Finally, one woman surmised that her family member used their religion or spirituality as a prop to deal with their schizophrenia. This third explanation identified positive elements of the association between religion or spirituality and schizophrenia. The family member's religious beliefs encouraged them to continue living and to a certain extent, helped the family member to make sense of the symptoms they continually lived with.

The participants also spoke of their family member having an altered sleeping pattern. Several of the women like Sonya spoke about lying in bed listening to their family member roam about the house:

**He'd walk up and down all night long with the gun in case anyone broke in. And of course I never got any sleep either. You can't sleep when there's someone walking round at night.**

Two of the women slept with their bedroom door locked. These women found that locking their bedroom door enabled them to be less interrupted by their family member during the night. It was the family members' altered sleeping pattern

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which most consistently interfered with those women who engaged in paid work. Jackie, considering her need to be at her paid employment the next day, explained: **"This is the thing, he's on an altered sleep pattern. He gets up at mid day and he might be awake at 3am or 5am, and if he wants company he wants company"**.

One of the myths about schizophrenia is that it is a 'Jeckyl and Hyde' condition (Jones, 1995) characterised by uncontrollable violence. Reports in the media have supported this understanding (Wanganui Chronicle 1995a; Wanganui Midweek, 1995). The material to follow should not be perceived as supporting this myth. Any violence or anger expressed by the family members was linked by the participants with times when the family member **"was not in touch with reality"**<sup>214</sup>. This was usually when the family member was either not taking their neuroleptic medication or was under considerable stress. This however, did not ease the fear and anxiety the women especially felt when their family member was exhibiting these symptoms. The fact that their family member had previously exhibited violence was often in the back of the women's minds. This is not surprising considering that the majority of the women were in their late fifties to mid sixties providing care to an adult son. Several of the women reported a considerable height, size, and weight difference between themselves and the predominantly adult males. The latter was amplified by the side effect of weight gain, associated with most neuroleptic medication (Falloon et al, 1984; Kalat, 1992; Kaplan & Sadock, 1991). However, it must be noted that not all women filling a care-giver role will necessarily be physically weaker than their family member diagnosed with schizophrenia. Consequently, some women may not feel as physically threatened by their family member as the women who participated in this research. Furthermore, some women providing care to a family member not exhibiting the symptoms of schizophrenia can also experience concern about

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<sup>214</sup> To use the words of the participants.

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protecting themselves from those they provide care to. An example of this situation is a young adult with challenging behaviours.

The violence and/or anger exhibited by the family member was reported by the participants to be directed predominantly at the women. An example of this violence was provided by Joy: **"He has attacked me. And I have felt fear for my life on several occasions"**. Helen also spoke of times in the past when she herself had been hit by Lidia:

**It was unexpected. Like suddenly she might get up and walk across the room and whack you. And she was a big woman then. I think she'd gotten to be about twelve to fourteen stone...She was quite a big woman and she had a fair punch too. So yes, like I say, she scared me then.**

Although the women were the main recipients of any violence or anger expressed by their family member, the participants did identify a few situations where their husbands were the targets of these symptoms. Anne's husband had been killed by Patrick while he was experiencing delusional thinking. Patrick, in thinking his father had the mark of the beast, from the book of Revelation, killed his father as a sacrifice. People outside the caring relationship had also experienced aggression from the family members. Joy provided an example of this situation: **"He went bizarre, berserk and threatened to hurt [a person he was working with]."**

Leafberg's (1994) recent research looked specifically at the issue of schizophrenia and violence from the family's perspective. Leafberg (1994:2) focused on four categories of violence and found that:

*Threats of violence were the most prolific as 88.78% (277) of the violent sample had threatened violence or acted in a threatening way. Of those 65.38% (204) had been violent against property, 65.06% (203) had been violent against others, and 61.22% (191) had directed violence at themselves.*

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The fact that the predominantly adult males exhibited violent behaviour when they were experiencing either hallucinations or delusional thinking is consistent with Leafberg's (1994) research. Leafberg found that persons diagnosed with schizophrenia were violent when they were either psychotic or under considerable stress, the former more so than the latter. Care-givers in particular were most at risk from violent behaviour exhibited by persons diagnosed with schizophrenia: *"...violence was generally directed at those in the caregiving role who were particularly available or vulnerable, mainly parents and spouses"* (Leafberg, 1994:19).

The finding that violence or criminal behaviour is linked with the relapse of the psychotic symptoms of schizophrenia has major implications for mental health services:

*The preventative message is clear, more active follow-up and better community care and supervision is needed for those with schizophrenic disorders. The effective response to the knowledge that schizophrenia may bring with it an increased risk of criminal behaviour is not to abandon community care and return to the incarcerations of the asylum, but to make community care a reality* (Mullen, 1991:91).

Discussion in previous chapters has highlighted the tensions which are currently present in New Zealand surrounding the issue of public safety and the rights of individuals exhibiting the symptoms of schizophrenia. Mullen's (1991:91) comment suggests that resolution of this tension may be achieved by ensuring that assurances from policy makers, about New Zealand's future mental health services being 'adequate' and 'accessible' (Minister of Health, 1994b) are implemented. In saying this, it is important to challenge the definition of these terms in adherence with the principles of market liberalism. As has already been argued in this thesis, the characteristics of schizophrenia require that a continuum

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of care is provided, including early intervention services, community-based services and institutionally-based services.

The participants reported that although their family member did not seem to recognise what they were doing when they were angry or aggressive, the women especially acknowledged their family member's shame, guilt, and disbelief when they were told what they had done. Their family member's self-esteem and trust in themselves was again shaken.

Several of the participants spoke of occasions when their family member's behaviour resulted in their total embarrassment. Helen provided us with an example of Lidia's past behaviour:

**One time we found her at the Women's Refuge. Someone had picked her up. She was carrying a suitcase, a huge suitcase. A suitcase on wheels. She was walking down the street. She was trying to get into this great big house that she believed was hers.**

Pat said the following about Rebecca's behaviour: **"I don't know quite whether you're ashamed of them or ashamed of yourself when you take them out actually. A bit of both"**. As will be demonstrated below, when the family members' behaviour was bizarre or inappropriate, not only were the family members treated as odd or crazy, but often the participants themselves were treated with caution.

The participants acknowledged the frustration and confusion they experienced when their family member exhibited seemingly senseless and inappropriate behaviour. However, when reflecting on their family member's past behaviour, the participants were sometimes able to understand their family member's actions. Harriet provided the following example:

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**...I was afraid I was going to have to go through committal. At that stage I found a piece of fish that had been under the bed for at least two or three days. And I understand now that the message was that she wasn't to eat.**

The theme of unpredictability permeated any discussion regarding the family members' symptoms. As existing research has suggested (Torrey 1983), this aspect of the schizophrenia resulted in extra stress, uncertainty, and tension for those providing care. Jackie's comment illustrates why this was the case: **"It's a bit hit and miss. Some days he's fine, and other days he's not, and you never know what kind of day it's going to be"**. Although Anne's experience has been a rare one, it highlights the potential ramifications of the family members' unpredictable behaviour:

**We were out the night before he killed Basil...This night he just sat there and chatted away to everybody. And of course the next day. That's what I can't understand. There was no animosity, no anything.**

In some cases, the women reported that their family member's mental state changed from morning to afternoon, sometimes from hour to hour. The women constantly had to reassess their family member's mental state. Harriet discussed the issue of unpredictability with regard to Rachael:

**...you're dealing with a lot of unpredictability. The mood changes are so sudden, particularly when she's unstable. She'd be happy one minute and tears the next, and shouting at you the next.**

Ralph said the following about Rebecca: **"One moment you've got a reasonably normal person, and the next minute you've got a screaming banshee"**. As noted above, the unpredictability associated with the symptoms of schizophrenia has been used to support the idea that persons diagnosed with schizophrenia are uncontrollable madmen. The belief in this myth is still strong. For example, Pat

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explained the behaviour of one person which reflected this view: **"I took her to one place one day, and they'd locked up all the scissors and knives and things"**. The participants explained that the unpredictability of their family member's symptoms increased in response to the family member either ceasing their medication, or their medication not being the right kind at the needed dosage level<sup>215</sup>.

The type and level of care the family members required was determined by the acuteness of their symptoms. In reflecting this, the participants' care provision was also unpredictable. As Jackie's comment highlighted, some days the family member was fine, other days they were not. The women never knew the type or level of care they would need to provide to their family member, sometimes on an hourly basis. The use of routines to schedule their provision of care was not an option open to the women. That the participants would not be able to use routines was suggested when considering the care provided to a family member with an intellectual, physical, or age-related disability. The care-givers of these individuals are generally able to foretell, to some extent, the type and level of the ongoing care they will need to provide. The use of routines reflects the relative predictability of this care (Munford, 1989; Opie, 1992). While Munford (1989) has noted the restriction that routines place upon women providing informal care, the women in this research described the restriction they experienced as a consequence of not being able to plan their lives beyond a day-to-day basis.

Discussion of the family members' symptoms raises the question as to why the women would continue to provide the majority of their family member's care. This discussion suggested that the women's care provision encompassed few positive aspects. First, assuming responsibility for their family member's care provision meant that the women did not have a break from their care-giver role. As already

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<sup>215</sup> This view is discussed more fully in the section on neuroleptic medication.

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argued, the women's care was provided on a continual (flat-line) basis rather than taking a U-shape as some feminist caring literature (Women's Affairs Victoria, 1994) would suggest. Second, the women experienced considerable anxiety and fear as a consequence of the potential violence their family member could exhibit. Third, there were times when the family members saw the women's care provision as detrimental to their wellbeing, sometimes to their survival. This meant that the women experienced little reciprocity from their family members. Fourth, the women were restricted by the unpredictability of their family member's symptoms. The women were constantly aware that their family member's symptoms could change in type, frequency, duration and intensity in a very limited time. This question of why the women continued to provide care to their family member, despite the issues raised above, will be revisited further on in this discussion. It was argued that the answer to this question reflects the reasons the women drew upon in explaining why it was them who filled a primary care-giver role for their family member in the first place.

Being able to identify the symptoms of schizophrenia removed any doubt the participants had about their family member not experiencing this disorder. The participants acknowledged the hell their family member lived in on a day-to-day basis as a result of their symptoms. The women especially spoke of the perseverance and stamina of their family members as they lived with their symptoms of schizophrenia. One of these women was Margaret who said: **"I admire all schizophrenics cause I really don't know how they cope with it. I think they must be very very strong people to survive it"**. Jill explained that for Joshua having schizophrenia had meant: **"A long hard fight. He has always fought it very very hard"**. The difficulty in living with the symptoms of schizophrenia has been written about by persons who have been diagnosed with this disorder (Green, 1978; North, 1987).

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As already argued, the characteristics of the family members' symptoms have particular implications for New Zealand's mental health services. Specifically, confirmation that the symptoms of schizophrenia varied between and within the family members in type, intensity, frequency and duration, indicates that mental health services need to be responsive to such variety. The unpredictability and changeability of the family members' symptoms highlight the benefits of informal care-givers being considered as part of the mental health team. Such a relationship could facilitate the flow of accurate and up-to-date information about the family members' mental state and lead to the family members' changing needs being met more effectively. Acknowledgment of the violence or anger the family members sometimes exhibited when they were **"not in touch with reality"**, challenges the current tendency for New Zealand's mental health staff to focus upon those in crises (Christchurch Press, 1995; Mason, 1994; Ministry of Health, 1993; O'Hare, 1994). Furthermore, the range of symptoms exhibited during the family members cyclical chronic and acute episodes suggest that a continuum of care is required. As already argued, such a continuum of care would include early intervention services, and a range of both community-based services and institutionally-based services. Further implications for New Zealand's formal mental health services will be noted in the discussion below.

It was also suggested that the symptoms of schizophrenia have particular implications for the 'commodification of care' (Ungerson, 1995). First, there may be times when the family member does not acknowledge their need for assistance. This difficulty could arise as a consequence of the family members' lack of insight, delusions and/or hallucinations. These symptoms could result in the family members spending the money targeted for conditional or 'quasi-wages payments for care' (Ungerson, 1995) instead of passing these funds onto their paid care-givers. Second, the changeability in the type, intensity, duration and frequency of the symptoms of schizophrenia could mean that the family members' needs change considerably in sometimes short periods of time. A

care-giver would need to be able to adjust their care provision to reflect the changes in the family members' levels of dependency and autonomy. A consequence of this adjustment could mean working variable hours and therefore not receiving a fixed income. Therefore, payment systems would need to be both flexible and innovative to reflect the changes in a women's care provision. Third, challenges would need to be made to the existing understanding of what 'care' involves (Twigg & Atkin, 1995). The need for this challenge arises from the unique characteristics of the care provided to a family member diagnosed with schizophrenia as reported in this thesis. An example of this uniqueness is the predominance of the more invisible supervision and monitoring tasks as opposed to the primacy of personal care tasks (Atkinson & Coia, 1995; Perring et al, 1991). Not identifying and acknowledging the characteristics and complexities of the care provided to a family member could lead to this care being discounted.

The discussion above has described the process the participants enacted in order to define and understand what the diagnosis schizophrenia meant for both their family member and their provision of care. Attention will now turn to identifying and describing the responses the participants made to their understandings of their family member's schizophrenia.

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## PART TWO - 'CHOOSING' TO CARE

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After having developed an understanding of what their family member's diagnosis of schizophrenia meant for their care provision, the women began to respond to this understanding. One crucial response was the women's decision to assume ongoing responsibility for their family member's informal care. The word 'choosing' in inverted commas indicates that the women's decision was influenced by a number of factors. It will be argued that these factors include: the extent to which 'care' was an important component of the women's identity; the extent to which the women were economically dependent upon their husband or the state; and, the dominant discourses of schizophrenia. The women's decision to assume ongoing responsibility for their family member's care provision is examined after the women's care-giver role has first been described<sup>216</sup>. This discussion again highlights how the characteristics of the symptoms of schizophrenia impact upon the women's informal care provision. The way in which the women's informal care reflected the complexity and changing nature of the family members' symptoms is described. While it is argued that the women's decision to assume ongoing responsibility was influenced by a number of factors, it is noted that some women, not participating in this research, have made the decision not to care. The ability of these women to make this decision is discussed. Attention is then turned to considering the men's secondary supporting role. It is explained how the men tended to fill such a supporting role after receiving the diagnosis of schizophrenia from the mental health profession. Discussion of the men's supporting role highlights some of the differences in the way in which the women and their husbands 'cared for' their family member. Finally, the participants' expectations about filling a care-giver/supporting role are noted.

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<sup>216</sup> The care-giver role is the role the women filled while providing ongoing informal care to their family member.

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## The Women's Care-giver Role.

Before describing the women's decision to provide ongoing care to their family member, the women's care-giver role will be described. This description will begin with identifying the various functions the women associated with their care-giver role. Attention will then be turned to discussing the tasks the women undertook.

The women spoke about their care-giver role encompassing multiple functions. Specifically, the women collectively associated the following functions with their care-giver role: supporter; nurse; motivator; protector; friend; mug on the end of the phone; occupational therapist; mother; instigator; and, care-giver. Examples of these functions are provided throughout the section, 'The Lived Experience'. For example, it was Pat who perceived herself as the 'mug on the end of the phone'. Pat<sup>217</sup> explained that she was the person formal mental health staff would call when either they considered that Rebecca was well enough to leave institutional care<sup>218</sup>, or, Rebecca had taken some action to hurt herself. In the former situation, Pat was usually expected by mental health staff to take Rebecca into her home, usually the afternoon she had been informed that Rebecca was going to be discharged from institutional care. Pat had usually complied with the requests that Rebecca return home no matter whether this decision was convenient or accepted by Pat. Trevor, James and Ben agreed with the women's descriptions of the functions they undertook in their care-giver role.

Reflecting their family member's symptoms, each function the women undertook varied in its complexity and the time and resources it required. The function which the women undertook was complementary to the state of their family

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<sup>217</sup> Pat's experiences of providing care to Rebecca are highlighted in the following chapter.  
<sup>218</sup> As was indicated when the participants were introduced, Rebecca had resided in New Zealand's traditional psychiatric institutions since she was nine years of age.

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member's mental health. The path of the family members' illness was the main determinant of the function the women would undertake. Harriet explained: **"And when she's well, yes I'm her support person. When she's sick, yes I have to be her care-giver"**. Inherent in Harriet's statement is the idea that the care-giver role is associated with constant change, this change reflecting the fluctuations in the type, intensity, duration and frequency of the family members' symptoms. Harriet spoke of the change inherent in her care-giver role:

**[My role] changes a lot. Because the illness changes from time to time. Although at the moment it's been relatively stable. Even when she's on medication there are times when you have to be a bit more responsible or bit more aware than at other times.**

The constant change inherent in the women's care provision is inconsistent with the ability to utilise routines as is reported in feminist caring literature (Briggs & Oliver, 1985; Munford, 1989; Opie, 1992). As already explained, the inconsistency reflects the nature of schizophrenia. Whereas these symptoms change in type, intensity, duration and frequency, both within and between individuals, the needs of an individual with an intellectual, physical, or age-related disability seldom change from day to day, month to month.

The women explained that the functions they undertook were increasing with the implementation of deinstitutionalisation and community care. The assertion that women, providing care to a family member diagnosed with schizophrenia, are having to provide care, previously the responsibility of New Zealand's formal mental health staff, is confirmed by Harriet's following comment:

**The move into the homes makes the homes the ward. This is a really difficult one because you're expected with no training, and with a lot of emotional involvement, to do the work of the hospital situation. Provide the occupational therapy, to provide the stimulus to get up and do**

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**something. To provide some routine. To provide everything. And a hospital can't provide everything so why should the family have to be expected to provide everything?**

Harriet's comment questions the politics of placing increasing responsibility upon women to provide care previously the domain of paid mental health staff. As Harriet has said, these women have had no training as to how to provide care to their family member diagnosed with schizophrenia. Previous discussion has highlighted the importance of informal care-givers receiving such training. This is especially the case when acknowledging that the current focus of New Zealand's formal mental health services, upon those in crises (Christchurch Press, 1995; Mason, 1994; Ministry of Health, 1993; O'Hare, 1994), means that informal care-givers are having to deal with the positive symptoms of schizophrenia. Harriet's question, **"And a hospital can't provide everything so why should the family have to be expected to provide everything?"**, challenges the understanding that 'the family' will be able to increase its caring capacity to the extent it is being expected to by Government. This challenge is revisited in the next chapter.

The tasks which the women undertook typically involved interacting with the family member at a personal level. Use of the term 'personal' requires some clarification. The term 'personal' is utilised in this thesis to denote the distinct differences between the caring tasks of the women and the men. As will be explained more fully when examining the men's role in the provision of care, the men's caring tasks tended to be more practical in nature. The men did not engage, to the same extent as the women, in trying to understand and respond to their family member's experiences of schizophrenia. While the women's caring tasks were more personal in nature than their husband's caring tasks, the personal nature of the women's care provision did not seem to be as high as is characteristic of the care provided to a family member with an intellectual, physical, or age-related disability. As was suggested in previous discussion, the

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women's care provision did not predominantly involve assisting with personal care tasks, such as toileting or bathing, as is stated in feminist caring literature (Perring et al, 1990; Twigg & Atkin, 1995).

Instead of revolving around the provision of personal care tasks, the women's care provision primarily involved the tasks of supervision and monitoring. Discussion in this and the following chapter will continue to highlight how the women first, continually assessed their family member's mental state and second, responded to their assessment. Examples of this process have already been provided. Initiating the committal process after the diagnosis of schizophrenia had been provided by the mental health profession is a case in point.

The predominance of the tasks of supervision and monitoring has several implications for the women's care provision. It is these implications which will now be discussed. First, previous discussion has noted the extent to which 'care' is defined by the presence of personal care tasks. It was noted that the lack of personal care tasks in the care provided to a family member diagnosed with schizophrenia has raised the question as to whether this unpaid work should even be defined as care (Twigg & Atkin, 1995). Therefore, in order for the women's caring work to be acknowledged the understanding that 'care' is characterised by the primacy of personal care tasks needs to be challenged.

Second, it was noted that the women were predominantly in their mid fifties to mid sixties. Acknowledgment of this highlighted the importance of establishing whether the women's care provision was hampered by restrictions arising from the aging process. In some ways, the women's caring tasks of supervision and monitoring were more befitting for their age than personal care tasks. For example, the former do not involve any heavy lifting. While the tasks of supervision and monitoring are not as physically demanding, these caring tasks are still psychologically taxing. The unpredictability and changeability of the

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symptoms of schizophrenia meant that the tasks of supervision and monitoring needed to be provided on a continual basis. The women had undertaken these tasks continually from the time their family member first exhibited the symptoms of schizophrenia. Consideration needs to be given as to whether it is appropriate to expect women, especially those later in years, to provide informal care to a family member diagnosed with schizophrenia within the current political and economic environment. As was noted above, pressure is being placed upon women to increase and extend their informal care provision.

The tasks of supervision and monitoring mean that it is difficult for an outsider to determine the extent to which women actually engage in their care provision. Supervision and monitoring is not characterised by any specific outward manifestations or activities, in comparison to for example, the outwardly obvious activities of making a bed, preparing a meal, or helping someone to dress. The relative invisibility of the women's caring tasks could mean their care provision is overlooked and disregarded.

The predominance of supervision and monitoring tasks has the potential for supporting the understanding that women providing care to a family member diagnosed with schizophrenia are simply over-protective. This is evident when considering that the majority of the family members are in their late twenties and early thirties. Usually there are no easily identifiable indications that a person has schizophrenia when they are not exhibiting the positive symptoms of schizophrenia. Individuals of this age are expected to have established their independence (Berger, 1986). Again, the understanding that the women are simply mollycoddling their family member raises the risk that the women's care provision will be overlooked.

The finding that the women primarily undertook the tasks of supervision and monitoring confirms the importance of the women receiving up-to-date information

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about schizophrenia and its manifestations. Furthermore, it can be argued that the women must be considered part of the mental health team. Without being provided information about their family member's prognosis and treatment, the women would for example, not know whether changes to their family member's behaviours and thoughts were the consequence of medication changes or the deterioration or improvement of their family member's mental health state. Knowledge of their family member's prognosis and treatment would allow the women to more appropriately respond to their family member. However, as already noted, inclusion of the women in the mental health team will only follow changes to some of New Zealand's legislation, such as the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Privacy Act 1993. The balance between patients' rights and the rights of informal care-givers will need to be readdressed.

To distinguish between the tasks the women and their husbands undertook, I have utilised the term 'interactive' to refer to the 'caring for' aspects of the women's care provision.

### **Choosing to Become a Care-giver**

Now that the functions and tasks of the women's care-giver role have been described, the women's decision to assume ongoing responsibility for their family member's care provision will be examined. The following discussion will provide some answers to the question which has been asked frequently in this thesis, 'Why was it the women who took primary responsibility for their family member's care provision?'

It was during the prodromal phase<sup>219</sup> of the schizophrenia that the women started to provide care to their family member which was not analogous to their age. The

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<sup>219</sup> The prodromal phase of schizophrenia was described in the previous chapter.

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women asserted that at this time they were simply responding to the needs of one member of their family. On reflection, the women proposed that the care and support they needed to provide increased gradually over time. For example, Jill stated that: **"It wasn't something that was dumped on me suddenly. It was a very gradual thing"**. As will be highlighted below, many of the women were assuming responsibility for the majority of their family member's informal care provision before they decided to continue to do so. The women's role as nurturer and home maker within their nuclear family allowed the women to gradually increase and extend their informal care provision to their family member.

It was the receipt of the diagnosis of schizophrenia from the mental health profession which lead the women first, to reflect upon their involvement in their provision of care and second, to decide to continue to be their family member's primary informal care-giver. Discussion will now turn to considering why the women had not previously decided to fill an ongoing care-giver role for their family member. First, the acuteness of the prodromal symptoms of schizophrenia increased gradually over time. Coupled with this was the family members' unsettled behaviour. As was explained, the family members tended to be very mobile, changing jobs frequently. The family members were also transient moving geographically both within and outside New Zealand. These factors meant that the women were able to adjust gradually to their family member's increased need for assistance. Second, the women's ability to increasingly match their family member's need for care was enhanced by the women not having to balance paid and unpaid work responsibilities. As already noted, the majority of the women had left paid employment at the birth of their first child. Third, the women's care provision did not fit within the bounds of what is typically accepted as 'care'. Instead of providing visible personal care tasks, such as bathing, toileting and feeding, the women primarily undertook the tasks of monitoring and supervision. Furthermore, these tasks can generally be undertaken in conjunction with other day-to-day activities, such as cooking a meal or tidying the house.

When telling their stories, the women provided little, if any, description and explanation of why they had filled a care-giver role. This led me to prompt the women to discuss their decision. The women were initially reluctant to talk about their decision to fill an ongoing care-giver role for their family member. It seemed that the women were not overly interested in considering or questioning their decision to care. According to the women, their decision had been the most obvious and logical one to have made. Furthermore, the women indicated that there was a certain amount of redundancy associated with considering their decision to fill an ongoing care-giver role. The women also could not perceive this decision being reversed.

In considering their decision to fill a care-giver role, the women did identify several factors which influenced their 'choice' to be their family member's primary informal care-giver. The women's reaction was similar to that found by Lewis and Meredith (1988:25) who researched the care daughters provided to their elderly mothers: "*...those drifting into or consciously deciding to care believed firmly in retrospect (not necessarily with bitterness) that they had had little alternative but to care...*". The following discussion will identify those factors which primarily influenced the women to decide to assume ongoing responsibility for their family member's care provision. Specifically, this discussion will refer to the extent to which care was encompassed in the women's identity, the women's economic dependence, and the discourses of 'schizophrenia'. As will be illustrated, the explanations the women gave for assuming responsibility for their family member's care provision were similar to the findings of Guberman, Maheu and Maille's (1992) research. These authors interviewed female care-givers of frail elderly or mentally ill relatives to establish why they provided care to their family member. Guberman et al (1992:609) have proposed that six factors primarily determined their care-givers' decision to care including:

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1) love, maternal feelings, feelings of family ties; 2) inadequacy of institutional or community resources; 3) a profound need to help others; 4) feelings of duty and obligation; 5) imposition of the decision by the dependent person; 6) women's socioeconomic dependence.

### Care And The Women's Identity

Many of the women's explanations of why they filled a care-giver role revolved around their understanding of the role women should play in society. The women's definition of the construct 'woman' included being caring, cooperative, loving, self-sacrificing, and, being situated in the private sphere of the home and the family. Reflecting this, most of the women and their husbands had formed a nuclear family with their children. While the women were responsible for the nurturing and other tasks inside the home, their husbands were responsible for earning an income which would support the family. Their nuclear family then was based upon the wage earner/home maker split (Koopman-Boyden & Scott, 1984), Jill for example, said: **"Right from the time I was married I had the nurturing role"**. Joy also believed that: **"It's a woman's role to have children, bring them up, and care for them"**. Joy's comment highlights the importance of acknowledging the value some women place upon their caring work. In talking about this Croft (1986:24) has explained: *"...some women want and value the role of carer, and this preference cannot be dismissed simply as the consequence of false consciousness or the dominance of male values"*.

That the women saw themselves as responsible for their family member's care provision was reinforced by the fact that the family members were predominantly the women's children. The women drew upon what they called their 'maternal instinct' to explain their role in the provision of their family member's care. Anne for example said: **"I think a woman always has a different feeling for her children. She's borne the child"**. Those women who were the mother of the predominantly adult sons and daughters argued that once you become a mother, you are always a mother. For these women, their caring fitted within the social

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rubric of duty. Their caring role reflected past relationships (Ungerson, 1983) and their expectations of the 'mother' role.

While noting the importance they themselves had placed upon maintaining the wage earner/home maker split, the older women, in particular, acknowledged that this family form is no longer the norm in New Zealand (NZDS, 1992; Social Development Council, 1991). Again it was Jill who said:

**...I think that perhaps our generation might have been one of the last ones where the roles are so clearly defined. That mum stays at home and looks after the family, and everything in the house. And dad goes out and provides the money.**

While the women defined meeting their family member's care needs as their responsibility, one can assume that their previous caring experiences would have been utilised by others in their family to confirm their decision to fill a care-giver role. For example, one of the implications of the women filling a home maker role was that precedents had been established about who, within the family, was responsible for caring work. As a consequence of the majority of the family members being adult children, it was the women who had previously been responsible for meeting their care needs. In turn, the women providing care during the prodromal phase of the schizophrenia, set precedents about who would provide care to their family member when their symptoms became acute. In other words, in examining the interpersonal histories of the women it was clear that the women were increasing their 'cumulative commitments' (Finch, 1989) in relation to their family member<sup>220</sup>. These cumulative commitments, then, could be utilised during negotiations about who should care, these negotiations including persuasion, manipulation, and coercion. The women's understanding that their

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<sup>220</sup> As already explained, this concept refers to the interaction between persons over time which establishes (both unconsciously and consciously) recognised precedents about who should care (Finch, 1989).

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decision, about filling a care-giver role for their family member, would not be reversed suggests that this had happened.

The idea of cumulative commitments is also relevant when noting that many of the women had also provided ongoing informal care to relatives other than their family member. Sonya spoke about the care she had provided to her mother:

**I looked after my mother the last few years of her life. Not having her living with me, but down the road in a flat. My sisters didn't want to be bothered and so, I'm not blowing my own trumpet but, I am like that, I would look after her.**

The women's understanding that they were responsible for meeting the welfare needs of the members of their family was reinforced by others outside of the women's immediate family. This was highlighted by Harriet. Harriet's unpaid and paid work responsibilities were assessed by her paid work peers as conflicting. Harriet felt she was forced to leave her paid work as a consequence of her peers asserting pressure on her to provide sole care to Rachael: **"I ran into some problems [at work]. The parents were aware that I had a daughter who suffered, and said my role should have been at home"**. Harriet's work peers expected her to alter the balance between her paid and unpaid caring obligations, which eventually Harriet did by leaving her paid work.

One of the women indicated that filling a care-giver role for her family member had meant that she needed to challenge her construct of 'woman'. As a consequence of her husband exhibiting the symptoms of schizophrenia, Mary had to take a more decisive role than what she thought was appropriate under different circumstances:

**I have to figure things out. Then I discuss it with Murray. Then if we agree we're okay. Whereas before, I would have let Murray be the boss. I know it's an old fashioned way of**

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**thinking, but I always tend to think of the husband being the boss of the family. But now I have to do the thinking. Things have turned around.**

Mary's comment highlights how slight changes to the internal factors of a caring relationship, in this instance the kinship relationship between the care-giver and care-recipient, influence the characteristics of informal care. While the family members being adult children supported the women's maintenance of the bread winner/home maker split within the family, the family member being a husband meant that Mary had to challenge her role as nurturer and take a more decisive role within the family. This discussion confirms Graham's (1991) assertion that the experiences of one group of women should not be generalised to all women. The way in which different kinship relationships impact upon the provision of care to a family member diagnosed with schizophrenia is highlighted later in this chapter.

The women also stated they filled a care-giver role because, in comparison to other members of their family, they had to make the least adjustment in order to do so. Helen provided the following explanation:

**I guess though it was sort of inevitable because I was a solo mother a few years ago, when it sort of all happened. And my sister is married with two kids, and a husband that didn't want anything to do with [my mother]. And my brother was just getting round to getting married then. So there was no way he would have taken responsibility. I guess it was me that thought oh well.**

The fact that it was Helen who took responsibility for Lidia's care and support is, however, puzzling. Helen being a sole parent not only had a child to raise, on a limited income, but she also had to undertake her caring responsibilities (for both her child and mother) on her own. It appears that Helen's gender, combined with the lack of a spouse, meant that Helen was defined as a more appropriate care-

already experienced in endeavouring to support herself and her daughter financially.

All of the men's explanations as to why it was the women who filled a care-giver role were related to the traditional construct of woman. As already noted, according to this construct, 'woman' involves being: associated with the private sphere; caring; submissive; cooperative; loving; dependent; and, self-sacrificing (de Beauvoir, 1972; Figs, 1986). Ben for example said Joy's decision to fill a care-giver role was a consequence of "...**just motherly love**". James said the following about Jill: "...**I think she has this vague notion that her love for John can sort of cure him**". The understanding that the women's care-giver role was part of, or an extension of, their role as 'mother' was also consistently proposed by the men. James for example spoke about Jill: "**She's a mother and she's really concerned that this child of hers is not developing in the expected manner**". The men's explanations for the women's decision to fill a care-giver role, focused on the naturalness of this decision. This view fits with Gilligan's (1982:17) statement that: "*Women's place in man's life cycle has been that of nurturer, caretaker, and helpmate*".

### **Women's Economic Dependence**

The women also filled a care-giver role as a consequence of their limited earning power in comparison to their husbands. The women's occupations and positions in the paid workforce earned less than their husbands<sup>221</sup>. Harriet's following comment highlights the implications of her lower earning power:

**...somebody had to be there and I saw myself as the least important. In the sense that well, practicalities. My job could never have fed and clothed the whole family. [My husband's] job can do that.**

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<sup>221</sup> The lower earning power of the women was consistent with existing research (NZDS, 1993a).

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As Novitz (1987) and Easting (1992) have asserted the lower earning power of women means that the opportunity cost of men leaving paid work to provide informal care is greater than if women do. As a consequence of Harriet's income not being adequate enough to support both herself and her family, it made economic sense for Harriet to leave paid work.

Mary's decision to leave paid work arose from financial reasons. As a consequence of Michael's invalid benefit and accompanying supplements being just lower than Mary's wage, Mary and Michael found it made sense to receive the benefit rather than for Mary to continue to juggle her paid and unpaid caring responsibilities (McDonald, 1994). Mary expressed her anger at losing her career and having her family's earning power reduced as a result of her husband's psychiatric disability:

**I had a good job there, senior nurse on my shift looking after the whole residents and staff. Which I left because it just wasn't worth while...with all the money going to the benefit, and losing our accommodation benefit. It just wasn't profitable in the end.**

The difficulty some of the women had experienced in combining their paid and unpaid work responsibilities is highlighted by Sonya's comment. For Sonya, the pressure of constantly being involved in caring work (both paid and unpaid) was too great. Sonya chose to continue to provide care to Paul:

**Looking after disabled, physically disabled people for eight hours a day and then going home to look after a mentally disabled person, I just couldn't handle it any longer. So I handed in my notice and left there.**

Sonya's decision was consistent with Finch and Mason's (1990) understanding that women place their unpaid caring responsibilities before their paid work.

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Sonya knew that someone else could be found to replace her in her paid work. However, Sonya knew of no-one, other than herself, who would fill a care-giver role in relation to Paul. The lack of assistance Sonya had received when trying to juggle her paid and unpaid caring responsibilities is explained in part when acknowledging the dominant discourses of schizophrenia.

### **The Dominant Discourses of Schizophrenia**

The women's decision to fill an ongoing care-giver role was influenced not only by their understanding of 'woman' and their economic dependence upon their husband or the state, but also by the dominant discourses of 'schizophrenia'. First, the women's decision to assume responsibility for their family member took into consideration the way in which these discourses had, up until then, impacted upon their provision of care. Foremost amongst this consideration was the participants' acknowledgment of how hard it was for them to unlearn the misconceptions regarding schizophrenia<sup>222</sup> (Jones, 1995). The participants knew that even though the various myths surrounding schizophrenia have been refuted by academic research (Brooker, 1990; Goldenberg & Goldenberg, 1985; Higgins, 1966; Leafberg, 1994; Straus & Carpenter, 1981), these myths are still perpetuated within media (Wanganui Chronicle, 1995a:1995b; Wanganui Midweek, 1995) and fiction, and acted upon by the wider public. As a consequence of this, the women knew of no one else, besides themselves, who would be prepared to provide informal care to their psychiatrically disabled family member.

The women also made several links between the dominant discourses of schizophrenia and the inadequacy of New Zealand's community-based mental

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<sup>222</sup> Examples of such misconceptions include that 'the family' and particularly mothers cause schizophrenia, that schizophrenia is another term for split personality, and that violence is a necessary component of schizophrenia.

health services<sup>223</sup>. These links were consistent with Waerness' (1984) understanding that the purpose of care is linked to the distribution of services and resources to those in the caring relationship. The women proposed that understandings, such as all individuals diagnosed with schizophrenia are violent and aggressive and schizophrenia is a kind of Jeckyl and Hyde condition (Jones, 1995), have typically closed people's hearts to those directly affected by schizophrenia. According to the women, the general public and health professionals have considered other causes to be more worthwhile of their attention and resources. Just like Walsh (1985:171), the women noted the public's reluctance to acknowledge and accept mental illness, specifically schizophrenia. The women explained that until this reluctance had changed, they would not feel comfortable trusting anyone, including mental health professionals, with the overall responsibility of their family member's care provision. The inconsistencies<sup>224</sup> the women noted between New Zealand's policy documents and the implementation of community care and institutionalisation led the women to believe that they would never be able to transfer their responsibility for their family member's care provision to someone else.

The above discussion has highlighted that there is not a single or simple answer to the question of 'Why was it the women who decided to assume ongoing responsibility for their family member's informal care?' Factors both internal and external to the caring relationship influenced the women's decision. Furthermore, these factors helped to maintain the women in their care-giver role.

The older women wondered whether women of future generations would make the same decision as they had about providing ongoing informal care to a family

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<sup>223</sup> The participants' assessment of New Zealand's mental health services is presented in the following chapter.

<sup>224</sup> These inconsistencies are highlighted in the following chapter.

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member diagnosed with schizophrenia. The women acknowledged the demographic changes that had occurred since they had married. Some of these demographic changes included: smaller sized families; women's increased participation in the labour market; and, increased divorce rates (NZDS, 1992; Statistics New Zealand, 1994). According to the women, these demographic changes reflect the different understandings of 'woman' currently held in New Zealand. Women no longer expect to automatically fill a nurturer/home maker role for the majority of their adult lives. Discussion on the changing demographics of 'the family' suggested that research will need to establish how these changes affect the ability of both women and men to care (Munford, 1995). The discussion in this thesis has highlighted the importance of determining specifically what the consequence of these demographic changes may have for the informal care provided to a family member diagnosed with schizophrenia.

### **Women Who Decided not to Fill a Care-giver Role**

While the women had decided to assume ongoing responsibility for their family member's informal care provision, some of the participants spoke of other women they knew who had made the decision not to provide this care. Recognising this decision is important because it shows that the 'choice' to care is not predetermined.

The participants provided two explanations for the decision not to care. The first explanation was that these women could not cope with the demands of providing care to someone with schizophrenia. Ben, for example, said the following: **...I can well understand some parents not being able to cope. We've known a number who have told their son "Don't come back".** Material already presented in this thesis highlights how distressing the women found their family member's unusual behaviours and thoughts to be before the diagnosis of schizophrenia was provided. Their distress was increased by the fact that they

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did not know intuitively or instinctively how to meet their family member's care needs. However, despite the distress the women interviewed for this thesis experienced, they still decided to provide informal care to their family member. The question of whether women care or not seems to involve a balancing between a social expectation to care against their perceived personal resources to care. That is: 'What provided some women with the commitment and strength to continue on an ongoing basis with their care provision whereas other women decided not to care because they felt they did not have these resources?'

The second explanation why women chose not to care was that, even though some of these women felt they had the personal resources to provide the caring work their family member required, these women decided that they would not draw on these resources and instead chose to live a 'normal' life. As Sonya explained, living a normal life could only be achieved without the restriction of the care-giver role<sup>225</sup>:

**...friends of Paul. And they say "my mother doesn't take an interest like you do". But I can understand that. I mean I'm so involved in it. But I can quite understand that they've got their own lives too. And their life is not being involved with it....**

Pat indicated that she understood and supported the decision some women had made not to provide care as a consequence of the relief this decision provided for the family:

**I take my hat off to these, sometimes couples but mostly the mum who say "Okay, I've had enough. Out. And don't come back". I take my hat off to the ones who can really do that. At least it saves the rest of the family. Maybe they're not worth saving, but at least you've got them.**

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This restriction is highlighted in material presented later in this thesis.

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Two more questions arise in response to the second explanation why women choose not to utilise their personal resources for caring work. First, 'What was it that these women wanted to do in their lives that seemed more important to them than providing ongoing informal care to their family member diagnosed with schizophrenia?' The second question raised from women choosing not to care is, 'What is it about the care they provide to their family member that they find so onerous?' The answers to both of these questions will facilitate an understanding of why a woman would decide not to fill a care-giver role. While this is the case, underpinning these questions is the presumption that a woman needs to justify her decision not to care. In contrast, one can suggest that women and men should not have to justify their decision to either care or not to care.

While the above questions seem germane, there appears to be little research that allows us to answer them. In acknowledging the need for research to determine why 'the family' does not provide for its member(s) diagnosed with schizophrenia, Winefield and Harvey (1994:564) stated that:

*Insofar as the mental health system wishes to strengthen community supports and caregiving for persons with chronic mental illness, it is regrettable that we know so little of how often and for whom family ties are likely to be unavailable.*

Winefield and Harvey's (1994) comment is of major significance to New Zealand. When considering the extent to which deinstitutionalisation and community care features in New Zealand's social policies and legislation, it seems incredulous that such information would not be available. The implementation of deinstitutionalisation and community care in New Zealand has placed increased responsibility upon women to meet the welfare needs of their 'family' via their informal care provision. In fact, when understanding the degree of influence social policy has on the provision of care, the absence of statistical data indicating the number of available female and male informal carers seems irresponsible.

## **The Men's Role While the Women Assumed Responsibility**

It was noted above that before the diagnosis of schizophrenia was provided by the mental health profession, the men tended to disregard the women's caring work. The men considered the women simply to be 'mollycoddling' their family member. The men generally increased their engagement in their paid work in order to buffer themselves from the women's concerns.

As a consequence of both their family member's increasing need for care and the women's care provision being legitimated by the receipt of the diagnosis schizophrenia, the men filled a secondary supporting role. This finding is consistent with feminist caring research which consistently identifies that women and men generally provide different types and levels of care (Finch, 1986; Ungerson, 1987; Women's Affairs Victoria, 1994).

In filling a supporting role, the men's primary aim was to protect their wives, as much as possible, from the stresses and strains they experienced as a consequence of their care provision. James clarified his primary purpose in the caring relationship:

**As I say, my main role is to make sure that [Bill] doesn't hurt my wife...Jill is my prime responsibility. I may be a little protective at times but, I don't want her hurt. Or hurt as little as possible. She's hurt enough as it is.**

Those men that had been in their supporting role for a period of time, likened themselves to a buffer.

The men, in filling the more removed supporting role, were not as involved in the caring relationship as the women, and were therefore able to continually stand

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back and assess the situation. After agreeing with, or modifying the men's assessment, the women worked with their husbands to draw the boundaries their family member was not to cross. Jill shared her experience of this:

**As James says, and he rightly says, that if it was up to Joshua, he would live here and he would push us around. If he had his way he would drive his father's car, he would live here. He'd go to the pub when it suited him. That's quite true. And that's why between us, well that just isn't on.**

The men also acted as a sounding board for the women whose interaction with their family member was at a personal level<sup>226</sup>. At their second group meeting, the women explained that the men usually had little choice about acting as a sounding board. First, the men were typically the only other person in the household, besides their family member, at the end of the day. The rest of the family member's siblings had left home, some siblings having moved overseas. Second, the stigma and discrimination surrounding schizophrenia meant that the women were hesitant about informing others outside their immediate family about their family member's schizophrenia<sup>227</sup>. Third, the women drew upon the distinction they made between their 'schizophrenia friends' and their other friends. The women would only talk to their schizophrenia friends as a consequence of their other friends having no real understanding of what the women were experiencing.

As well as acting as a buffer, the men also undertook tasks which directly assisted their family member. In comparison to the women, the tasks the men undertook were practical in nature in that they involved no extensive interaction with their

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<sup>226</sup> As already explained, the women spent more time trying both to understand their family member's experiences of schizophrenia and assessing their family member's mental state.

<sup>227</sup> The degree to which the participants were open about their family member's diagnosis of schizophrenia is discussed later in this thesis.

family member at a personal level. Harriet for example noted that: **"The men seem to be able to care on the practical things. Help [Rachael] with the car...And she goes to the men for the practical things".** Ben gave the following example of a practical task he undertook:

**And every now and again I'd get a ring and he'd say "So-and-so's car has broken down, we're out here, would you come and get us". And I'd jump in the car in the middle of the night and tow him from there to here.**

That the men undertook practical tasks is consistent with feminist caring literature. Within this literature it has been argued that whereas women tend to undertake direct caring activities, such as personal care tasks and meal preparation, men are typically involved in house and garden maintenance (Women's Affairs Victoria; 1994).

The men were reluctant to be responsible for the interactive tasks undertaken by the women. This reluctance was highlighted by James when discussing whether he would rather care for a spouse, parent, or child with schizophrenia: **"I don't want any of them. I don't want any of them really. No, no, don't look at me for nursing"**<sup>228</sup>. Again, the reluctance of the men to undertake interactive tasks is reflected in other research:

*Researchers have shown that in households where men have begun to share more of the caring and household work, the running of the house and the emotional caretaking of family members and friends are the last and most difficult roles for them to fully share (Ministry of Women's Affairs, 1989:2). (See also Bittman, 1992; Finch, 1986).*

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<sup>228</sup> The impact that different kinship relations have on the care provision examined in this thesis is highlighted below.

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That the majority of women had held complementary roles to their husbands has already been noted. While the women worked at home providing (amongst other things) the main component of their family member's unpaid care, the men undertook paid work in the public sphere. It was the men's wages that financially supported the caring relationship. As Jill stated: **"There's a lot of nurturing in going out and earning money and bringing it back home. This is all part of bringing up a family"**. Undertaking paid work then was considered by the participants to be one of the caring tasks the men carried out in their supporting role.

The participants considered the men's paid work to be a legitimate factor which prevented the men from assuming ongoing responsibility for the majority of their family member's care provision. As already noted, the women knew that they themselves would be unable to engage in paid employment which would overcome the opportunity cost (Easting, 1992; Novitz, 1987) of the men leaving their paid work. While acknowledging this, it appeared that the men actually utilised their paid work participation to preclude them from increasing their involvement in their family member's care. For example, previously it was described how the men had purposefully increased their involvement in their paid work, before the diagnosis of schizophrenia had been formally provided, in order to remove themselves from the site of care. In acknowledging that the men had no desire for taking on a care-giver role in relation to their family member, it could be assumed that the men continued to use their paid work as a reason for them only being able to fill a secondary supporting role. This assertion is supported when considering Ungerson's (1987) proposition that the full-time work of men acts as a buffer and reduces their availability for caring.

As Ben's following comment notes, the men did not find their supporting role to be an easy one:

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**I've always felt that I could cope with most situations, all situations. But having to cope with Bill during his illness was difficult. I actually think it was even more difficult coping, if that's the word, with my wife, when she was upset. That's the hardest part. It's quite the hardest.**

The men described how filling their secondary, more removed supporting role, had been a conscious decision. As already noted, the men's ability to limit the degree to which they engaged in their care provision was facilitated by their involvement in their paid work. The men explained that in filling a secondary role, the tension and confusion between themselves and their wives was reduced. It was the women's responsibility both to make the major decisions and take action related to their son or daughter. Ben for example described how his role in relation to Bill had become a secondary one:

**She's always done most of the organising. Early on in his illness, I needed to leave it to Joy more. Partly because I was working and she was home with more time. Partly because if we didn't agree as to what should have been done...both courses might have been all right. It was easier, rather than to have more strain on her and argue with her to try and get my point across and have it done my way...I backed her rather than push it up hill. So a lot of it fell on her.**

Jackie and Trevor were still working out their respective roles as a consequence of Luke just having recently exhibited the symptoms of schizophrenia. Trevor was experiencing some of the tensions and frustrations the other men spoke about early on in the caring relationship. As Trevor stated:

**I don't know any longer whether she finds my input helpful or just another layer to deal with. When she's already got her agenda basically worked out, and perhaps doesn't want to consider another level of suggestions.**

The distance that Trevor had placed between himself and the decisions related to Luke's schizophrenia is partly explained by acknowledging that Trevor was Luke's stepfather. Trevor explained he was less directive with Luke being his stepson than he would be if Luke was his son by birth.

There were exceptions to the pattern of the men taking on a secondary supportive role. One of these men was Basil, Anne's deceased husband. Anne reported that Basil had always had an equal role with herself in relation to Patrick: **"With Basil and I it was equal. And far more in his life because he employed, worked with him, and lived with him too"**. The predominant role that Basil played in the provision of Patrick's care indicates that future research needs to examine the care, provided to a family member diagnosed with schizophrenia, by men who provide the majority of their family member's informal care. Fisher's (1994) proposition that further examination needs to be given to the role men play in the provision of care is supported.

A second exception to the men taking on a supporting role was highlighted by those women who were alone in their care-giver role. These women's husbands had removed themselves from any real involvement in relation to their son or daughter's care. As Sonya said: **"As far as my ex-husbands concerned...caring hasn't meant anything for him. 'Give him a kick in the behind' and 'he's just being a lazy slob'..."**. That Sonya saw the provision of care to Paul as her main responsibility has already been established. The question is raised however, as to why her ex-husband decided to continue not play a supportive role with regard to Paul's care. Mary was also alone in providing care, Michael her husband being the family member diagnosed with schizophrenia.

The women acknowledged the assistance their husbands provided via taking on a supporting role. The extent of this assistance was highlighted by those women

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without husbands present to fill a supporting role. These women proposed that their care provision would be easier if they had another adult they could consistently confide in and who could take responsibility for some of the practical tasks which needed doing. The fact that these unpartnered women found their care-giver role more stressful is consistent with Carpentier et al's research findings. As already noted, Carpentier et al (1992) found that single parents providing care to an adult child diagnosed with schizophrenia reported higher levels of burden and expressed a need for more services than women in two-parent families. Demographic changes in New Zealand, such as the increase in divorce and separation (NZDS, 1992; Statistics New Zealand, 1994), may contribute to the care-giver role being associated with burden. However, this burden would be significantly reduced if formal mental health services were adequate enough to support those male and female carers who provide informal care to their family member diagnosed with schizophrenia.

### **Expectations About Filling a Care-giver/Supporting Role**

The majority of the women and their husbands had not foreseen the need for them to fill either a care-giver or supporting role. This lack of foresight arose primarily in response to the secrecy which shrouded the presence of schizophrenia. When the diagnosis of schizophrenia was initially given to explain their family members' behaviours and thoughts, eight of the women were not aware of whether schizophrenia had previously occurred in their side of the family. At the time of the one-to-one interview, two of the women were still uncertain about a genetic link. These two women were certain that even if schizophrenia had been present in their family, they would not have been told of its presence. As Margaret explained, **"...when I think back in my earlier days, well, I had never heard that word...Things were just not talked about like that. So who knows if there was [schizophrenia in the family]"**.

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Considering both their lack of knowledge about schizophrenia generally and their lack of awareness about the presence of schizophrenia in their family, it is not surprising that eight of the women never expected to take on a care-giver role. One of these women was Pat who said: **"Lord no. Never expected to have a schizophrenic daughter"**. Mary when marrying Michael never expected she would need to take on a care-giver role: **"No, no way. No. It was a real shock [to have to provide care for Michael]"**. Several of these women stated they would not have had children or married if they had known there was a chance of their sons or daughters being diagnosed with schizophrenia. Again, it was Pat who said: **"Well if I knew what I know now, I wouldn't have had her would I"**. Mary said the following about her marriage to Michael: **"No, I wouldn't have married him. If I'd known he was going to be ill. I know it sounds awful, but I wouldn't have. No. I wanted as normal a marriage as possible"**.

Two of the women had expected to take on a care-giver role as a result of members in their immediate family experiencing schizophrenia. The stigma surrounding mental illness meant that even though the presence of schizophrenia was acknowledged within the immediate family, secrecy had still been maintained when it came to persons outside the family. As Jackie explained:

**Like I think that the strength that my parents had, were that they did sort of treat us as adults up to the limits of our understanding. They were very good in talking to us about sex and everything to do with that from an early age. And they were sort of similar about the schizophrenia except that it was made clear that it was a family secret. You didn't mention it to people. But I think from that point of view, they were probably streets ahead of their time.**

Several of the women in their one-to-one 'interviews' spoke of other women who filled a care-giver role for two or more members in their family. According to the women who participated in this research, these women experienced considerably

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more stress than themselves. Jackie was the only woman participating in this research who spoke about more than one person in her immediate family being diagnosed with schizophrenia. In the past, Jackie had provided care to her mother diagnosed with schizophrenia<sup>229</sup>. As well as providing support to her mother, Jackie acknowledged her own health needs arising from her schizophrenia, and provided informal care to her son Luke also diagnosed with schizophrenia.

None of the men had expected to take on a supporting role. The men spoke of the love they held for their children, but admitted that they would rather have had their experiences with their child over again without the schizophrenia. As Ralph stated: **"I'd like the same thing to happen again without the schizophrenia"**.

That the women and their husbands were despondent about their family member having schizophrenia is understandable, especially when considering the participants' care-giving experiences. The participants' stories highlight the changeability and unpredictability of their caring work. The time of onset of their family member's schizophrenia meant that the participants were looking at filling a care-giver/supporting role until either they died or could not provide care as a consequence of poor health.

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<sup>229</sup> Recently, the care Jackie's mother required had reduced to the extent that Jackie acted more as her mother's 'supporter' than 'care-giver'.

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## **PART THREE - RESPONDING TO THE DECISION TO CARE**

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The women's decision to assume responsibility for their family member had numerous implications for themselves, their husbands who filled a supporting role, and their family member. This discussion will identify and describe some of these implications. First, the skills and knowledge the women developed in order to provide more effective care to their family member are outlined. The importance of this skill and knowledge is highlighted when acknowledging the unique characteristics and complexities of the care provided to a family member diagnosed with schizophrenia. The extent to which the women were protective of their family member is then acknowledged. It is noted how the women endeavoured to protect their family member from their symptoms, the rest of their family, and from the wider public. This discussion is followed by describing the restriction the women experienced on a day-to-day basis as a consequence of their care provision. This restriction arose not as a consequence of the use of routines, but in response to the unpredictability and changeability of the family members' symptoms. It is then noted that the restriction the women experienced could be reduced in part by their family member's compliance to neuroleptic medication. Discussion then follows about the way in which the participants' expectations regarding their family member changed. Their family member's cyclical acute and chronic episodes of schizophrenia led the participants to steadily lower their expectations about their family member's future. A connection is then made between the stigma and discrimination surrounding schizophrenia and the extent to which the participants were open about their family member's diagnosis of schizophrenia. It is then proposed that the participants degree of openness was reflected in the type of strategies the participants took to initiate change in their caring relationship. Finally, attention is paid to the way in which different kinship relationships impact upon the provision of care.

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## Skills and Knowledge

The fact that the women did not naturally know how to provide care to their family member has already been established. The care the women needed to provide their family member was outside of their previous caring experiences. The women then could not draw upon the dominant understanding of 'care' in dealing with their family member's symptoms. As has been illustrated, the care examined in this thesis challenges and necessitates an extension of feminist analytical caring frameworks. Without a diagnosis, the women had no formal understanding of why their family members were acting the way they were. In trying to respond to their family member, the women primarily utilised the strategy of trial and error. The frustration, guilt and regret the women experienced as a consequence of their use of the strategy has been highlighted.

Receipt of the diagnosis of schizophrenia not only legitimated the women's care provision, but also provided the women with the opportunity to 'name the moment' (Barndt, 1989). The understanding of schizophrenia the women developed indicated to the women that their care provision would be ongoing. Their experiences with the use of trial and error led the women to develop the skills and knowledge they needed in order to provide more effective care to their family member.

Fisher and Tronto (1990) have identified the complexity of the knowledge and skills required for care-giving. The following comment highlights the ongoing adjustments care-givers must make to respond to their particular caring relationship on a day-to-day basis:

*Those who take responsibility for care may have to change the caring plan periodically: the caregiver must be ready to revise her caregiving strategy according to moment-by-moment or day-by-day conditions. To make such revision requires*

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*experience, skill, and, ultimately, judgement* (Fisher & Tronto, 1990:43).

In acknowledging the changeability and unpredictability of the family members' symptoms, one can assume that the complex and ongoing adjustments Fisher and Tronto (1990) have spoken about are particularly relevant to the care examined in this thesis.

The women worked at developing an understanding of their family member's experience of schizophrenia. The process that the women went through to establish the definition of schizophrenia via contacting health professionals, reading relevant literature and fellowshipping, has already been identified. After gaining an understanding about schizophrenia generally, the women began to understand the uniqueness of their family member's schizophrenia. The benefits of understanding the illness were identified by Harriet:

**I think that you do have to understand something about the illness., So that you can accept the behaviour is not just purely bad behaviour. There are somethings you can do some behaviour modification on...and there are some things you just have to accept.**

Helen explained that one of the skills she needed to effectively provide care was: **"...knowing how to read the signs, that they may be going into an acute phase of the schizophrenia"**. The skill of being able to read their family member's symptoms was developed during the women's day-to-day interaction with their family member. The women reported that their family member exhibited various behaviours which were indicative of their mental state. Harriet noted the behaviours which indicated Rachael's mental health was deteriorating:

**I knew that [Rachael] was deteriorating. I'd found messages were being left all round the house. Trinkets were arranged and there'd be a snake hanging up on the tree outside.**

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In being able to read the signs of their family member's symptoms, the women then needed to know how to manage these symptoms.

Being able to manage their family member's symptoms of schizophrenia was another skill identified by the women. Helen for example stated that it was important to: **"Know how to deal with delusions and violent tendencies"**. In order to manage these symptoms, the women stressed the importance of having a self awareness. Development of this self awareness began when their family member was diagnosed with schizophrenia. As Mittleman's (1985:300-301) comment suggested, most of the women spoke of experiencing a process of soul searching in order to determine whether they had caused their family member's symptoms. Sonya explained the process she went through:

**For years I blamed myself because when Paul was born, and I had no family support [where I was living], oh I did some really wonderful things with that baby. God how the hell he survived I don't know. And so, you know. It had to be what I did. I believed that that was what did it to him...and then it was because I didn't have a husband....**

The women were aware that certain actions, such as raising their voice, escalated their family member's behaviours and thoughts, whereas other actions, such as leaving the room to calm down, defused the situation. The women spoke of how they monitored their own behaviour when interacting with their family member. Harriet spoke of her self awareness in relation to Rachael:

**And I think I'm learning to change the pitch of my voice, to try and keep it down so that it doesn't provide an emotional charge for her. Because if it's high pitched she picks it up very quickly...so you do have to have a self knowledge about how you relate.**

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The women explained the importance of being self aware by referring to two of the theories explaining the aetiology of schizophrenia already outlined in this thesis. One of these theories was the Attentional Deficit theory which suggests that individuals experiencing schizophrenia find attending to various stimuli a difficult or impossible task (Hudson, 1982). The second theory was the Expressed Emotion theory (Brown et al, 1962) which links a person experiencing a relapse of acute schizophrenia with an environment which is emotionally charged, especially with negative criticism. Being self aware meant further restriction for the women. In monitoring their own reactions to the extent that they did, the women narrowed the range of emotions and responses which they could exhibit while interacting with their family member. To an outside observer, this self imposed restriction was invisible.

The tasks the women undertook in their care-giver role meant they communicated with persons of varying backgrounds such as their family member, other care-givers, mental health professionals, friends and neighbours. The women acknowledged that they needed to develop their communication skills in order to effectively liaise with these persons. The women also found that being articulate increased their chances of receiving the services and resources they required. However, it is important to acknowledge that the women were often refused information regarding their family member's health status as a consequence of a patient's right to confidentiality. This response of mental health professionals continued despite the increased responsibility the women were taking for their family members care provision as a consequence of the implementation of deinstitutionalisation and community care.

The Mental Health Act 1992 and the Privacy Act 1993<sup>230</sup> have undoubtedly increased the difficulty the participants have since experienced when trying to

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<sup>230</sup> The Privacy Act 1993 was been passed into legislation since the participant's one-to-one 'interview'.

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obtain information regarding their family member's health status. As was demonstrated, obtaining information about another can be difficult enough (Morton, 1994; The Press, 1994) without the added complication of mental health professionals not utilising the Privacy Act 1993 correctly<sup>231</sup> (Crowe, 1995).

The difficulty experienced by the participants in receiving information about their family member's health status again highlights the tensions between the rights of care-givers and the rights of care-recipients. As noted already, Ungerson (1993) has highlighted the difficulty and complexity associated with constructing an established set of rights for carers and the cared-for. Some of this difficulty was identified by Helen:

**The patient's rights thing is a bit of a bug bear. Well I know that it is a moral dilemma, and they've got to look after the patient's rights, but then the rights of the carers to know what medication [the family member is on] should be a priority to. I don't know what the solution to that one is.**

Joy also articulated her thoughts about the difficulty associated with balancing her own need for information about her family member's health status and her family member's right to confidentiality:

**If [the family member was] in hospital, their nurse for that day would want to know everything that happened to them, because they were responsible for them. And the care that they gave that person would depend on what that person was going through. But when you're a member of the family, your caring twenty four hours a day, seven days a**

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<sup>231</sup> Further issues associated with the conflict between the rights of the women and the rights of their family member will be identified below. An example of such issues is the right for the family member to cease their neuroleptic medication despite the extra stress and strain this decision placed upon the women.

**week. You're not given anything to go on. And that's why I say patient confidentiality is a hard one<sup>232</sup>.**

In noting the tensions between the power and autonomy held by care-givers and care-recipients, and the degree to which power and autonomy defines 'need', Fisher and Tronto (1990:45) have suggested that there may be no solution to the tensions which exist between the rights of care-givers and the rights of care-recipients: "*Indeed to some extent, conflict between caregivers and care-receivers seems unavoidable*". This would particularly be the case for caring relationships in which a family member is diagnosed with schizophrenia. Previous discussion has highlighted the frequent and intense struggles for power and autonomy between the women and their family member. These struggles arose in response to the frequency in which the family members' symptoms changed in type, frequency, duration and intensity. The seriousness of these struggles for power and autonomy were highlighted when considering the consequences for both the women and their family member. A decrease in the family members' power and autonomy could lead to them being committed to New Zealand's institutionally-based mental health services. Similarly, a decrease in the women's power and autonomy could lead to them dealing with the symptoms of schizophrenia without any assistance or information about their family member's prognosis or treatment.

The women also identified the need for parenting skills. This related to issues regarding the adult status of their family member. For example, in agreeing with Leggatt (1994:2), the women explained that although their family member was an adult, when they were unwell they often exhibited behaviour associated with persons younger in years. Harriet spoke of Rachael:

**"...she's sort of stuck about young adolescence I think.  
There are times when she comes through as a mature**

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As Atkinson's (1989) research found, the issue of carers' rights versus the rights of care-recipients was raised primarily by the participants regarding the collection and dissemination of information regarding their family member's mental health status.

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woman, but a lot of the time she's very much a young adolescent"<sup>233</sup>.

The women spoke of the importance of ensuring that their family member was given the opportunity to develop and be treated as 'normally' as possible. The women asserted that the man or woman receiving care was still their son, daughter, mother, or husband first, as opposed to being a 'schizophrenic'. When talking about this issue, Mary said: **"I always remember [a social worker] saying that [a person with schizophrenia's] intelligence is not affected, so why talk down to them"**. For most of the women, this meant educating the rest of the family and their friends to see the person their family member was, as opposed to the schizophrenia they had.

Distinguishing between the illness and the person, was identified by the women as an ongoing difficulty. This issue was often phrased in the question, 'Is their family member acting the way they are because of the illness, or because of who they are?' As Jill's comment indicates, this question had often been asked by Jill and James about Joshua:

**I mean we've had a lot of discussions, James and I, as to whether Joshua does it on purpose, or he really can't look after himself. Whether he really deteriorates so much on purpose.**

Sonya noted how difficult it was to find an answer to this question: **"You don't know. You see there is a thin line. You just don't know when they're putting it on and when they're not. Oh well, only they'd know"**.

The issue of distinguishing between the person and the illness was a prominent one, primarily because of the cyclical nature of schizophrenia. Some of the

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<sup>233</sup> How the family members' adult status impacted upon the provision of care will be further discussed in the next chapter.

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women saw snippets of the person their family member used to be before the schizophrenia, when their family member's symptoms were reduced in response to medication. Harriet explained that with Rachael living at home: **"I see the little bits of her that were coming out"**. Distinguishing between the person and the schizophrenia was an important part of the women establishing realistic and achievable expectations of their family member. If their family member was unwell, they could be excused, for example, for being unmotivated. If their family member was well, this behaviour would be unacceptable. No matter what they had experienced as a result of their family member's schizophrenia, the women in particular offered positive descriptions of the family member themselves. For example, Margaret spoke of Daniel: **"He's such a super guy. He's got a lovely nature"**.

As identified above, the knowledge and skills the women developed were specific to providing informal care to a family member diagnosed with schizophrenia. For many of the women, the skills and knowledge they had learnt in order to equip themselves for their care-giver role had become second nature. The skills and knowledge specific to the care-giver role were defined by the women as **"just part of their job"**. The women tended to play down their own experiences when acknowledging the experiences of other women who also provided care to a family member diagnosed with schizophrenia. The women spoke of how lucky they were not to have experienced the trials they knew were associated with other caring relationships. Pat's comment summarises the women's opinion about others who fill a care-giver role: **"...with what some of them<sup>234</sup> go through, they deserve a medal. With what some of them put up with"**. The women's view of the skill and knowledge they had developed is consistent with what Barrett (1980:166) has reported: *"Women have frequently failed to establish recognition of the skills required by their work"*. In comparison, men tend to have an

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<sup>234</sup> 'Them' refers to the women providing the majority of their family member's ongoing care.

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awareness of the knowledge and skills they have developed in their provision of care. Feminists writers have proposed that skill is gender based. As Game and Pringle (1983) have explained: "*The process by which some jobs are defined as skilled and others as unskilled is complex, but by and large women's 'skills' are not recognized as such in the definitions of their jobs. Skilled work is men's work*".

While the men were able to identify some of the activities or tasks that the women undertook in their care-giver role, they were however less able to identify first, whether these tasks required any specialised skills and knowledge, and second what skills and knowledge were utilised in undertaking these tasks. As Trevor commented: "**...I know that [those who provide care] are all under a lot of stress and strain. As to specific skills, well. No I don't know**". One explanation for this is related to the men's explanation as to why it was the women who provided the main component of their family member's care. As was highlighted when the women's decision to fill an ongoing care-giver role was discussed, the men considered the women's caring work as simply an extension of their mother role, and therefore defined it as natural. The understanding that women's work is considered to be 'unskilled' as a consequence of this work being a 'natural' extension of their gender role has been reported in the literature: "*Because many tasks in traditional female occupations are considered 'natural' for women - an extension of their gender role - they are not classified as skilled work, and often are not classified as work at all*" (Needleman & Nelson, 1986:295). This assumption is one reason which explains the reported undervaluation and invisibility of the effort, skill and knowledge of those who provide care to a family member diagnosed with schizophrenia (Atkinson, 1986; Doll, 1976).

### **The Women Being Protective**

As already noted, receipt of the diagnosis of schizophrenia by the participants altered the process and interpretation of the women's care provision. One outcome of the knowledge that there was something legitimately wrong with the

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family members was the women assuming responsibility for their family member's wellbeing. In assuming this responsibility, the women became more protective of their family member. The women tried to protect these men and women from their symptoms, the rest of their family, and from the wider public. As Margaret explained: **"I was more of a protector for Daniel in the early days. I tried to stop the knocks"**. Pat's aim with regard to Rachael was similar to Margaret's: **"What I was doing I suppose was trying to protect her...from what people say. And, make her look the same as everyone else"**.

The women proposed that their protectiveness was primarily in response to the dominant understandings and practices regarding schizophrenia. Joy for example, spoke of people's reactions to Bill: **"Well, I think you've got the stigma all the time too. People are never quite sure about Bill"**. Foremost amongst these discourses was the understanding that their family member would spontaneously become violent. This was the case even if their family member was being compliant with medication. However, the participants also proposed that the implications of the dominant discourses of schizophrenia did not remain with their family member. For example, this stigma and discrimination was often transferred to the participants themselves. Again it was Joy who spoke of people's reactions after she had told them of Bill's diagnosis: **"They give you some space between you and them. You can see them sort of moving away"**.

The implications of the dominant discourses of mental illness and schizophrenia were illustrated in the reactions of the public in one of the geographical locations from which the women came. Large sections of the public were actively working to prevent persons with a psychiatric disability living in their neighbourhood. Margaret spoke about this NIMBY (not in my backyard) mentality in her region:

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**They've actually said that they will not have these people [from a psychiatric institution] in their streets...And it makes me so wild that we are all supposed to be in this modern age today. Our outlook's supposed to be better.**

The inadequacy of New Zealand's mental health services has already been identified and described in previous chapters. The women asserted that their protectiveness of their family member also arose in response to this inadequacy. As already noted, the women proposed that they were the only ones who would consistently and closely monitor and supervise their family member. The women argued that if their family member's care was left to formal mental health staff, their family member would soon be in the same situation as those individuals living on Auckland's streets and boarding houses (Chapple, 1994). As will be argued in the next chapter, adequate mental health services must be in place if the women are to be able to reduce their provision of care.

### **Living Day-To-Day**

While feminist caring literature has highlighted the restriction women may experience as a consequence of the routinisation of care (Briggs & Oliver, 1985; Munford, 1989) the women participating in this research described the restriction they experienced as a consequence of the unpredictability associated with their family member's symptoms of schizophrenia. As Ralph said about Pat: **"I think she's just playing it by ear and day-to-day. Just going along with what comes up. I think that's what it amounts to"**. The women never knew what to expect with regard to their family member's symptoms, and therefore the type and level of care they would need to provide. The women learnt both not to plan too far ahead and to be prepared to respond to their family member as needed. Mary for example spoke of the extent to which she was able to plan with Michael: **"On the night before the next day arrives, we say, 'What are we going to do tomorrow?"**. Lamb and Oliphant's (1978:803) comment has captured this

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restriction: *"The relatives may begin to feel not only as if they are jailers but also as if they themselves are in jail"*.

The question of the women's care-giver status is raised by the restriction the women experienced on a day-to-day basis. Instead of being restricted by the use of routines and the need to provide visible personal care tasks (Twigg & Atkin, 1995), the women were restricted by the continual need to supervise and monitor their family member's symptoms and health status. The rapidness of change in the type, intensity, degree and duration of their family member's symptoms enforced the consistency of the women's mainly invisible supervisory and monitoring tasks. The degree to which the women engaged in the tasks of supervision and monitoring meant that they fitted more easily into the category of full-time rather than part-time carers<sup>235</sup>.

The women, and to a lesser extent the men, were not alone in experiencing the restriction associated with the unpredictability of their family member's symptoms. As Ben said about Bill: **"...and I'm sure Bill only lives from day-to-day. He doesn't have any long-term plans"**.

### **Neuroleptic Medication.**

One way in which the participants could reduce the extent to which they lived 'day-to-day' was to ensure that their family member took their neuroleptic medication. As already noted, drug therapy is generally recognised as the most effective treatment for schizophrenia, particularly for reducing the presence of psychotic symptoms (Taylor, 1989). Not surprisingly, the diagnosis of schizophrenia was soon followed by issues pertaining to medication.

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<sup>235</sup> Material presented in the following sections of this chapter will further illuminate the appropriateness of the terms 'full-time' and 'part-time' when defining the women's care-giver status.

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The fact that there is not one single outcome of the diagnosis schizophrenia (Kaplan and Sadock, 1991) has already been acknowledged in this thesis. Reflecting this, several of the women spoke of persons they knew who had been previously diagnosed with schizophrenia and who had continued to lead a 'normal' life, either with or without the need to consistently take neuroleptic medication. As Jackie stated, these persons are not usually acknowledged in the related research:

**I believe there's far more hope than would be said [about the outcome of schizophrenia]. Because the ones who do what I do, pick up the pieces, come to terms with it, work through it, get on with their lives and live a normal life, well they're not very interesting to present at a case conference are they? They'd be just like the person you pass in the street.**

However, while acknowledging that not everyone who has experienced schizophrenia needs to take neuroleptic medication on an ongoing basis, all of the participants recognised the importance of medication for reducing and managing their family member's symptoms<sup>236</sup>. Jill, Jackie, Joy and Sonya's comments reflected this:

**Jill "But John is very non violent. He's never hurt anybody. But I've seen the scars after he's torn his face. He must go through mental agony sometimes. Now that he's on medication, it doesn't happen any more".**

**Jackie "Well [Luke's psychosis has] been going on now, for, about a month or six weeks. Because he's not taking his medication regularly".**

**Joy "As I said to someone, I would never let Bill dry a carving knife...And I don't let him stand behind me...but it's only when they go off medication that they do these things. It's not other-wise".**

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<sup>236</sup> At the time of the one-to-one interviews, none of the family members were in receipt of clozapine or risperdal.

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Sonya **"Well he can't go off medication...it's like it maintains him. But goodness knows what he'd be like now without any medication".**

The effectiveness of neuroleptic medication for controlling the family members' positive symptoms, directed the women to both overtly and covertly keep track of the neuroleptic medication their family member was taking. This ensured that at least the positive symptoms of schizophrenia were reduced. The women were aware of both the type of medication and the dosage levels their family member had taken in the past, and were currently taking. The women were also well informed about the various types of medication prescribed for schizophrenia and their potential side-effects. Some of the women reported that their family member assessed the women monitoring their medication as interference and detrimental to their privacy.

Daniel was an exception when it came to his medication use. Margaret explained how Daniel took medication when his symptoms warranted it:

**Well, [Daniel is] not on [medication] at the moment. His psychiatrist at the moment is aware of it, and he keeps in contact with Daniel...He said "Right Daniel you can come off [medication] for a certain amount of time. But when you realise signs then you need to come back [for medication]".**

The women admitted that their family member taking medication was imperative for their own sanity. Harriet highlighted this situation: **"I can't handle her abuse or behaviour. Medication makes life easier for me. So sometimes I wonder whether I've got her on medication because I can't handle her eccentric behaviour".** For Harriet, the issue of whether Rachael was taking her medication was a major source of worry: **"I have a constant fear that Rachael might stop taking her medication. I know when the medication time is coming up I start to worry".**

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The women emphasised the fact that their family member took medication only after they had accepted that something was wrong. Denial by the family member was a primary reason for non-compliance with pharmacological treatment. In some cases, even if the family member began to take medication they did not always openly admit that the medication was for psychological reasons. Jill provided us with Joshua's explanation for taking medication: **"Joshua believes that he is taking the medication in order to put on weight"**. This particular response to medication use has been described by Hatfield (no date: 3):

*Sometimes patients can be persuaded to take medication even though they are still denying the illness. They often feel that something is wrong but they see it as a lesser problem. They may say that they are nervous, not sleeping well, not getting along with others, or are having difficulty concentrating.*

The participants reported that their family member usually stopped taking medication as a result of the accompanying side-effects. These side-effects affected their self-esteem, relationships and interactions with others. The participants spoke of their family member experiencing various combinations of those side-effects including: blurry vision; stiffness; increased appetite; tardive dyskinesia (involuntary movements such as tremors); impotence; constipation; nausea; fatigue; and, hypertension. The connection between ceasing medication and side-effects is reported in the literature (Falloon, et al, 1984; Van Putten, 1974). As Hatfield (no date: 2) has explained:

*It is understandably difficult for people to continue to do something to themselves that produces discomfort. Medications used to treat mental illness are known to have an array of potentially unpleasant side effects.*

The participants agreed that the side-effects of neuroleptic drugs are not pleasant. As Joy said: **"Yes [people taking neuroleptic medications] get all sorts of double vision. All sorts of horrible side effects"**. The majority of the

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participants explained that they did and would understand their family member stopping their medication because of the side-effects they experienced. At the same time, these participants questioned what was the greater of the two evils for both themselves and their family member, the symptoms of schizophrenia or the side-effects of medication.

The family members also stopped taking their medication in thinking they were cured. As Sonya acknowledged: **"Often [people diagnosed with schizophrenia] have a good spell and they think they're okay. That's when they can think they don't need medication"**. The participants explained that all they could do in this situation was wait until their family member began exhibiting the more acute symptoms of schizophrenia. Eventually, the family members began taking medication after realising that they had not been cured, or, after being committed and treated in institutionally-based mental health services.

Another reason for the family members ceasing their medication was the preference they had for their own reality. Harriet, for example, reported that Rachael had said: **"...I love my thoughts. I love my reality which is different to yours, I want to keep it"**. For some of these family members, everything made sense when they were delusional or hallucinating. An example of this is provided by Luke who reportedly spoke of Jackie's reality: **"Oh well, if this is reality, it stinks"**. According to the participants, these family members held the point of view that being on medication was when they suffered. They found it difficult trying to be 'normal', trying to get a job, living off the benefit and putting up with society's prejudice towards mental illness. Again it is Hatfield (no date: 5) who has explained that:

*Sometimes schizophrenia, with its heightened sense of personal significance, the extra energy of a manic episode, or the desire to evade the responsibilities of a well person, may interfere with a person's willingness to learn to manage the*

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*illness with medications. If people's delusional worlds indicate that they have special importance to the universe, they naturally hesitate to trade this state for the ordinary world in which they feel no special significance.*

Sometimes the family members forgot to take their neuroleptic medication. Sonya spoke about Paul's tendency to forget:

**I said to Paul "You've got to take responsibility for your own medication, cause if I'm not here whose going to". And when he forgets, I know he's actually forgotten. He can't remember if he's forgotten or not. But I can pick it up.**

Hatfield (no date: 1) has also linked non-compliance to people forgetting to take their medication:

*It is generally known that most people who are supposed to be taking medications, whether mentally ill or not, tend to forget from time to time. It is not surprising that men and women with mental illness frequently forget, for they may be suffering considerable cognitive confusion much of the time.*

Ensuring their family received the most effective type and dosage of medication was the next hurdle the participants identified. As Jill explained: **"It's a question of finding the right thing for that person. And in the right doses and trying not too have many side effects"**. For Paul, this was an ongoing process: **"He goes on drugs for a while and then they seem to stop working. And then they put him on another one and he goes along for a while. And then they seem to stop working"**. In comparison, Michael's experience of medication had been more positive: **"And we're lucky that the medication has stabilised him on a low dosage. You know, he's not on much at all"**.

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For some of the participants, the necessity of safe, effective, available and accessible medication for their family member had meant taking up an advocacy role for the accessibility of antipsychotic medication such as risperdal. The women filled an 'extended caring role' (Traustadottir, 1991) in order to highlight the effectiveness of risperdal and clozapine and advocate that these medications be freely available for people diagnosed with schizophrenia, including their own family member. In their extended caring role, the women asked similar questions to those suggested by Schizophrenia Fellowship New Zealand Inc (1995a) for their letter writing campaign. The women's advocacy of the newer neuroleptic medications such as risperdal was typically answered with claims that these medications were too expensive to warrant their extensive use in New Zealand. The participants' stories have however highlighted the importance of factoring both the direct and indirect costs of schizophrenia when considering the opportunity cost of not increasing the accessibility of these medications. Furthermore, the material presented in this thesis has suggested that Miller's (1995:15) calculations, of the indirect and direct costs of schizophrenia to New Zealand, need to include the direct and indirect costs to the informal care-givers of a family member diagnosed with schizophrenia as well as the costs to 'schizophrenic patients'. Such calculations would undoubtedly indicate that the newer neuroleptic medications should be made available.

The implementation of deinstitutionalisation and community care also suggests that individuals diagnosed with schizophrenia should be provided with treatment which effectively manages their symptoms. This is particularly the case when acknowledging the consequences of an individual's non-compliance to neuroleptic medications. For example, it was emphasised that the family members only exhibited anger or violence when they were '**not in touch with reality**'. This occurred when the family members were either under considerable stress or when they were non-compliant to their medication.

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Those family members who utilised non-prescription drugs before receiving the diagnosis of schizophrenia generally continued to do so. As Ben said of Joy, it was hard for some of the participants to accept that their family member would continue to use alcohol and illegal drugs, especially when this reduced the effectiveness of the neuroleptic medication:

**[Bill] would have the occasional beer even though it didn't go well with his medication. And the other, cannabis too, which he had now and again. And we can't stop him. But it took [Joy] a long time to accept the fact that he does have both of those.**

At the time of their one-to-one interview, after years of filling a caregiver/supporting role, most of the participants were resigned to the fact that their family member continued to take alcohol and illegal drugs intermittently with their medication. Margaret for example acknowledged that Daniel: **"Still smokes happy grass, that's what I call it. But nothing like he was. In those very very early years I used to say my incinerator was the happiest incinerator out"**. Margaret used to burn Daniel's 'happy grass' if she found it hidden in the house.

### **The Changing and Lowering of Expectations**

The extent to which their family member was affected by the symptoms of schizophrenia, even when they were complying with pharmacological treatment, indicated to the women that their family member may never be free of these symptoms. When initially assuming responsibility for their family member, the women had been hopeful that their family member's symptoms would disappear. The women expected that their family member would live a 'normal' life after their first (and last) acute episode of schizophrenia. However, as time passed, the enthusiasm the participants linked to both their family member becoming better and the hope of a cure, increasingly dwindled. Jill for example explained:

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**We don't really want to lose hope entirely. I think it would be the biggest thing in my life if something could happen. It really would at this stage. But I'm realistic enough to know that its not going to happen. Well, I mean okay, there's perhaps a half a percent chance that it will. But, I can't see it.**

All of the participants were aware that there was no available cure for schizophrenia. This was acknowledged by Jill who said: **"There's no cure, or at least not in my case. I can't hope for a cure now"**. Pat shared her experience of accepting there is not cure:

**...okay, you go into hospital and you've had your appendix out and you come out all better. So go over to [long-term care unit]. Say to myself, "Oh well they're better when they come home". Mine was a damned sight worse than when she went in there. That took a lot of understanding. Took me ages to realise that there is no cure, or acknowledge that there is no cure. That was a hang of a shock to my system.**

Margaret compared this situation with the developments which have been achieved in allowing persons with a physical disability to live a more independent life: **"Well I'll tell you Leigh, what remarkable work that's been done over the years with paraplegics. Look what they can achieve...but there's nothing for a schizophrenic"**<sup>237</sup>. While the participants proposed that they were being realistic in acknowledging they had no expectation of a cure being developed for schizophrenia in the near future, the participants did express their frustration at the inadequacies inherent in New Zealand's mental health services. While correction of these inadequacies would not make their family member's symptoms vanish, the participants argued that such correction would more effectively manage the symptoms of schizophrenia. Improvement in the quality of New Zealand's mental health services would lead to an improvement in their family

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<sup>237</sup> It is important to note here that Margaret did not attend either of the women's group meetings at which the most recently released neuroleptic medication, clozapine and risperdal, were discussed.

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member's quality of life, which would then be reflected in the quality of their own life. This would be the case if New Zealand's mental health services reflected the continuum of schizophrenia including accessible early intervention services, and a range of institutionally-based and community-based mental health services<sup>238</sup>.

While, the participants spoke of changing (often lowering) their expectations about all aspects of their family member's life, from their family member's paid working potential to whether their family member would establish a commitment with a partner, the most dramatic initial adjustment the participants made was accepting that their family member had schizophrenia. Margaret compared the process she went through with a parent whose child has an intellectual disability:

**With an intellectual disability you know that from birth, or within the first few years of life. You don't raise them for sixteen years. But you see, schizophrenia can hit people at the age of forty.**

The U-shape of care (Women's Affairs Victoria, 1994) does not indicate the need for care to be provided during an individual's younger adult years. As already noted, the women providing care to their family member diagnosed with schizophrenia on a continual (flat-line) basis is a distinctive feature of their care provision.

The cyclical pattern of their family member's schizophrenia led to many of the participants giving up on maintaining any goals or aims regarding their family member. As Sonya said: **"Well I did have [aims, goals], but...its just like beating your head against a brick wall"**. Eventually, the majority of the participants had settled with the aim or hope that their family member be safe and happy, or at least as happy as they could be. Margaret's following comment

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<sup>238</sup> The required shape and content of New Zealand's mental health services in order to more effectively manage the symptoms of schizophrenia is discussed more fully in the next chapter.

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reflected the opinions of these participants: **"I don't think I have any goals Leigh. I think the only thing I really want is for him to be safe. Secure and happy"**.

The cyclical nature of schizophrenia also added to the difficulty the participants experienced in changing their expectations. As already noted, sometimes the participants saw their family member the way they used to be before they began exhibiting the symptoms of schizophrenia. These moments instilled hope in the participants that their family member could be on the way to recovery. According to existing literature on schizophrenia and care, the participants were not unique in experiencing difficulty in altering their expectations directed towards their family member (Hatfield, 1978; Seeman, et al, 1982; Torrey, 1983).

The process of changing and lowering their expectations seemed to be harder for the men to undertake than the women. As already noted, the men often took longer in comparison to their wives, to accept that their son or daughter's behaviour was more than the result of a teenage phenomenon or drug use. Pat for example said: **"That was hard to take for a long time. [Ralph] wouldn't even admit, really that she was schizo I s'pose. But then, most men seem to be the same, so there's nothing unusual"**. Once the diagnosis of schizophrenia was given, the men were also slower at accepting the implications of this diagnosis. This reluctance to alter their expectations could be explained by the men's lower level of reading about the illness, and the men's limited one-to-one interaction with their son or daughter in comparison with the women. The men's participation in their paid work almost certainly protected them from many of the implications of their family member's symptoms (Ungerson, 1987). Therefore, in comparison to the women, the men would have had limited indication as to whether their expectations regarding their family member were appropriate.

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Any alterations the participants did make to their expectations were linked to their accommodating to their family member. The participants spoke of becoming more tolerant of various aspects of their family member's behaviours and thoughts. Mary for example, spoke of Michael's lack of motivation:

**I s'pose now I've accepted it. So I don't see it as a problem any more. But when he was first diagnosed, it was a real problem, because he was lying in bed. Wouldn't get up and do any jobs around the house, and it fell on me to do it...it was really heavy going.**

Joy explained that Ben and herself had become more accommodating of Bill's symptoms. Joy's statement illustrates that for herself and Ben, this accommodation between themselves and Bill was bi-directional: **"So we've accommodated to him, and he's accommodated to us"**. If the participants had not altered their expectations to become more accommodating the caregiver/supporting role would be more stressful and difficult to fill. As Ben said: **"If you don't [accommodate] then you're making a real cross for yourself"**. Creer (1975:6) however has acknowledged how becoming too tolerant of the symptoms of schizophrenia can become detrimental to the lives of those relatives who provide their care:

*...relatives may become so used to an unhappy state of affairs that they cease to regard their situation as anything remarkable or worthy of complaint. This is not to say that their distress is relieved but rather that they come to regard their distress as a normal state of mind. They cease to expect anything better from life, and therefore no longer seek solutions to their difficulties.*

For some of the participants, the process of altering their expectations about their family members was transferred to other members of the family. For example, Ben noted his tolerance for whatever his children chose to do with their lives so long as they were happy and healthy:

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**As far as Bill is concerned, I have changed my attitude to my sons...Every father has ambitions for their children. My ambitions are now changed, in that all I ask is that they're healthy and happy. And you realise how important those two things are.**

It can be assumed that the dominant discourses of 'schizophrenia' influenced the tendency for the participants to lower their expectations about their family member's abilities and future prospects. Prominent amongst these discourses is the understanding that schizophrenia is characterised by dependency and burden (Atkinson & Coia, 1995). As Jackie has explained, those people with schizophrenia who **"...pick up the pieces, come to terms with it, work through it, get on with their lives and live a normal life..."** are typically not as publicly acknowledged as those individuals who continually experience the positive symptoms of schizophrenia. This has been evidenced by the recent media attention upon the latter (Sunday Star Times, 1995; Wanganui Chronicle 1995a, 1995b).

### **Openness About Their Family Member's Diagnosis**

In realising that their family member was likely to continue to exhibit the symptoms of schizophrenia, despite compliance to neuroleptic medication, the participants had to grapple with the decision of who, both inside and outside the family, should know about their family member's diagnosis. This decision is in some ways unique to the care provided to a family member diagnosed with schizophrenia. The outward characteristics of physical and some intellectual disabilities mean that it is difficult, if not impossible, to hide a family member's disability. The presence of the former type of disability is sometimes even visually enhanced with the need for aids such as wheelchairs. However, many of the participants in this research did have the option of not disclosing to others the diagnosis of schizophrenia, as a consequence of there being no easily identifiable outward

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manifestations of schizophrenia to the untrained eye, when the family member was not exhibiting the positive symptoms of schizophrenia.

According to the participants, several factors were considered when making this decision. One of these factors was the dominant discourses of 'mental illness' and 'schizophrenia'. A possible consequence of being open about the family members' diagnosis was that the family members could experience discrimination and ill treatment by those who either did not understand, or were ignorant of the issues of mental illness. According to Trevor, confidentially about Luke's diagnosis was an important issue for Jackie:

**And it [schizophrenia] also means a great anxiety for her [Jackie]. In terms of she feels very very strongly that confidentiality is of utmost importance, and that to reveal anything about Luke's condition to people outside of a very close circle, could in fact prejudice Luke's future options and career chances.**

The smallness of the geographical regions in which the participants lived, and of New Zealand itself, also added to the participants' caution about releasing information about the diagnosis of schizophrenia.

On the other hand, the disclosure of the family members' diagnosis could help people outside the caring relationship to understand the family members' behaviours and thoughts and their need for care. The important task of education then could be coupled with informing people of the family members' diagnosis. Ben identified this process as an important one:

**And I always talked about it. If people say what children have we got. I say "I've got three boys, the eldest one suffers from schizophrenia. That's the first one". No good hiding it. You've got to educate other people.**

With the stigma and discrimination the participants and the family member experienced, it should not be surprising that the participants wholeheartedly

acknowledged the need for public education about schizophrenia. As Ben stated: **"I think one of the very big things is public education"**. In order to dispel the myths and misunderstandings associated with schizophrenia, the participants stressed the importance of educational material being up-to-date, reliable and accessible.

For some of the participants the issue of whether or not to disclose their family member's diagnosis had been taken out of their hands. When exhibiting the acute symptoms of schizophrenia, the behaviours and thoughts of the family members meant that an explanation needed to be provided. Harriet for example, shared the following: **"I mean she's there jumping naked under the next door neighbour's clothes line. An elderly spinster. You can expect them to sort of wonder what's going on"**. Helen spoke of similar experiences with Lidia:

**The neighbours around found out because of her behaviour really. She verbally abused neighbours and things like that. So, it wasn't really a case of us not telling them. We had to go and explain.**

### **Initiating Change in the Caring Relationship**

Because of the constantly changing, often lowering, of expectations, it would be understandable if the women and their husbands became despondent. The participants becoming too tolerant about their family member's symptoms was also a possibility (Creer, 1975). This possible despondency and tolerance could arise from the degree of energy the participants had to spend on a day-to-day basis in providing their informal care. As Atkinson and Coia (1995:203) have explained:

*There are ethical and political issues which frequently get side-stepped as people under pressure tackle practical day-to-day provision of care. The awareness that decisions are influenced*

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*by political, ethical and value judgements is, if not ignored, allowed to take a back seat.*

However, the majority of the participants worked towards making changes which would improve both their own and the caring relationships of others. The participants then linked the personal with the political. In making this link the participants took action described by Fisher and Tronto (1990:51): "*Women may find it necessary to go beyond the boundaries of both household and community to improve the conditions of caring and to affect the structures that shape caring activities*". The strategies the participants utilised to challenge the social, cultural, political, legal and economic conditions which influenced their caring, reflected their decision about to whom they would disclose their family member's diagnosis. Those who saw the importance of educating others, via disclosing their family member's diagnosis, tended to be involved in collective, as well as individual strategies, for initiating change in their caring relationship.

Collectively, the women had utilised strategies to implement change both on the individual and collective level. Individually the women had developed the knowledge and skill related to schizophrenia and care, joined Schizophrenia Fellowship, and, had written to both their local newspaper and Member of Parliament, and Government Ministers. Harriet spoke of action she personally had taken on an individual basis: "**I'm endeavouring to get more involved in the Fellowship to help me be better in the supportive role...And I happen to be one who believes in a bit of lobbying and writing to papers**".

A few of the women also undertook part-time paid work. The extra stress this paid work placed on the women, in terms of combining their paid and unpaid caring responsibilities, was counteracted by the opportunity the women gained both to leave the site of their unpaid caring work and to meet persons not related to the issues of schizophrenia. The women's part-time work then acted as a stress ameliorator (Edgar, 1992).

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The action taken to initiate change on a collective basis was predominantly undertaken in 'extended caring roles' (Traustadottir, 1991) as volunteers within Schizophrenia Fellowship. The women had gone beyond their care provision to their family member to become involved in work which would help others in a similar situation to themselves. Joy for example spoke of how she acted as a buddy for new members of her branch:

**I now have people, schizophrenia carers that come to me. They've been directed to me by someone else. And they say, "Well, would you like to talk to someone who's a carer. Would you like to go and talk" And I have people come here to me, and they'll sit there for a couple of hours. And they pour it all out, all of it. Or I go to their place. And they feel better for it.**

The action taken by the women to improve both their own circumstances and the circumstances of others, supports the challenge made by Munford (1992:173) who has asserted that women care-givers should not be viewed solely as victims. Via their participation in Schizophrenia Fellowship, the women were both identifying and challenging the parameters<sup>239</sup> under which their care provision took place.

While the men acknowledged the importance of initiating change, they had to be encouraged to think about strategies they utilised to create change. In comparison to the women, the men provided a narrower range of strategies which could be utilised to improve the process of care. The strategies the men did identify usually involved individual as opposed to collective action. For example, the men focused upon writing letters to their local Member of Parliament or Government Ministers rather than participating in voluntary work.

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<sup>239</sup> The inadequacy of New Zealand's mental health services is an example of the parameters the women were both identifying and challenging.

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When asked how they would make changes to their caring relationship in the future, the participants voiced the opinion that strategies which utilised a group or existing organisation would be more successful because of their collective power. As Sonya explained: **"I s'pose I'd go about it through the Fellowship. Because of it being a bigger body and a louder voice"**. Ralph's comment supported Sonya's proposed action:

**You've got to do as a whole. You've got to have a body behind you. Like Grey Power. Get the people behind you, and then attack. Yes. You can't do it on your own, you're only butting your head against a brick wall.**

### **Care-giver/Supporting Role and Kinship**

While feminist caring literature has noted the predominance of either young children or older adults receiving care (Lewis & Meredith, 1988; Opie, 1991), this research and other research on schizophrenia and care has highlighted the over-representation of young adult sons amongst care-recipients (Bulger et al's, 1993; Winefield & Harvey's, 1994). While the women were generally providing care to an adult child, other kinship relations existed in the caring relationships examined in this research. Mary was providing care to her husband Michael whereas Helen was providing care to her mother Lidia. The participants also knew of other caring relationships, not examined in this research, in which care was provided to a parent, spouse or sibling. Discussion of these caring relationships highlighted how each kin relationship is associated with a different set of dynamics, tasks and feelings. The kin relationship had particular implications for: the participants' degree of emotional investment in their care provision; the level of assistance the women received from others with regard to their care provision; and, how long the participants' care needed to be provided. Some of these implications are identified in the following comments:

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- Ben "I think it would probably be [harder to care for] a child. Every parent has great hopes for a child, and seeing any child sick is more upsetting than seeing an old person sick. Seeing an old person sick, you accept the fact that old people are going to be sick. But a sick child is lost potential particularly".
- Helen "I'd hate to try to deal with a teenager or somebody who's a lot younger. I think they would scare me. Well, if they were anything like what mum was"<sup>240</sup>.
- Trevor "It would be hardest to care for a parent because they have seen themselves as caring for you, and they won't give you that right to care for them. Caring for a spouse, would probably vary widely depending on the personalities involved. But I think it can be quite a big stress...trying to be both financial provider and carer at once".
- Joy "If you had an old person, you know that their life is finite. They're going to die aren't they, to put it simply. So they're going to go in a shorter time than your son is, or daughter".
- Mary "Being in a family, and being a wife, and having a partner as a sufferer, I feel I've got more responsibilities...whereas if it was a son or a daughter, my partner or husband could help me raise the children. I'd have more support"
- Pat "I mean you can't dump a child cause you wanted to could you...but I could dump a husband very easily, if I wanted to".

The above comments highlight how important it is to take into account the kin relationship between those who provide care and those who receive care when conceptualising caring work. While discussion in this thesis had identified some of the issues associated with care provided to a parent and spouse, it is important to acknowledge that this research is based primarily upon examining those caring relationships in which an adult child is receiving care from an elderly parent. As already noted, this findings of this research may not generalise easily to those

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<sup>240</sup> Lidia's behaviour was perceived by Helen to be more predictable and less violent now than when Lidia was younger.

caring relationships in which care is provided to a sibling, spouse, or parent diagnosed with schizophrenia.

### **Assuming Responsibility: The Key Themes**

Discussion in this chapter has identified and described the events and issues which arose in response to the participants receiving a diagnosis of schizophrenia from the mental health profession. These events and issues revolved around: first, the participants establishing what the diagnosis of schizophrenia meant for their family member and care provision; second, the women 'choosing' to assume ongoing responsibility for their family member's care provision; and, third, the women responding to their 'choice' to assume this responsibility. It was noted that the participants spoke most comprehensively about the events and issues which occurred in response to the receipt of the diagnosis.

Part one of this chapter highlighted the importance of the women receiving the diagnosis of schizophrenia from the mental health profession as early as possible. The understanding individuals, both within and outside the women's immediate family, held about the women simply 'mollycoddling' their family member, as a consequence of being over-reactive mothers, could at last be challenged. The women's perception that there was 'something not quite right' with their family member was confirmed.

Receipt of the diagnosis schizophrenia allowed the women to 'name the moment'. It was noted that the participants instigated a three-pronged approach when researching the meaning of the diagnosis schizophrenia. Specifically, the participants contacted health professionals, particularly their general practitioner, read relevant literature, and, 'fellowshipped' with others. Several implications for the women's care provision arose from this approach. First, the process of naming the moment provided the women with the first opportunity they had had to

connect the personal and the political. The women were able to talk and join with others to establish that they were not alone in their caring experiences. Second, the participants experienced great difficulty in finding health professionals who would inform them of the diagnosis schizophrenia and help the participants translate this definition into implications for their informal care provision. That the participants initially went to health professionals for information with which they could define 'schizophrenia' suggests that health professionals need to up-date their own knowledge base about this disorder. Third, the process the participants undertook, in establishing an understanding of the recently received diagnosis of schizophrenia highlighted the need for reliable, accessible and up-to-date information about schizophrenia being available. Without this information women, who provide care to a family member diagnosed with schizophrenia, are expected to meet their family member's need for assistance with limited, or worse incorrect, information. As already noted, this difficult situation creates frustration, guilt and regret.

Armed with an understanding of schizophrenia, the participants were increasingly able to identify the symptoms of schizophrenia their family member was exhibiting. Discussion illustrated how the participants translated their definition of schizophrenia into their every day experiences. Collectively, the participants identified the following negative symptoms: lack of motivation; lack of personal grooming; lack of concentration; reduced ability to converse; and, withdrawal from social interaction. Coupled with these negative symptoms were the following positive symptoms of schizophrenia: hallucinations and delusions; paranoia; an altered sleeping pattern; and, potential or actual aggression and violence.

The symptoms exhibited by the family members had particular implications for the type and level of care the women provided. First, the unpredictability of the family members' symptoms meant that the type and intensity of the care required by the family members varied sometimes in very short periods of time, for example,

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hourly. While the care provided by the women was less visible than that described in feminist caring literature, it was not less time consuming. The women were primarily responsible for monitoring and responding to their family member's care twenty-four hours a day. This finding suggested that the status of 'full-time' care-giver was more appropriate than that of 'part-time' care-giver. Second, the positive symptoms of schizophrenia, such as delusions and hallucinations, meant there were times when the participants and their family member had different perceptions of their environment and the interactions within it. A major implication of this difference in perception was the limited reciprocity which existed within the caring relationships. This lack of assistance and acknowledgment from the family members undoubtedly increased the isolation generally experienced by all informal care-givers. Third, the women sometimes had to deal with potential or actual violence when their family member '**was not in touch with reality**'. While it was not common for the family members to exhibit violence, the women's comments highlighted the extent to which the family members' potential for exhibiting violence was at the forefront of their minds. The participants' assessment that violence was exhibited when the family member was not in touch with reality highlighted the importance of having effective neuroleptic medication available and accessible. Fourth, it was explained that the stigma and discrimination associated with schizophrenia did not remain with the family members. Instead, the participants were often treated with caution as a consequence of their family member's behaviours and thoughts. This response of friends, neighbours, and the general public made it difficult for the participants to establish alliances to support them in their care provision. Again, the fact that the women were not assisted with their provision of informal care is acknowledged.

It was argued that the informal care-givers of individuals diagnosed with schizophrenia should be considered as part of the mental health team. If the women were active members of the mental health team this could ensure that

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their assessments were articulated quickly to the appropriate mental health staff, and vice versa.

Potential implications for the 'commodification of care' (Ungerson, 1995) were also identified when discussing the family members' symptoms. It was noted that the family members' symptoms could result in: the family members not acknowledging their need for assistance; care-givers having to readjust their care provision continually to reflect the family members' changing levels of dependency and autonomy; and, the need for flexible and innovative payment systems to reflect any changes in the women's care provision.

After having developed an understanding of what their family member's schizophrenia involved, it was noted in part two of this chapter that the women made the decision to assume responsibility for their family member's ongoing informal care provision. Discussion highlighted that the making of this decision was not a simple process. The women's decision to assume responsibility for their family member's ongoing care provision was influenced by a number of factors internal and external to the women. Attention was initially directed towards acknowledging the extent to which 'care' was encompassed in the women's identities. A further factor which led to the women to fill a care-giver role was the women's economic dependence, typically upon their husband. The dominant discourses of 'schizophrenia' were also factors which influenced the women's decision to assume ongoing responsibility for their family member's care provision.

Consideration of why it was the women who assumed ongoing responsibility for their family member's care provision was followed by the acknowledgment that there were women who had decided not to make this decision. The need for women to justify their decision not to care was challenged. Acknowledgment that some women had decided not to provide ongoing care to a family member

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diagnosed with schizophrenia was important, as it suggests that women are not predestined to provide the majority of their family member's informal care.

The women associated multiple functions with their care-giver role, including being a: supporter; nurse; motivator; protector; friend; mug on the end of the phone; occupational therapist; mother; instigator; and, care-giver. It was explained how the women were having to increase the functions they undertook in response to the implementation of deinstitutionalisation and community care. The women referred to this implementation as the **'move from the ward to the home'**. The women were increasingly taking responsibility for tasks previously the responsibility of New Zealand's formal mental health staff. The politics of the state devolving its caring responsibilities to women who have had no formal training was challenged.

It was explained that the women's caring tasks revolved primarily around the themes of supervision and monitoring. The women's main caring tasks involved observing their family member's mental state, guiding their family member through the everyday, and overseeing their family member's total care provision, particularly that provided by formal mental health staff. The women interacted with their family member on a personal level. 'Personal' refers to the continued attempts the women made to understand their family member's experiences of schizophrenia. I utilised the term 'interactive' to refer to the 'caring for' aspects of the women's care provision.

Several implications arose from the predominance of the women's supervision and monitoring tasks. First, it was noted that the understanding of 'care', described in feminist caring literature (Twigg & Atkin, 1995), needs to be extended in order to reflect the care examined in this thesis. Second, it was proposed that the tasks of supervision and monitoring may be more befitting for the women who were predominantly aged in their mid fifties to mid sixties than personal care

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tasks. The tasks of supervision and monitoring do not include the same physical exertion that often characterise personal care tasks. However, the fact that the women's care provision was still psychologically taxing, as a consequence of the unpredictability and changeability of the family members' symptoms, was noted. Third, it was suggested that the predominance of the tasks of supervision and monitoring may lead to the women's care provision being overlooked. Fourth, it was asserted that the women's caring tasks may support the understanding that women providing care to a family member diagnosed with schizophrenia are simply over-protective. A consequence of this is that the women's care provision could again be dismissed and overlooked by those outside the caring relationship. Fifth, the primacy of supervision and monitoring suggested that the women should be considered as part of the mental health team.

In response to the women's informal care being legitimated by the diagnosis schizophrenia, the men decided to fill a secondary supporting role. Distinct differences were found between the care provided by the women and their husbands. Whereas the women undertook what I have termed 'interactive tasks', the men undertook what I have termed 'practical tasks'. Practical tasks were characterised by their lack of significant interaction with the family members at a personal level. The men expressed their reluctance to engage in the women's interactive tasks. Whereas the women's care provision revolved around their family member, the women themselves were the men's primary focus. The men's main function was to act as a buffer to reduce the harm and hurt the women experienced as a consequence of their care-giver role. The men also acted as a sounding board for the women and financially supported the caring relationship.

The participants associated several events with the women's and men's decision to fill a care-giver/supporting role. These events were identified and described in part three of this chapter. An initial response to their decision was the women's development of the knowledge and skills related specifically to schizophrenia

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care. As Barrett's (1980) work suggested, the women were hesitant to acknowledge that they were providing specialist care despite having spent considerable time developing their knowledge and skills. The women's knowledge and skills had become what they called '**second nature**'.

While the women undertook various functions in their care-giver role, the women explained that overriding the implementation of these functions was the theme of protectiveness. In having had their family member's need for care legitimated by the diagnosis of schizophrenia, the women openly protected their family member from the symptoms of schizophrenia, the rest of the family, and, the wider public. The restriction the women experienced on a day-to-day basis as a consequence of their care provision was reduced, in part, by the family member's compliance to neuroleptic medication. The women identified the noticeable improvement in their family member's mental state when their family member was taking their prescribed medication. This improvement translated into a reduction in the level of care the women needed to provide and therefore an increase in the women's quality of life. The women both overtly and covertly monitored their family member's compliance to the medication they had been prescribed even though many of the family members saw this as interfering with their privacy. The need for the newer medications to be accessible in New Zealand in order to improve quality of life for both the participants and their family member was noted (Schizophrenia Fellowship New Zealand Inc, 1995).

It was noted that the cyclical nature of the family members' symptoms led to the participants changing (often lowering) their expectations about all aspects of their family member's life, from their family member's paid working potential to whether their family member would establish a commitment with a partner. The participants explained that after years of having filled a care-giver/supporting role, they wished only for their family member to be safe and as happy as they could be. The women's care provision reflected Waerness' (1984) category of

stagnation. Although the family member's mental health fluctuated, the family member's health on the whole neither deteriorated nor improved.

Because there were no obvious external indicators of the family members' schizophrenia, when they were not exhibiting the acute symptoms of this disorder, the participants needed to decide when and to whom they would tell of their family member's diagnosis. The participants varied as to whether they thought others outside the caring relationship should be informed of their family member's diagnosis. The important task of education could be coupled with telling others of their family member's diagnosis. However, the benefits of educating others had to be weighed against the ever present possibility that the family member, and the participants themselves, could be discriminated against. As a consequence of their family member exhibiting acute symptoms, some of the participants had had no option but to provide an explanation for their family member's unusual behaviours and thoughts.

The participants' decisions about to who they would disclose their family member's diagnosis to impacted to some extent upon the action they took to initiate change in their caring relationship and the caring relationships of others. The participants indicated that change taken on a collective basis was likely to be more successful.

Finally, attention was paid to how the kinship relationship between the family member and the participants impacted upon the characteristics and complexities of the participants' care provision. The kin relationship had implications for the participants' degree of emotional investment in their care provision, the level of assistance the women receive regarding their care provision, and, how long care needed to be provided. Discussion in this section highlighted first, the importance of acknowledging the influence that kinship can have upon the provision of care

and second, the importance of not generalising the caring experiences of one group of women to all women (Graham, 1991).

As was noted at the beginning of this chapter, the participants spoke most comprehensively about the events associated with, and the implications of, the women assuming responsibility for their family member's care provision. The participants' focus on these events and implications is understandable after the discussion presented in this chapter. It was when the women were assuming responsibility for their family member that the participants were most engaged in their care provision. The following chapter however confirms that there were times when the participants were able to reduce the extent to which they provided care to their family member. The unpredictability of the family members' schizophrenia and the inadequacies of New Zealand's mental health services meant that these times were also imbued with uncertainty.

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## 8. BEING ON CALL

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The discussion in the previous chapter highlighted the restriction the women experienced as a consequence of their care provision. This restriction reflected the changeability and unpredictability of their family member's symptoms. The women needed to monitor and respond continually to their family member's mental state. In contrast to this restriction, the majority of the women identified times when the need for them to provide care to their family member reduced. One of the events which allowed the women to reduce their care provision was their family member assuming responsibility for their own health needs after acknowledging and accepting the diagnosis of schizophrenia. The second event was their family member entering institutionally-based mental health services. The consequence of either of these two events was a transference of some of the responsibility for providing care from the women to either the family member themselves, or, to paid mental health staff. It is important to note that the prognosis of the family members meant that few of the family members were able to meet their own health needs, even for a limited time. In reflecting this, the women generally reduced their care provision as a consequence of their family member entering institutional care.

The women acknowledged how precarious the process of being on call was. First, the women were reliant on their family member or mental health staff becoming more responsible for their family member's care (events which might never happen in the first place). Second, the women were also aware that their investment in the care-giver role could again increase, depending on the path of their family member's illness, or the availability and appropriateness of mental health services. While the women were able to reduce their involvement in the provision of their family member's care, the women were still ultimately responsible for their family member's care provision. The women were in fact on twenty-four hour call. When mental health service staff relinquished their role in

their family member's care, or their family member could no longer attend to their own health and medication needs, it was the women who would again assume responsibility for their family member's care.

When being on call, the women noted that there was not a corresponding reduction in the extent to which they 'cared about' their family member. Instead, the 'caring about' component of the women's care provision was often heightened. The extent to which the women 'cared about' their family member when on call is understood when acknowledging the cyclical nature of the family member's schizophrenia and the inadequacies in New Zealand's mental health services. The women were concerned that their family member may enter an acute episode of schizophrenia without the women knowing. Furthermore, although the women knew they could not provide the treatment their family member required when acutely unwell, the women questioned whether New Zealand's mental health staff would do so. In other words, the women were worried that their family member would fall between the cracks which characterise New Zealand's mental health services.

The men's supporting role was described in the previous discussion. In reflecting the women being on call, the men decreased their involvement in their supporting role. The men did not need to buffer the women as much from their care provision. The different ways in which the women and their husbands 'cared about' their family member is noted.

### **The Family Member Assuming Responsibility**

As already noted, the prognosis for the majority of the family members was an ongoing and cyclical pattern of chronic and acute episodes of schizophrenia. Therefore, the women did not often reduce their care provision as a consequence of their family member both accepting their diagnosis of schizophrenia and being

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well enough to take responsibility for monitoring and meeting their own health and medication needs. Furthermore, the times the family members were able to meet their own health and medication needs were often short in duration. Nevertheless, a few of the women spoke of times when their family member's mental state had significantly improved. Margaret for example, explained why she was able to reduce her level of care provision:

**I can stand back because it's Daniel that's there with us now...Daniel I think has been able to stand back and accept he has an illness, that he is going to have to have medication...now I don't feel he needs protection. He's strong enough now to protect himself.**

Daniel participating in the paid labour force, via an employment scheme, also helped Margaret to stand back or reduce her care provision:

**Now with these courses I think it's great he's mixed with people in the work force. It's not a great deal of pressure put on him, and it just gives him something to do. Because that's one of the big things. Day in and day out with nothing to do.**

In taking more responsibility for their health and medication needs, the family members increased their autonomy and therefore power relative to the women. Contradicting the 'schizophrenogenic mother' theory was the women's responses to the shifts in the dynamics of power between themselves and their family member. Specifically, the women were pleased, if not relieved, about being able to reduce their involvement in their care provision. As Atkinson and Coia (1995) suggested, the changes in the dynamics of power and autonomy resulted in the women taking on new responsibilities and tasks. The particular characteristics of the women's care provision while being on call will be outlined below.

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Jackie likened her role when Luke took responsibility for his own health needs with waiting in the wings, being ready to applaud any achievements that Luke made, but also being prepared to carry him off the stage:

**It's as if he's walking a tight rope, and you're the safety net. You can't say to him, "Don't climb the ladder". You can't say to him, "Don't walk the rope". You can't say "Don't do that you'll fall". You've just got to be there underneath waiting. Because sometimes he'll make it and sometimes he won't. And you just have to be there for when he doesn't. And say "All right we've picked you up, we've bounced you. Now have a bit of a break and then have another go".**

Like Jackie, the rest of the women associated being on call with determining when and how they needed to assist their family member. The cyclical pattern of their family member's schizophrenia meant that the women were aware of the possibility that their family member may need more assistance some days than others despite their family member taking overall responsibility for their health and medication needs. In order to make the assessment about when and how to provide assistance, the women kept tabs on their family member. Keeping tabs involved for example ensuring appointments were kept, especially those with mental health professionals, being aware of their family member's mental health status, and, checking the personal care and hygiene of their family member. Maintaining contact with their family member was a main concern of the women when they were on call. As Jill explained, while Joshua was living in unsupported accommodation, she needed to maintain contact with him: **"He doesn't live here, but I still have to keep in contact with him"**. Without this contact, the women were unable to monitor their family member's health and well-being.

The women proposed that maintaining contact with their family member was vital as a consequence of the inadequacies inherent in New Zealand's mental health services. In being consistent with the many formal reviews of these services (Committee of Inquiry, 1988; National Advisory Committee, 1993; Minister of

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Health, 1994), the participants asserted that New Zealand's community-based mental health services were not comprehensive or accessible enough to support persons with a psychiatric disability. Helen's comment was a well supported one: **"I still don't think there's enough support for [persons with a psychiatric disability]"**. Joy spoke about how individuals exhibiting the symptoms of schizophrenia were being discharged from institutionally-based services without the community-based services being developed:

**We were told, no way would they discharge people from [the long term care unit] until they had accommodation to receive them all. They [policy people] promised they wouldn't do it, but they are. They are putting them out on the street. That's what we feared and that's what they're doing.**

The inadequacy of these services increased the difficulty the participants' family members experienced in monitoring their own health and medication needs. Harriet spoke of the action many family members have had to take in order to get help from paid mental health staff: **"You've got to have committed suicide, or slashed your wrists, or taken an overdose. To get help you shouldn't have to go as far as that"**. This understanding is consistent with Dave's (O'Hare, 1994:22) comment about how difficult it is to access New Zealand's mental health services and Moore's (Christchurch Press, 1995:11) examples of people being turned away from New Zealand's mental health services. It has already been argued that the tendency for mental health professionals to focus upon those persons in crisis reflects the narrower definition of 'mentally disordered' contained within the Mental Health (Compulsory Assessment and Treatment) Act 1992 (Author Unknown, 1992; Mason, 1994; Ministry of Health, 1993; Ross, 1995).

The extent of the change occurring within New Zealand's mental health services also reportedly reduced the family members' ability to receive the help they

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required. As Sonya explained: **"And it's changing so rapidly that its frightening for most of us [care-givers]. And for somebody whose been mentally ill, to ask them to cope is, I think, cruel"**. The increased potential for client uncertainty (Williams, 1994) has already been noted when examining the changes to the way New Zealand's welfare services are being purchased, provided and regulated. It was proposed that these changes have been influenced primarily by the transition from Fordism to Post-Fordism. This transition has meant an increased emphasis placed upon services reflecting and being responsive to individual need as opposed to services being universally applied regardless of individual circumstances. State responsibility for the provision of public welfare services has been transferred to an array of differing providers through the separation of the provision, purchase, and regulation of welfare services. Further, there has been the implementation of various reporting, monitoring, and accountability mechanisms and, increased competition amongst those who provide welfare services for both funds and clients (Bowie & Shirley, 1994; Craig et al, 1992; Malcolm et al, 1993; Opie, 1992).

Concern was also expressed about the extent to which clients will experience 'choice' (Munford, 1995; O'Brien & Wilkes, 1993), be empowered (Cochrane, 1994) and receive a higher quality of service (Biehal, 1993). The structural and organisation change which has occurred in the New Zealand welfare arena since the 1984 Labour Government (Boston, 1991; O'Brien & Wilkes, 1993) has meant that the traditional benchmarks which have previously guided clients through the welfare system have been removed. As Rogers'<sup>241</sup> (Wanganui Chronicle, 1995d:3) comment about the closure of Lake Alice illustrated, the fragmentation of mental health services is particularly confusing. Traditionally, New Zealand's mental health services have revolved around the large psychiatric institutions positioned throughout the country. It has been argued in this thesis that increased client

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<sup>241</sup> The chairperson of the Wanganui Committee on Community Care.

choice is dependent upon an individual having both the skills to identify and contact the appropriate provider and argue that their circumstances meet the criteria for accessing the provided services.

## **The Family Member Entering Mental Health Services**

The women were also able to be on call when their family member entered institutionally-based mental health services. It has been noted that the family members' diagnosis meant that this event occurred more frequently than the family members taking responsibility for their mental health needs. Despite this, previous discussion has highlighted the difficulty the participants experienced when trying to utilise committal procedures in order to ensure their family member entered institutionally-based mental health services. It was noted that the family members entered institutional care as a consequence of becoming acutely unwell.

In response to the family members becoming hospital inpatients, paid mental health service staff took responsibility for providing the family member's care. As Jill explained:

**You know that they're not lying in the gutter rotting away somewhere. That at least they are physically comfortable. You know mentally they are probably not, but physically at least they are fed and clothed and that.**

While there was a reduction in the degree to which the women 'cared for' their family while they were resident within one of New Zealand's nine public psychiatric hospitals or fifteen psychiatric units, there was no similar reduction in the concern and anxiety the women experienced regarding their family member's care provision. This anxiety and concern arose primarily from the characteristics

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of New Zealand's institutionally-based mental health services, some of which will be detailed below.

'Institutionalisation' was previously defined as that process whereby people are cared for custodially within institutions removed from their communities. The participants' discussion of this type of care typically focused upon its negative aspects. Specifically, the participants spoke of the containment function of psychiatric institutions. The participants noted that these institutions have traditionally been viewed as warehouses or bins where the mentally ill are stored. This view of New Zealand's psychiatric institutions was not allayed by the physical characteristics of these buildings. As the material from Williams' (1987) book, titled 'Out of Mind, Out of Sight: The Story of Porirua Hospital', highlighted, a result of the majority of these institutions being built around the beginning of the twentieth century, is that they tend to be large in size, their decor outdated. Not surprisingly, the environment of the current psychiatric institutions was described by the participants as **"depressing"**, **"disgusting"**, and **"unconducive to rehabilitation"**.

Indicative of the containment function of psychiatric institutions is their geographical location. New Zealand's psychiatric institutions have traditionally been situated in rural areas and are surrounded by high walls or grass verges. The physical and geographical aspects of these institutions have supported those discourses which view people with a psychiatric disability as somehow animal like (Foucault, 1967). The understanding that psychiatric institutions should be geographically isolated and heavily fenced reflect the view that people with a psychiatric disability need to be locked away for their own and their society's protection (Manning, 1987).

The participants also noted the routinisation and depersonalisation inherent in the organisation of psychiatric institutions. According to the participants, these

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aspects of institutionalisation negated the acknowledgment of the person, as opposed to their mental illness, and the meeting of their individual needs. Helen's discussion of institutionalisation covered the majority of these points:

**Throwing someone in a big institution and leaving them there to become dependent on the routine that they set up for them out there. Not really encouraging them to think for themselves. Sitting round smoking all day, even if they didn't smoke before they went in there. Just sort of staring at walls, and staring at other people that have some big problems. And losing peoples clothes, losing your identity because you've got someone else's undies on.**

The consistency in the way the participants viewed New Zealand's institutionally-based mental health services was initially surprising considering the variability in their family member's experience of institutional life. Rebecca for example, had spent the largest part of her life in institutional care, entering her first psychiatric institution before her teenage years. According to Pat, it was the length of time which Rebecca had spent in institutionally-based mental health services which was causing problems with her current rehabilitation:

**And [when she was eleven] Rebecca was in [the long-term stay unit] for a year. By that time she was completely institutionalised. She told me herself, "I'd much rather live here than at home". And that's mainly the main problem now. She's so institutionalised.**

While Rebecca had spent the majority of her life time in institutionally-based mental health services, most of the family members had spent less than three months in total in a psychiatric institution, one family member spending no time at all. Sonya spoke about Paul: **"He's mostly gone [into institutionally-based**

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mental health services] when I've gone away...and that was only for three or four days"<sup>242</sup>.

The negativity expressed by the participants towards New Zealand's institutionally-based mental health services is understood when the participants' experiences of these services are revealed. For example, the participants commented on the ineffectiveness of institutional care. On discharge, the family members' health status had often not improved from when they were committed.

As Helen explained:

**It's a bit of a dilemma actually, because I feel that sometimes they've discharged her too soon from the institutions and she's almost like she was when we put her in there.**

The emphasis the women especially placed upon highlighting the inadequacy of New Zealand's institutionally-based mental health services is understandable when remembering that once their family member was discharged from these services, it was the women who again assumed responsibility for their care. This is highlighted further on in this chapter.

Visiting was a task the women consistently associated with their family member residing within institutionally-based mental health services. The time and resources it took for the women to visit their family member depended to a large extent on where their family member resided. For example, visiting their family member in a long-stay unit, situated out of town, required access to transport and considerable amounts of time. Even visiting within town was difficult for some of the women in their later years who had not learnt to drive. Jill was one of these women:

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<sup>242</sup> Sonya was unable to find a replacement care-giver for when she went away on holiday. When Sonya was away, Paul's symptoms would become acute to the extent that he would be admitted to institutional care. Not surprisingly, Sonya had not gone on holiday very often.

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**I mean [the supported accommodation] is at the other end of town. I'm at least ten kilometres away and I don't drive. There are no buses or anything and so I can't get out there directly<sup>243</sup>.**

The rewards for visiting their family member were often minimal if not non-existent. Many of the women identified times when their family member, while residing in a long-term stay care unit, either refused to see them, verbally abused them, or did not recognise them. Helen shared her experience of one of these situations:

**We'd go out to [the long-term stay unit] for a visit. You'd be verbally abused when you got out there, so you'd wonder why you went out there in the first place. But we did. I guess that's responsibility.**

When explaining their family member's behaviour, the participants acknowledged the way in which the committal process had damaged the rapport which had existed between those in the caring relationship. As already explained, a common consequence of the committal process was for the family member to blame the participants, especially the women, for their stay in institutionally-based mental health services. This ill-feeling, mistrust and blame which arose during the committal process reduced the likelihood that the caring relationship would be characterised by collaboration, reciprocation and trust. The lack of reciprocity between the women and their family member is highlighted by Pat's comment which describes Rebecca's response to being visited while in a public psychiatric hospital out of the city limits:

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<sup>243</sup> Those women who could not drive reported that in their generation driving a car was not considered a necessary skill for a woman to learn. This was seen as a consequence of the women filling a home maker role.

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**She came out, "Bring me any fags?" "Yes dear, here you are". [Rebecca] smokes about two fags. "Hooray I have to go now". And I had to wait sitting there for the shuttle to come.**

An important part of visiting was checking whether their family member was being looked after appropriately by the mental health staff. While many of the women's caring tasks had been transferred to mental health staff, for example keeping tabs on the family member, the women made sure that their family member was being looked after and their rights were being respected. As Sue commented, the person in the care-giver role: **"...must make sure that their [family member's] rights are being followed up. It's up to you to know that they are being looked after"**. The role of supervision and monitoring in the women's care tasks is again highlighted.

No matter where their family member was residing, the women reported that they often had their family member home for short stays. However, this situation occurred more often when their family member was resident within one of New Zealand's public psychiatric hospitals. As Pat pointed out, mental health staff often expected her to accept Rebecca home on leave from institutional care: **"They [paid mental health staff] used to ring up and suggest that she come home for two or three days"**. The women highlighted the contradiction inherent in the expectations and actions of mental health professionals. While expecting the women to have the family member home for short stays, mental health professionals repeatedly failed to consult the women about their family member's health status. The women were expected to instinctively know how to best meet the complex and changing needs of their family member even when their family member was very unwell. Furthermore, mental health professionals could not guarantee the women that their family member would continue to take their prescribed medications while at home and therefore reduce the likelihood that they would exhibit the acute symptoms of schizophrenia or violence.

Discussion above indicates that the women never completely disengaged from their care provision regardless of whether their family member assumed responsibility for their health and medication needs or entered New Zealand's institutionally-based mental health services. As Marley (1992:412) explained: *"Even if the mentally ill person is hospitalised or is involved in various outpatient treatments, the family is still intimately involved in the daily care and management of the person and the illness"*. The material from the participants' stories however has argued that instead of 'the family', it is women, typically older mothers, who are intimately involved in their family member's care.

The men also reduced the extent they engaged in their supporting role while the women were on call. For example, their family member residing in institutional care meant that the men did not need to put as much energy into acting as a buffer. The men's primary aim of reducing the hurt and harm the women experienced was more easily achieved as a consequence of the distance the women had placed between themselves and their family member. The need for the men to undertake practical tasks for their family member was also reduced. The family members either took responsibility for these themselves or did not require practical tasks to be undertaken for them. Not surprisingly, the men preferred the times when the women were on call.

The revolving door syndrome (Butler, 1993; Lamb & Shaner, 1993) will undoubtedly affect the women's ability to disengage from their care provision. As already explained, individuals requiring formal mental health care are being treated via shorter but more frequent stays in New Zealand's institutionally based mental health services (New Zealand Health Information Service, 1993). First, gaining access to New Zealand's mental health services has become more difficult as a consequence of the higher threshold for entry to these services (Author Unknown, 1992; Mason, 1994; Ministry of Health, 1993; Ross, 1995).

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Second, the more frequent and shorter stays in institutional care are likely to heighten the tensions surrounding the shifts in the power and autonomy of the women and their family member. The family members may direct more ill-feeling, mistrust and blame towards the women as the committal process occurs more frequently. Third, the shorter stays in institutional care will mean that the time the women are able to disengage from their care provision is reduced. This third implication is particularly concerning when acknowledging that the family members' stays in institutional care were the means of respite for the women<sup>244</sup>.

Paralleling the participants' discussion of New Zealand's institutionally-based mental health services was the concern the participants expressed regarding the number of persons experiencing mental illness who were entering the justice system. As Ben stated: "I feel that a lot of people are in prison who have got a mental illness". According to the participants, this pattern arose as a consequence of the inadequacies of New Zealand's mental health services. Helen for example said:

**The community is not providing the support for people to be supported within it. Ideally we should be able to live with people [with a psychiatric disability] in the community. But, if they haven't got the support or the supervision some of them may develop totally unacceptable behaviour unchecked. This can give schizophrenia a bad name. Somebody who's been out in a community house has killed somebody. If they'd had enough support with keeping tabs on that person, they should have known that that person was needing a lot more help. They shouldn't have got to that stage.**

The participants noted two main implications of persons with a psychiatric disability entering the justice system. First, the discourses which link schizophrenia and violence are supported. This assertion has been supported

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<sup>244</sup> The issue of respite care is discussed later in this chapter.

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when acknowledging the way in which the media has portrayed mental health and specifically schizophrenia (Wanganui Chronicle 1995a, 1995b; Wanganui Midweek, 1995). Second, those persons contained within New Zealand's justice system are not receiving the treatment and support they require.

The participants were well aware that the organisation of New Zealand's mental health services was closely following the direction taken by America and Britain. In making this connection, the participants expressed their concern that New Zealand was consistently implementing the bad along with the good. For example Helen said:

**I'd hate us to end up like England and all those people out there in hovels. This is the thing though. A lot of policies that have come through, health policies and that, are heading the way England went. And they've failed. That's a big worry. I do worry about the ones that haven't got families that can keep an eye on them.**

Mary noted the following: **"But see, if America has tried it in the community. Now why aren't we listening. Why aren't we looking at their results<sup>245</sup>.**

### **Being on Call: 'Caring About'**

The above discussion identified those caring tasks associated with the women being on call. Consistent with Ungerson's (1983) concept of care, the participants associated various feelings with this caring work. This section will identify and describe the 'caring about' aspects of the participants' care provision. The feelings the participants associated with their care provision were consistent no matter whether their family member's schizophrenia was a conundrum, the women had assumed responsibility for their family member's ongoing care provision, or

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<sup>245</sup> The implementation of community care in New Zealand is discussed later in this chapter.

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the women were on call. As already noted, while the degree to which the women 'cared for' their family member was reduced while they were on call, the women reported no similar reduction with regard to 'caring about'. Attention will be first directed towards those feelings experienced by the women, after which the extent to which the men 'cared about' their family member will be described.

### **The Women**

When describing the 'caring about' aspects of their care provision, the women primarily identified the negative emotions reported in existing literature on schizophrenia and care (Atkinson, 1986; Laffey, 1978; Torrey, 1983; Wiltshire et al, 1991). These negative emotions, such as worry, resentment, anger, frustration, grief and anxiety, were primarily in response to the unique characteristics of their family member's schizophrenia. Some examples of this connection will be provided below.

The time of onset of schizophrenia meant that the women's care provision did not reflect the U-shape reported in feminist caring literature (Women's Affairs Victoria, 1994). Instead, the women realised that their care provision was going to be provided on a continual (flat-line) basis. The commitment required from the women to meet their family member's care needs was a primary reason for their resentment. As will be argued further on in this chapter, the women not only had their young and middle years impaired by their caring responsibilities, but also had to continue to meet these responsibilities during their retirement years.

The feelings of worry, anger, frustration and anxiety were linked by the women to the changeability and unpredictability of their family member's symptoms. As already argued, these characteristics of their family member's schizophrenia in turn meant that the women's care provision was unpredictable. Instead of being restricted by the routinisation of their care (Briggs & Oliver, 1985; Munford, 1989; Opie, 1992) the women never knew, on an ongoing basis, the type and level of

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the care they would be required to provide. The symptoms of schizophrenia, such as paranoia, hallucinations, and delusions understandably caused concern. The women could not assume that their family member perceived the same reality as they did.

The cyclical pattern of their family member's symptoms was the main source of the grief the women experienced. The women explained how they had lost the person their family member used to be as a consequence of the schizophrenia. The women were reminded of this fact when their family member's symptoms became acute. Sometimes the women saw glimpses of the person their family member used to be before they exhibited the symptoms of schizophrenia. The women's grief then was long-term and recurring. This was in comparison to the person who has been able to build a memorial to their deceased relative and move on towards completing the grieving process.

While noting the prominence of their negative emotions, the women also reported that they did associate some positive feelings with their care-giver role. However, these positive feelings were fewer in number and were harder to recall. The positive emotions the women reported were consistent with Bulger et al's (1993) research, in which they reported that their research participants associated positive aspects with both the personal growth they experienced as a consequence of their care, and the affection they felt for their family member. Jill's comment provides an example of this: **"...I have absolutely no doubt that he loves me...And that is a big positive as far as I'm concerned. Because it gives me the feeling that it's worthwhile what I'm doing"**. The women then experienced a degree of ambivalence between their positive and negative feelings. However, as Munford's (1989) concept of 'mutuality and conflict' suggests, it was these positive aspects, although fewer in number, which contributed to maintaining the women in their care-giver role. Just as the women in Munford's (1989:228) research found it difficult to *"... challenge those people with whom they had shared many happy*

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*times*", the women in this research would have found it difficult to stop providing care as a consequence of the affection they felt for their family member.

The ambivalence the women sometimes experienced is highlighted by Harriet's following comment: **"I have lots of feelings, sometimes negative sometimes positive...There's some quite strong negative feelings"**. Helen also acknowledged the contradiction in the feelings she associated with her care-giver role and caring relationship:

**Sometimes I feel angry that I've put myself in this situation. I just think, why did I take that on board? Then other times I think, oh she's just so easy to look after. Other times you feel guilty cause you think, have you done the right thing by her?**

The strong and contradictory feelings identified by the women are captured well by Dearth et al's (1986) analogy of a roller coaster which they used to describe the emotions parents of the mentally ill feel as they respond to, manage and survive their child's schizophrenia.

When considering the feelings they experienced when being on call, the women indicated their preference for their family member to live at home. This preference remained even if this meant an increase in the 'caring for' aspects of their care provision. This living arrangement reduced the women's concern, anxiety and worry about for example, whether their family member was living in a doss house or was acutely unwell with no reliable help available. For example, Harriet was particularly concerned about Rachael becoming sick when not at home because in the past: **"When she was sick she was exploited by anybody and anything"**. The fact that the women reported no decrease in the intangible aspects of the care-giver role when being on call is consistent with Bulger et al's (1993) research on the burdens and gratifications of parental care-giving for adults diagnosed with schizophrenia.

## **The Men**

While the men told their stories, it was clearly visible that they were often experiencing intense emotions. Ben for example spoke about committing Bill:

**From the police station he rings up and says, "Dad will you come and get me?" And when I went down he said "Do you still want me home?" That hurt. I said "Of course we do". It's very hard to do those things to him [committal] and still make him understand we love him. And we do love him, there's no question.**

Further on in his 'interview', Ben acknowledged that: **"Regardless of his behaviour, I always still felt I wanted to give him a hug".**

The men solely focused on the negative feelings they associated with their supporting role. Trevor's comment reflected the majority of the men's replies: **"Oh it's negative without doubt. I don't see anything positive in it for anybody".** James stated:

**It's the frustration of being unable to do anything worthwhile to help the guy. I mean he's in deep trouble and I've realised that for twenty odd years now. And I've been unable to do anything to help him.**

The men spoke of the powerlessness they felt in not being able to relieve their adult child from the symptoms of schizophrenia.

While the men also experienced concern, worry, anxiety, and frustration, they also spoke of the disappointment they felt regarding their family member's future options. As Ralph stated: **"You'd have to be disappointed. What else could you be".** The men's reports of the disappointment they experienced is consistent

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with them taking longer to adjust their expectations regarding their family member's potential.

Ben was the only husband who associated anything positive with his supporting role. Ben acknowledged the "...increased understanding [and a] tolerance of difference" he had received from his involvement in the caring relationship. Again, the finding is consistent with Bulger et al's (1993) research. Ben related the positive aspects of his supporting role to the personal growth he had achieved via his care-giving experiences.

In comparison to the men in their lives, the women acknowledged that they were more expressive of their emotions. As Jill stated:

**I probably have more deep feelings than he has...I think in many cases, men like things somewhat simpler. To be able to explain it in black and white terms, this is so and that is so. But I can't quite see it that way.**

Margaret agreed with Jill's interpretation that women and men expressed emotions differently in saying: **"I think men and women have a different outlook to things. I think a woman feels deeper, can sense more"**.

The men also assessed that they could better control the expression of their emotions. The men's ability to be less illustrative of their emotions than the women was reflected in James' comment: **"Judging from my wife's response to the situation, she gets more emotionally involved"**. Mary also spoke of the tendency of men to be less expressive of their emotions: **"[Men are] not emotional like a female. They're more stern. They're not so giving as a female"**. It is important to note that the men being less expressive of their emotions did not mean that they loved or felt less for their son or daughter than the women. Jill's comment highlights this point: **"I'm the one who can cry about it when it gets really bad. And he can't. But I mean, that doesn't**

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mean it doesn't hurt him just as much. I think it does". While the participants of this research described distinct differences in the level of emotion the women and their husbands expressed, it cannot be assumed that all women providing care to their family member diagnosed with schizophrenia are more expressive of their emotions than their male partners.

The participants forwarded two main explanations for the women's deeper emotional involvement in their care provision. The first of these reasons related primarily to those caring relationships in which the family member was a son or daughter. The women had given birth to the child and therefore had a deeper and stronger connection than that of a father or step-father. Ben's comment was a common one: **"The obvious maternal aspect is stronger"**. The second reason given to explain the women's emotional expression related to where the caring relationship was situated, the family home. Again Ben explained:

**Women tend to, as far as I can see, have an overall worry about it [the caring relationship and the family member]...Partly because they're at home all the time. The problem is at home, they're not out of the home. If they get out and away, they can forget about it a bit more.**

In acknowledging the level of involvement they had in their family member's care provision, and the negative effects this involvement had on their health, the women had made repeated requests for respite care or time out from their care provision. The women felt that they would be able to perform the tasks associated with their care-giver role better if they could have regular relief from being primarily responsible for the provision of care for their family member<sup>246</sup>.

The men explained their ability to be less expressive of their emotions by the way they transferred the coping mechanism they used in their work, to their caring

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<sup>246</sup> The issue of respite care is discussed more fully later in this chapter.

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relationship. This coping mechanism was described by the men as assessing the problem, solving the problem, and, moving on to the next problem. The men stated that this was something they had learnt to do in order to be successful in their jobs. Ben for example explained:

**All successful men would have to do that...All the time they've got problems coming up. Never know when another problem is going to come round the corner. And they've got to assess it, and say "This is what we'll do". They may solve the problem, or they may just say "Well you go find out something about that and come back to me. And then I'll make a decision". And they've got to learn to divide things up into compartments.**

The men transferring their coping mechanism from their paid employment supports Ungerson's (1987) assertion that men situate their caring in the same context as their paid work. The men's method of problem solving was not always effective in dealing with issues related to their child's schizophrenia. James for example explained:

**If there is a broken leg get them out of there and gone in ten days time. Ok, I could probably cope with that...It's got an objective, I know what to do. Get on with the next one. But this here, there is no end. There is no objective.**

Issues related to their family member's schizophrenia could not always be assessed, solved and then forgotten. For the majority of the family members, their symptoms of schizophrenia were unpredictable, long term, and without cure. As already noted, the men's inability to procure a cure for the symptoms of their son or daughter explained the common feeling of frustration identified by the men.

The women on the other hand explained the men's limited emotional expression differently. One of the explanations the women provided was that it is not in a man's make-up to be able to deal with illness generally, let alone mental illness,

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specifically schizophrenia. Men were considered by the women to be more likely to look after their own needs rather than the needs of others. As Pat stated: **"Well most of the men I've met over the years, they just can't damned well cope. And that's it"**. Anne's view on men's objectiveness was similar to Pat's: **"But they...can't handle illness"**. This explanation is consistent with the understanding that men are not expected to both 'care for' and 'care about'. As already proposed, those men which do both 'care for' and 'care about' are often considered unconventional, effeminate or saintly (Dalley, 1988; Game & Pringle, 1983; Ungerson, 1983).

The women also drew on the process of socialisation to explain the men's objectiveness. For example, Jill explained:

**I think they are [less expressive of their emotions] because of the way they are brought up. I think it's a social thing rather than an inherent difference. I think it would take a few generations to probably change it.**

Edgar and Glezer's (1992) research indicated that changes are occurring in the attitudes and behaviours of women and men. Instead of maintaining the traditional male wage earner and female home maker split, increasingly women and men are sharing paid and unpaid work responsibilities. However, it was also noted that state, private and community interests need to support the changes occurring in the attitudes and behaviours of women and men if these changes are to proceed without difficulty. The likelihood of state, private and community merging is discussed below.

The women did question how expressive of their emotions the men would be if they were situated in the care-giver role as opposed to a supporting role. The majority of the women did not believe that the men would be able to continue to distance themselves from the issues related to their son's or daughter's

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schizophrenia if they undertook interactive tasks on a full-time basis. This was particularly the case with the move from the ward to the home. Increasingly greater responsibility has been placed upon the women to meet more of their family member's care needs. Questions such as these illustrate the importance of involving men, where possible, in caring research. The need to include men in research on caring has also become more important with existing research acknowledging the proportion of men who fill a primary caring role (Arber & Gilbert, 1993; Bottomley, Rooker & Pitkeathley, 1991; Fisher, 1994).

At times, the women found the men's limited emotional expression quite hurtful and isolating. However, overall, the women and their husband's level of emotional involvement worked to complement each other. As Jill explained, **"Its probably just as well that we both don't think the same way. If we were both terribly emotional and that, probably things would have fallen apart a long time ago"**. Again, the practical and emotional support the men provided probably accounts for the greater burden and need for services single parents providing care to an adult child diagnosed with schizophrenia experience (Carpentier et al, 1992).

### **The Women Increasing Their Level of Care Provision**

As already noted, those women who had been able to reduce their involvement in their care-giver role spoke of how hard it was to reduce their level of care provision in the first place. Margaret drew on her own experience in admitting that: **"...it takes you a long time to stand back, many, many years to stand back"**. These women also noted the difficulty they experienced in continuing to remain on call. After years of assuming responsibility for their family member's care, it would have been easy for the women to slip back into that role. As the discussion below will highlight, the lack of coordination and consultation between the participants, the staff of New Zealand's institutionally-based mental health

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services, and, the staff of New Zealand's community-based mental health services meant that the participants were critically aware that they may have to increase their provision of care at any time.

Arrangements for the discharge of the family members from institutionally-based mental health services were perceived by the participants to be either "ad hoc" or "on the spur of the moment". Joy had the following to say about the way Bill had been released from institutional care:

**I'm not complaining about [the long term care unit] but there were some things we were concerned about. Sometimes we'd go down to see him and he'd be at [the local acute unit] and they wouldn't have told us. And other times we'd go to see him at [the local acute unit] and he'd be at [the long term care unit]. And then he was discharged without our knowledge. So we've had a lot of bad experiences in a way.**

The degree of coordination and consultation between the participants and mental health professionals was a current concern for Pat at the time of her 'interview'. Pat was aware of moves being made by mental health staff to release Rebecca from a long-term stay unit. Pat, from past experience, knew of the lack of coordination, planning and support involved when releasing patients from this particular long-term stay unit. Pat was sure that if Rebecca was released under similar circumstances, she would be expected to assume responsibility for Rebecca's care. As Pat stated:

**It's taken a long time to get to the rejecting mum<sup>247</sup> I think. But there again, how rejecting would I be if they plonked her on the doorstep and said "Right she's out, she's all yours?" Which could happen.**

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<sup>247</sup> Pat made the distinction between being the 'over-protective mum', or being protective, and being the 'rejecting mum', or trying not to assume responsibility for Rebecca's care provision.

The lack of consultation, planning and support from mental health services meant that although the women were not primarily responsible for providing care to their family member when they were resident within one of New Zealand's psychiatric institutions, the women still experienced uncertainty knowing that each day they might be expected to play a main role in their family member's care again. As noted above, this explains in part why the 'caring about' aspects of the women's work did not reduce when the women were on call.

The negative aspects of institutionally-based mental health services, as identified above, were utilised by the participants to explain their family member's dislike of entering New Zealand's traditional psychiatric institutions. The family members, in being geographically separated from the rest of society, easily lost their personal identity and rights. Also, as already noted, after being maintained within this custodial form of 'care', the family members' mental health would not necessarily have improved. The family members were reportedly likely to be discharged without any noticeable planning or forethought regarding the family members' experiences of being released. The latter was identified by Jackie who in drawing on her own experience, shed some light on the contradictions in institutionally-based care:

**Well it's a strange thing. You're in [the long term care unit] and you're mad. Ok, hop on the bus and now you're normal. And you think, what's the difference. Five minutes or somebody's made a judgement on you...it's too much and too sudden.**

At the time of their 'interviews', the women (and their husbands) spoke of changes to New Zealand's institutionally-based mental health services. The trend towards community care meant that institutional care was no longer the norm. Institutional care was utilised only when a person was a danger to themselves or others. Previous discussion has noted that now even when treatment is enforced, people

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under the jurisdiction of the Mental Health (Compulsory Assessment and Treatment) Act 1992 can receive treatment in their homes. This option has become available as a consequence of Community Treatment Orders (New Zealand Government, 1992). The option of receiving treatment at home has undoubtedly increased the responsibility of informal care-givers, such as the women, regarding their family member's care provision. As already noted, the women would no longer receive respite from their informal caring work.

### **The Telephone**

The telephone was often the means by which the participants received reports on the behaviours and health status of their family member, these reports indicating that the women needed to assume responsibility for their family member's care provision. Anne's statement highlighted the impact such reports had on the women:

**Because in the meantime he was doing stupid things in [my home town], and people would ring us up and say, "Oh I hate to say it but do you realise Patrick has" ...It was just horrible.**

In responding to the information they received by telephone, the participants sent money and air tickets to their family member, travelled to other parts of the country to track down their family member and/or picked up their family member and brought him or her home. The participants also contacted mental health professionals working both in and out of New Zealand and instigated committal procedures. Further, the participants picked up their family member from the local police station, rescued their family member from a safe house, and/or increased their involvement in their care-giver or supporting role.

The telephone was one of the mechanisms which continually reminded the women of the tenaciousness required by being on call. One telephone call could

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indicate the need for them to again assume responsibility for their family member. The unpredictability of the women's care provision is again highlighted. Not surprisingly, as Margaret's comment illustrates, the women associated the telephone with varying levels of dread and anxiety:

**And, it might seem strange Leigh, but that was one of my biggest fears with Daniel, every time the phone rang in the early times. That Daniel would have been in the gutter somewhere, or attacked.**

### **Wanting To Be Less Protective**

As already noted, in opposition to the now out-dated family theories about the aetiology of schizophrenia (Bateson et al, 1956; Fromm-Reichmann, 1948; Lidz et al, 1957), all the women proposed that they looked forward to the time when they could reduce or remove themselves completely from their care-giver role. In explaining this position, the participants acknowledged the physical, emotional, and psychological cost that providing care to their family member had on the women especially. They also acknowledged that with the majority of the women being in their late fifties to mid sixties, the care-giver role had become harder to undertake. Tasks that the women performed in their care-giver role now were taking longer to do and required more physical effort than when the women were say ten years younger. Jill explained why she wanted to reduce her involvement in Joshua's care:

**I'll be sixty two in November. Okay, I'm not old, but I'm not as strong as I was ten, fifteen years ago. My husband is in his mid sixties and I think that we would like to sort of gear down a little bit.**

Some of the women also noted that they were becoming less tolerant of the restriction they experienced as a consequence of the care they provided their family member. The women's care-giver role had already restricted a

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considerable period of their lives. The women expressed their concern that continuing their care-giver role could mean not only losing their career but also their retirement. As Jill explained:

**Well the thing is of course, we'll always be here for him. But I would like to let go of that role a little bit. Because, I've done it for so long and, well, even I get tired. I can't have my own life completely ruled by the fact that I have a son who's got schizophrenia.**

Jill's comments are consistent with Lefley's (1987) arguments regarding elderly 'parents' providing care to adult children diagnosed with schizophrenia. As Lefley (1987) has asserted, elderly parents such as the women who participated in this research are being asked to provide very complex and demanding caring work at a time when they should be able to reserve their energies for more pleasant and less demanding activities. Typically, retirement is a time when most older adults engage in leisure pursuits and social and hobby related activities (Hayslip & Panek, 1989). The women voiced their desire to have the freedom to engage in such activities, especially since their husbands had fully or partly retired from paid employment. Joy, speaking about Ben said:

**He thought, perhaps when he was retired if you wanted to go to Wellington on Tuesday, you go to Wellington on Tuesday. When Bill was living with us, we couldn't do that.**

Discussion in this thesis has suggested that the current political and economic climate will not provide the women with the opportunity to disengage from their care provision. In fact that opposite seems to be the case. The state appears to be increasingly devolving its caring responsibilities to the women.

### **Respite Care**

The issue of respite care was raised by the women when they talked about wanting to reduce the extent to which they were responsible for their family

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member's care. Respite care would allow the women to reduce their involvement in their caring work, even if this was only on a short-term basis. As Sonya said: "I mean ideally for someone to come in and look after him while I went on holiday would be brilliant. Just to have a weeks break. But you can't even get anyone to do that". The need for respite care to provide valuable relief for care-givers of family members diagnosed with schizophrenia, has been identified in related literature from as early as the late seventies (Hatfield, 1979; Lamb & Oliphant, 1978).

All of the women noted how they had been unable to access respite care. According to the participants, the formal mental health services in their region would not provide the family members the support they required while the women experienced respite. Mental health staff had a high enough workload assisting those individuals who had been committed to formal mental health services. This meant that the women had to turn to their informal networks when trying to find a substitute care-giver for their family member. As was noted above, the women were often unsuccessful in finding a relative or friend who would assume responsibility for their family member while they went on holiday. The women explained that their relatives and friends refused to provide care to their family member in response to the dominant discourses of 'mental illness' and 'schizophrenia'. Of main concern to the women's relatives and friends was the understanding that the family members would be uncontrollably violent. The women's inability to find someone from their informal network to substitute them in their care-giving role meant that they were unable to utilise the 'Aid to Families' programme'<sup>248</sup>.

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<sup>248</sup> The 'Aid to Families' programme was funded by the New Zealand Income Support Service. When certain criteria are met, a full-time care-giver could request payment for twenty eight days per year respite care. This payment was transferred to the person (other than the full-time care-giver) or organisation which undertakes the relief care. The twenty eight day payment varied depending on the agent which undertakes the relief care. A person from the full-time care-giver's family received the lowest payment of \$24.19 per day. This is compared to the highest payment received by, for example, IHC \$69.87 per day (Department of Health, 1994). As of the 1st July 1995, the Aid to Families programme was transferred to the various Home Management Services around the country.

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Receiving respite care as a care-giver of a family member with a psychiatric disability continues to be a difficult task despite the establishment of Home Support Management Services. These services only manage carer relief for older people<sup>249</sup> and people with a primary physical or sensory disability<sup>250</sup>. Care-givers of a person with a psychiatric disability have to approach their community mental health team who will then complete the required paper work and complete the referral for respite care. However, it appears as if some mental health teams are just as confused as the care-givers referred to them about how to access respite care. These mental health teams seem to be unaware of both the criteria for accessing respite care and how to contact potential providers of respite care.

The women proposed that even if they could find someone to assume responsibility for their family member, it was likely that their family member would either not see the need for a substitute care-giver or not agree with the women's replacement. The family members' lack of insight explains the first response. As already noted, the family members' lack of insight sometimes meant that they perceived everyone else as unwell instead of acknowledging their own symptoms. The women then spoke of the tension that often exists in caring relationships between the rights of care-givers and the rights of care-recipients. Arrangements which would best benefit care-givers can be detrimental to those who receive care (Ungerson, 1993). In this case, the benefits the women could have received by being replaced by a substitute care-giver would have been at the expense of their family member who was strongly opposed to having their care needs met by a substitute care-giver.

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<sup>249</sup> 'Older persons' refers to those individuals over 65 years.

<sup>250</sup> This is despite the difficulty which sometimes arises when an individual has multiple disabilities.

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While noting their past and current inability to receive respite from their care provision, the women considered the particular type of respite care they required. Foremost amongst this consideration was the need for respite care to be able to deal with a wide range of symptoms, including those associated with both acute and chronic episodes. This need arose from the changeability and unpredictability of the symptoms of schizophrenia. If respite care only covered those individuals who were not exhibiting the acute symptoms of schizophrenia, the women would still be unable to plan ahead. The women had no idea as to what symptoms their family member was going to be exhibiting in two weeks let alone the following day.

### **A Continuum of Care**

While the women acknowledged the responsibility and obligation they felt towards providing care to their family member, they proposed that they could not meet all of their family member's care needs, at least not on a long-term basis. This was particularly the case with those women who were in their retirement years. As Lefley's (1987) work has suggested, these women were increasingly finding that their care provision taxed them, physically, emotionally, and psychologically, to the extent that their own health was being adversely effected. The women's need to reduce their involvement in their family member's care provision was being challenged by the trend the women called '**the move from the ward to the home**'. As already explained, the women were referring to the actions the state was taking in order to reduce its caring responsibilities. The women proposed that they were being expected to increase their care provision in order to perform caring tasks which were previously undertaken by formal mental health staff. The move from the ward to the home then was consistent with care by the community. As already explained, care by the community refers to who undertakes the caring work (Abrams, 1977; Finch, 1990; Lewis & Meredith, 1988).

When considering the context which would allow the women to reduce the extent to which they assumed responsibility for their family member's care, the participants identified the need for a continuum of care. The participants' call for a continuum of care reflected the complexity of the symptoms of schizophrenia. Harriet spoke of this complexity:

**I don't think either [institutionalisation or community care] is the perfect answer. The illness has such a wide range. There are times when somebody has to be institutionalised, even for a period of time. Just time enough for them to stabilise. Some people have to stay in an institution, in some sort of care for much longer. Some people need permanent twenty-four hour supervision. They just can't cope without it, and society can't cope with them if they don't have twenty-four hour supervision.**

In order to meet the divergent and varying needs of persons diagnosed with schizophrenia, the participants called for a range of institutionally-based and community-based services. Joy's comment that these services needed to be "...well run and well financed..." was repeated within the other participants' stories.

The participants also noted the importance of mental health services incorporating a 'duality of focus' (Twigg & Atkin, 1995). Not only the health of their family member should be considered, but the women and their husbands also need to be consulted and supported in their care provision. Mary suggested that informal care-givers such as herself should have their own key worker. It would be the key worker's responsibility to maintain contact with the care-givers: **"I do feel that we should have a key worker that makes contact with us. They contact us, not us contact them"**. As the material presented above indicated, this 'duality of focus' would be in direct comparison to the participants' previous experiences of New Zealand's formal mental health services. The participants were used to being excluded from their family member's involvement with mental health staff.

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As was highlighted above, even when it came to their family member being discharged from these services, the participants were not usually informed or consulted.

The participants proposed that the continuum of care they talked about could be achieved via care in the community. The participants associated care in the community with many potential positive outcomes for the treatment and rehabilitation of their family member. In general, the participants believed that there was increased potential for the overall needs of their family member being met by this pattern of care. This was especially the case if New Zealand's mental health services were integrated with other welfare services. The participants discussion of care in the community was consistent with the recommendations reported in the consensus development conference documents 'Living at Home' and 'Managing Major Psychosis'. As was explained, these documents called for a holistic approach to care (McGeorge & Femando, 1993) and an integrated social policy (Naylor & Lardner, 1994). Trevor spoke of his view on what community care could involve. Trevor's view was representative of the participants' understandings of community care:

**[Community care] looks towards developing the clients own abilities, by giving them responsibility. By assessing the level of responsibility they can cope with, and gradually building on each success that they've achieved, and then giving them that slightly higher level of responsibility. And through that means, enhancing their own self esteem. Gradually, sort of reintegrating them into the community, but under a level of supervision if the client asks for it.**

While identifying care in the community as the ideal mental health policy, the participants acknowledged that implementation of this ideal was unlikely. This acknowledgment was in response to the action the Government had taken in order to reduce both the expenditure and caring responsibilities of the state. The participants referred to the 1991 benefit cuts (Craig et al, 1991) and the

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assumptions inherent in the Mental Health (Compulsory Assessment and Treatment) Act 1992 about care-givers, such as themselves, increasing their care provision<sup>251</sup>. The participants proposed that while they were experiencing increasing pressure to extend their care provision, the emphasis recent legislation<sup>252</sup> has placed upon the primacy of patient's rights (New Zealand Government, 1992; Morton, 1994; The Press, 1994) meant that the women were excluded from their family member's involvement in formal mental health services. The participants asserted that instead of a continuum of care being developed, care-givers such as themselves would have more pressure exerted upon them to increase their care provision. As Mary proposed: **"I think there's going to be more pressure on the care-giver of the future"**. According to the participants, it would be out of character for the current New Zealand Government to advocate and resource mental health policy based on care in the community as the participants had defined it.

The politics of placing more responsibility for care provision upon women who are stating their need to reduce the level of informal care they are providing, must be questioned. First, the health of these women is being jeopardised by the stress and strain they experience as a consequence of the characteristics and complexities of the care they provide. As already noted, instead of their care provision reflecting the U-shape reported in caring literature (Women's Affairs Victoria, 1994), the women had provided care on a continual (flat-line) basis. The women's commitment to their care was further tested by the fact that the women had not been able to receive respite from their care provision. The continual nature of their care was further restricted by the unpredictability and changeability of their family member's symptoms of schizophrenia. These symptoms also meant

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<sup>251</sup> As already argued, the narrower definition of 'mentally disordered' within the Mental Health Act 1992 means that care-givers, such as the women who participated in this research, are having to increase the level of care provision. This is in response to threshold for entry into New Zealand's formal mental health services being increased ((Author Unknown, 1992; Mason, 1994; Ministry of Health, 1993; Ross, 1995).

<sup>252</sup> An example of such legislation is the Mental Health Act 1992.

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that the women were in caring relationships which at times consisted of little or no reciprocation and were threatening to their safety. Second, the inadequacies in New Zealand's mental health services placed pressure upon the women to engage in, and extend, their care provision. Discussion above highlighted the lack of coordination, integration, support and consultation which characterise the participants' experiences of New Zealand's mental health services. Third, the women continuing their care provision is only a short-term solution. The age of these women mean that their ability to meet their family member's care needs will soon cease. The effectiveness of care by the community will be highlighted as the question of who will fill the women's care-giver role is raised. This is especially the case when acknowledging, for example, that women are increasingly entering the paid work force (Statistics New Zealand, 1995). Discussion on the intersection of women's paid and unpaid caring responsibilities highlighted the difficulties women experience when trying to balance their paid and unpaid work (Finch & Mason, 1990). Changes in the attitudes and behaviours of women and men regarding their respective roles (Edgar & Glezer, 1992) suggest that it can no longer be assumed that younger generations of women will decide to make unpaid care their primary responsibility. The question of who will take on the women's care-giver role in the future is further addressed in the section titled 'When I Am Gone'.

### **Attempting to be Less Protective.**

In trying to reduce their involvement in their care-giver/supporting role, some of the participants had acquired accommodation for their family member outside of the family home. The intention behind acquiring this accommodation, was to ensure that their family member could move from the family home, but live without being at risk. An example of this solution was provided by Trevor.

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Jackie and Trevor who, at the time of their 'interview' were organising alternative accommodation for Luke:

**We've purchased a property which has got tenants in the main house and has a sleep-out attached to the house...we're organising it so that Luke will have his own living arrangement there. We hope that he will be able to manage his own life there without much assistance from us.**

The participants' attempts at reducing their provision of care were usually unsuccessful. For example, Sonya talked about the events that took place after she had organised alternative accommodation for Paul:

**It was a nice little flat, too...so he moved in...I suppose he had it for about six months. Then something went up and he had to repay more. The whole thing was getting a bit out of hand. He was never there. And I was having to look after my garden and his garden, look after my house and his house, do his washing, feed him at home with no board. I mean the whole thing was just impossible. And then he thought that the man was trying to get into the house from next door all the time.**

Joy also provided an example of how the provision of alternative accommodation for Bill was unsuccessful:

**And then we thought he was doing all right so we bought him a flat for his own, which he lived in. But then trouble started again...he got into trouble with the law, taking cannabis actually. He was also beaten up by people, they took things, stole. The flat became impossible. I had to go down and rescue him sometimes. People would go and bash their way in and beat him up. And he would escape, then move into a safe house. And I'd have to go and get him. And he had a lot of negative experiences.**

Those participants who had provided alternative accommodation for their family member expressed their disappointment at their family member having to return

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home. As already noted, the young adult years are typically associated with a person establishing their own life and career path (Berger, 1986). As a consequence of their family member's age and ethnicity, it was socially expected that they would have moved into alternative lodgings. This expectation was voiced by Joy who said: **"...but it's not natural to have a thirty five year old son living at home"**.

As the above comments highlight, simply providing alternative unsupported accommodation was not sufficient for the family members to develop some independence. The examples provided by Sonya and Joy illustrate the need for a range of accessible accommodation options for persons diagnosed with schizophrenia. The National Mental Health Consortium (1989) has identified the different forms which accommodation can take: home ownership; co-operative housing; flat or house rental; living with family; boarding houses; sheltered beds; foster home arrangements; group homes; therapeutic communities; transitional hostels; semi-staffed homes; fully staffed residential homes and hospital care. Furthermore, if the principles of independent living advocated by people with a disability (Morris, 1993a; Wood, 1991) are to be implemented, these accommodation options need to part of wider and more supportive approach to disability. Such an approach would be consistent with the calls for a holistic approach to care (McGeorge & Fernando, 1993) and an integrated social policy (Naylor & Lardner, 1994).

Action which Helen had taken to ensure that Lidia did not live in the same house as her, but received the care she required was the most successful. Helen, her husband, and Lidia had arranged for a granny flat to be attached to Helen and her husband's home. Helen explained the benefits of this arrangement:

**There is no way that I could bear living with her in the same house, but I thought maybe I could cope with her if she's independent. If she became psychotic she would not be in the**

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**same house as us...I think that being independent in her own flat, she is quite happy. And she doesn't have the stresses living with others brings.**

On the other hand however, Helen and her husband were restricted by Lidia having a financial share of the house. Again Helen explained: **"If we ever wanted to go somewhere like Australia to live, she'd have to be a large part of the decision. My husband finds that a bit of a strain".**

The need for Helen and her husband to make alterations to their home in order to accommodate Lidia arose from the limited housing options available in New Zealand. As was argued, New Zealand's social policy has generally assumed that 'the family' is nuclear in form (Briar, 1994a; Koopman-Boyden & Scott, 1984). This is despite the variations between family forms recorded in available statistical data (NZDS, 1992; Social Development Council, 1991) and acknowledgment of the active role that the *whanau* plays in the lives of Maori (Bradley, 1994; Selby, 1994). In reflecting the primacy of the nuclear family within New Zealand's social policy, housing in New Zealand has been built primarily to meet the needs of the nuclear family as opposed to other family forms (Thorns, 1988).

### **The Family Member's Adult Status**

The women's descriptions, about attempting and being able to reduce their involvement in their family member's care, were imbued with issues related specifically to providing care to a young adult. The fact the family members were primarily young adults is explained by the time of onset of schizophrenia. As was noted, the age of onset of schizophrenia for women is predominantly twenty five to thirty five years, for men fifteen to twenty five years (American Psychiatric Association, 1994a). Any implications of the young adult status of care-recipients

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have not generally been reported in feminist caring literature<sup>253</sup>. As already noted, feminist research on caring has primarily examined the care provided to young children or older adults (Lewis & Meredith, 1988; Opie, 1991). This section will identify and describe how the family members' adult status impacted upon the women's care provision.

First, as a consequence of their age and physical stature, the family members were automatically accorded the status of adults by society. One negative consequence of their family member having the rights of an adult was that if their family member did not accept there was something wrong with their mental health, there was little the participants could do except wait until their family member was committed. Jackie was in this predicament with Luke at the time of her one-to-one 'interview': **"But then trying to get him to accept to go to treatment. That's the problem. That's where we're stuck at the moment"**. This predicament was a common one as a consequence of the lack of insight the family members experienced at times.

Second, the participants raised issues similar to those identified by Leggatt (1994) when speaking about the conflict they experienced in reconciling their family member's emotional age and chronological age. Sonya spoke of the dilemma she experienced regarding Paul:

**I almost feel as if I'm looking after a little wee boy at times. A little boy in a man's body. You know, he would respond to sitting on my knee and having a cuddle. But you can't do that with a man.**

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<sup>253</sup> This is despite the issues surrounding a young adult receiving care sometimes being a feature, for example, of the care provided to a family member with an intellectual disability.

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As Hyde and Goldman's (1993:70) comment indicates, this conflict is not unusual:

*Generally, people who are ill, including those who have schizophrenia, tend to regress to a less mature state. During the treatment and rehabilitation of schizophrenia, most families are confronted by the problem of relating to the adult patient as if he or she were much younger than his or her chronological age.*

Although the women were aware of their family member's adult status, when the family member was unwell, the women were honest about relating to them as a teenager or young child. For example, Harriet explained that:

**Well it's eighteen months since Rachael's been unwell. The fact that she was behaving like a four year old, you have to treat her that way...She can't understand why [her behaviour is] unacceptable.**

On the same subject Pat said: **"Which really once she was sixteen I suppose I was still thinking she was nine...It took me quite a while to get through that. Mind you she acted like she was nine, not sixteen".** Harriet's and Pat's comments confirm the need for parenting skills as a consequence of the family members reverting to child like behaviour when unwell.

The adult status of the family members also affected the treatment and professional follow-up they received. If their family member decided to stop taking their medication because of the side-effects they experienced, or because of their drug use, the participants could not force their family member to continue with treatment. Joy's comment reflected this dilemma: **"...And you've got to realise that he's now a man of thirty-five. He's not a child and you can't tell him what to do really".** As was noted, non-compliance is a common response with persons diagnosed with schizophrenia (Falloon et al, 1984; Hatfield, no date).

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Third, the adult status of the family members had implications for the way in which the caring relationships were perceived by those outside it. As already noted, unless the family members were exhibiting the acute symptoms of schizophrenia, there was often no obvious external indicator<sup>254</sup> that the family members had schizophrenia. A consequence of this was that the caring relationship was often deemed by those outside it as unnecessary or odd. The understanding that the women were simply being over-protective and mollycoddling the family members was drawn upon. This understanding increased the difficulty the participants experienced in providing their care. As Ben explained: **"And so it's the other people's perception of [the caring relationship] as well. It all adds to the difficulties of the carer"**. The women experienced difficulty in finding friends who first, could understand their family member's schizophrenia and second, support them in their care provision. This difficulty further explains the distinction the women made between their 'schizophrenia friends' and their 'other friends'.

Finally, another consequence of the adult status of the family members, was associated with their expressed anger or violence. As Leafberg's (1995) research suggested, anger or violence expressed by the family members was rare and usually occurred as a consequence of either non-compliance to medication or the family members experiencing considerable stress. Although their family member's anger or violence was rare, the women were always aware that their family member could exhibit these behaviours. The women were also aware of the potential harm they themselves could experience as a consequence of their family member's anger or violence. As Harriet explained: **"But I'm the one she attacks when she's unwell"**. The women were more at risk if their family member did become angry or violent, than if they were a young child or an older person. This was particularly the case with the women being in their late fifties to mid-sixties.

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<sup>254</sup> An example of such an indicator is a wheelchair which indicates that a person may require some support.

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## When I am Gone.

It has already been noted that as a consequence of the majority of the women being in their late fifties to mid sixties, the question of who would provide ongoing care to the family members in the not too distant future was a prominent one. This question gained particular prominence when the women were on call. Their family member requiring care and support, even when they assumed responsibility for their own health needs, indicated to the participants that the WIAG question needed to be resolved. As Ralph said: **"My worry is that if Mum and I go ahead of Rebecca who's going to look after her?"**

When the women spoke of who could provide care to their family member when they could no longer do so, they distinguished between the tasks and feelings encompassed in their care provision. This distinction was consistent with Ungerson's (1983) concepts of 'caring for' and 'caring about'. For example, the women knew that even if they could arrange payment for a nurse or some other health professional to care or support their family member, this professional might 'care for' but not necessarily 'care about' their family member. The women stressed that good care must combine both these aspects. Those women who were providing care to an adult child, did expect their family member's siblings to fill a care-giver role when they could no longer do so. For siblings to continue the provision of care to their family member was, according to the women, the only way they could ensure their family member was both 'cared for' and 'cared about'.

The women's expectations about the type of care their other children would provide to their family member has, however, been challenged by Finch's (1989) research. As already noted, Finch (1989) found assistance exchanged between siblings to be less reliable and require reciprocity to be maintained. Finch's

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(1989) findings suggest that siblings would not assume responsibility for their family member's care on an ongoing basis. Discussion in this and the previous two chapters has identified that the women's care provision required constant commitment and involved limited, if any, reciprocity.

Although the women expected the family members' siblings to fill a care-giver role when they could no longer do so, the majority of the women stated that they would not ask their children to commit themselves to this responsibility. The women felt that it was up to their children to decide for themselves whether they would assume responsibility for their family member's ongoing informal care. The contradiction inherent in the women expecting their other children to provide future care, but at the same time not wanting their children to experience what they had in the care-giver role, was apparent. The women expressed their wish for their other children to be able to make the most of their lives. Joy's comment summed up the women's ambivalence about their family member's siblings taking up the care-giver role:

**Young people have their lives to lead. And I definitely don't want them to have that problem [providing care for a family member diagnosed with schizophrenia]. I'm thrilled that they are caring people and will do it, I'm sure of that. They're young. It's only fair that they ought to be able to have their own life to lead.**

Filling a care-giver role would necessarily be restrictive if the family members' siblings met the women's expectations about them both 'caring for' and 'caring about'. Discussion in the previous chapters has illustrated that provision of both of these facets of care, for example, increases the difficulty women face in combining and meeting their paid and unpaid work responsibilities.

In comparison to the women, the men were more open about the expectation that their other children fill a care-giver role. For example, although Ben spoke of the

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burden Bill's brothers would take on in continuing the provision of care for Bill, Ben still expected Bill's brothers to take on this responsibility:

**...we don't want him to be a burden to his brothers. Particularly Sam who's got a young child. But it's going to have to be that way. They'll slowly have to look after him more and more. And that's especially when we've gone, when we're not here.**

Feminist analysis of informal care (Lewis & Meredith, 1988) suggests that it would actually be Ben and Joy's daughter-in-laws which took primary responsibility for Bill's care provision.

Ultimately, the women acknowledged that the only step they could take with regard to the WIAG (Lefley, 1987) question was to ensure that their adult son and daughter was financially provided for. Like Sonya, the women mentioned how they had ensured their wills were in order: **"I've made my will so that they all get a third share, and no hold ups"**. Provision for younger generations via wills is an issue which has recently been hotly debated in New Zealand. This debate has arisen from the introduction in 1993 of means-testing for elderly people requiring long-stay health care (NZPA, 1995a). Older people are not only being expected by Government to provide care to younger generations, but also make provision for their own future care needs. A main consequence of this is the possibility that there may be little inheritance left to provide financially for their family member or other children.

## **Being on Call: The Key Themes**

The discussion in this chapter has identified and described those events which allowed the women to reduce their involvement in their provision of informal care. One of these events was their family member assuming responsibility for their own health needs after acknowledging and accepting their diagnosis of

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schizophrenia. The second event was their family member entering institutionally-based mental health services. Consistent with the family members' prognosis, the first event rarely occurred. The family members entering New Zealand's mental health services also occurred infrequently. The participants explained that this was particularly the case as a consequence of the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the higher threshold for entry contained within it. The limited opportunity the women experienced for reducing their care provision is concerning when considering the continual (flat-line) basis of the women's care provision. The two events just identified, were the only forms of respite the women experienced. The need for the women to have to request a break from their care provision is itself disgraceful. The working conditions of the women are deplorable when considering the statutory rights accorded to paid workers.

When on call the women did not completely disengage from their care provision. Instead, the prominence of some tasks, such as checking if the family member had taken their medication, reduced while the prominence of other tasks, such as visiting the family member, increased. The women's caring tasks again revolved around the themes of supervision and monitoring. The implication that the women were unable to completely disengage from their care provision, as a consequence of the inadequacies inherent in New Zealand's mental health services, was present within the participants' stories. This was particularly the case when considering the 'caring about' components of the women's care provision. The women knew that the need for them to assume responsibility for their family member's care could again arise abruptly. This finding confirms the assertion that New Zealand's mental health services need to be improved if informal care-givers, such as the women, are to be given the opportunity to disengage from their provision of care. The women clearly expressed their wish to decrease their involvement in their care-giver role. The women did not want to continue to be taxed emotionally, psychologically and physically throughout their retirement

years. They had already committed the majority of their adult life to their family member's care provision.

In wanting to increase their family member's independence, the majority of the participants arranged alternative accommodation for their family member. The failure of this action, in terms of reducing the participants' involvement in their care-giver/supporting role, indicated to the participants that their care provision would be directed by their family member's symptoms of schizophrenia, rather than vice versa. From this discussion, the need for a range of accommodation options (National Mental Health Consortium, 1989) was noted.

The participants proposed that in order for the women to disengage from their care provision, a continuum of care needs to be developed. According to the participants, a continuum of care includes early intervention services, and a range of community-based and institutionally-based mental health services. This continuum of care was reported to be needed in order to meet the complex and changing symptoms of schizophrenia. Certain tensions, which exist between the participants' requests for assistance and the current political, legal and economic environment of New Zealand, were identified. Specifically it was noted that instead of the development of a continuum of care, the state was implementing what the women called '**the move from the ward to the home**'. The women were experiencing pressure to increase and extend their caring responsibilities to include those previously performed by mental health staff.

Evidence suggests that New Zealand's formal mental health services are unprepared to deal with demands schizophrenia currently places upon them, without the added pressure of care-givers not being able to meet their caring responsibilities. The state devolving its caring responsibilities to women who themselves are unable to maintain their care provision needs to be seriously and quickly reconsidered. This is particularly the case if the state's devolution of its

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caring responsibilities is simply a mechanism for reducing formal mental health services. The consequences of this mechanism will become all too clear in the not too distant future. The participants' experiences of New Zealand's mental health services suggest that the terms 'comprehensive', 'sufficient', 'effective', 'efficient', and 'adequate' are being defined by those who adhere to market liberalism. As already asserted, it is the future which will advise us if this will continue to be the case with the strategies in the document 'Looking Forward' (Minister of Health, 1994b).

The difficulty the women experienced in finding someone willing to provide respite care to their family member, will almost certainly have implications for the commodification of this type of care. This is particularly the case when considering conditional 'quasi-wage payments for care' (Ungerson, 1995)<sup>255</sup>. First, people diagnosed with schizophrenia would almost certainly experience difficulty in finding individuals who were willing to undertake caring tasks for them. This assertion is supported by the difficulty the Home Support Management Service based in Palmerston North<sup>256</sup> has experienced in finding people willing to provide home support to those individuals with a psychiatric disability. Second, the smaller number of potential providers willing to provide paid care to a person with schizophrenia may mean that these providers could request a higher rate of financial reimbursement than that received for care provided to an individual with an intellectual, physical, or age-related disability. A possible consequence of this higher reimbursement is that individuals diagnosed with schizophrenia receive less care. The pool of money people with a psychiatric disability have allocated to them is utilised more quickly as a consequence of the higher financial reimbursement their providers receive. Furthermore, those who experience difficulty in finding paid work may establish a niche in providing this unpopular

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<sup>255</sup> This discussion assumes that an individual diagnosed with schizophrenia has the insight to acknowledge that they do require a degree of care and support from another.

<sup>256</sup> Palmerston North is a city in the central North Island of New Zealand.

form of care. This is a similar concern to Ungerson's (1995:41) warning about the establishment of "...*unregulated and informal 'grey' labour markets*". Again, people diagnosed with schizophrenia receive a lower standard of care than that received by other care-recipients.

The discussion above suggests that 'carer-allowance payments for care' (Ungerson, 1995) may be a more effective way of ensuring that individuals diagnosed with schizophrenia receive the level and type of care they require. However, to ensure that care-givers are not compromised by 'carer-allowance payments for care' (Ungerson, 1995), considerable work would need to be undertaken on a number of issues. First, the level of financial reimbursement care-givers should receive needs to be established. Care needs to be taken to ensure that women are not exploited further by the receipt of inadequate payments for care. Second, the difficulty in categorising care-givers of a family member diagnosed with schizophrenia as either 'full-time' or 'part-time' care-givers is raised. Discussion in this thesis about the changing and unpredictable symptoms of schizophrenia has however argued that the status of 'full-time' care-giver is more appropriate. Third, debates may also arise about what constitutes care. The development of 'carer-allowance payments for care' (Ungerson, 1995) will need to be based upon the understanding that informal care provided to a family member diagnosed with schizophrenia has its own unique complexities and characteristics. The understanding of care presented in feminist caring literature needs to be extended in order to reflect the care examined in this thesis. Fourth, the conditions under which these care-givers should work also needs to be established. The discussion in this thesis has highlighted, for example, how vital it is for care-givers of a family member diagnosed with schizophrenia to receive respite. It has also been argued that these care-givers need to receive information about their family member's mental state if they are to respond effectively to their family member's complex and changing care needs. The need

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for care-givers to receive assistance and acknowledgment from formal mental health staff was also emphasised.

Particular attention was paid to those implications for the participants' care provision arising from the age of onset of schizophrenia. The adult status of the predominantly sons and daughters influenced the treatment and professional follow-up they received, the perception of the caring relationship by those outside it, and, the impact of the family member's symptoms upon the participants. The family member's adult status also caused conflict for the participants when it came to them deciding whether to relate to their family member as an adult or child.

Discussion of the family members' adult status suggested again that the issue of 'rights' needs to be resolved. From the participants' perspective, it was incredulous that their family member had the right to make various decisions, about their treatment and the dissemination of their information, when the ability to take responsibility for decisions was absent. In this situation, adherence to patients' rights meant that the participants' rights were ignored. Furthermore, adherence to patients' rights meant that it was the participants who had to respond to their family member's decisions, usually by increasing their involvement in their care provision.

Discussion in this chapter has completed the presentation of the participants' experiences, feelings and thoughts. The discussion in this and the previous two chapters has given understanding and meaning to the care the women provided before their family member's behaviours and thoughts were named, and to the care the women and their husbands provided while the women assumed responsibility and were on call. It is this understanding and meaning which will be further integrated and examined in the following chapter.

**S**ection Four:

**Looking Forward:**

**Policy**

**and**

**Practice**

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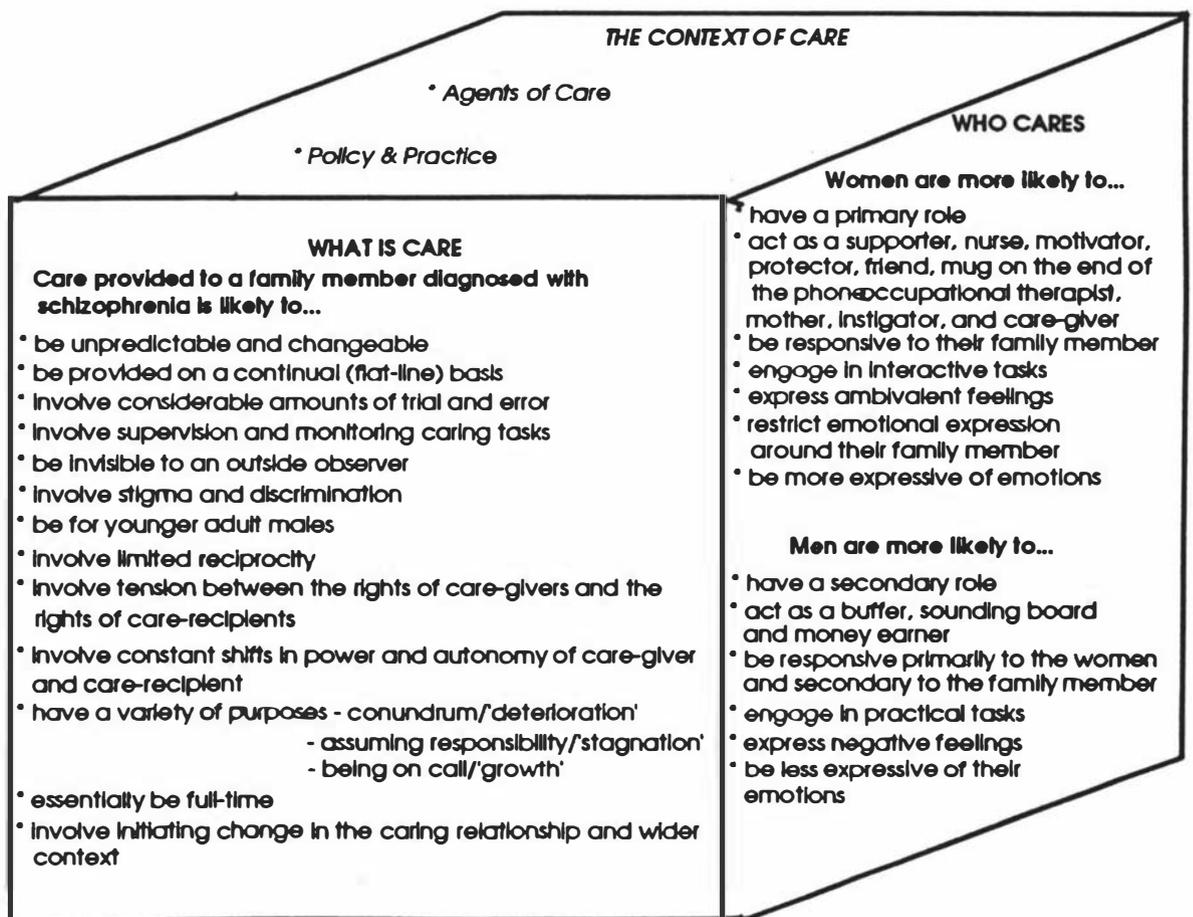
## 9. LOOKING FORWARD: POLICY AND PRACTICE

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This research has examined and developed an understanding of the unpaid care provided within a family to a member diagnosed with schizophrenia, specifically within the New Zealand context. The research question guiding this research was 'What are the characteristics and complexities of the informal care provided within a family to a member diagnosed with schizophrenia, in New Zealand?' This question was divided into two components. The first of these components was, 'What are the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia?' The second component was, 'How is this care provision influenced by the social, political, cultural, legal and economic context of New Zealand?' The research question is important for three reasons. First, while feminist researchers and writers have undertaken detailed examinations of informal care, the attention of these researchers and writers has traditionally been focused upon the unpaid care provided to a family member with an intellectual, physical, or age-related disability (Lewis & Meredith, 1988; Munford, 1989; Opie, 1991). The unique characteristics and complexities of the care provided to a family member with a psychiatric disability, have, until recently, remained unexamined by feminists. Second, use of the positivist research paradigm has predominated when researching issues related to schizophrenia, including informal care provision. This methodology, combined with the stigma and discrimination associated with schizophrenia itself, has meant that those who provide care to a family member diagnosed with schizophrenia have had limited opportunity first, to tell their stories and second, to interpret this caring process (Atkinson & Coia, 1995; Perring et al, 1990; Twigg & Atkin, 1995). Third, the existing research on schizophrenia and care has primarily been undertaken overseas. Research is needed which notes the impact of the New Zealand context upon the provision of care to a family member diagnosed with schizophrenia.

In answering the research question, a vast amount of material has been presented, examined and critiqued. In this fourth section of the thesis the key findings of the research are revisited and extended. Guiding this discussion is 'the framework for analysis of informal care provided within a family to a member diagnosed with schizophrenia'. This framework, presented below in Figure 3, reflects the experiences and understandings the participants articulated in their stories about the informal care they provided to their family member. The framework provides a structure for understanding and researching the care provided within a family to a member diagnosed with schizophrenia.

**Figure 3.** 'The framework for analysis of informal care provided within a family to a member diagnosed with schizophrenia'.



In following the 'framework for analysis of informal care provided within a family to a member diagnosed with schizophrenia', attention first is directed towards the question of 'What is Care?' The complexities and characteristics of the informal care provided to a family member diagnosed with schizophrenia are identified. This discussion is followed by considering 'Who Cares?' -- specifically, the way in which informal care was distributed between the women and their husbands is described. Following this, attention turns to the context of care, specifically, how the participants' care provision was influenced and shaped by New Zealand's social policy and formal mental health services. Implications arising from the research process are then raised. This discussion is followed by considering issues for future research.

Several issues need to be considered when reading the material presented below. First, it is important to remember that the diagnosis of schizophrenia is associated with varying prognoses (Kaplan & Sadock, 1991; Keefe & Harvey, 1994; Miller, 1995). Not every person with this disorder experiences a cyclical pattern of chronic and acute episodes of schizophrenia resulting in significant impairment for the rest of their lives. This, however, was the case for the family members spoken of in this thesis. Acknowledgment of the family members' diagnosis is important. It was the family members' symptoms that primarily influenced the nature of the women's care provision.

Second, the women participants were predominantly older mothers providing care to a young adult child. The different complexities associated with the various kinship relationships (Finch, 1989) suggest that it would not be wise to simply generalise the findings of this research to caring relationships encompassing other kinship relationships.

Third, a similar warning is given about generalising the findings of this research to Maori. All of the participants in this research identified as *tauiwi*, specifically

European. It has been suggested in previous discussion that the different ways in which Maori view health and illness may lead to different practices and responses to schizophrenia. This in turn could lead to different care-giving experiences. As Graham (1991) has argued, the care-giving experiences of one group of women should not be considered as representative of the care-giving experiences of all women.

## **What is Care?**

In this thesis, it has been argued that existing analytical caring frameworks need to be extended in order to reflect the care provided to people with schizophrenia. The unique influence of the symptoms of schizophrenia upon the participants' provision of informal care is discussed in the following section entitled 'The Key Components of Care'. This section discusses the first six points presented in the 'What is Care' section of the framework above. Attention is then turned to the profile of the care-recipients. It is noted that the family members tended to be younger adult males. Following this, those tensions revolving around the rights of the participants' and the rights of the family members' are highlighted. Focus is then directed towards the purpose of the participants' care provision. Finally, the way in which the participants made the link between the personal and the political is described.

## **The Key Components of Care**

In reflecting the family members' changing symptoms of schizophrenia, the care examined in this thesis primarily was characterised by its unpredictability and changeability. The women's care provision could change within the hour when their family member exhibited the positive symptoms of schizophrenia such as hallucinations and delusions. The difficulty the women experienced as a consequence of the unpredictable and changeable nature of their care was furthered by the fact that this care was provided on a continual (flat-line) basis.

The women had committed the majority of their adult years to the complex and demanding task of meeting their family member's care needs. In not having access to respite from their care provision, the women experienced the restriction and pressures of their care-giver role three hundred and sixty five days a year, twenty four hours a day.

The women utilised the strategy of 'trial and error' to establish effective ways of dealing with their family member's symptoms. The care the women needed to provide their family member was outside of their previous caring experiences. Use of the strategy trial and error was often detrimental to the caring relationship, causing psychological, emotional and, sometimes, physical harm to both the women and their family member. Before the diagnosis of schizophrenia was provided by the mental health profession, the harm that the women experienced as a consequence of their care provision was often ignored.

The symptoms of schizophrenia, involving an inappropriate match between cognition, affect, and perceptions, meant that caring tasks of a supervisory and monitoring nature were primarily required of the women. Supervision and monitoring tasks involved not only assessing the current state of the family members' mental health, but also involved anticipating those responses required to ensure that the family members were not placed in avoidable stressful situations. Personal care tasks were sometimes required, but were not the mainstay of care.

The relative invisibility of the women's caring tasks was identified. This invisibility was explained by the fact that the tasks revolving around supervision and monitoring generally did not involve obvious physical activities, such as bathing or dressing someone. Further, when they were not exhibiting the positive symptoms of schizophrenia, there were not obvious outward indications that the family members had schizophrenia. It was asserted that this invisibility increased the

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likelihood that the women's care provision would again be dismissed and overlooked. The women's care provision to their adult child could be perceived not to be necessary or legitimate, which in turn could lead to the women not receiving the assistance they required with their care-giving.

The stigma and discrimination associated with schizophrenia hindered the participants' care provision both directly and indirectly. Foremost was the difficulty the women experienced in establishing an accurate definition of schizophrenia and convincing others that their care-giving work was legitimate and beneficial for their family member. The frustration and distress participants associated with this process cannot be underestimated.

The characteristics of the women's care provision, just discussed, emphasize the importance of not entrapping women within care-giver roles. However, if women do decide to care, they need to have access to information about their family member's schizophrenia and the role they are playing in meeting their family member's care needs. One way of providing this information is through the development of training programmes targeted specifically at those who fill a care-giver role. Participants of these programmes need to be able to develop an understanding of their family member's complex, changing and unpredictable symptoms of schizophrenia along with ways to respond to these symptoms. Attention also needs to be paid to considering why it is usually women who fill a care-giver role. That the women's care provision is not being assisted by appropriate support services also needs to be explored. The lack of support and acknowledgment the women received from individuals both inside and outside their immediate family suggests that consideration needs to be given to the development of educational programmes targeted at the general public. These programmes need to challenge the dominant discourses of schizophrenia, in order to reduce the stigma and discrimination associated with this disorder. Furthermore, inclusion of care-givers as active members of their family member's

mental health team, from the time the diagnosis of schizophrenia is given, must be considered as a further mechanism for providing informal care-givers with the information and resources they require. Finally, the continual nature of the women's care provision suggests that one crucial resource required by the women is accessible respite care which can respond to the range of the symptoms of schizophrenia.

### **The Profile of Care-Recipients**

The majority of the family members in this research were males, predominantly younger adults. One consequence of the family members' adult status, combined with the lack of easily identifiable indicators of schizophrenia when the positive symptoms of this disorder are not being exhibited, was the perception of those persons outside the caring relationship that the family members were simply being 'molly-coddled'. The care provided by the women was sometimes seen by those outside the caring relationship as detrimental to the family members' independence. Again, these understandings of the women's care provision often meant that their care was overlooked or dismissed.

That it was predominantly young adult males receiving care also had particular consequences when the family members were exhibiting some of the symptoms of schizophrenia. Again, it is important to acknowledge that the family members only exhibited aggression or violence when either they had not taken their medication or if they were placed under considerable stress. While noting this, the women were more at risk from these behaviours than if their family member was a child or an older person. Furthermore the consequences of family members exhibiting aggression or violence were magnified when acknowledging that the primary care-givers of these family members were generally older women.

The participants proposed that their family member did little to reciprocate the care they received. If the family member did take responsibility for undertaking

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tasks, such as mowing lawns, the participants spoke of how they needed to initiate this action and then supervise the completion of these tasks. The lack of reciprocity between the participants and their family member was especially acute when the family member was experiencing hallucinations and delusions. These symptoms not only meant that the participants and their family members were experiencing different realities, but also meant that there were times when the women and their husbands were the subjects of suspicion and paranoia. The high level of commitment the women had towards their family member is highlighted when acknowledging that the women continued to assist their family member despite the lack of acknowledgment or reciprocity the women received from that family member.

The consequences for the caring relationship of the family members exhibiting the positive symptoms of schizophrenia indicate that it is imperative that New Zealand's mental health services be accessible and responsive. An individual can move into an acute episode of schizophrenia in a very short period of time. Also of high importance is the availability of neuroleptic medications because compliance to these medications improves an individual's functioning. The increased effectiveness of, and compliance to, the newer neuroleptic medications challenges the difficulty individuals currently face in receiving prescriptions for these medications. Finally, the issue of the family members' future care is raised. First, the understanding that the women's care provision is a short-term solution, as a consequence of the aging process, needs a prompt response from policy makers. If New Zealand's mental health services continue to be developed in response to the higher threshold for entry, it will be unlikely that New Zealand's mental health services will be able to respond to the WIAG (Lefley, 1987) question. Second, demographic changes in the New Zealand population suggest that the question of women filling care-giver roles needs to be reconsidered. For example, the increased participation of women in the paid work force may mean

that younger women will not be willing or available to meet the ongoing care needs of care-recipients.

### **Rights of Care-Givers Versus Rights of Care-Recipients**

The participants spoke of many situations which emphasised the tensions between their own rights as care-givers and the rights of their family members as care-recipients. Prominent amongst the participants' discussion on rights was the collection and dissemination of information. The participants stressed the importance they placed upon receiving information regarding their family member's mental health and treatment in order to improve the quality of their informal care provision. The emphasis that the participants placed upon the receipt of information was, however, in conflict with their family member's requests for their information to remain confidential.

The family members' ability to withhold information from the participants placed the participants in the difficult situation where they were to assume responsibility for their family member's informal care provision without any information about their family member's prognosis or treatment. The women then, had to make assessments about their family member's behaviours and thoughts, and respond in accordance with these assessments, without being able to draw upon the information held by formal mental health staff.

The participants questioned why the family member, who had been committed because they were so unwell, was then allowed by mental health professionals to decide whether the participants should receive information regarding their health status. Although the family members had the right to make decisions about their treatment, the family members when unwell were often unable to take responsibility for and to respond to their decisions. This in turn left the

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participants in the position where they had to deal with the family members' psychotic symptoms until the family members were either committed or decided to receive professional assistance. The emphasis on patients' rights, within, for example, the Mental Health (Compulsory Assessment and Treatment) Act 1992, sometimes placed the women in dangerous situations.

The above discussion suggests that protocols for the rights of care-givers and the rights of family members diagnosed with schizophrenia, will have to consider the changing nature of the family members' symptoms and the degree to which an individual is able to assume responsibility for their own welfare needs. Further, tensions arising from the Government's expectation that care will be provided by 'the family', in reality women, and the reduction in the resources available to 'the family' need to be resolved. Information and resources need to be provided to those who decide to fill a care-giver role for their family member diagnosed with schizophrenia.

### **The Purpose of Care**

In reflecting the cyclical nature of the family members' symptoms, the women's care provision had a variety of purposes. The women's care primarily fluctuated between the categories of 'deterioration' and 'stagnation' (Waerness, 1984). Specifically, the women's care provision typically reflected the purpose of 'deterioration' before the diagnosis of schizophrenia was provided. Despite the care the women increasingly provided, their family member's symptoms of schizophrenia worsened until their family member entered an acute episode of schizophrenia. 'Stagnation' equated with the women assuming responsibility for their family member's care provision after the diagnosis of schizophrenia was provided by the mental health profession. Despite the women developing their knowledge and skill base in order to improve their provision of care, their family member's symptoms tended to be cyclical in nature becoming more or less acute over time. Over a long period of time, their family member's level of functioning remained constant. The category of 'growth' could only be applied loosely to the

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women's care provision when they were on call. It was only valid when their family member both acknowledged their diagnosis of schizophrenia and took responsibility for their own health needs. As already noted, the prognoses for the family members meant that this event seldom occurred. The cyclical nature of the family member's symptoms also meant that the women again needed to assume responsibility for their family member, typically after a short period of time.

The changes in the purpose of the women's care reflected the changes in the level and type of assistance the family member required over time. These changes in turn reflected corresponding changes in the degree of power and autonomy (Atkinson & Coia, 1995; Waerness, 1984) held by the family member and the participants. The participants' stories highlighted the constant shifts in the power and autonomy between themselves and their family member, these shifts occurring as the family member was more or less impaired by their symptoms of schizophrenia. These shifts in power and autonomy added further tension and difficulties to the caring relationship as both the participants and their family member adjusted to their new responsibilities and position in the caring relationship (Atkinson & Coia, 1995). The changeability and the cyclical nature of the family members' symptoms meant that these shifts were frequent and intense. This frequency and intensity was increasing in response to the revolving door syndrome. The higher threshold for entry to New Zealand's mental health services meant that the family members had to be more unwell before professional assistance was provided, this assistance being provided for a shorter period of time.

The changing purpose of the women's care provision also meant that the women often could not, and were not, categorised easily or consistently as either 'full-time' or 'part-time' care-givers. While noting the changing degrees to which the women had to engage in their care provision, in essence the women had to view themselves as having the caring commitments of 'full-time care-givers' in order to

meet the changing needs of their family member, even though this commitment was not always required. This commitment the women made to their informal care restricted the women from engaging in other activities. Despite the lack of reciprocity the women received and the complex and unpredictable nature of their care, the women placed their caring work before other possible commitments.

Examination of the purpose of care highlighted that although the tasks of supervision and monitoring may be relatively more invisible than personal care tasks, the women's commitment to their care provision equated with the status of full-time carer. This finding supports the understanding that the services and resources made available to those who decide to fill a care-giver role should reflect their full-time status. Furthermore, the higher threshold for entry to New Zealand's mental health services is challenged. The revolving door syndrome is likely to mean that the purpose of the women's care provision equates with 'stagnation' than 'growth'. Further, the revolving door syndrome heightens the shifts of power and autonomy between those individuals in the caring relationship.

### **The Personal is Political**

The participants made the link between the personal and the political by identifying the importance they placed upon initiating change to improve both their own individual caring relationship and the life circumstances of persons generally who have been affected by schizophrenia. Acknowledgment of the potential negative social outcomes of identifying as a care-giver of a family member diagnosed with schizophrenia did, however, influence the strategies the various participants used when acting as change agents. Specifically, the change strategies the participants utilised reflected their decision about to whom they would disclose their family member's diagnosis of schizophrenia. Those participants who were afraid of either themselves or their family member experiencing discrimination or stigma were less likely to be engaged in collective action.

Despite the despair associated with schizophrenia, the participants collectively indicated that they undertook change strategies on an individual and collective level. Individual action included the participants writing to both their local newspaper and Member of Parliament, and Government Ministers. The women had also participated in research, developed their own skill and knowledge base, and some had engaged in part-time work. It was the women who typically joined with others to improve the circumstances of persons affected by schizophrenia. In their 'extended caring role' (Traustadottir, 1991), the women acted as 'buddies' for newer Schizophrenia Fellowship members, participated in service provision and undertook an advocacy role in an effort to increase the amount of resources directed towards mental health services.

The above discussion notes the role the women especially played in challenging the structural factors which impacted both directly and indirectly upon their informal care provision. Tensions existed however between the participants acting as change agents and the potentially negative consequences of publicly identifying as a care-giver of a family member diagnosed with schizophrenia. In the current context it will be important for individuals in care-giver roles to continue to make the link between the personal and the political. The Government will assume, for example, that the current threshold for entry to New Zealand's mental health services and the level of choice care-givers and care-recipients experience are adequate if care-givers do not continue to express their concerns and suggestions.

## **Who Cares**

It was evident from the participants' stories that it was the women who provided the majority of the family members' care provision. The women's care provision was complemented and supported by the men filling a secondary supporting role.

The women's, and their husbands', care provision will be described below, respectively.

### **The Women's Caring Work**

The women associated multiple functions with their care-giver role. Specifically, the women said they needed to be their family member's: supporter; nurse; motivator; protector; friend; mug on the end of the phone; occupational therapist; mother; instigator; and, care-giver. The function the women undertook reflected the path of their family member's illness. In this sense, the tasks the women undertook were reactive to their family member's symptoms of schizophrenia. The women were having to extend their involvement in their care-giver role. The women were undertaking functions previously the responsibility of formal mental health staff as a consequence of the higher threshold for entry to New Zealand's mental health services.

In 'caring for' their family member, the women undertook what I have called 'interactive tasks'. Interactive tasks involved the women both making some assessment about how their family member was coping with their symptoms of schizophrenia and then responding to this assessment. Examples of the interactive tasks the women undertook include: monitoring their family member's personal grooming and hygiene; initiating committal procedures; trying to convince their family member to take their neuroleptic medication; and, assisting their family member with budgeting. While the women interacted with their family member at a personal level, this interaction seemed to be a step removed from the kind of interaction engaged in by care-givers of a family member with an intellectual, physical or age-related disability. The latter's interaction is generally more intimate as a consequence of the provision of personal care tasks such as toileting and bathing (Twigg & Atkin, 1995).

The women spoke of the ambivalent emotions they associated with their care provision. Worry, concern, and anxiety predominated amongst the emotions they felt. While noting the prominence of their negative emotions, the women also reported that they did associate some positive feelings with their care-giver role. These positive feelings, which were fewer in number and were harder to recall, were typically associated with both the personal growth they experienced as a consequence of their care, and the affection they felt for their family member. The participants indicated that it was the latter which maintained the women in their care-giver role. However, it seems incredulous that the feelings of affection they felt for their family member were strong enough to maintain the women in their care-giver role when their care provision was often dismissed or overlooked, and their caring relationship was characterised by limited, if any, reciprocity and at times, violence. As Munford's (1989) concept of 'mutuality and conflict' suggests, the reasons for women continuing to care are complex. The assumption cannot be made that the care provision of women is solely positive or negative. Further, it can be argued that policy makers rely upon the diverse and contradicting emotional experiences of care-givers to maintain women within their caring relationships.

In being aware of the Expressed Emotion theory (Atkinson, 1986; Brown et al, 1962; Hudson, 1982; Kuipers & Bebbington, 1987; Seeman et al, 1982) the women acknowledged the importance they placed upon not exposing their family member to negative criticism. The women explained that they restricted their emotional expression in endeavouring to exhibit only those emotions which did not negatively impact upon their family member's mental health status. The women then not only monitored their family member but also constantly monitored themselves when interacting with their family member. This self-imposed restriction, although invisible to an outsider, was emotionally taxing for the women.

The women were defined by themselves and the men as more expressive of their emotions. The participants explained this by acknowledging the greater involvement of the women in the provision of care, the fact that care was provided in the sphere in which the majority of the women both worked and lived, and, as a consequence of the women's maternal instinct -- it appeared to be natural for the women to be so emotional about their child. A further explanation for the level of the women's emotional expression is related to the extent to which the women monitored the expression of their emotions around their family member. The time the women spent talking with their husbands at the end of the day was usually the only time the women did not need to monitor their emotional expression. It may have been then that the women used this time as a release for the frustration, worry, concern and anxiety they had stored up during their day.

The over-representation of women in care-giver roles is questioned. Attention needs to be paid to how the informal care provided to a family member diagnosed with schizophrenia, currently assigned to women, can be more equally distributed between the 'state, the community and the family. This assertion is supported when considering the understanding that women in care-giver roles are being expected to increase and extend their care provision. The complex and unpredictable symptoms of schizophrenia suggest that this expectation is misguided. It will only be a matter of time before the care-givers become care-recipients themselves. In order to overcome the over-representation of women in care-giver roles, consideration also needs to be given to how care can be shared more equally within the family. Those individuals who decide to fill a care-giver role need to be supported in their decision with the information and resources they require. Those individuals who decide to care must also be supported in their decision. This latter decision may be made more frequently by the women as women find themselves unavailable and unwilling to care as a consequence of their participation in paid work.

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### The Men's Caring Work

The main function the men undertook was to act as a buffer in order to reduce the stress and strain the women experienced as a consequence of their provision of care. In acting as a buffer the men, in conjunction with the women, drew and then enforced the boundaries which regulated the interaction between the women and their family member. Further, the men acted as a sounding board for the women when they came home from work and financially provided for the caring relationship. The men increased their engagement in paid work when they wanted to remove themselves from the site of caring. By utilising their paid work, the men were better able to choose the time and extent to which they would engage in their supporting role.

While the men's caring tasks were primarily reactive to the women, the men also undertook practical tasks when 'caring for' their family member directly. In comparison to the women's interactive tasks, practical tasks are characterised by their lack of personal interaction with the family member. The men shied away from any suggestion of them undertaking interactive tasks even though these tasks did not involve intimate contact with the family members. This suggests that other aspects of the women's care, such as the level of commitment required, did not entice the men to fill a care-giver role. Even though the extent of the men's care was limited, it both complemented the women's care provision and provided the women with support.

The men tended to associate solely negative feelings with their care provision. In comparison to the women who spoke of the worry, concern, and anxiety they felt, the men spoke of the powerlessness, frustration and the disappointment they felt primarily. The participants consistently reported that the men were more objective or less expressive of their emotions than the women<sup>257</sup>. The men explained their ability to be more objective by transferring a strategy they utilised in their paid

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<sup>257</sup> The generalisability of this finding was questioned.

work to their care provision. Specifically, this strategy involved: assessing the problem; solving the problem; and, moving on to the next problem. This strategy was not as successful in terms of the men's care provision as a consequence of the cyclical nature of schizophrenia. The women questioned whether the men would be able to continue to be as objective if they were managing, on a continual basis, with the day-to-day issues dealt with by the women in their provision of care. The importance of examining the care provision of men in primary care-giving roles is highlighted. While the women, at times, found the men's objective stance quite disconcerting, the overall consequence of this difference was a balancing effect. The men's emotional expression neutralised the women's higher emotional expression.

The men's secondary role complemented and assisted the women in their care provision. However, the men enacted the reluctance they expressed about undertaking interactive tasks by using their paid work to limit the assistance they provided. This highlights the importance of considering the incentives needed to entice men into care-giver roles. The structural changes needed to allow men to care and women not to care also need to be identified and actualised. The changes occurring in the attitudes of women and men from the wage earner/nurturer split need to be supported and furthered.

## **The Context Of Care**

Discussion in this chapter has discussed the 'what is care' and the 'who cares' section of the framework. Specifically, the complexities and characteristics of the care provided to a family member diagnosed with schizophrenia and how this caring work was distributed between the women and their husbands. Attention will now turn to examining how the context in which the caring relationships were situated influenced the provision of this care. The following discussion will focus first upon the agents of care and then on policy and practice.

### **The Agents of Care**

It has been argued that there are three main caring agents in New Zealand, these agents being the state, the community and the family. The discussion below will identify how the care examined in this thesis was distributed between these three caring agents. Challenges to this distribution are then noted.

All of the participants spoke of how since they had first provided care to their family member in response to the symptoms of schizophrenia, changes had been occurring with regard to the overall provision of the family members' care. When speaking of this change the women used the phrase '**the move from the ward to the home**'. The women used this phrase when referring to the expectation of the Government that they would both increase and extend their informal care provision.

According to the participants, the Governments' expectations regarding their caring role were primarily reflected in the way in which New Zealand has implemented deinstitutionalisation and community care. The participants noted the discrepancies between the statements made in New Zealand's policy documents and the lack of community based mental health services. Adding to the inadequacies in New Zealand's mental health services was the increase in the threshold for entry to these services. In effect, options for receiving care were disappearing. Community care had come to mean care by the community, community meaning the women. The women had soon become their family member's main source of care and support. The participants also spoke of how community care had been implemented within a wider context which emphasises reduced state expenditure and reduced state caring responsibilities. While the women were being expected to increase and extend their informal care provision, the women had access to fewer resources in an environment increasingly characterised by uncertainty and fragmentation.

Expecting women, such as those participating in this research, to increase and extend their care provision was challenged. First, the women were finding it increasingly difficult to meet the demands of their care-giving role as a consequence of the aging process. Second, the WIAG (Lefley, 1987) question suggests that identifying the women as their family member's primary care-giver is a short-term solution. In the not too distant future, the women, and the rest of their cohort, will be unable to meet their caring responsibilities as a consequence of their own deteriorating health or death. Individuals will be experiencing the complex, changeable and unpredictable symptoms of schizophrenia without assistance from both their current care-giver and formal mental health staff. Third, the women were not trained, nor were they prepared, to deal with the more psychotic symptoms of their family member's schizophrenia. The implications of this are potentially dangerous for the women, their family member, and the wider public. Fourth, demographic changes in New Zealand suggest that women in the near future may not be able or willing to respond to their family member's changing need for assistance. It appears that policy makers need to resolve conflicts arising from the Government's expectations about women and their care-giving role and the actual availability and willingness of women to provide care.

The concerns the participants had about their ability to meet increasing amounts of their family member's care needs, and the potentially dangerous consequences of their family member not receiving the assistance they need, led the participants to advocate changes to the current configuration of state, community and family care. Specifically, the participants called for a collaborative relationship between the state, the community and the family. The participants justified their call for a merger of these three caring agents in identifying the complex, unpredictable and wide ranging symptoms of the family members. Collaboration was needed in order to provide the range of community-based and institutionally-based mental health services required to respond to the family members' chronic and acute

episodes. Further, the participants noted that the symptoms of schizophrenia affected all areas of the family members' functioning. The participants were unable to provide an holistic approach to care their family member required. In other words, the participants call for a merger between the state, the community and the family reflected the participants' understanding that their family member required a continuum of care. This continuum of care included early intervention services and a range of institutionally-based and community-based mental health services.

While calling for a merger between the state, the community and the family in order to provide a continuum of care, the participants wondered about the futility of this action. The participants were certain that the New Zealand Government would be more interested in making financial savings instead of providing themselves or their family member with the assistance they required. However, in the light of this futility, the participants noted the importance of continuing to challenge, of making the link between the personal and the political.

### **Policy and Practice**

'The framework of informal care provided within a family to a member diagnosed with schizophrenia' indicates that New Zealand's policy statements and legislation, and the practices arising from these, influence the informal care provided within individual caring relationships. The participants consistently described how the informal care they provided to their family member was either supported or hindered by the context in which their caring relationship was situated. Discussion below suggests that the latter was usually the case.

Of primary concern to the participants was the higher threshold for entry to New Zealand's mental health services as a consequence of the definition of 'mentally disordered' contained within the Mental Health (Compulsory Assessment and Treatment) Act 1992. As already noted, the women were having to increase and

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extend their care provision in response to the difficulty their family member experienced in receiving assistance from New Zealand's paid mental health staff. As a consequence of the focus upon these individuals in crisis, the women were placed in the position where they were having to respond to their family member when they were in an acute episode of schizophrenia. The potential dangerousness of this situation for both the women and their family member was consistently identified by the participants. In the light of this, the participants noted how crucial it is for the definition of 'mentally disordered' to be redefined in such a way that the threshold for entry be lowered. The need for this redefinition is increasingly being recognised as events involving people exhibiting the positive symptoms of schizophrenia are reported in the media.

Lowering the threshold for entry to New Zealand's mental health services would also facilitate the development of services which can provide the prompt receipt of the diagnosis schizophrenia. The participants repeatedly emphasised the need for the prompt receipt of this diagnosis. Foremost was the access to New Zealand's formal and voluntary support services provided to the participants by this diagnosis. The diagnosis of schizophrenia also provided the women with the opportunity to 'name the moment', to begin to ascertain the implications of this diagnosis for their care provision.

The participants spoke of how the Mental Health Act 1992 supported the rights of patients to the detriment of their own rights as care-givers. For example, individuals exhibiting the symptoms of schizophrenia are being given the opportunity to have their care needs met in the community. Increasingly, these same individuals are not being provided with the resources or services they need to have their decisions adequately supported. Informal care-givers are having to respond to their family member's decisions until they are committed or are well enough to meet their own health and support needs.

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The Mental Health (Compulsory Assessment and Treatment) Act 1992 was not the only legislation which increased the difficulty the women experienced in their care-giver role. The Privacy Act 1993 is a case in point. The incorrect implementation of this legislation (Crowe, 1995; Schizophrenia Fellowship (NZ) Inc., 1995) meant that the women were typically refused receipt of information by mental health professionals about their family member's health status and treatment at the request of the family member. This refusal by mental health professionals was given despite the pressure placed upon the women to increase and extend their care provision. Again, the question is raised as to when the Government will take steps to rectify the conflict between their expectations of the women as primary informal care-givers and the lack of information these women receive about their family member's mental health and treatment.

The participants' stories clearly indicated that neither institutionalisation nor community care, as currently implemented, have adequately met the care and treatment needs of their family members nor supported themselves adequately enough in their care provision. The participants identified many discrepancies between the outcomes successive New Zealand Governments have been describing and the outcomes the participants themselves had been experiencing and witnessing. Prominent amongst these discrepancies was the lack of choice and freedom the women, and their family member, had experienced. The participants identified the uncertainty and fragmentation characterising the welfare arena resulting in part from the contracting process. The women were concluding that filling a care-giver role themselves increasingly was becoming the only means by which their family member would have their care needs met. The uncertainty, fragmentation and limited choice the participants and their family members were experiencing questioned whether business principles can and should be applied successfully to the mental health arena. This is particularly the case when considering the dominant discourses of schizophrenia. In the light of

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these discourses, potential providers of services will almost certainly see services areas, other than mental health, as more profitable and inviting.

The contracting process is resulting in the 'commodification of care' described by Ungerson (1995), this commodification of care, at present, is being managed around the country by the Home Support Management Services. Discussion of the participants' experiences suggested that payment systems need to be flexible in order to respond to the complex and unpredictable symptoms of schizophrenia. It was also argued that these symptoms of schizophrenia must be considered when decisions are being made about 'quasi-wages payments for care' or 'care-allowance payments for care' (Ungerson, 1995).

The action the state has taken to reduce both its expenditure on welfare services and its care provision meant that the participants could no longer assume the kind and level of services their family member would be eligible for and receive in the future. This realisation was particularly concerning to the participants when acknowledging the WIAG (Lefley, 1987) question. The participants could not rely upon the state to support their family member when they themselves could no longer do so as a consequence of old age or death. The participants proposed that the way policy makers were defining terms, such as 'adequate', 'comprehensive' and 'cost-effective', would mean that formal mental health services would not be available or able to meet their family member's future complex and changing needs. As already noted, the Government is soon going to have to respond to the dilemma arising from its reliance upon a group of elderly women providing care to a group of young adults with very complex and changing care needs. The importance of responding to this dilemma has already been raised by other researchers in New Zealand (Munford, 1988, 1994; Opie, 1991, 1992).

The participants indicated that they did not want to completely disengage from their care-giving. When discussing what they would need to support them in their

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care provision, the participants advocated for a continuum of care which includes early intervention services, and a range of community-based and institutionally-based mental health services. It can also be argued that this continuum would need to be consistent with a holistic approach to care (McGeorge & Fernando, 1993). A holistic approach to care would include the integration of New Zealand's support services including, for example, housing, employment and recreation. It was suggested that the provision of such a continuum of care would require a collaborative relationship between the state, the community and the family. This relationship could be developed in such a way that the over-representation of women in informal care-giver roles is challenged. However, while waiting for the informal caring responsibilities of women to be shared more equally between the state, the community and the family, and within the family itself, the importance of supporting women within their care-giver roles was emphasised. Particular emphasis was placed upon the women receiving respite and information related to their care-giver role and women being an active member of the mental health team. Further, it was noted that family members need access both to effective neuroleptic medications and to responsive mental health services.

In conclusion, informal care provided to a family member diagnosed with schizophrenia is complex, changeable and unpredictable. It is provided on a continual (flat-time) basis typically without access to respite. The provision of this informal care is undertaken with limited acknowledgment and reciprocity from the family member. The move from the ward to the home has meant increased restriction, difficulty and lack of choice for the women as their care provision has increasingly become the only means by which their family member's care needs could be met. Competing with this reality was the Government's propositions that increased flexibility and choice abound. The women were unanimous in their need to disengage from their care-giver role. The challenge for the Government is to respond to this request by providing the increased flexibility and choice it has promised. For as Jill explained:

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**Well the thing is of course, we'll always be here for him. But I would like to let go of that role a little bit. Because, I've done it for so long and, well, even I get tired. I can't have my own life completely ruled by the fact that I have a son who's got schizophrenia.**

## **Reflecting on the Research Process**

Now that 'the framework for analysis of informal care provided within a family to a member diagnosed with schizophrenia' has been considered, attention will turn to reflecting on the research process. As May (1993) suggested, the methodology utilised in this thesis impacted upon all aspects of the research from who participated to how information was collected. Positivist, interpretive and participatory research paradigms were combined with feminist principles. This strategy was taken in order to provide the participants with an opportunity first, to identify those issues they considered were important for examination, second, to articulate and analyse their own caring work and third, to provide the participants with the opportunity to instigate change in their own caring relationship and in the caring relationships of others. While the participants were provided with such opportunities, suggestions for strategies, which could both increase the participants' involvement in the research process and increase the understanding of the care provided to a family member diagnosed with schizophrenia, will be provided below.

First, the women were recruited by responding to a request for participants contained in the structured questionnaire. This initial contact with the participants did not provide an adequate indication of the nature of the research and the process which would be followed. More enthusiasm for participation may have been achieved if the initial contact with the women had emphasised the

importance placed upon elucidating the understandings, interpretations and meanings associated with providing care to a family member diagnosed with schizophrenia. Running workshops on schizophrenia and care-giving is one mechanism by which care-givers could be contacted and invited to participate in research. This forum would provide an opportunity to identify issues for study and suggest proposed methodologies.

Second, when recruiting participants, the researcher may need to actively encourage certain groups to participate if an understanding of their care provision is to be obtained. For example, the over-representation of women in a primary care-giver role may mean that a researcher would need to carefully consider when to invite men in primary care-giver roles to participate, and how these men could participate, in research. Similar consideration would need to be given, for example, to the participation of Maori and of individuals who have different kinship relationships with their family member.

Third, this research presented the experiences, feelings, thoughts and understandings of the care-givers providing care to a family member diagnosed with schizophrenia. New insights of this care provision could be gained by involving both care-givers and care-receivers in the research process. This is particularly the case when acknowledging how some of the symptoms of schizophrenia can alter an individual's perceptions and understandings of the events around them. Having access to both the perspectives of care-givers and care-recipients would undoubtedly further challenge current understandings about for example, the shifts in the autonomy and power between those who provide and receive care and the tensions between the rights of care-givers and care-recipients.

While considering these suggestions for the development of methodology, it will be important for the researcher also to take into consideration various factors.

These factors include: acknowledging the participants' time and resource constraints; acknowledging the stigma and discrimination surrounding schizophrenia and the implications of this for those individuals who openly participate in research and action which identifies them as a care-giver of a family member diagnosed with schizophrenia; and, being cognisant of the tensions and difficulties which surround the sharing of information between care-givers and care-receivers. Consideration of these factors will assist the researcher to have a positive and productive research experience.

### **Future Research**

Discussion in this thesis has reviewed what was previously known about the informal care provided to a family member diagnosed with schizophrenia. This knowledge was then extended by the findings of this research. It is the task of future research to build again upon these extensions. Specifically, discussion in this chapter has indicated that future research needs to focus upon those areas of study that will establish the availability and conditions under which individuals will and will not fill a care-giver role for a family member diagnosed with schizophrenia. The participants' stories suggested discrepancies between the Government's prescriptive and descriptive understanding about who provides care and why they provide it placed the women in compromising positions, these positions being detrimental to the women's psychological, emotional and physical health. Furthermore, the women's experiences indicated how irresponsible it was for the Government to implement deinstitutionalisation and community care, in adherence with the principles of market liberalism, without knowing who, why, and why not individuals decide to fill a care-giver role. The following discussion will identify potential issues which need to be closely examined.

It is important to acknowledge that the participants of this research were predominantly older mothers (and fathers) providing informal care to an adult child

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diagnosed with schizophrenia. The complementary caring relationship which existed between the women and their husbands was identified and described. While the women provided the main component of their family member's care, their husbands filled a secondary supporting role. According to the participants, this complementary caring relationship reduced the stress and strain the women experienced as a consequence of their care provision. Statistical data, however, suggests that this complementary relationship between the women and their husbands has been replaced by other configurations. First, the nuclear family is not the most common family form in New Zealand as a consequence of, for example, the rising rates of separation and divorce (NZDS, 1992). Previous discussion has proposed that the caring capacity of these different family forms, at different times of their development, needs to be examined (Munford, 1995). This examination will need to establish how care is distributed within these families and whether different family forms are better able to meet the complex and changing care needs of a family member diagnosed with schizophrenia. Research has already established that unpartnered women experience more stress and strain in their care-giver role (Carpentier et al, 1992) and therefore request more assistance.

Second, the clear division between the roles of women and their male partners are not necessarily as clearly defined as was the case with the participants. For example, Edgar and Glezer's (1992) research highlighted that the attitudes of women and men about their caring responsibilities are changing. Discussion in this thesis has, however, indicated that future research will need to establish the incentives required for encourage men to increase their involvement in the provision of care to a family member diagnosed with schizophrenia. Examination of the role of men in care-giver roles is important when considering the assertion made by Fisher (1994) that the distinction feminists have drawn between women's and men's care is not as clear and pronounced as feminists have suggested. Furthermore, future research will also need to examine the decision by women not

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to care. The acknowledgment and examination of this decision suggests that women are not predestined to provide the majority of their family member's informal care provision.

Third, while the participants were predominantly older mothers and fathers providing care to a family member diagnosed with schizophrenia, other kinship relationships were examined. This examination supported Finch's (1989) finding that informal care provision is influenced by the kin relationship between those who provide and receive care. The emphasis the participants placed upon their other children assuming responsibility for their family member's informal care provision, when the participants could no longer continue to do so themselves, suggests that future research needs to determine first, when siblings do and do not assume responsibility, and second, whether sibling care differs from the care provided by their parents.

The experiences, feelings, thoughts, and understandings articulated in this research were those of participants who identified as *tauiwi*, specifically European. Future research needs to confirm the extent to which the key findings of the present research reflect the experiences, feelings, thoughts, and understandings of people from varying cultures. The over-representation of Maori within New Zealand's formal mental health services (Ministry of Maori Development, 1993) suggests that future research needs specifically to examine the care-giving experiences of New Zealand Maori. As already argued, Maori will be particularly affected by the implementation of deinstitutionalisation and community care as a consequence of the time they traditionally have spent within New Zealand's institutionally-based mental health services. The Treaty of Waitangi also suggests that New Zealand's research needs to pay particular attention to the informal care provided by Maori to Maori diagnosed with schizophrenia. In previous discussion it was proposed that Maori may define and view schizophrenia differently from their *tauiwi* counterparts (Durie, 1994). It

cannot be assumed then that the understanding of care developed in this research is the same as for Maori. The Treaty of Waitangi directs that the different understandings of Maori and *tauiwi* about schizophrenia, and the implications of these understandings, for example about how informal care is viewed and distributed, need to be respected and resourced. Examination of the informal care Maori provide to Maori diagnosed with schizophrenia may not only extend the understandings developed in this thesis, but will undoubtedly have implications for New Zealand's mental health services as these understandings are translated into practice.

Finally, future research will need to continue to establish how successful the contracting process has been in terms of improving the number and quality of service providers in the mental health arena. It was argued that the stigma and discrimination associated with schizophrenia may result in providers being unwilling to compete for contracts for the provision of mental health services, continuing to leave care-givers of a family member diagnosed with schizophrenia without adequate assistance. Future research needs to examine whether care-recipients are receiving individually tailored packages of care characterised by increased flexibility and choice, these packages of care reportedly being a positive outcome of the contracting process.

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## APPENDICES

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### APPENDIX 1

#### INFORMATION SHEET

##### WHO IS DOING THE RESEARCH?

Leigh Richards-Ward is a Ph.D student in the Department of Social Policy and Social Work, at Massey University. Leigh's interest in this area stems from personal experience - a member of her family has been diagnosed with schizophrenia.

##### WHO IS SUPERVISING THE RESEARCH?

All research students have staff supervisors. These people help guide and support the students through their research. Leigh's supervisors are:

Dr Robyn Munford

Department of Social Policy and Social Work

Massey University

Dr Celia Briar

Department of Social Policy and Social Work

Massey University

##### WHAT ARE THE AIMS OF THE RESEARCH?

- \* To determine how care givers come to fill the role of care giver.
- \* To establish with care givers what caring for someone with schizophrenia involves.

- \* To establish the needs of care givers of people with schizophrenia, under current mental health policy.

### **WHAT IS INVOLVED IN THE RESEARCH?**

As a research participant you will be invited to:

- 1) Come together with other research participants as a group to discuss the research and issues related to the topic. This information will help form an interview guide.
- 2) Participate in a one-to-one interview with Leigh.
- 3) Come together with other research participants as a group, to hear the research results presented by Leigh and to provide feedback on the results.

Each of these stages will be taped to ensure that nothing is missed, misunderstood or changed.

### **DO I HAVE TO PARTICIPATE?**

Whether you participate is your choice. If you do decide to participate you can still withdraw from the research at any time. To withdraw, you let Leigh know either personally or by letter that you do not wish to participate. At any time during the research you have the right to ask Leigh any questions about the research, or refuse to answer any questions you are asked.

### **WHAT WILL HAPPEN TO THE INFORMATION I PROVIDE?**

Leigh will be using the research results for her Ph.D. thesis and possible future publications. Whenever the research results are presented, no information which could identify you will be reported. The only people who will see the information you provide in its original form will be Leigh and yourself.

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The tape of the one-to-one interview will be given to you after the information on it has been transcribed. This tape will then be your property.

A copy of the transcription of the one-to-one interview will be provided for you to read. At this time you will be invited to indicate what information you do not want used in Leigh's thesis or in future publications.

If any direct quotes from you are used in a chapter from Leigh's thesis, a copy of this chapter will be provided for you to read before final publication. At this time you will be able to re-check for any information that will identify you.

**WILL I BE REIMBURSED FOR ANY TRANSPORT COSTS INCURRED?**

For those of you who travel from.....you will receive a ..... dollar reimbursement.

For those of you who travel from.....you will receive a ..... dollar reimbursement.

Transport will be arranged for you if you are unable to get to the sessions yourself.

**WILL I BE INFORMED OF THE RESULTS?**

The results of the research will be presented by Leigh at the second group meeting you will be invited to attend. A copy of Leigh's Ph.D thesis will be made available for you to read through Schizophrenia Fellowship.

If you have any questions about the research, please contact any of the following people:

Leigh Richards-Ward

Department of Social Policy and Social Work  
Massey University  
Phone 356 9099 ext 7234

Dr Robyn Munford  
Department of Social Policy and Social Work  
Massey University  
Phone 356 9099 ext 5219

Dr Celia Briar  
Department of Social Policy and Social Work  
Massey University  
Phone 356 9099 ext 8463

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## APPENDIX 2

### AN EXAMINATION OF THE INFORMAL CARE PROVIDED TO PEOPLE DIAGNOSED WITH SCHIZOPHRENIA

#### CONSENT FORM

I agree to attend two group meetings of research participants. One of these meetings being before a personal interview with Leigh Richards-Ward, the second meeting being after this interview.

I agree to be interviewed on a one-to-one basis with Leigh Richards-Ward on the above topic. I understand that this interview will be taped to ensure that nothing is missed, misunderstood or changed.

I will participate in the research under the following conditions:

- \* I have the right to ask any questions about the research and/or refuse to answer any questions, at any time during the research.
- \* I have the right to withdraw completely from the research at any time.
- \* I will not be personally be identified as a participant in the research results - any information I disclose will be only seen by Leigh - the information being secured when not being worked on by Leigh.

I agree to allow Leigh Richards-Ward to use the results of the research in her Ph.D. thesis, and any future publications as long as my privacy and confidentiality is ensured.

Signature of Participant.....

Date.....

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## **APPENDIX 3**

### **INTERVIEW GUIDE (WOMEN)**

**Please start by telling me about yourself.**

**Please tell me the story behind (the family member) being diagnosed with schizophrenia.**

- \* How long between you recognising that 'something was wrong' and the diagnosis of schizophrenia?
- \* What did you know about schizophrenia before (the family member) was diagnosed with this illness?
- \* How would you define schizophrenia now?
- \* What do you think having schizophrenia means to (the family member)?
- \* What does (the family member) having schizophrenia mean to you?

**Please describe for me your present role in relation to (the family member).**

- \* What does providing care to (the family member) mean for you?
- \* Do you think men provide care in the same way as women?
- \* Did you ever expect to find yourself providing care to (the family member)?
- \* How long have you been providing care to (the family member)?
- \* Why are you providing care to (the family member)?
- \* Do you have any aims or goals you are trying to achieve in providing care to (the family member)?
- \* Did you feel pressured to provide care to (the family member)? From where/whom?
- \* Who else could have provided care to (the family member)? Why didn't they do so?
- \* Does anyone help you in providing care to (the family member)? Who? How? How often?

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- \* Do you think you could stop providing care to (the family member)?
  - \* Do you feel pressured to provide care to (the family member) now?
  - \* Are there any benefits or positives which you receive in providing care to (the family member)?
  - \* What are the 'not so good' things about providing care to (the family member)?
  - \* Is providing care to (the family member) then a more positive or negative experience?
  - \* Is there anything that would help make providing care to (the family member) more positive?
  - \* Can you think of any symptoms of schizophrenia which impact upon you providing care to (the family member)?
  - \* Do you have any worries or concerns in relation to providing care to (the family member)?
  - \* Does (the family member) ever get the better of you? How?
  - \* Do you think (the family member) gets things the way they want more than you do?
  - \* Are there any feelings which you associate with providing care to (the family member)?
  - \* Do you think providing care to (the family member) requires certain knowledge and skills?
  - \* Are these skills and knowledge recognised by others?
  - \* How did you learn about schizophrenia? Care-giving?
  - \* What qualities do you think someone needs to provide care to someone diagnosed with schizophrenia?
  - \* Do you have any advice for someone who is thinking of providing care to a relative diagnosed with schizophrenia?
  - \* Do you think providing care to someone diagnosed with schizophrenia is different from providing care to someone with a physical and/or intellectual disability?

**Please tell me about your role as care-giver for (the family member) in the future?**

- \* Who will provide care to (the family member) in the future? Why?
- \* Do you think providing care to (the family member) will be different in the future? How?

**Please tell me how New Zealand's various social and economic policies have influenced your provision of care for (the family member).**

- \* Have you heard of institutionalisation? How would you describe this policy?
- \* What does providing care to (the family member) mean under institutionalisation policy?
- \* Have you heard of community care policy? How would you describe this policy?
- \* What does providing care to (the family member) mean under community care policy?
- \* Do you think one of these policies - institutionalisation or community care - is better for yourself in providing care to (the family member)? For (the family member)?
- \* Can you identify any changes in providing care to (the family member) with the move from institutionalisation to community care?
- \* What are the benefits of providing care under community care policy?
- \* What are the not so good things of providing care under community care policy?
- \* If you had a choice, describe how you think (the family member's) needs would be best met.
- \* Have you tried to bring about change to improve your role? What have you done?
- \* How would you try to bring about change in the future?

**Please tell me what you will need if you continue to provide care to (the family member) in the future?**

- \* What sorts of specific services/support do you need to provide care to (the family member) under community care policy?
- \* Can you think of any services/support that would help (the family member) that would also help you?
- \* Which of these services/support are most important?
- \* Are you receiving any services/support at the moment?

**Is there anything else you would like to say or comment on?**

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## **APPENDIX 4**

### **INTERVIEW GUIDE (MEN)**

**Please start by telling me about yourself?**

**Please tell me the story behind (the family member) being diagnosed with schizophrenia?**

- \* How long between you recognising that 'something was wrong' and the diagnosis of schizophrenia?
- \* What did you know about schizophrenia before (the family member) was diagnosed with this illness?
- \* How would you define schizophrenia now?
- \* What do you think having schizophrenia means to (the family member)?
- \* What does (the family member) having schizophrenia means to (the care provider)?
- \* What does (the family member) having schizophrenia mean to you?

**Please describe your present role in relation to (the family member).**

- \* Did you ever expect to find yourself providing care to (the family member)?
- \* Why are you providing care to (the family member)?
- \* Do you have any aims or goal you are trying to achieve in providing care to (family member)?
- \* Are there **any** benefits of positives you receive in providing care to (family member)?
- \* What are the not so good things about providing care to (family member)?
- \* Is there anything that would help make your care provision more positive?
- \* Does (the family member) ever get the better of you?
- \* Do you think (the family member) gets things they way they want more than you do?

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- \* Are there any feelings which you associate with providing care to (the family member)?
  - \* Do you think providing care to (the family member) requires certain knowledge and skills?
  - \* Are these skills and knowledge recognised by others?
  - \* How did you learn about schizophrenia? Care-giving?
  - \* What qualities do you think someone needs to provide care to someone diagnosed with schizophrenia?
  - \* Do you have any advice for someone who is thinking of providing care to a relative diagnosed with schizophrenia?
  - \* Do you think providing care to someone diagnosed with schizophrenia is different from providing care to someone with a physical and/or intellectual disability?
  - \* Do you have any worries or concerns in relation to filling a supporter role?

**Please describe for me (the care-giver's) present role in relation to (the family member).**

- \* What does providing care to (the family member) mean for (the care-giver)?
- \* Do you think men provide care in the same way as women?
- \* Do you think (the care-giver) expected to be providing care to (the family member)?
- \* How long has (the care-giver) been providing care to (the family member)?
- \* Why is (the care-giver) providing care for (the family member)?
- \* Do you think (the care-giver) has any aims or goals they are trying to achieve in providing care for (the family member)?
- \* Who else could have provided care to (the family member)? Why didn't they do so?
- \* Does anyone help (care-giver) in providing care to (the family member)? Who? How? How often?

- 
- \* Do you think (the care-giver) could stop providing care to (the family member)?
  - \* Do you think (the care-giver) felt pressured into provide care to (the family member)
  - \* Do you think there any benefits or positives (the care-giver) receives in providing care to (the family member)?
  - \* What are the 'not so good' things about providing care to (the family member)?
  - \* Is providing care to (the family member) then a more positive or negative experience?
  - \* Is there anything that would help make proving care to (the family member) more positive?
  - \* Can you think of any symptoms of schizophrenia which impact upon (the care-giver) in providing care to (the family member)?
  - \* Does (the family member) ever get the better of (the care-giver)? How?
  - \* Do you think (the family member) gets things the way they want more than (the care-giver) does?

**Please tell me about your provision of care in the future.**

- \* Who will provide care to (the family member) in the future? Why?
- \* Do you think providing care to (the family member) will be different in the future? How?

**Please tell me how New Zealand's various social and economic policies have influenced your provision of are for (the family member).**

- \* Have you heard of institutionalisation? How would you describe this policy?
- \* What does providing care to (the family member) mean under institutionalisation policy?
- \* Have you heard of community care policy? How would you describe this policy?

- 
- \* What does providing care to (the family member) mean under community care policy?
  - \* Do you think one of these policies - institutionalisation or community care - is better for yourself in providing care to (the family member)? For (the family member)?
  - \* Can you identify any changes in providing care to (the family member) with the move from institutionalisation to community care?
  - \* What are the benefits of providing care under community care policy?
  - \* What are the not so good things of providing care under community care policy?
  - \* If you had a choice, describe how you think (the family member's) needs would be best met.
  - \* Have you tried to bring about change to improve your role? What have you done?
  - \* How would you try to bring about change in the future?

**Please tell me what you will need if you continue to provide care to (the family member) in the future.**

- \* What sorts of specific services/support does (the care-giver) need to provide care to (the family member) under community care policy?
- \* Can you think of any services/support that would help (the family member) that would also help you?
- \* Which of these services/support are most important?
- \* Are you receiving any services/support at the moment?

**Is there anything else you would like to say or comment on?**