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THE HIDDEN COSTS OF CARING:
WOMEN WHO CARE FOR PEOPLE WITH
INTELLECTUAL DISABILITIES

A thesis presented in partial fulfilment
of the requirements for the degree
of Doctor of Philosophy at
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...the mother is really the one that looks after the handicapped children because the husband has to work. And then when he comes home tired from work he doesn't want to know how many times that day _____ wet on the floor or was sick or she had a row with the neighbour because of the kid or something else...

(Quote from a mother)

They're always in the caregiving roles. Direct hands on caregiving roles....I think it goes back to the traditional myth of women as being primary caregivers. The men in positions of power.

...I think mainly the men I've come into contact with within the IHC have been administrators or managers or executive staff, something like that, and it's the women who do all the hands on, all the middle management - not usually top management...

(Quote from a mother)

ABSTRACT

This dissertation examines the ways in which patriarchal systems structure and control the lives of women who care for people with intellectual disabilities. It is argued that the power relations which derive from these systems have remained hidden and that the richness and diversity of the experiences of these women have not been adequately portrayed.

In an attempt to authentically capture the lived experiences of women who cared for people with intellectual disabilities this dissertation provides an account of the perceptions of thirty women. These women were mothers of people with intellectual disabilities and/or paid workers employed by the New Zealand Society for the Intellectually Handicapped, a large voluntary Organisation providing services for people with intellectual disabilities in New Zealand, hereafter designated the Organisation.

Certain key principles of feminist theory and research are used to develop an analysis which seeks to not only reveal pertinent relations of power, but to examine and critique them. This process contributed to the development of a means for transforming both the practices that control the women's lived experiences and the meanings used to interpret these experiences.

The analysis of the relations of power that controlled women who care for people with intellectual disabilities was advanced in relation to two key sites: the household and the Organisation. The explanatory framework developed to explore the lived experiences of the women was derived from certain intellectual strands in the French tradition. Irigaray's writings were used to elucidate the ways in which patriarchal systems operate to control the women's lives. Foucault's theoretical concepts contributed to the development of certain technologies of power that operated in the household and the Organisation. These technologies of power which pervaded the daily

lives of women relate to both the material conditions of their existence and to the social meanings used to define their lives.

Several significant themes emerged from the analysis of the women's experiences. One of the most important of these related to the women's views on the policies of community care. In examining these the women's ambivalent feelings about the implications of these changes are articulated.

Associated with this finding the themes also clearly supported the view that new ways of explaining women's lived experience must be developed. A definitive example of this was the way in which feminist theory must continue to re-examine the explanatory usefulness of the now familiar private and public dichotomy as a concept for describing women's experiences. The present research identifies some alternatives for explaining and understanding women's experiences in the private and public realm. Some possibilities for extending this process further are also addressed.

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PART ONE

CHAPTER ONE: INTRODUCTION

This thesis describes and analyses the ways in which power operates to control the lives of women who care for people with intellectual disabilities.¹ It aims to give an authentic account of the experiences of these women. In order to reveal the power relations and the women's perceptions of these an examination of the daily lived experiences of women is offered.

The stories² of thirty women who care for people with intellectual disabilities are told. These women are all part of the New Zealand Society for the Intellectually Handicapped (IHC). Their experiences are described and analysed using a framework that seeks to provide an explanation for how gender relations operate to structure women's lives.

Feminist theory informs the way this research has been carried out. The very essence of feminist theory embodies a process that demands that not only existing theoretical perspectives and methods for carrying out research are critiqued but that alternative ways for understanding the world are also developed. In so doing women can develop strategies for bringing about change both in their lived experiences and in the ways in which these are interpreted (Gross, 1986).

Feminist theory and research are based on a politics that is:

¹ In this thesis I use the definition of intellectual disability that is adopted by the IHC (1986). The term refers to those individuals whose intellectual functions are significantly below average. This state has been present from an early age and they have marked impairment in their ability to adapt to the daily demands of society.

² Throughout this thesis I use the word 'story/stories' because it captures the way in which women talk about their lived experiences. The telling of stories is often the first opportunity for women to talk at length about their perceptions of the reality of their lives.

directed at changing existing relations between women and men in society. These power relations structure all areas of life, the family, education and welfare, the worlds of work and politics, culture and leisure. They determine who does what and for whom, what we are and what we might become (Weedon, 1987: 1).

Contemporary feminism has its roots in a women's movement that has many strands. Feminist theory is not unitary because it is derived from a range of concepts and views about the world. While feminists may agree that one of the primary issues is concerned with exploring and understanding power relations, feminists have over time developed a variety of ways of determining how this power is structured and from where it is derived.

Although as Weedon (1987: 2) points out feminists may take as their starting point gender and "the patriarchal structure of society" they will have "different ways of understanding the meanings and implications of patriarchy from within feminism" (Weedon, 1987: 4). In this thesis I will briefly describe three major strands of feminist thought: liberal feminism, socialist feminism and radical feminism.

Liberal feminists believe that women are oppressed because of their lack of equal rights and educational opportunities. They attempt to achieve full equality for women in all spheres of life but do not focus on radically transforming political and economic systems.

In her publication A Vindication of the Rights of Women (1792), Mary Wollstonecraft² takes the prevailing egalitarian principles and dares to apply them to women, arguing that women have the same capacity to reason as men do. For Wollstonecraft the key to women's emancipation

1 The term patriarchy refers to power relations wherein women's interests are subordinated to those of men. These power relations take many forms "from the sexual division of labour and the social organisation of procreation to the internalized norms of femininity by which we live" (Weedon, 1987: 2).

2 I have been selective in referring to only certain writers in order to provide examples of the three strands of feminism I discuss. I have attempted to cite those writers who provide a comprehensive overview of the feminist thinking they adopt, represent, or critique.

is education. Nearly two centuries later this belief persists. Betty Friedan, for example, in The Feminine Mystique (1963) attacks sexist discrimination and invites women to develop to their full potential through education and employment.

Eisenstein's work The Radical Future of Liberal Feminism (1980) provides an excellent review of the strengths and weaknesses of modern liberal feminism. According to Eisenstein, liberal feminism needs to be radicalised and its strategies extended to include an analysis of the ways in which the State can be challenged.

Socialist feminists believe that there is not a natural femaleness but that gender is "socially produced and historically changing" (Weedon, 1987: 4). These feminists link patriarchy to class and any change for women must of necessity embody a total transformation of current economic and social systems.

Although socialist feminists basically accept the historical materialism of Marx and Engels most are critical of their analysis of women. Juliet Mitchell in her work Women's Estate (1971) uses Marxist theory to try to understand the reasons behind women's oppression. Mitchell attempts to explain women's exploitation in the workplace and she links this to women's role in the family. Michelle Barrett's text Women's Oppression Today (1980) illustrates and provides an extensive analysis of some of the objectives of socialist feminism and outlines the current debates associated with this strand of feminism.

Radical feminism "envisages a new social order in which women will not be subordinated to men and feminity and femaleness will not be debased and devalued" (Weedon, 1987: 4). Radical feminism attempts to separate women from the patriarchal structures in order to allow women to recover and assert their true nature.

Key proponents of radical feminism are Simone de Beauvoir, Shulamith Firestone and Mary Daly. Luce Irigaray, whose ideas I utilise in this thesis, would also be located within this category. de Beauvoir's classical text The Second Sex (1972) examines the constraints on women, argues that "women are made, not born" and advances the notion of women as the Other.

Firestone's definitive work The Dialectic of Sex (1972) argues that the basic class division and opposition in society is the sexual-reproductive organisation - the family, and she argues that all other oppressions, such as economic and radical oppression derive from the sexual division between men and women. In Gyn/Ecology (1978) Daly also attempts to articulate the nature of women's oppression and to emphasise this she creates a language of her own. Daly encourages women to withdraw from men and develop a separate women's culture. Some theorists would categorise her as a cultural feminist.

While I acknowledge the important contributions of all of these strands of feminism, I do not wish to critique these further as this is beyond the scope of the present project. Rather, I use these as a point of departure for articulating the commitment of feminism to make sense of current conflicts in the daily lived experiences of women. This is, I argue, the first stage in the process of change and it must be accompanied by a process that begins to develop alternative ways of viewing the world from a woman's perspective. This leads to the transformation of both the material conditions and also the way knowledge is used to interpret the lived experiences of women. In order to do this, I believe one must begin from a detailed understanding of women's daily lives. However, as Weedon (1987) suggests, to make sense of this one must have a "theory" about "the relationship between experience, social power and resistance..." (Weedon, 1987: 8). Weedon (1987) argues that any theory:

must be able to address women's experience by showing where it comes from and how it relates to material social practices and the power relations which structure them....This involves understanding how particular social structures and processes create the conditions of existence which are at one and the same time both material and discursive (Weedon, 1987: 8).

This "theory" must also show how resistances develop and how "new modes of subjectivity" emerge to open up the "possibility of political change" (p.9).

While recognising that such theories must recognise the importance of the structures of class and the ways in which patriarchy operates within the systems of capitalist relations, this thesis adopts a different aspect of feminist analysis. Much of the feminist literature used by New Zealand feminist theorists is derived from those writers who have examined the ways in which the capitalist system operates to control women. This work generally originates from Europe and the USA.

It is not my aim to provide a definitive and extensive critique of the debate about the relationship of patriarchy to capitalism as this is already clearly articulated in the literature. In this research my interest is in understanding one particular aspect of women's existence and the ways in which men have controlled the lives of women. The perceptions of women who care for people with intellectual disabilities and their interpretations of the social and cultural processes are explored and analysed. If this perspective is to be categorised one would likely place it within the framework of radical feminism. However, my concern is not to show how women have a different essence from men but to show, by examining women's perception of their daily lived experiences, how these experiences are socially constructed and given meaning.

This view is derived both from my readings of feminist theory and from my experiences in working alongside women who care for people with intellectual disabilities (Munford, 1983, 1986, 1987). My experience has shown that although women have contributed substantially to the development of services for people with intellectual disabilities in New Zealand the work they have done has been hidden and men continue to control the ways in which the daily lives of women are constructed.

My research is based on material derived from the French tradition. One of the primary concerns of the French feminists is to disrupt and

then reconstruct the symbolic discourses which manifest themselves through language (Barrie, 1987). For writers such as Irigaray an essential project for women is to develop a language which correctly portrays the way in which women view themselves and the world they are part of. Women begin this project by reflecting on their current reality and their daily lived experiences. In so doing they reveal the ways in which phallogocentric discourses represent the male as "normal" and women as the "other" (Irigaray, 1985).

I use the writings of Irigaray and in particular her approach to the analysis of the place of women in the social order as a basis for developing a framework that explains how power relations operate in the daily lives of women who care for people with intellectual disabilities. I am concerned with discovering what happens to these women on a daily level and how structural systems support the power relations. My interest is in the unpaid and underpaid work carried out by women who care for people with intellectual disabilities at two key sites - the household and the Organisation. Women's unpaid work generally takes place in the household and in a private realm. This work is intricately linked to women's relations with the Organisation.

The relationships between the private and public sphere and the way women's work in the household is viewed as marginal in an economic system, that determines what is and what is not valuable, must be addressed. Women's work in the household and in the organisations they are part of may be categorised by men in ways that their labour will be useful but at the same time devalued (Barrett, 1981).

Barrett and MacIntosh (1982) also point out that the dichotomy between the public and private realm can lead us to make incorrect assumptions about the influence each sphere has on one another. They argue that the interplay between the two spheres must be more clearly articulated. Women have in fact had some influence in the public realm but their contributions may have either been devalued or ignored. The public realm also has an impact on what happens in the

private realm. The household cannot be viewed as a haven for women as this is where the power relations can have the most intensity and impact on women's lives.

It is my understanding that feminist theory should, in the process of telling women's stories, provide new ways of understanding the meaning and perceptions of women's lives. I adopt Irigaray's (1985) view that not only the social practices but the theory used to describe these practices must be challenged. It is not enough that women are added on to the existing social scientific categories and methods of investigation. New categories for describing and understanding the reality of women may have to be created. If not, suggests Irigaray (1985), the order of power is not challenged but merely reversed.

In this thesis, Irigaray (1985) and Foucault (1977, 1978, 1980) are used as a basis for developing a theoretical framework for exploring and analysing the relations of power experienced by women who care for people with an intellectual disability. I am concerned with discovering women's perceptions about these power relations by exploring the meanings they give to their daily lived experiences.

Power relations will have different meanings for women depending on the roles they are carrying out. To understand the specific effects of power the techniques that are used to control women who care for people with intellectual disabilities are described. I present a detailed description of the women's daily lives. Irigaray (1985) argues that an understanding of the intricacies of how power operates at this level will provide a clearer image of the global effects of power.

Foucault's writing (1977, 1978, 1980) identifies some techniques for exploring the technologies of power. As Weedon (1987) points out Foucault's categories are useful in that they help one understand the precise effects of power and they also allow for the articulation of women's perception of power relations. I show how certain

technologies of power operate within the household and the Organisation in order to maintain the current positions of women who care for people with intellectual disabilities.

Women who care for people with intellectual disabilities may have similar concerns to those of other women but they will also have some unique experiences. These are directly related to the daily activities they carry out in the process of caring for and working alongside people with intellectual disabilities.

The Context: The New Zealand Society for the Intellectually Handicapped (IHC)

The women¹ I interviewed are part of the IHC (The New Zealand Society for People with Intellectual Handicaps). The IHC is one of the major service providers for people with intellectual disabilities in New Zealand. The State through the Department of Health funds large institutions and these are administered by Hospital and Area Health Boards. The majority of the community services are run by the IHC (Singh and Wilton, 1985). The State funds the IHC to carry out its responsibilities. The level of funding has to be re-negotiated each financial year.

The IHC was set up in 1949 because it was perceived that the State was not providing for the needs of people with intellectual disabilities and their families. Parents were concerned that they could not gain access to appropriate community services, for example, educational resources and relief services. They wanted to have specialised services set up for their children (Botting, 1972) in the community so they could keep their children at home. This meant that adequate education and relief services was a first priority. Up until this time they had been forced to send their children away to institutions or to keep them at home with no support to do this.

1 Although one of the women in my study was Maori I did not examine the implications that ethnicity has for the lives of these women. I acknowledge the importance of ethnicity but it requires extensive examination which is beyond the boundaries of this research.

The parents who began the IHC sought government funding to help them set up services. There was over the years a constant battle for funding (Riseborough, 1983). In 1973 the government took a more active financial role when Hospital Boards were given funding to build group homes and vocational centres and the IHC was given the task of administering these. The IHC also continued to build its own facilities.

In 1988 the IHC employed approximately 3000 staff in over 41 branches spread throughout New Zealand. The Organisation is managed by an elected committee made up of parents and any member of the public interested in developing policy for the implementation of services for people with intellectual disabilities. The voluntary sector of the Organisation employs staff to implement its policy. It is estimated that seventy percent of all staff are women but that of the total staff only twenty percent of women are in senior management positions.¹

The primary aim of the Society is "to promote the physical, educational, economic and social welfare of the intellectually handicapped" (The New Zealand Society for the Intellectually Handicapped (IHC) 'Constitution and Rules', 1984, p.1). The organisation employs a National Director and a number of Regional Directors. These people are supported by regional service personnel and Regional Accountants. Branches are administered by the elected committee and a Branch Manager. Services and caregiving staff are employed to provide and coordinate services; to provide direct care in preschool, residential and vocational facilities; to provide social work, support services and community outreach programmes, and to provide staff training (Annual Report, 1987).

¹ It is predicted that this figure is also representative of the composition of women involved in the committees that control the decisions made by the IHC (1987).

Parents and other volunteers had until the 1960s the major responsibility for developing policy for the Organisation. In 1968 the IHC employed a National Services Adviser (Riseborough, 1983). From this point on an increasing number of the major decisions were initiated by paid employees. Parents can still have a voice through the committee structures but it is the paid staff and other professional groups who have a major influence upon the direction the Organisation takes (Riseborough, 1983).

The near monopoly that the IHC has on the provision of services for people with intellectual disabilities can restrict the choices families have. If families are not satisfied with the services of the IHC the alternative option is to send the child to a large institution. This institution will generally be geographically isolated and families will have to travel long distances to visit their child.

In 1975 the Disabled Persons Community Welfare Act was passed. One of the Act's sections allowed for the provision of paid relief services to families who had members with a disability. The State passed the role of providing relief services in the community over to voluntary agencies. However, there has not been a comprehensive State policy for people with intellectual disabilities (Annual Report of IHC, 1985).

The Ministerial Task Force on Social Welfare Services (1987) has recommended that changes be made to the provision of services for people with disabilities. The Task Force proposed that an Office of Disability be established to ensure that there is equity for people with disabilities. The Task Force was concerned that people with disabilities are often subject "to negative stereotyping which contributes to their low political status and the neglect of their needs" (p.63). The Office would operate to coordinate the services of community groups providing services. It would have to develop a comprehensive policy that could ensure that there is adequate provision for people with intellectual disabilities and their families.

The lack of a comprehensive policy for people with intellectual disabilities was a major criticism presented in some of the submissions received by the Royal Commission on Social Policy (1987/1988). The Commission received a large number of submissions detailing the ways in which services for people with disabilities and their families should be extended. These pointed out the need for a review of how community services are provided (Preliminary Report of Royal Commission on Social Policy, 1987/1988).

The Commission received submissions which highlighted how the burden of care is usually the responsibility of women. These submissions outlined the dilemmas facing women who often have to choose between meeting their own needs or those of their children. The two are sometimes in conflict.

The submissions and subsequent reports of the Royal Commission on Social Policy have been some of the first official documents to accentuate the difficulties women have. Bright and Wright (1986) who have analysed policies of community care in Australia make the point that there is absence of critical studies on the role women have in caring for people with disabilities. There is an expectation that women will care and if they do not it may be viewed as an individual failing. The links with policy and possible policy failures and misconceptions may not be revealed.

Women Who Care

Although in New Zealand there have been a number of studies carried out about women who care for people with intellectual disabilities, these generally provide only a description of their experiences. There are very few that provide an adequate analysis of women's experiences.

Botting (1972) has been one of the only writers in New Zealand to mention the unique role women have had in the development of IHC's services. Botting (1972) in his oral history of IHC suggests that women have had to carry out the wishes of those who make the decisions. These women may have no input into these decisions. He states that although the:

mothers of the intellectually handicapped were not actual leaders, they were certainly the great 'powers behind the throne' which produced the leaders to do the ground work that led eventually to providing the present day services of the intellectually handicapped... (Botting, 1972: 1).

However, Botting (1972) only mentions the role of women. No formal analysis of this role was carried out. Chetwynd, Calvert and Boss (1985) carried out a New Zealand study on the impact of an intellectually handicapped child on family life. They make some interesting comments about the isolation women feel and their difficulty in accessing appropriate services for their daughters/sons. This created stress for these women and often had a negative impact on other family members.

Although this study was useful in revealing women's experiences it did not use this information to show how gender relations influence these experiences. Neither did it analyse women's involvement with the voluntary agency and the State and the relationships between these spheres. One must use overseas studies to provide some guidelines for how New Zealand studies may proceed. Finch and Groves (1983) in their book A Labour of Love include several articles by authors who outline the experiences associated with caregiving.

Graham (1983), for example, in her chapter 'Caring: A Labour of Love' examines the concept of care and what it really means for women. She examines how different branches of social science such as psychology may have been useful in examining the roles of women and the demands the caregiving role places on women. However, she also

points out the inadequacies of many of these frameworks in that they do not link individual experiences to global policies. She suggests that a framework that also encompasses activities on the level of policy is necessary.

Ungersen (1983) in her chapter 'Why Do Women Care?', states that "women rather than men predominate amongst informal carers because there are powerful material and ideological forces that determine that they will do so" (p.49). She suggests that the State uses social policies to reinforce ideas about sex roles. The State's perceptions may be incongruent with the actual experiences of women.

In their chapter on 'Employment, Women and Their Disabled Children', Baldwin and Glendinning (1983) describe the daily care tasks women carry out. They show how these tasks can restrict a woman's choices. For example, they can prevent women from taking on paid employment. Baldwin and Glendinning argue for a re-evaluation of the roles of men and women with respect to the domestic sphere and a move towards better relief services. Chetwynd, Calvert and Boss (1985) in their New Zealand study also point out the inadequacy of relief services both in the quantity and quality of these. Additional services such as adequate equipment, travel arrangements and management programmes for the child are required.

Lesley Rimmer (1983) in her chapter 'The Economics of Work and Caring' illustrates how there is a misconception that community care alternatives cost less than other alternatives such as state-run facilities. She comments that it appears that community care costs are lower because funding criteria only account for public expenditure costs. The costs that women experience are generally not calculated. ~~Costs~~ such as the psychological costs of coping with a child who will always require care are not included in official statistics. These are the hidden costs of care. Rimmer (1983) suggests that the State will continue to pass on the burden of care to voluntary groups. The costs voluntary agencies incur may then be passed on to women. As Rimmer (1983) comments, the roles of women

and men must be re-negotiated so that caring for dependents becomes a valued task.

Ayer and Alaszewski (1984) in their extensive study of mothers of children with intellectual disabilities also point out the need for a re-examination of roles. They suggest that feminist theory can help reveal how patriarchy has functioned to control decisions and resource allocation. They also comment that women carry the burden of care and many do not make their own needs known.

All of the English studies cited have a common element in that each recommends the need for a planned approach to care. This would begin with a re-evaluation of the role of men and women and the ways in which the State and community organisations view the place of caregiving in our society. The problem of who will care for those people who are non-productive and require extensive support will not vanish. It requires more than an ad hoc approach to planning and both the material and ideological forces that impact on the caregiving role must be examined.

Bright and Wright (1986) make some interesting comments about services in Australia. They discuss the ways in which "the move to community-based services has a 'hidden agenda' for keeping women out of the labour market and in their homes to provide unpaid welfare services for their families" (Bright and Wright, 1986: 225). They suggest that there is an assumption that women will choose to stay at home and that in the planning for services there is no mention about why it is not men who will choose this. There is a belief that women are the "natural caregivers". Bright and Wright (1986) are concerned that women who care for people with disabilities provide a low-cost form of residential care which extends far beyond that of other mothers. People with intellectual disabilities may require lifelong care.

They state that government policies:

do not encompass a holistic perspective of the family in an economic and cultural context, the demand for their development, is increasingly heeded. Much of the present development calls for needs to be met at a local level by the participation of community groups and agencies, as well as by families. That is to say, the current ideology supports the shift of responsibility away from the control of centralized governments (Bright and Wright, 1986: 226).

Voluntary agencies such as the IHC accept this responsibility which may then be passed on to the women who care. There is an inherent conflict as Bright and Wright (1986) point out between the needs of people with intellectual disabilities and those of their families. This also happens in New Zealand. For example, the National Conference of the IHC in 1986 discussed the ways in which people with intellectual disabilities could be encouraged to use a large range of community services. This required more support from their families and the people who are currently working alongside them. Policies of normalisation and integration which exist alongside policies of community care to ensure that people with intellectual disabilities have the same choices as their non-disabled peers, may have the unintended outcome of putting more pressure on families. The person with an intellectual disability may be only able to 'reach their potential' if their family has the economic means to allow them to do so. Bright and Wright (1986) suggest that the policies of government must be matched with the needs of local communities and of individuals. The implications of State policies must be examined at all levels.

My research examines the experiences of women at two key sites - the household and the Organisation - in order to describe and analyse their experiences in detail. The sacrifices women have made have not been critically examined with respect to the context of the IHC as a major service provider. The issues revealed in the studies cited are useful in guiding the setting up of this research. It is essential to not only describe the context of care but to also examine why

women remain in these roles. The research is also based upon my findings in previous studies and work in this area, both in New Zealand and in Canada (Munford, 1983, 1986, 1987).

Thirty women were interviewed. Fifteen of these women were mothers and fifteen were paid workers. All of the mothers had adult children over twenty years old. The paid workers had all been employed by the IHC for more than five years. This enabled me to capture the women's perceptions of their lived experiences over a substantial period of time.

The many years of involvement of these women with the IHC and in caring for people with intellectual disabilities enabled me to gain an understanding of their experiences over a long period. Appendix One describes the characteristics of these women. I was able to describe and explore the impact on women's lives of changes in the policy of the Organisation and of the State. Some of the mothers had been involved in the establishment of the IHC. The everyday experiences of these women will be examined in detail and their experiences in their households and with the Organisation will be described and analysed. The concept of gender enables me to show some common experiences between the lives of the mothers and of the paid workers. By describing the experiences of both groups on a daily level it will be shown how the practices of the Organisation functioned in ways that assumed certain roles for women.

The Form of the Thesis

Chapter Two discusses the theoretical framework I used to explore and analyse the experiences of women who care for people with intellectual disabilities. This includes a discussion of the nature of power and the levels wherein it operates. It begins with a discussion of the way power operates to control women in the household and then considers how power relations operate in the Organisation. It examines the ways in which certain technologies of

power uphold the relations of power. This chapter also includes a discussion of the ways in which women may develop resistances to power relations.

Chapter Three examines the research process - the methodological framework that orders the way I carried out my research. It describes how I chose my research topic and the women interviewed and explains the way the investigation was carried out. The way the information was analysed is also outlined. Feminist principles of research are articulated in this chapter.

Chapter Four and Chapter Five describe and analyse in detail the experiences of the women in the household. A number of themes that emerged from the women's stories of their lived experiences will be discussed. The theoretical framework outlined in Chapter Two is used to interpret the stories the women have shared with me.

Chapter Six and Chapter Seven describe and analyse the women's stories about the Organisation. As with the analysis of women's experiences in the household, the theoretical framework outlined in Chapter Two is used to interpret the stories the women have shared with me about the Organisation. Chapter Eight analyses the responses women have made to the relations of power present in the household and in the Organisation.

The final chapter summarises the major findings and makes some predictions about the ways in which the lived experiences of women who care for people with intellectual disabilities can be further explored and analysed. It discusses the dominant themes that emerged from the women's stories and the ways in which these can contribute to further studies about women who care for people with intellectual disabilities.

Some links with other groups of women are made and some observations about women's lives are shared with the reader. The aim is to show how women do share some common experiences and how these can be used

to challenge the current theoretical constructs that may not have acknowledged the place of women in social science research. It is not to say that all women's realities must be categorised in the same way but rather that out of the diverse experiences of these women there are some common themes that can be used to further our understanding of the reality of women who care and in many instances about women in general.

CHAPTER TWO: THEORETICAL PERSPECTIVES

This chapter develops a theoretical framework for examining the relations of power experienced by women who care for people with intellectual disabilities. The aim is to discover the ways in which power operates to control these women.

The first section explores current thinking about feminist theory and research. This provides a context for developing a framework for examining the relations of power that operate to control women. In this section I explore the relationship between gender and class and the ways in which power has traditionally been defined. This leads into a discussion of the ideas of Michel Foucault and Luce Irigaray. Both these writers have influenced the ways in which I view power relations in that they provide alternative ways for looking at the way power operates. A theoretical framework for analysing the experiences of the women who care for people with intellectual disabilities in the household and the Organisation is developed.

Feminist Theory and Research

Feminist theory and research have influenced the way in which I have carried out this study. As described in Chapter One feminist theory and research is concerned with discovering ways that more authentically represent the diverse experiences of women. It begins with a critique of patriarchal structures and the manner in which these have controlled social scientific investigation. This critique identifies a process whereby alternatives to patriarchal systems can be constructed. Gross argues:

On the one hand, feminist theory has radically questioned and attempted to undermine the presumptions, methods and frameworks of phallogentric or patriarchal discourses and disciplines. On the other hand, feminist theory has simultaneously attempted to explore and develop

alternatives to these phallogocentric systems, bringing into being new, hitherto unarticulated, feminine perspectives on the world (Gross, 1986: 185).

Feminist theory is about challenging and deconstructing current social discourses and social practices and simultaneously creating new categories for describing and understanding the reality of women. Because the unique experiences of women must be revealed, women as a group must not be added on to existing social scientific categories and methods of investigation. The systems that have ignored or misrepresented women's experiences must be transformed not merely reversed.

Theoretical constructs cannot be developed without an ongoing dialogue with the reality of women's lives. I take the view that theory is practical in that its very formulation must take into account and incorporate what is the lived experience of the women one wishes to study. Research is not a process wherein the social scientist removes herself from the daily experiences of women in order to develop an explanation of what reality is like. I acknowledge the important role women have in the development of alternative theoretical frameworks. There must be a dynamic interplay between theory and practice "in which women's subjectivities and experiences of everyday life become the site of redefinition of patriarchal meanings and values and of resistance to them..." (Weedon, 1987: 6).

This process begins by retelling familiar stories (Goodnow, 1986). If women's stories are to be retold in order to write new ones and to challenge the myths about women's lives, theory and research must begin with women's experience. Ballou and Gabalac (1985) emphasise this point and discuss how research must use theoretical categories in ways that will allow women should speak for themselves. They argue that:

One of the key pieces in a feminist view of women, is the reliance on women's experience. Women's experience as felt, lived and processed is the trusted base of knowledge. Potential bias is acknowledged, and serious attempts are made, to clarify and articulate the experience. This consciousness raising process seeks its validation through generalisation among many women's experiences rather than in fitting with traditionally accepted theories and organisation of knowledge. Information coming from standard theories and causative explanations are systematically inspected for sexism in motivation, assumption, method and goal (Ballou and Gabalac, 1985: 58-59).

Green and Kahn (1985) have a similar view and believe that the rewriting of women's history lets "silences" speak and shows how history has misrepresented women's experiences.

However, the sharing of the women's experiences is not sufficient in itself. Sharing must also be accompanied by a critique of patriarchal discourse and the building of an alternative theory. Women may have, as Grimshaw (1986) suggests, remained on the fringes of mainstream social science investigation because their experiences have not been adequately described and analysed. If women are to challenge, dismantle and reconstruct existing frameworks they must produce alternatives. Gross illustrates this:

...feminist theory does not simply aim to reveal what is 'wrong' with, or false about, patriarchal theories - to replacing one 'truth' with another. It aims to render patriarchal systems, methods and presumptions unable to function, unable to retain their dominance and power. It aims to make clear how such a dominance has been possible; and to make it no longer viable (Gross, 1986: 197).

It is necessary to show what it is that makes "discourses patriarchal" (Gross, 1986: 198) and to discover how these discourses devalue women and place them in the role of the "other" (de Beauvoir,

1972). Gross suggests women researchers can "tactically use" some of the existing theoretical ideas to develop their own. They use them "as a starting point for new directions in theoretical research" (Gross, 1986: 198).

Women researchers must not be guilty of the very things they criticise and as Gross argues, feminist research is part of a strategy for change as it:

Seeks effective forms of intervention into systems of power in order to subvert them and replace them with others more preferable (Gross, 1986: 196).

Feminist social scientists can "tactically use" existing theories "without necessarily retaining general commitment to their framework and presumptions" (Gross, 1986: 193).

Critique of Economic Explanations of Power

This thesis begins with a critique of some examples of the major notions of power and a demonstration of how these must be re-examined. My aim is to show how existing frameworks for exploring power relations do not take into account the effects of power on the lives of women who care for people with intellectual disabilities.

Laclau and Mouffe (1985) argue that economic explanations of power have been dominant in the social science literature. These explanations assert that the relations present in the economic realm determine how all other social relations are maintained and how they can be transformed.

Gramsci has been one writer who has modified the "traditional" Marxist view of structure and superstructure in that he demonstrated how the economic base does not solely determine how social relations are derived. His ideas (1971) attempt to show how the economic realm

cannot exist independently of the political and ideological superstructures. Gramsci's ideas are useful because he attempts to provide a framework for examining power relations that are not always directly influenced by the economic realm.

For Gramsci, questions of political practice cannot be reduced "to those concerned with the mode of production or fundamental economic relations" (Jessop, 1982: 145). This does not mean that Gramsci regards the economic sphere as unimportant for it is the contradictions inherent in the capitalist mode of production that will form the basis of the revolutionary process. However, the effects of the capitalist system are neither "unconditional nor unilateral" (Jessop, 1982: 145) in that these effects cannot always be adequately predicted:

The claim presented as an essential postulate of historical materialism, that even fluctuations of politics and ideology can be presented as an immediate expression of the structure, must be contested in theory as primitive infantilism, and combated in practice with the authentic testimony of Marx, the author of concrete political and historical works (Selections from Prison Notebooks, 1971: 407).

Gramsci aims to elucidate how the ideological and political superstructures can shape the way capital reproduces its class domination. Gramsci used the concept of hegemony to show how both the structures and super-structures operate to maintain the current system. The ruling group not only controls the economic structures but also exercises its control throughout society by influencing the ideological and cultural relations, spiritual and intellectual life and the expression of such relations.

Although Gramsci desires "to restore the possibility of conscious creative human activity in the historical process" (Femia, 1981: 70) he still regards economic struggles as the "moving force of history" and views the "productive techniques" as "constituting the backbone

of any given society" (Femia, 1981: 120). He fails to provide an adequate explanation for the power relations that fall outside the realm of economic production. He does not, for example, illustrate how power operates to control women. Nor does he address the role of patriarchal systems of domination. His framework for understanding how order is maintained does not take into account the local and specific effects of power relations. That is, the immediate effects of power and what they mean for women. One must move beyond his views in order to provide an adequate explanation of the power relations controlling women.

More recently, Laclau and Mouffe (1985) are two writers whose attacks on economism challenge explanations that cite the "economic" as the dominant factor in an understanding of social phenomena. They emphasise the need to not only challenge "economism" but to also clearly identify how other struggles including those of women will bring about a transformation in existing power relations. In her study of the effect of patriarchy and capitalism Rowbotham (1983) emphasises the need to stop viewing "patriarchy and capitalism as two separate interlocking systems" and look at how both gender and class have developed historically. She submits that all 'relations of power' must be rooted in a cultural context. In this way the local effects of both these systems must be revealed.

Delphy (1984) has also explored the nature of the relationship between patriarchy and capitalism. She believes that the relationship between a "materialist analysis" and the ways men benefit from "patriarchal exploitation" has not been adequately defined.

I argue that economic analyses are insufficient in that they do not address all aspects of power relations. Their explanations of power may not always clearly identify the immediate effects of systems, other than economic, on women's lived experience. The power relations that act upon women who care for people with intellectual disabilities do not only operate in an economic sphere. Much of the

work these women carry out is unpaid but to understand why this is so I argue that one requires a perspective that can accommodate not only economic exploitation but also domination in other spheres such as the political, social and cultural.

I address these issues in my discussion of the writings of Michel Foucault and Luce Irigaray. I use the work of these writers because as I discussed in Chapter One they provide an explanation of how power operates in the daily lived experience of women. They are interested in discovering the ways in which power operates to control individuals. They also attempt to show in what ways the power relations that operate at the level of women's daily lived experiences connect with global forms of domination.

Foucault and Irigaray's Understanding of the Nature of Power

Both Foucault and Irigaray emphasise the need for a more encompassing analysis of power that does not rely solely on the economic. They argue that power does not have as its only function that of supporting economic relations and as this is a central focus of my study their work and their views on the nature of power will be examined in depth.

Foucault asserts that what is needed is a non-economic analysis of power in order to explain the experiences of:

people situated outside the circuits of productive labour: the insane, prisoners and now children. For them labour, insofar as they have to perform it, has a value which is chiefly disciplinary (Foucault, 1980: 161).

Foucault (1979) assigns three functions to labour: productive, symbolic and dressage or discipline. With the category of individuals Foucault is concerned with, the productive function is

virtually zero, whereas the symbolic and disciplinary functions are very important. Foucault is referring to the economic sphere when he uses the term production. He suggests that groups such as women carry out labour that may be devalued but which functions to maintain their current positions.

Foucault insists that a Marxist view of power does not allow one to understand the way power operates to control those groups who may not be paid for their labour. The Marxist tradition, argues Foucault, is based on an "economic functionality" of power in that power relations are viewed as originating from and directly related to the economic system:

This economic functionality is present to the extent that power is conceived primarily in terms of the role it plays in the maintenance simultaneously of the relations of production and of a class domination which the development and specific forms of the forces of production have rendered possible. On this view, then, the historical 'raison d'être' of political power is to be found in the economy (Foucault, 1980: 88-89).

A primary interest of Foucault is to show how power relations do not always have their origins in the economic system. This means, as Pratt points out, that resistance to power may no longer be class based and is not likely to "contain within it the possibility of the ultimate overthrow of society" (Pratt, 1987: 10). Any resistance then must transcend notions of class.

Irigaray (1985) also challenges the explanatory usefulness of economic frameworks. She maintains economic frameworks do not account for the issues surrounding gender. They do not focus on the specific ways in which power operates to control women. Moreover:

...the relation between the system of economic oppression among social classes and the system that

can be labelled patriarchal has been subjected to very little dialectical analysis, and has been once again reduced to a hierarchical structure (Irigaray, 1985: 82).

Irigaray (1985) critiques what she defines as a "masculine view" of power and argues that it forces an alternative between class struggle and gender and assumes in many instances that class struggle takes precedence. This view makes an assumption that women's struggle will come after a struggle between classes.

Irigaray speaks about the ways in which the patriarchal foundation of women's existence is overlooked in contemporary politics and even in leftist politics. She comments that:

Up to now even Marxism has paid very little attention to the problems of the specific exploitation of women, and women's struggles most often seem to disturb the Marxists (Irigaray, 1985: 165).

Irigaray seeks to find ways in which we can discover why women's struggles remain marginal to class struggles.

Women's struggles are unique and although class positions are important they are not the unifying factor that subsumes all other struggles. Both economic and patriarchal structures control the experiences of women and contribute to the operation of the relations of power (Irigaray, 1985). Because Foucault and Irigaray focus on the struggles of groups that do not constitute a clearly defined economic class, it is to a discussion of their major theoretical ideas that I now turn. I use some of their ideas to construct a theoretical framework for analysing the power relations that control women who care for people with intellectual disabilities.

Michel Foucault

The particular ideas I am interested in are those that are found in three of Foucault's translated works Discipline and Punish (1977), History of Sexuality Vol I (1978) and Power and Knowledge (1980). It is in these publications that Foucault articulates his view of power. Foucault's central notion is that of the "microphysics of power". He believes that one must begin with an examination of the body¹ as the specific target for the mechanisms of the relations of power. In Discipline and Punish (1977) Foucault examines the particular ways in which the body can be subjected in order to derive the maximum utility from it. He shows how the power relations not only operate to control individuals but also groups.

Foucault is concerned with building an "analytics of power" as he wants to discover what power looks and feels like for those individuals who are experiencing the effects of this power. He begins with examining the specific effects of power on a daily level. He is not only concerned with why certain people wish to dominate and what their goals and strategies are but he also aims to discover how power operates at the "level of on-going subjugation, at the level of those continuous and uninterrupted processes which subject our bodies, govern our gestures, dictate our behaviours, etc" (Foucault, 1980: 97).

Foucault is not interested in solid, global or central domination but the "multiple forms of subjugation that have a place and function within the social organism" (Foucault, 1980: 96). He is concerned with how individuals are brought under the control of others.

¹ Foucault uses the word body to refer to and emphasise both the biological/physical and emotional/psychological aspects of the body because he wants to show how society controls and uses both individual and groups of bodies to get its work done.

Foucault (1980) argues that power is not a mechanism that remains fixed and unchanged; it is not homogenous. It manifests itself in different ways at different levels. It is not the property of one group, for example, economic classes are not privileged subjects who dominate power relations. Nor does it operate at or derive from one level of society, for example, power relations do not necessarily originate from or are organised by the State apparatus.

Foucault aims to direct his analysis towards a focus on local power relations which are to be discovered in the daily experiences of people in schools, families, prisons, hospitals and to examine how techniques of power are administered by teachers, parents, wardens, psychiatrists, etc. Foucault (1980) shows that there are other power relations besides those that are consistent with formalised law and legal contracts. He calls these the "microphysics" of power.

Given that power is not a property or possession that belongs exclusively to one class or group, Foucault (1980) rejects a liberal view that power can be exchanged on a contractual basis. It can not, according to Foucault, be contained and quantified in such a way that it can be exchanged.

Foucault also discusses the ways in which power relations can be analysed. The exact operations of power may be difficult to detect as they infiltrate all types of relationships. According to Foucault's view all social relations have an element of power, in that:

Relations of power are not in a position of exteriority with respect to other types of relationships (economic processes, knowledge, relationships, sexual relations), but are imminent in the latter; they are the immediate effects of the divisions, inequalities, and disequilibriums... (Foucault, 1978: 94).

Power, then, can only be understood in its action and in the way it is exercised. Power is not a fixed and static entity. The way it is exercised and its form is always changing. The groups that control the relations of power must always be seeking ways to ensure that they are maintained.

Power relations are not necessarily repressive. They do not always have "a role of prohibition" but rather they may "have a directly productive role..." (Foucault, 1978: 94). In his criticism of systems that view power in a purely judicial sense Foucault maintains that power must "mask a substantial part of itself" (Foucault, 1978: 86) in order to be successful. It must have a productive function in that it can be used to achieve certain goals for those who control the power relations. The elements of power must permeate all aspects of people's lives:

Its success is proportional to its ability to hide its own mechanisms. Would power be accepted if it were entirely cynical? For it, secrecy is not in the nature of an abuse; it is indispensable to its operation. Not only because power imposes secrecy on those whom it dominates, but because it is perhaps just as indispensable to its operation (Foucault, 1978: 86).

Because Foucault did not directly focus on the repressive and productive aspects of power with respect to women's experiences, I intend developing this point further in my theoretical framework. It is often difficult for women to expose the relations of power for these relations may appear in some instances to be based upon relationships of reciprocity, that is, the productive aspects of power function to hide power's negative effects. Women simultaneously experience both the repressive and productive aspects of power.

Foucault emphasises that we cannot assume that the operation of power is always the expression of an opposition between the rulers and

ruled. The existence of such a relationship is an empirical question that can only be answered by a detailed examination of people's experiences. As Foucault puts it:

...power comes from below; that is, there is no binary and all-encompassing opposition between rulers and ruled at the root of power relations, and serving as a general matrix - no such duality extending from the top down and reacting on more and more limited groups to the very depths of the social body (Foucault, 1978: 94).

He posits that this power "runs through the social body" and is manifest in relationships of economic production, in families, in groups such as the insane, and in groups both in the community and in institutions. Power can be exercised by the people that are the closest to us.

Power relations can be intentional but they may also become institutionalised to the extent that it is difficult to determine their original intent (Foucault, 1978). Although power generally has aims and objectives, the way in which it operates is not always a conscious decision of an individual or a group. Foucault in his explanation of what an "analytics" of power may look like describes this:

...let us not look for the headquarters that presides over its rationality; neither the caste which governs, nor the groups which control the state apparatus, nor those who make the most important economic decisions direct the entire network of power that functions in a society (and makes it function); the rationality of power is characterised by tactics that are often quite explicit at the restricted level where they are inscribed (Foucault, 1978: 95).

Foucault is referring to the local operation of power. The techniques he describes can become connected to one another and support each other. They may form comprehensive systems of power

that may give a clue as to who formulated them and the aims they had initially identified.

Foucault illustrates the ways in which the nature of power relations change with respect to the level in which they are administered and are operating within. When Foucault speaks about the level of power he is referring to the site that the relations of power are operating at. The levels include local and specific power relations which operate on the body and in the daily experiences of individuals; power relations that operate on groups of individuals at the level of organisations and of the State and power relations that are one part of the discourses of knowledge which provide meaning to social practices.

In Discipline and Punish Foucault (1977) includes a description of what the technologies of power look like at each level. These mechanisms are closely linked to the characteristics of the person administering the power and to their perception of the group being controlled. Foucault shows how power relations operating within prisons may look very different to those operating within families. The latter may be more subtle and difficult to detect.

Foucault (1977) uses an "ascending analysis of power" to describe and understand power relations. This means that the "infinitesimal mechanisms" and immediate effects of power and their history and relationship to global forms of power are examined.¹ It is his belief that:

...the manner in which the phenomena, the techniques and the procedures of power enter into play at the most basic level must be analysed, that the way in which these procedures are displaced, extended and

¹ "Infinitesimal mechanisms" refers to the very minute effects and operations of power, for example those that take place in the most intimate places of people's lives.

altered must certainly be demonstrated; but above all what must be shown is the manner in which they are invested and annexed by more global phenomena and the subtle fashion in which more general powers or economic interests are able to engage with these technologies that are at once both relatively autonomous of power and act as its infinitesimal elements (Foucault, 1980: 99).

An understanding of how the mechanisms of power operate on each level and how dominant groups use these to maintain their position is, according to Foucault, essential.

In describing the way in which power operates, Foucault (1980) uses the term "technologies of power". These technologies may operate in differing ways with respect to the level they are situated within. In defining the "technologies of power" Foucault begins his analysis with a description of what happens to individuals. Foucault shows how there is a centering on the:

body as a machine, its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls... (Foucault, 1978: 139).

The concept of "disciplinary" power present in institutions such as those that "contain" the insane is used by Foucault (1977) to show how power functions to optimise the capabilities of individual bodies. As Foucault shows in his study of the insane abnormal "bodies" are enclosed, ranked and organised in space. They are organised in such a way that they will not disrupt the social order and in a way that extracts the maximum of work for the minimum utility.

The body becomes subjected in a number of ways:

...power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs. This political investment of the body is bound up, in accordance with complex reciprocal relations, with its economic use; it is largely as a force of production that the body is invested with relations of power and domination but, on the other hand, its constitution as labour power is possible only if it is caught up in a system of subjection (in which need is also a political instrument meticulously prepared, calculated and used); the body becomes a useful force only if it is both a productive body and a subjected body (Foucault, 1977: 25-26).

In Discipline and Punish (1977) Foucault explores the diversity of mechanisms that are used to make the relations of power operational. The three dominant modes are hierarchical observation, the use of the "norm" to observe individuals and the use of examinations to monitor the activities of individuals.

Foucault uses the concept of hierarchical observation to show how everything that individuals become engaged in can be watched in order to define "disciplinary goals" for individuals. This observation takes a number of different forms. Foucault (1977) cites "panopticism"¹ as a way of categorising and organising individuals in space and utilising their time and bodies effectively. This includes the assessment and examination of bodies.

Foucault uses the concept "norm" to measure the amount and level of surveillance and training required to control the work of individuals and groups:

¹ "Panopticism" refers to the way in which certain mechanisms will be used to observe the activities of individuals. In an institution it can refer to something physical such as a watchtower; in an organisation it can refer to the rules and regulations that will ensure that individuals are performing adequately.

Like surveillance and with it, normalization becomes one of the great instruments of power at the end of the classical age for the marks that once indicated status, privilege and affiliation were increasingly replaced - or at least supplemented - by a whole range of degrees of normality indicating membership of a homogeneous social body but also playing a part in classification, hierarchization and the distribution of rank. In a sense, the power of normalization imposes homogeneity; but it individualizes by making it possible to measure gaps, to determine levels, to fix specialties and to render the differences useful by fitting them one to another (Foucault, 1977: 184).

The "examination" is also a powerful mechanism for controlling bodies. Individual bodies are observed, categorised and contained. In the management of bodies Foucault (1977) suggests that individuals can become "cases". The behaviour of bodies may be documented and sophisticated systems designed to extract more from the body. For example, organisations may have procedures that will ensure that the maximum of labour is derived from each individual. These mechanisms may also be used to control groups of bodies.

Foucault (1977) argues that there has been a diffusion of "disciplinary mechanisms". He bases this upon his observations of European society in the 1960s. Organisations may become unofficial centres of observation. A "carceral network"¹ extends into those very social agencies whose function is supposedly to support individuals. What in fact may happen is that these organisations will attempt to extract the maximum utility from bodies.

He calls the technologies that control the population "regulatory controls: a biopolitics of the population" (Foucault, 1978: 139).

¹ "Carceral network" refers to the ways in which the population can be controlled in order to be rendered more productive. In modern society it refers to laws, regulations and systems that will ensure that individuals obey societal norms. Certain groups such as teachers, social workers, psychologists can be used to control the population.

In his discussion on the role of the State Foucault shows how the State cannot operate in isolation from other technologies of power. The tactics the State uses must connect with those on other levels if dominant groups wish to maintain their hegemony. He argues that:

because the State, for all the omnipotence of its apparatuses, is far from being able to occupy the whole field of actual power relations, and further because the State can only operate on the basis of often already existing, power relations....These networks invest the body, sexuality, the family, kinship, knowledge, technology and so forth. True, these networks stand in a conditioning/conditioned relationship to a kind of 'meta-power' which is structured essentially round a certain number of great prohibition functions; but this 'meta-power' with its prohibitions can only take hold and secure its footing where it is rooted in a whole series of multiple and indefinite power relations that supply the necessary basis for the great negative forms of power (Foucault, 1980: 122).

Foucault suggests that the success of the State's tactics can be measured with respect to the way it can control the "microphysics" of power. He identifies the technologies of power operating "at every level of the social body and utilised by very diverse institutions (the family and the army, schools and the police, individual medicine and the administration of collective bodies)..." (Foucault, 1978: 141).

Foucault refers to the use of the "norm" as being as important as the formal judicial system for maintaining the relations of power. He states that "continuous regulatory and corrective mechanisms" (Foucault, 1978: 144) organise themselves around the norm. The judicial apparatus and the operation of the law increasingly uses a wide range of apparatuses in order to function.

He emphasises that in a society that focuses on "bio-power", that is, the control of bodies in more sophisticated ways, the outcome will be

a normalized hierarchy. He asserts that this is essential if the State is to keep track of and control bodies who are widely dispersed throughout society. The State can operate to regulate the population and make it more visible. Surveillance is used to categorise and regulate the population. Disciplinary training is put in place if the norm is not met.

Foucault also shows how power relations function at the level of the knowledge in that he is concerned with the ways in which knowledge operates to provide meaning to social practices. Foucault has a particular way in which he uses the term "knowledge" such as the writing of history and creation of ideas and the use of knowledge by certain groups in order to control individuals.

Foucault argues that history can be written in such a way as to misrepresent the experiences of individuals. He believes that it is necessary to focus on what has been missing from historical and social science investigation. Foucault submits that history can be written in such a way that the present state of affairs is justified and that it is the historian who determines what will come under the microscope. The historian has, according to Foucault, power over the problems being posed and over the theoretical decisions being made.

He uses the example of the creation of "ideas" to show how phenomena may be incorrectly linked in order to imply continuity in support of a particular theme. Foucault proposes new ways of carrying out history that will reveal the operation of power relations. He uses his analysis of power relations on a daily level to facilitate this process. An understanding of individuals' daily experiences and the subjection of bodies may begin to cast doubt on some of the ways history has been written.

Foucault also has definite views about the ways in which applied science can operate to maintain power relations. Foucault includes in his definition of science the "disciplines". Members of the "disciplines", for example the discipline of medicine, can control

individual bodies and groups of bodies by adopting certain scientific principles. These "disciplines" "regularly reinforce one another in a circular process" (Foucault, 1977: 224). They use a technology that has specific effects in different domains. What is common to these "disciplines" is that they can be used to justify complex modes of subjection.

The position of members of "disciplines" allows them to use a myriad of technologies of power and many of these, such as the practices of the medical profession, are beyond question. These technologies may be hard to expose. Their effects can intrude into all parts of the body and monitor several social practices at any one time. The "disciplines" may operate to support other relations of power in that they may be part of the organisations that function to control "groups of bodies".

Now that Foucault's views on the nature of power have been introduced, it is important to outline some of the criticisms of his work. Gross (1986a) submits that Foucault's ideas are not beyond those of feminist thought. His rejection of theories that have a commitment to a universal view of truth without accepting the specific effects of history, culture and environment appear to be congruent with a feminist view of the world. However, Gross (1986a) also points out that Foucault fails to acknowledge that many of the difficulties women have are directly related to the perception of women as the "other" and devalued sex.

Although Gross (1986a) makes a relevant point when she comments that Foucault does not refer specifically to women and address their particular concerns, he does refer to groups that are devalued and places women in this group.

Balbus (1986) also critiques Foucault's work and is critical of Foucault's "gender-neutral" assumption of oppression and refers to a confusion in Foucault's thoughts on the role of women in the transformation of power relations. It is his view that:

Foucauldian genealogy disciplines women by depriving them of the conceptual weapons with which they can understand and begin to overcome their universal subordination (Balbus, 1986: 120).

Whilst Foucault does not explicitly confront the problems of how women can in fact bring about change, he has a very clear analysis of the way that individual bodies are controlled. This contributes to an understanding of how groups such as women may respond to the relations of power. Foucault's analysis helps us understand why certain discourses and social practices become dominant and how subjects and groups become constituted.

It is Foucault's "analytics of power" that informs the methods used to construct the theoretical framework used in the present research for analysing the power relations experienced by women who care for people with intellectual disabilities.

Luce Irigaray

Irigaray is concerned with the connections between language and representation, power relations and women's bodies. She aims to challenge patriarchal definitions of women's experiences and to seek alternative ways of representing women.

The central work of interest for this thesis is Irigaray's (1985) work This Sex Which is Not One¹. Irigaray has a commitment to gaining an understanding of what the daily experiences of women look and feel like. She aims to understand what is happening to women's bodies and to discover what power feels like for women.

¹ Irigaray's publication Speculum of the Other Women (1985) also contributes to our understanding of women's experiences. However, This Sex Which is Not One is the key reference used in this dissertation.

Irigaray "tactically" uses the methods of psychoanalytic theory to show how women's bodies have been subjected. She deconstructs ideas and assumptions about women's positions and begins to replace these with new ways of viewing women. Her target is phallogentrism - the system wherein man is the symbol of authority. Irigaray aims to challenge these discourses and any others that have functioned to maintain women's position as the "other".

Irigaray is also committed to showing how women can change oppressive structures and social relations. She asserts the need for a transformation in systems of representation, of language and seeks to reveal those experiences that have been obscured - to let women speak and to expose the "silences". Irigaray acknowledges the individual struggles of women and the complexity of these struggles. She emphasises the importance of linking the individual experiences of women to global systems of exploitation and domination such as economic and political systems and their influence on women's lives. It is in this way that these systems can begin to be transformed.

Irigaray's (1985) thesis involves an examination of women's bodies and lived experiences. Irigaray is not concerned with the anatomical or biological body but rather about the way in which this body is subjected. For her the:

...object of analysis is the body as it is lived, the body which is marked, inscribed, made meaningful both in social and familial and idiosyncratic terms, the body physically, socially and discursively established: the body as socially and individually significant (Gross, 1985b: 136).

Irigaray examines ~~with~~ the ways in which meaning is attached to social practices and in discovering ways that show how women's activities are defined. The body is the starting point for revealing the intricacies of power. She posits:

From this encircling projective machinery, no reality escapes unscathed. Alive. Every 'body' is transformed by it. This is the only way for the 'subject' to enjoy the body, after having chopped it up, dressed it, disguised it, mortified it in his fantasies. What is disturbing is that of these fantasies he makes laws, going so far as to confuse them with science - which no reality resists. The whole is already circumscribed and determined in and by his discourse (Irigaray, 1985: 88).

This use of the body happens in all spheres of a woman's life, but as Irigaray suggests the woman is "closeted" in a family for most of her life so that the family has always been the privileged focus of women's exploitation.

Irigaray shows how there is an assumption in a patriarchal family and society that the man is the "proprietor of women and children". She argues:

The same is true of the objection involving 'the mother's power', as this power exists only 'within' a system organised by men. In this 'phallogocratic' power, man loses something too: in particular the pleasure of his own body. But historically, within the family, it is the father-man who alienates the bodies, desires and work of women and children by treating them as his own property (Irigaray, 1985: 142-143).

Irigaray speaks about the ways in which men try to extract utility from the bodies of women. In her discussion on value and the definition of commodities she examines how women function "as image for man, but lacks specific qualities of her own. Her value-invested form amounts to what man inscribes in and on its matter: that is her body" (Irigaray, 1985: 187).

The use of women by men implies that the participation in society requires that their bodies submit themselves "to a specularization, a speculation, that transforms it into a value-bearing object, a

standardized sign, an exchangeable signifier, a 'likeness' with reference to an authoritative model" (Irigaray, 1985: 179-180).

To exercise power over the women's bodies and ensure that they become commodities, men must create a "phenomenal form" of the body. This is distinct from the "natural form" of the body.

A commodity - a woman - is divided into two irreconcilable 'bodies': her 'natural' body and her socially valued, exchangeable body, which is a particularly mimetic expression of masculine values (Irigaray, 1985: 180).

Men, according to Irigaray, are the group who generally control the means of production and are also the head of the household. In these roles they have the power to determine the "value" of commodities - in this instance, women.

Commodities have an "ek-static"¹ nature as:

An abstract and universal value preserves them from use and exchange among themselves. They are, as it were, transformed into value-invested idealities. Their concrete forms, their specific qualities and all the possibilities of 'real' relations with them or among them are reduced to their common character as products of man's labour and desire (Irigaray, 1985: 181).

The establishment of 'value' and the relationships between commodities cannot be established by the commodities themselves, but is dependent upon the functioning of exchange:

The exchange value of two signs, two commodities, two women, is a representation of the needs/desire

¹ Irigaray uses the prefix "ek" to denote a separation or differentiation from nature.

of consumer-exchange subjects: in no way is it the 'property' of the signs/articles women themselves. At the most, the commodities - or rather the relationships among them - are the material alibi for the desire for relations among men. To this end, the commodity is disinvested of its body and reclothed in a form that makes it suitable for exchange among men (Irigaray, 1985: 180).

In the process of being viewed as a commodity women's development is restricted. They become stifled as they are unable to transcend the limits the commodity places upon them. This can happen in all spheres of women's existence - her body is not only subjected in the domestic realm but also in areas such as sexuality.

Irigaray argues that women become "fetish-objects" for men. They may remain socially and naturally isolated from other women:

...just as commodities cannot make exchanges among themselves without intervention of a subject that measures them against a standard, so it is with women. Distinguished, divided, separated, classified as like and unlike, according to whether they have been judged exchangeable. In themselves, among themselves, they are amorphous and confused: natural body, material body, doubtless useful to the consumer, but without any possible identity or communicable value (Irigaray, 1985: 188-189).

Women's bodies may be kept in a private realm unable to infiltrate the public sphere (Irigaray, 1985).

Irigaray (1985) focuses on the ways women's bodies may have been unable to "voice" and speak about their experiences. Women have lacked a position where they have been able to define their own experiences. She "seeks an adequate language and modes of representation...a language beyond the hierarchical regulation of metadiscourse" (Gross, 1986b: 137).

Irigaray challenges the assumption that knowledge and language is neutral and in so doing contends that it has been dominated by particular styles and perspectives. This knowledge and language has, she argues, been controlled by patriarchal systems. She aims to reveal what this domination looks like and to construct a language wherein women can speak. Irigaray seeks to show how women can find a position where they can begin to explore alternative discourses and language.

Irigaray (1985) links the experiences of women and language to the ways men have subjected women and their bodies. She shows that if women are outsiders to language they are not in a position to counter male-centred conceptions of the role of the sexes. This is part of the process of the subordination of women's bodies to the economic and sexual demands of men.

According to Irigaray (1985) women have to construct a space for themselves and in this process they must not speak for one another but rather with one another in order to identify what knowledge is meaningful for them. In this way women will begin to construct alternative frameworks for examining and understanding their lives:

Women's social inferiority is reinforced and complicated by the fact that women do not have access to language, except through recourse to 'masculine' systems of representation which disappropriate her from her relation to herself and to other women (Irigaray, 1985: 85).

To construct an alternative social order the language women use must of necessity change so that it can be a "true" representation of women's experiences. Irigaray explains that if women keep speaking "to each other as men have been doing for centuries" and as they "have been taught to speak", they will "miss each other, fail themselves". She states that "again...words will pass through our bodies, above our heads. They'll vanish, and we'll be lost. Far off, up high. Absent from ourselves. We'll be spoken machines, speaking machines" (Irigaray, 1985: 205).

Irigaray proposes a technique called "mimesis" for exposing power relations. Irigaray uses this term to show how women can begin to find a place to be themselves and to learn how to bring about some positive change. Change can only happen after women have analysed what oppression feels like. She suggests that women must take on the role of the "feminine" in order to "convert a form of subordination into an affirmation, and thus begin to thwart it" (Irigaray, 1985: 161).

According to Irigaray women can use "mimesis" to obtain a feeling about the immediate effects of exploitation without being reduced to it. They act out their roles and while doing this they try to analyse what is happening to them.

They use "mimesis" as an interim strategy for exposing how the relations of power have become oppressive. For example, to make "mimesis" work women will remain in the household and carry out their usual activities. They discuss their activities with other women in order to determine how power relations operate.

Irigaray emphasises that women must support one another in determining how "mimesis" will work. They must come together to find a place where they can identify "their own desires in the absence of overly immediate pressures and oppressions" (Irigaray, 1985: 127).

For Irigaray, transformation must not be a reversal of roles or a few minor changes attached on to the existing categories of theory and experience:

When women want to escape from exploitation, they do not merely destroy a few 'prejudices', they disrupt the entire order of dominant values, economic, social, moral and sexual. They call into question all existing theory, all thought, all language, inasmuch as these are monopolised by men and men alone. They challenge the very foundation of our

social and cultural order, whose organisation has been prescribed by the patriarchal system (Irigaray, 1985: 165).

Irigaray argues that women must challenge all forms of "power and power relations". These movements must not simply aim for a change in the distribution of power because this leaves the power structure intact. This would mean that they would be "resubjecting themselves, deliberately or not, to a phallographic order" (Irigaray, 1985: 81).

There have been a number of challenges to Irigaray's work. She has been challenged for her focus on the "body" as a point of departure for exposing systems of oppression. Some Anglo-American feminists such as Gross (1986a) and Barrie (1987) point out they have difficulty accepting Irigaray's emphasis on the "difference" between the bodies of men and women. These feminists argue that frameworks such as Irigaray's, return feminist theory to a form of biological determinism.

Segal (1987) is concerned that writers such as Irigaray in their focus on women's "difference" from men and their belief in a superior view of women may lead us to a project that brings about individual changes in women's lives but does not link these to global forms of domination. This may, asserts Segal (1987), result in an impasse wherein the only option for women is to remain aloof and apart from any contact with men. This project she argues will not bring a transformation in the structures that dominate the lives of women.

Despite Segal's (1987) comments, Barrie (1987) makes a cogent point showing Irigaray's definition of "difference" is one wherein "difference" should not be used to refer to a difference in value. The biological characteristics of women have, as Irigaray (1985) submits, been interpreted in ways that label women as the "other" sex.

The definitions of men and women require transforming so that the presence of one does not mean the devaluing of the other. Irigaray

(1985) does not view women as the passive sex trapped in their bodies and waiting for others to free them. For her, the project for women is not about discovering what is "feminine" but rather it is about showing how these roles are socially inscribed and identifying old roles and activities women wish to take on. Irigaray attempts to put this theory into practice by encouraging women to rewrite their experiences in order to show how their personal experiences are culturally defined and are linked to patriarchal systems of domination.

A Framework for Analysing the Experiences of Women Who Care for
People with Intellectual Disabilities

In this thesis I use certain theoretical ideas of Foucault and Irigaray to develop a framework for examining and understanding the experiences of women who care for people with intellectual disabilities.

Like Irigaray an understanding of gender relations is my point of departure. It is, I argue, an understanding of gender that will determine how we can analyse and explain how other social relations influence women's lives. This understanding includes an examination of the cultural and historical conditions of women's existence. This view informs the way I have developed a framework for describing the experiences of women who care for people with intellectual disabilities and discovering what it is that maintains their existing positions. I aim to show how certain relations of power have maintained these positions. I explore the nature of power on the level of women's daily experiences and examine how the power that operates to control women's bodies¹ can be linked to global systems of domination.

¹ When I use the word body I am referring to both the physical body and to the way its functions are socially constructed. Like Irigaray I believe that one must clearly identify the effects of power relations on the immediate experiences of women. I claim that by using the word 'body' we are reminded of the ways in which women are subjected.

In describing and understanding the experiences of the women in my research it is, I argue, important to have an analysis of power that can account for non-economic relations. The observations of Foucault and Irigaray about power and its effects have relevance for my study. The power relations that women who care for people with intellectual disabilities experience are always changing their form and may be difficult to detect. The technologies of power may be administered by the people women live and work with. The women's relationships with these people may appear on the surface to be free of domination as they are not necessarily repressive, but in fact they ensure that women who care remain productive. The task is to discover the nature of power relations. Feminist theory proposes that one of the first steps in understanding women's position is to provide women with an opportunity to reveal and speak about their experiences.

Bearing in mind Foucault's and Irigaray's observation about the dynamic nature of power and in particular how this may make the detection of power in the lives of women difficult, I propose to analyse power relations in the experiences of women who care for people with intellectual disabilities at two critical sites: the household and the Organisation. I describe and analyse the immediate effects of power at these sites.

The household is where women live and care for their children/adults. In this thesis the Organisation refers to the IHC, the Organisation that provides most of the services for these women and their families. It will be shown how the relations of power operate by identifying a number of technologies whose function is to uphold power relations and to ensure that these are sustained.

A number of different technologies of power are applied in order to determine how power relations may operate in the lives of women who care. It is likely that these may be found operating in both the household and the Organisation. They include:

- the observation and examination of women to ensure they are carrying out their prescribed activities and the measurement of these activities against a norm that is defined by men;
- the use of knowledge including the writing of history, social scientific investigation and knowledge used by professional groups to examine the activities of women;
- the use of language to provide meaning to women's experiences.

These technologies of power help in the understanding of the way women who care for people with intellectual disabilities are subjected.

Because women who care for people with intellectual disabilities spend much of their time in the household this is where the relations of power have the most significant impact and where this analysis must begin. I argue that an understanding of the technologies of power will reveal the ways in which patriarchal power relations maintain control over women.

The Household - Women's Daily Lives and Experience of Power

An examination of power relations operating in the daily lives of women is essential if we are to discover the ways they have been subjected. Many texts that explore power relations do in fact make the assumption that male and female experience can be categorised under the common title of humanity (Walby, 1986). The interests of men are often portrayed in a way that suggests their experiences are universal. These accounts do not show how a woman's body can be viewed in a negative sense and how and why women are viewed as the "other" sex (de Beauvoir, 1982).

Male power functions in ways that will optimise the capabilities of women (Irigaray, 1985). The concept of disciplinary power as explored by Foucault (1977) helps to explain how women are subjected. Their capabilities are ranked and they are expected to occupy positions (for example in the family) wherein maximum utility is derived from their body. It is anticipated that I will find in the analysis of the women's lives that they are organised in ways that keep them apart and I suspect that many are compelled to remain in a private space. Even if they do leave the home their influence on social practices can be blocked. When women have influenced the public sphere this influence may be hidden or devalued. The assumption that women remain in a private realm and do not influence the public realm is a particular view of women (James, 1982). It is assumed that women must not venture out of the private realm. Women may be reassured that this private space is a more attractive place to be situated (Irigaray, 1985).

Given these points, it is important to recognise that women who care for people with intellectual disabilities are controlled in very specific ways. They are encouraged to make sacrifices in order to care for others. They can become exhausted and ill-treated in the process of caring for others (Baldwin and Glendinning, 1983).

The intricate nature of power relations that dominate women reinforce their position of powerlessness and although this process may be subtle and diffuse and occur gradually over many years it is no less harmful for women. Women who care may be isolated from one another. They are expected to do certain tasks and these tasks and the activities they are organised to carry out (for example, caregiving activities) are defined for them by others (Ayer and Alaszewski, 1984). This is defined by Irigaray as the way in which men label women as "commodities" and establish the "value" of women's work (Irigaray, 1985).

Dalley (1988) discusses the ways in which women are expected to not only service non-disabled members of the household but that their

love for household members is used to justify why they should become the primary caregiver for disabled household members. This work despite its repetitiveness and intensity is continually devalued.

The Observation, Examination and Comparison of Women in the Household

Women who care for people with intellectual disabilities are observed by others in the household in order to determine whether they are effectively carrying out their tasks and they may find it difficult to find a space for themselves where they are free from scrutiny (Graham, 1983). Accompanying this one would expect to find that they may be ranked and assessed with respect to how well they care for their children. They may be expected to observe their child's behaviour in order to improve it. This may become a way of monitoring their own activities. There is an expectation from their partners and other household members that they will be the primary caregivers (Baldwin and Glendinning, 1983). This expectation may also be reinforced by members of the extended family and the wider community (Dalley, 1988).

These women may be compared with other women or measured against a norm. The norm is a mechanism to be used to measure the amount and level of surveillance required in that women who do not obey the rules and who try to change their norms of behaviour may be ostracised. Women who care for people with intellectual disabilities may be made to feel inadequate if they choose to send their child away to an alternative living environment. It is, I argue, the woman not the man who feels guilty for carrying this out. It is in fact the woman who is asked to make this decision. Women's activities must fit certain norms and these are usually devalued (Dalley, 1988).

It is very difficult for women to challenge these norms. Men use a number of mechanisms to ensure that the norm is not challenged. For example, the role of women is often labelled as "natural" or "inevitable" (Goodnow, 1986). It can be viewed as "natural" for

women to remain in the private realm and not venture out. It is assumed that the private realm (the household) and the public realm of paid production do not influence one another. In this system women's primary responsibilities are to be concerned with caregiving activities (Barrett and MacIntosh, 1982). A model woman is often used as an example to show how other women can perform their role more effectively. Woman in her role as the "other" may be ridiculed, criticised and ostracised if she challenges the norm. Many women will in fact accept the norm because if they are ill-treated their child may also be. It is difficult to break out of one's role if this is going to hurt the one you love.

These technologies are used to ensure that the maximum utility is extracted from women and their work. Irigaray (1985) talks about this when she describes how commodities are defined. She argues that it is men who will determine what value women's work has and how it will be exchanged. In the household women who care are viewed as a commodity for family members to utilise in the most effective manner. These women can become alienated from other women. Women who care often have difficulty transcending their role as a commodity and hence remain fixed in their role. Irigaray (1985) claims that the value of their body does not derive from their natural form and this may mean that for some women they are no longer able to determine their real value.

Women who care may have difficulty identifying the skills they possess. Although they perform many complex activities within the span of one day, these activities may not be viewed as valuable. The way women use their time may be defined by others. The organisation of women's time by others is a very powerful mechanism for controlling women. Waiting for others is part of this process. These women may have to wait for others to define what tasks are valuable. They also remain in the household while others leave it each day to act upon nature in the realm of economic production. Work in the economic sphere has more value than the work of women in the household.

Women who care for people with intellectual disabilities spend long hours alone with the child waiting for their partners and husbands to return to the household. They also wait for doctors, psychologists and other professional groups to proclaim what tasks they should be engaged in. They expend much energy waiting for these people to meet with them and while they are waiting they are trying to keep the child occupied. Women who care spend hours waiting for something to happen and this waiting can result in apathy and exhaustion (Glendinning, 1983). These professional groups will prescribe how women should work with their child/adult. These women may have to meet certain goals and if they do not achieve these they may be criticised and sometimes taught new skills so they will meet the norm.

The Use of Knowledge to Control Women in the Household

In this thesis I use the term "knowledge" in the way that Foucault does, to include history, scientific investigation and the application of such knowledge by professional groups such as lawyers and doctors. It may be possible to show that the ways this technology is used in the household can, as with the other technologies outlined, be part of the practices of both the household and Organisation or predominate at one site.

History in this thesis will include the ways women's lived experiences are written about. The way women's activities are documented can set up certain expectations for how women's lives should be organised. Historical documentation has a function in maintaining power relations. Certain events have remained hidden in our historical records. This means that certain assumptions have been made about the history of women.

History has generally concentrated on the "powerful in the public sphere" (Grimshaw, 1986: 36). Women's activities have either been

ignored or misrepresented. Many of these activities have been trivialised. For example, the tasks that women who care perform may not be viewed as productive or necessary for social existence (Graham, 1983). Women's activities may be marginal to both social science investigation and to concrete social practices.

If women are devalued and viewed as the "other" historical writing can function to reinforce this view. Women's achievements may be hidden and they may be viewed as hapless victims (Grimshaw, 1986). Certain events and behaviours may be portrayed as being natural and inevitable. The activities of women who care may be described without any critique taking place as to why they carry out certain activities and why these activities may be devalued (Bright and Wright, 1986).

Historical documentation and scientific investigation may claim an adherence to "objectivity" and this process may incorrectly portray men and women. This documentation may not acknowledge the different social positions of men and women and in so doing it presumes a neutral and interchangeable subject. Gross (1986a) argues that in the process of searching for "objectivity" women's real experiences can be incorrectly portrayed. The misuse of "objectivity" can be used to misrepresent and in some situations ignore the lived experiences of women by not adequately investigating the different experiences of men and women (Walby, 1986).

In the search for historical continuity historical investigation can function to hide the concrete experiences of individuals. A preoccupation with trying to find a continuity of historical phenomena may mean that we ignore certain events or make incorrect links between events. Many of the myths about women's experience develop and are maintained in this way. For example, it may imply that women have always been the primary caregivers and should carry on these tasks.

The Use of Language to Control Women's Experiences in the Household

The knowledge used to control women's lives will be reinforced by the language used to describe women's experiences. Language can be used to give meaning to the social practices women are engaged in. It has a powerful effect in determining how events will be represented. Language can be used to maintain women as inferior and in the position of the "other" (Irigaray, 1985). Language and symbols are also used to define women's reality. Language contributes to the maintenance of the relations of power by giving a "voice" to experiences and categorising these in particular ways.

Language operates at all levels of society and its effects are reinforced in a number of different ways. The words used to describe women's activities in the household may also be used by the Organisation. Women's caregiving activities may be devalued and given negative labels that reflect this view. The work may be described as non-essential. It may not in fact be called work as it is unpaid and does not appear to contribute to the realm of economic production.

The words 'care' and 'housework' may have negative connotations which reinforce women's devalued status. Caring for people with intellectual disabilities may not be viewed as real work and can be labelled as such (Graham, 1983).

The technologies of power described reinforce one another within the confines of the household and also operate within the Organisation that women who care are part of.

The Technologies of Power Operating in the Organisation

I argue that the Organisation uses similar technologies to those operating in the household in order to ensure that women perform adequately and power relations are maintained. As in the household

relations that are, simultaneously, oppressive and reciprocal will operate within the Organisation. The mutuality that may exist can function to hide the oppressive nature of the technologies of power (Foucault, 1978). For example, women who care may enjoy some aspects of the caregiving role. They may also be given some support by the Organisation. They can find it difficult to challenge the very people that may at times support them. Women may be challenged if they threaten the goals that may be seen to lead to an enhanced quality of life for people with intellectual disabilities. The needs of women may be put in competition with the people they care for (Ayer and Alaszewski, 1984). I anticipate that women who care for people with intellectual disabilities are often in this position. Any questioning of the Organisation's goals may in fact have detrimental effects for the children they are caring for.

The Observation, Examination and Comparison of Women in the Organisation

The technologies used in the household are often present in women's relationships with the Organisation. For example, women may be compared with one another and criticised for not fulfilling certain tasks. The Organisation may have a standard that it expects women to meet (Bright and Wright, 1986). Women's activities will be defined in certain ways. For example, men may take on the decision-making position in the Organisations while the women are expected to carry out tasks associated with servicing committees or those in management positions (Bright and Wright, 1985).

The Organisation may have ways of hiding the conflicts women are experiencing. For example, women who care for people with intellectual disabilities may be embraced by the Organisation as being part of a large family which is struggling to achieve the same goals. The Organisation may reinforce the view of women being part

of a "large happy family" that cares for them (Bright and Wright, 1985). Just as the father is viewed as the head of the household, in most instances the head of the Organisation is also likely to be male.

A key aspect of patriarchal domination is to reinforce this view of the family as being "natural" and "inevitable" (Barrett and MacIntosh, 1982). Hence roles which women may be expected to play in the Organisation can be fashioned in a way that is a reflection of family structure in a patriarchal society.

Families may be viewed as the most suitable way to organise for the care of non-productive members of society such as people with intellectual disabilities. However, being part of a family (in the sense of the household and the Organisation) may mean that the women are further oppressed in that they are the ones who are expected to take on the primary responsibility for the child. I argue that if women try to expose these oppressions they are likely to be challenged, criticised and even ostracised by family members and by those who run the Organisation.

Although women's caregiving abilities are needed by the Organisation in order that it can fulfill its goals, certain skills are valued above others (Ungerson, 1985). The roles women perform, for example direct caregiving activities, may be viewed as less important than administration and management tasks. It is possible that a hierarchy of tasks is constructed by the Organisation; not only are women prevented from reaching the top of this hierarchy but their caregiving activities are defined by men as having less value. The Organisation can insist that women are part of the process of naming and defining tasks and that women can choose what tasks they wish to perform (Ayer and Alaszewski, 1984). However, women may remain in positions wherein their job is to support men in the important work men carry out. If they do take on management positions they may be forced to do it in a way that is acceptable to men. If women's tasks do gain status men may then take these over and redefine them (Ungerson, 1985).

As Foucault (1978) argues, the relations of power are amorphous and confused. Power relations are always changing because the groups that control them are always regrouping in order to maintain their dominance. Men do not want to give too many concessions. If they do women may force a major change in an Organisation's activities (Laclau and Mouffe, 1985).

I will attempt to show in my thesis how women are kept apart and are encouraged to identify with only those women who support the Organisation's activities. It may be shown that they are compared with one another and ranked with respect to how well they carry out caregiving activities. It may be difficult for women who are part of an Organisation to come together as a group if men use a divide and rule strategy. Women may be encouraged to either relate to those women who uphold the Organisation's practices and to the men in their family or the Organisation. They may be actively discouraged from defining themselves as a group that may become strong enough to challenge the relations of power. I anticipate that this situation can be experienced by both the mothers who care and by the women who work in the Organisation.

Some women may be used by the Organisation to show how other women should carry out their role. Their success at caring will be emphasised (Graham, 1983). Women may have difficulty believing that the people they love or have a close relationship with can actually administer technologies of power that will become oppressive. This is the very essence of the power the Organisation has. It uses a strategy of keeping women in a continual state of hope that things will improve and that the Organisation believes that women's interests have a priority. Women may be unable to discover exactly how the bureaucratic machinery operates and when and how decisions are made. The common good may always be invoked when women challenge this machinery in its functioning and identification of goals. The procedures of the bureaucracy can be difficult to understand and follow and women may not be able to identify their precise effects (Ferguson, 1984).

The State can be used to reinforce the practices that take place at the site of the Organisation and of the household. Its connections with these sites can help uphold the mechanisms that control women. The State has policies that may reinforce the dominant view of women. For example, policies relating to the function of the welfare state with respect to the role of women and families can help maintain the mechanisms that control women's lives. Its policies may be based on an assumption that women are the primary caregivers (Graham, 1983).

The Use of Knowledge to Control Women in the Organisation

The Organisation can use various kinds of practices to reinforce its knowledge base. It will use, as was introduced and has already been discussed in the previous section on the household, a number of methods for writing history and carrying out social scientific research to emphasise certain aspects of women's existence. Knowledge can also be used by certain professional groups to control women's lives. These groups include those in the educational, social, health and medical spheres of the social order (Foucault, 1980).

Professional groups can use certain strategies to reinforce their dominance and they use knowledge to maintain their position. For example, their knowledge may not be shared with women caregivers and members of the disciplines can name themselves as "experts" who have the authority to control other groups (Ayer and Alaszewski, 1984). The knowledge women have about caregiving will not necessarily be valued as the "experts" wish to have the monopoly on knowledge in order to protect their role (Ungerson, 1985).

The professional groups can subject women and administer technologies of power. These technologies may appear as being supportive for women but they may in fact be used to maintain women in oppressive relationships. For example, it may be found that women are asked to perform certain tasks for their children/adults that are aimed at improving the quality of life of the child but may also create

additional pressure for women. Professional groups will at times ask women to perform quite complex tasks but women will generally receive no additional rewards or resources for carrying these out (Ayer and Alaszewski, 1984).

A careful examination of women's lives may show how knowledge can in fact reinforce the technologies associated with observing and examining women in that it may provide the means for showing how women can be compared. This knowledge will identify, I argue, certain activities women should be performing with respect to caregiving and they may be challenged if they do not perform these activities in the prescribed ways.

The Use of Language to Control Women in the Organisation

Language can be used, as I have already suggested in the section on the household, by the Organisation to give meaning to the experiences of women. Certain discourses may operate to keep power relations concealed (Foucault, 1978). It may be difficult for women to show how language is oppressive and how it acts to misrepresent their experiences in organisations (Irigaray, 1985). It may be found that women have difficulty discovering how language operates to mask power relations and how the Organisation can encourage this confusion.

Language will support other technologies in that it can be used to describe and then categorise certain activities as being more appropriate for women, rather than men, to carry out (Greene and Kahn, 1985). This description of women's work links to the way women's activities can be examined and compared with one another.

Thus far I have described some of the technologies of power that operate to maintain women's current positions in the household and in the Organisation. In the next section I will describe some of the resistances women have developed as a way of challenging the relations of power.

Women's Resistance to the Power Relations

I anticipate that the technologies of power that operate in the household and within the Organisation have been resisted by women. Feminist theory and research shows how we can expose power relations and analyse these in order to challenge and transform them. However, although women have developed a number of resistances to the relations of power these have often remained hidden or have not been organised into well-formulated strategies (Irigaray, 1985).

Feminist writers are beginning to show that women have a history of resistance (Spender, 1985). They have not been passive but have found ways to challenge power relations. However, many of these resistances have not been documented or researched. One of the strategies of the dominant group is to keep these hidden.

It will be difficult, I suspect, for women to challenge oppressive relations as their relationships can be based on mutuality wherein they provide some support for them. The technologies of power may be administered by people that women care about or that have some positive influence on the lives of the children women care about. It is difficult to challenge someone you have an intimate relationship with or someone whose actions can hurt the very people you care most about.

There are a number of factors to be considered when discussing women's resistance to power and in this thesis the resistances of women who care for people with intellectual disabilities. One of the most important factors is to gain understanding of how power operates differently at each level of the social order. If women are to bring about change they must challenge power relations at all levels (Lac|au and Mouffe, 1985).

Different strategies and sites may need to be adopted with respect to the level of power and the tactics being used. Change at one level

does not mean that there will be change at another. If change is to take place and be sustained it must be part of each of these levels. For example, a change in policy at the level of the State does not mean that the Organisation will implement this policy in ways that will benefit women who care (Bright and Wright, 1986).

Foucault (1980) discusses this when he describes the resistances that may arise to challenge power. He emphasises that because power is not conceived as operating in a binary relationship and that it operates from several points throughout the social order, resistances should also be organised in this way. He contends that power always has resistances but that these are only successful when they can be organised into well-formulated strategies.

Another important factor to consider is that women who care for people with intellectual disabilities are likely to have a unique struggle because they do not constitute a class in a strict economic sense and their dispersion among other class groups may make their struggle difficult. Economic issues are only one of many that these women will be confronted with.

Another factor relates to the plurality of women's struggles (Irigaray, 1985). It is incorrect to speak of a unified women's struggle that will encompass all women. There are a number of struggles taking place at any one time. These may have common themes and, according to a woman's personal experience, certain issues will take priority. The task for women is to show how their struggles can be supportive and reinforce each other rather than neutralise the achievements of one another. For example, one of the tasks for women who care for people with intellectual disabilities is to find what issues will be common to them as a group and to use these to define how change may take place.

The Process of Change

A number of elements contribute to the process of change. One of the

first tasks of women who care for people with intellectual disabilities and who are seeking to bring about change that will result in genuine improvements in their daily lived experiences, is to expose the relations of power and show how these are oppressive. Women must attempt to describe what power feels like and discover its immediate effects. In this research, the relationships between two crucial sites of power - the household and the Organisation - will be uncovered. For the women in this research, the daily and immediate effects of power must be examined prior to trying to discover the aims and objectives of power (Foucault, 1978). We may miss some key elements in women's oppression if we look for causes and origins before trying to obtain a view of what power feels like for women. An examination of power relations that are part of women's daily activities in the household and with the Organisation is necessary.

It may be difficult to expose power relations for "resistance is never in a position of exteriority..." (Foucault, 1978: 95). It is possible to show how women will need to determine what is antagonistic about the relations of power. Laclau and Mouffe (1985), for instance, claim that women must discover what is antagonistic in the subordinated positions they occupy and they must discover what it is that maintains them in the role of the "other". Irigaray also discusses this and states:

I think the most important thing to do is to expose the exploitation common to all women and to find the struggles that are appropriate for each woman, right where she is, depending upon her nationality, her job, her social class, her sexual experience, that is, upon the form of oppression that is for her the most immediately unbearable (Irigaray, 1985: 166-167).

In this research I will examine whether "mimesis" is one of the strategies women can use to understand their oppression (Irigaray, 1985). Irigaray asserts that women can use "mimesis" to begin to learn about what the power relations feel like and they may meet with

other women to talk about this. In talking about the power relations women begin with describing their daily lives (Irigaray, 1985). Women who care, for example, could carry out an analysis of their daily routines and activities in order to expose the power relations and hence the ways in which they are oppressed.

An examination of women's oppression may reveal that one of the difficulties is that women do not spontaneously come together to form a 'natural' group. They are scattered among different households. They may not often come together to meet. They can remain physically isolated from one another (Irigaray, 1985). Although, in this study the women all care for people with intellectual disabilities, they have contrasting interests and concerns. It may be determined that they have individual resistances that disrupt the immediate effects of power but these may not challenge power on a sustained basis because these have not been organised into strategies.

In his discussion on resistance Foucault refers to this and observes that resistance is like the relations of power:

distributed in irregular fashion: the points, knots, or focuses of resistance are spread over time and space at varying densities, at times mobilizing groups or individuals in a definitive way, inflaming certain points of the body, certain moments in life, certain types of behaviour...(Foucault, 1978: 96).

It may be difficult to identify the aims of power relations and who initiates such relations (Foucault, 1978). Not only is it difficult for women to identify power and to challenge it on a sustained basis but the forming of groups and the challenging of power relations often has unexpected consequences. These may actually cause further oppression for women as the dominant group's hegemony is threatened and it finds new and more subtle forms of oppression (Foucault, 1980). However, the result may be that more overt forms of oppression may arise and women can use these to bring their experiences further into the public realm and available for closer

examination. In order to prevent this happening the dominant group may make certain reforms that help some women but do not improve the conditions for all women. This may have the effect of discouraging some women from joining in the struggle as their situation has been improved (Laclau and Mouffe, 1985).

The dynamic nature of power relations makes women's task difficult since the oppression is not always clearly defined; moreover there may be no major ruptures that intensify women's struggle. The power relations are ingrained in the social fabric and it is as a group that women must articulate what antagonisms do exist. Antagonisms do not just arise spontaneously - women have to expose them and show the power relations for what they really are (Laclau and Mouffe, 1985).

Women must try to discover just what the possibilities for change are. There will be times when the conditions make it easier for change to take place (Laclau and Mouffe, 1985). It is essential for a group to be organised and have strategies in place that will enable them to take advantage of unstable conditions when they arise. For example, it may be concluded that women who care for people with intellectual disabilities must take advantage of any of the positive changes the Organisation may initiate.

Women who care need to develop a clear notion of how conditions could improve. The demands of women must not merely critique the current social order but must have a viable project for the reconstruction of another social order. A "strategy of opposition" must be transformed into a "strategy of construction of a new order" (Laclau and Mouffe, 1985). Laclau and Mouffe point out that in the absence of a positive strategy struggles will remain marginal in that no lasting structural change can be affected.

Irigaray maintains that women must challenge all forms of "power and power relations". Women must not simply aim for a change in the distribution of power because this leaves the power structure intact and would mean that they would be "resubjecting themselves, deliberately or not, to a phallographic order" (Irigaray, 1985: 81).

Transformation is not a reversal of roles or a few minor changes that are attached to the existing categories of theory and experience. I argue that women who care for people with intellectual disabilities will need to be aware continually of this issue and take the time to reflect on whether their struggles can be used to bring about structural change or whether they only benefit a few women for a limited time.

Sometimes women will be forced by men to compete with one another. Women must break out of the positions of "mutual rivalry" that men place them in (Irigaray, 1985). In order to build an alternative social order they must find a place for individual and collective "consciousness raising" concerning the specific oppression of women. This allows women to regroup. Women begin then to work on their own analysis by experiencing the relations of power at a personal level and relating these to the more global terms of power. Women, according to Irigaray (1985), must then seek to break away and challenge the hierarchical power relations and construct a new order based upon non-hierarchical forms of discourse that influence the daily experiences of women.

In the process of change women who care must have realistic goals that are rooted in daily experiences and are also related to a vision of what the future for women could look like. Women must be realistic in that there may be no utopia for which to strive; a new order has to be constantly renegotiated and redefined and each achievement has to be reflected upon and the next tactic formulated. Women may use different strategies with respect to the level they are attempting to change and to the nature of the power relations. For example, resistances that challenge global forms of oppression may be different from those that challenge the immediate and intimate social networks of women. Women live in a contradictory world and like many other groups they may have difficulty being specific about their oppression. This may be especially so if the positive aspects of their situation are constantly undermined.

It is possible to show that any process that challenges the Organisation must not merely be reactive but must clearly identify how women see the role of the Organisation and how this influences their lives. Because power and its effects are inevitably multifaceted it is important that women understand its nature and effects in their daily lived experiences. They must carefully choose their struggles so as to avoid counter-productive tactics that may in fact create more oppressive structures. Helping women to be more aware of the policies of the Organisation and how these may support the current order is, I believe, an essential strategy.

Because it is highly likely that in a patriarchal society policies of the State will tend to reinforce the practices of the Organisation these may also need to be challenged. I argue that community care is an example of this as it is often assumed that care in the community is better than any other more formalised alternatives. However, this often means care by women but it will be labelled in euphemistic and humanistic terminology which will cite the advantages of such a policy (Offe, 1984). For example, it will be said that the quality of life of people with intellectual disabilities will be improved without showing how additional burdens will be placed on women caregivers (Dalley, 1988).

The Role of Change Agents in the Process of Change

Using ideas based on Gramsci and Foucault's analysis of the intellectual I attempt to identify a group of women I call the 'change agents'. This group has a role in helping to develop and reconstruct knowledge with other women and a role in helping women transform their current reality. They help to link the experiences of diverse groups of women in order to extract common themes of oppression. This group must not be removed from the daily experiences of women but must have an active relationship with the women they are working with. It can be shown that the strategies for challenging knowledge and the social practices are derived from

actual experiences. This will mean that the 'change agent' does not construct frameworks and test them out on other women but that women help in the construction of these frameworks.

An examination of women's lives can show how the group of 'change agents' can work with women to confront the immediate effects of power and to identify ways that women can, on a daily level, resist power. Each unique experience is analysed and the individual resistances are translated into well-formulated strategies that can bring about collective change for women. This group can help women devise strategies that will enable them to cope with daily power relations at the same time they are struggling for collective change. It is important that women's immediate needs are met. I would expect, for example, to find that women who care for people with intellectual disabilities may have difficulties in the relationships they have with the professional disciplines. I wish to discuss whether there is a group that can, with their specific knowledge, help women find personal ways of coping with these while also trying to discover ways that will bring about sustained and structural changes.

I believe that it is the 'change agents', whether individually or as a group, who act to provide a mediating link between the different levels and sites of struggle, for example, between the household and the Organisation. They ensure that change does not only take place on a theoretical level but that it transforms all levels. These 'change agents' must not become part of an elite group wherein they become experts who are removed from the reality of women's experiences but one of their key roles is to construct frameworks that incorporate the experiences of women and which acknowledge these as being of value.

As Foucault puts it:

A new mode of the 'connection between theory and practice' has been established. Intellectuals have

got used to working, not in the modality of the 'universal', the 'exemplary', the 'just-and-true-for-all' but within specific sectors, at the precise points where their own conditions of life or work situate them (housing, the hospital, the asylum, the laboratory, the university, family and sexual relations). This has undoubtedly given them a much more immediate and concrete awareness of struggles (Foucault, 1980: 126).

Foucault refers to these intellectuals as the "specific" intellectual, as opposed to the "universal" intellectual (Foucault, 1980). The "specific" intellectual may not be employed in a role that is generally associated with the carrying out of "intellectual" activities. This group is comprised of individuals from diverse backgrounds and their common characteristic is that they have a commitment to bringing about change. Gramsci (1971) claims that intellectuals emerge as a result of their immediate experiences with oppression. They take the time to reflect on their experiences and attempt to find some explanation for these. They will seek out others who are beginning to examine their position and from this a group of intellectuals may begin to form. The 'change agents' I refer to have similar characteristics to the intellectuals Gramsci and Foucault refer to. However, I do not call them intellectuals as I believe that the term 'change agent' describes more clearly their role and the way in which they work with women to bring about change.

A key task of 'change agents' is to link the unique struggles of women with one another and with other groups. They can help women keep the struggle active and to carry out activities that women may be too exhausted to do on a daily basis. They can work quietly for change and when necessary can, with other women, bring these changes in to the public realm. They help determine when the conditions are unstable and when change can effectively take place (Gramsci, 1971). The 'change agent' also consults with women to determine the process and outcome of change.

In this thesis I aim to show that there is a possibility that a group of 'change agents' will form and that this is an essential phase in

women's struggle. It is this group who may, in fact, be able to help women transcend their daily oppressions and take the opportunity to reflect and then act upon and change these. It can be this group which brings new knowledge to these women on a daily basis and constantly links these women's personal experiences to global issues. It may be shown that it is the task of this group to ensure that this change is sustained and that it is their efforts that will help women find a place that is a valued part of the social order.

This process must begin with a description and understanding of women's experiences. It is only after this has been done that oppressions can be exposed, oppressive structures critiqued and deconstructed. This will enable women to construct and formulate their own frameworks for discovering what kind of world they wish to live in. It is to this task that I now turn.

CHAPTER THREE: THE RESEARCH PROCESS

This chapter sets out the methods used to carry out the research including a discussion of the links between the theoretical framework and the research methods. It provides background information on the women who were interviewed and describes the process used to select the women. A discussion of how the analysis was ordered and some reflections on this will also be included.

Theory and Research

As was discussed in Chapter One, I view feminist research as a way of revealing the experiences of women and in this thesis of those women who care for people with intellectual disabilities. Feminist theory and research also entails seeking to change some of these experiences and providing alternative ways for interpreting them. Not only have the contributions of these women been devalued but the ways in which they have been described have not revealed the richness and diversity of their lives.

My views on women and their role in social scientific research have influenced the way I chose to carry out this study. These views have been influenced by my personal involvement with women who care for people with intellectual disabilities. I have been in direct caregiving roles and in positions that function to provide support to women caregivers. Significant insights for the present study were developed from previous studies carried out between 1980 and 1984 (Munford, 1983; 1986; 1987).

My experiences have shown me that much of what those women who care for people with intellectual handicaps do is hidden. Many of these women work behind the scenes to ensure that people with intellectual disabilities can achieve their goals. Their contributions may be devalued and may not have been adequately

described and researched. Chapter Two emphasised that in order to understand the way patriarchal structures control women's experiences it is important to obtain an understanding of the daily lives of women who care for people with intellectual disability. The very process of doing research can be used to reveal and help these women explore some of the power relations they experience on a daily level. As Grimshaw (1986) writes, feminist theory and research seek to take such experiences and bring them into the mainstream of social scientific investigation and writing. Stanley and Wise also claim that women's everyday experiences have been on the periphery and that feminism must function to bring these experiences into the public realm:

....Feminism argues that systems and social structures whether concerned with the economy or the family, or the oppression of women, more generally can best be examined and understood through an explanation of relationships and experiences within everyday life (Stanley and Wise, 1983: 53).

They argue women must "reclaim, name and rename" their experiences beginning with the daily lives of women (Stanley and Wise, 1983: 165).

Rowbotham (1983) has a similar view and argues that women researchers must recognise that women should no longer remain in a "twilight world". Research must include the experiences of women in order to show how these experiences can expand our knowledge about the social order by helping us to link phenomena that may not have been previously recognised let alone understood. The diversity of women's lives must be explored and be put into a context that shows their relevance to the major issues of economic and social well-being. Grimshaw explains:

Women were never unimportant or marginal from the perspective of their own lives; they become unimportant only through male historical constructs that ignored or trivialised their world...(Grimshaw, 1986: 55).

It is Grimshaw's view that: "Writing women into history implies not only a history for women but also a new history" (Grimshaw, 1986: 55). Women's history has, as Grimshaw (1986) suggests, not only been ignored but also misconstrued. By writing women into history a new history of women can be created.

The women I have interviewed have been on the fringes of the Organisation's activities. Moreover, their service and involvement has been under-estimated, if it was written in the history at all. It is also difficult to find literature that not only describes but also analyses the involvement of women in the care of people with intellectual disabilities (Bright and Wright, 1986). For many of the women in my research, the interviews were the first opportunity they have had to tell their story in such detail.

The Role of Feminist Methodology in This Study: Factors That Have Influenced the Research Design

Feminist research is concerned not only with making women visible but also with the theoretical and methodological issues about women's experiences (Roberts, 1981). Research that does not challenge the existing social science frameworks inevitably results in research "on" and "about" women rather than "for" women (Klein, 1983). The relevance of these assumptions to my research is exemplified in the ways that I reveal the experiences of women who care for people with intellectual disabilities and accompanying this the analysis of the ways in which these experiences are interpreted.

It is not sufficient to merely tell the women's stories. These must be linked to broader issues in order to demonstrate how the women's individual experiences have a number of common themes. In this way the researcher can begin to accumulate knowledge about women that can contribute to a critique of the way women's experiences are written about. It can also contribute to the process of reconstructing women's history to be used in a way that will challenge why these women are viewed and treated in certain ways (Weedon, 1987).

Feminist literature shows how the process of research will influence the ways in which the documentation of women's experiences can be reconstructed. Oakley (1981) describes how the researcher's experiences must be an integral part of carrying out the research process. A process which in turn is influenced by a particular cultural, social and historical context. Women researchers should not manipulate data from a safe distance but must view the research process as more than a technical strategy. Oakley (1981) suggests that a feminist methodology of:

social science requires that the mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others into their lives (Oakley, 1981: 58).

This research uses a qualitative research design that reveals both descriptive detail and an understanding of lived experiences from the perspectives of the women interviewed.

I wished to uncover "the meaning of social events and processes, based upon understanding the lived experience of human society from the actor's point of view" (Finch, 1986: 9). Such a

process was essential, I believe, if I was to uncover some of the hidden history of these women and capture the richness and diversity of this history. In so doing, I do not reject the usefulness of quantitative research as I believe that both kinds of evidence can support one another.

The Process of Carrying Out the Research

Setting the Scene

My feelings, beliefs and attitudes have significantly influenced the way I related to the women I interviewed and the stories they shared with me. The women knew that I have had a long involvement with the IHC and that I had cared for children with intellectual disabilities. I was, for this reason, better able to understand what they were telling me. I understood their language because the words they used were familiar to me and I was able to relate my experiences and knowledge to the feelings they shared with me. I knew what they meant, for example, when they talked about how at times they loved their child, but at other times they wished they had "never been born". I was able to listen to these experiences with sensitivity. I believe as Oakley (1981: 49) states that there is "no intimacy without reciprocity". I could not treat the interview as merely a means to gather information but rather, in exchange for this information, I had to be intimately aware of and have respect for what the women were telling me. The act of giving information about oneself can be very liberating in that it can help women identify with the experiences of other women (Oakley, 1981). This can have the effect of allowing women to feel less isolated.

Oakley (1981) emphasises the importance of the researcher ensuring that they do not set up a hierarchical relationship with those being interviewed. I tried not to impose myself upon

the women and act as an "expert", as this could have had the unintended consequence of devaluing the experiences the women were sharing with me. It was essential to set up a non-threatening environment so that the women would feel comfortable in sharing their experiences. It was important that the women knew they could trust me. I set up such an environment by emphasising that I had the time to listen to their stories and by demonstrating how I was genuinely interested in what they had to tell me.

Although I used an interview schedule the questions were organised in a way that would encourage the women to explore fully their feelings and perceptions about their situation. This, in itself, helped to support the setting up of an environment that made the women feel comfortable. It was an important consideration if the women's diverse experiences were to be recorded and revealed authentically.

By listening in a way that showed I understood and respected the feelings of these women I was able to establish a rapport with them in the interview. I was careful not to probe and ask questions that the women might feel uncomfortable about. Nevertheless, perhaps as a measure of their trust in me, the women did share some very personal information with me. I wanted to be sensitive about this as these women are often interrogated about their private lives. For example, in my previous studies (Munford, 1983) I found that women were often asked by specialists such as medical practitioners, to share some very intimate details about their personal lives to enable, so they were told, these specialists to more fully understand the child. Women may not be informed of the results of these interviews and interrogations because feedback is not necessarily provided. As a researcher I had to give something back to these women. I could not just take from them. One of the things I was able to do was to listen and to be clear that any personal information would not be used in an inappropriate

and insensitive manner. Some of the women used the interview to vent their frustrations. They commented that it was helpful to talk to someone who was not directly involved in their personal lives. These women explained that they are often reluctant to share their experiences because it can be too painful. Once these have been verbalised they pointed out that they were scared that it may be difficult to carry on with their routines of daily living. For some it was better to ignore the problems they were having and in so doing avoid having to confront the pain these can cause.

The interviews had a dual function: they not only provided me with data but I was also able to share some of my knowledge with the women (Oakley, 1981). There was then a reciprocity between myself and the women and this I believe contributed to the success of the interview. In this research, I was able to clarify some of the concerns these women had and in some situations give them some advice about services. For example, some of the women were concerned about changes in the Organisation's goals and wanted some clarification on these. Several wanted to talk about some of the daily pressures they were experiencing such as getting proper equipment for their child. I allowed time to discuss these concerns. Finch (1984) talks about this when she describes how women are often willing to share their time and stories with the researcher because it is a welcome contrast to their daily experiences. It gives them an opportunity to reflect upon their experiences in a non-threatening manner.

The researcher must not devalue the roles women carry out and in doing this must acknowledge the significance these roles have for them. It was essential to try to understand their feelings about their roles in that for some women the only power they have is embodied in the way they carry out these roles. It was important to respect this and not undermine it. Some of the women had difficulty expressing the confusion they felt in

carrying out these roles and they viewed many of their feelings as ambivalent and contradictory. Time, as James (1985) comments, must be given to allow women to explore these feelings in the interview. The researcher must convey to the women that this is a legitimate part of the interview. The women in my study shared their feelings about their partners and about the Organisation. For example, many felt uncomfortable criticising the IHC as it had helped them out in a variety of ways and some women also felt this way about their spouses and partners. The interviews were useful because they enabled some women to work through these issues and in my role as researcher I had to ensure that women felt able to do this. This I argue is, as Oakley (1981) suggests, an essential aspect of feminist research.

These factors have been an integral part of this study and are the reasons why I chose to research the experiences of this particular group of women. These factors have influenced the ways in which I chose the women to be interviewed and the ways in which I constructed my interview schedule and analysed the results of these interviews.

The Procedures and Criteria Used to Select the Women

Several criteria guided the selection of the women. I chose those mothers who had adults over 20 years of age, and paid workers who had a minimum of five or more years involvement with the Organisation. At least ten of the mothers had been involved for over ten years. The length of involvement in the Organisation was important as this also enabled them to reflect on the changes that had taken place in the IHC.

I interviewed thirty women; fifteen mothers and fifteen women who worked for the Organisation. I believe that these women, in the sharing of the experiences they have in caring for and

working with people with intellectual disabilities, give us an impression of what it is like for women in this situation at this time and during the last twenty to forty years.

The selection of the women was not random. I asked two local Branches of the IHC to provide me with a list of women who fitted the criteria outlined above. Pragmatic factors determined the selection of these Branches. They were of close physical proximity to my home. They were urban Branches, and I acknowledge that these women may have different experiences from rural women. The Branches gave me the names of thirty-six women who met the criteria outlined above.

Once I obtained the list of names I systematically proceeded down the list. Each woman selected was contacted by telephone to establish whether she wished to participate in the study. Only two women refused to be interviewed: one who was unwell and another who was travelling out of town for the next few months. From the list of women I was given I had no difficulty finding thirty women to interview as all were very willing to be interviewed. Hence, I did not need to go back to the Branches for more names.

I was given the feedback that many of the women stated that they were excited about the possibility of being interviewed. These social workers also pointed out that some of the women felt more comfortable in being interviewed by me because I had knowledge about the Organisation and had been involved in caregiving. This is significant and worthy of consideration as it does, I believe, reflect the ways in which the research process can be more effectively organised and carried out (Oakley, 1981). It is easier to establish rapport with those being interviewed when they are interested in the research and feeling comfortable about this research.

The interviews took place in the middle months of 1987. The thirty interviews took a total of three months to carry out.

The women came from a variety of cultural, social and economic backgrounds.¹ It is important to describe the context within which these women care. An understanding of the daily commitments and concerns of the women can help us understand the views they have. To facilitate this I asked each woman to talk about her typical day. This is recorded in the next section on the descriptions of the women's daily experiences.

One of the women in my study was a Maori woman. However, I have not examined ethnicity as a key variable. Given the size of the group I cannot make any conclusions about this. The needs of Maori women who care for and work with people with intellectual disabilities however, cannot be ignored and requires further research.

The Interviews

Several factors influenced the way I devised the interview schedule. A semi-structured interview format was adopted. The design of the interview schedule provided the women with an opportunity to begin with describing their daily routines. This set the context for the rest of the interview (see Appendix Two for a copy of the interview schedule). I chose a semi-structured interview format as it provided the flexibility required to enable the women to explore in depth all aspects of their daily lives. I did not begin with a rigid framework that may have caused me to miss certain key phenomena that did not fit neatly into preconceived categories. It was important to firstly encourage the women to describe their experiences in their own language and to ask them to provide meaning to these

¹ Appendix One provides a summary of the personal characteristics of the women.

experiences. I asked questions that were open-ended and that encouraged the women to give as much information as possible. I used the schedule as a guide to check that I had not missed anything. However, I did not necessarily ask all of the questions included in the interview schedule as many of these were covered in previous responses.

In phrasing questions I used the word "describe" rather than "why" which may have restricted the range of possible answers. The "why" questions were only asked once the women had described the details of their experiences. I made it clear to the women that no detail was insignificant. When I asked, for example, about a "typical day" for these women I wanted to learn about all the activities no matter how insignificant they may have appeared.

Thus these concerns guided the construction of the schedule. Although I was concerned that the schedule should not be so rigid that it would prevent women from exploring in depth their daily lived experiences, I also needed to have a means through which the data could be organised and managed effectively. As Weedon (1987) suggests, it is important to allow women to explore freely their "personal" lives. However, theory helps the researcher to structure this data in meaningful ways; ways that enable us to preserve the diversity of women's experiences while simultaneously extracting common themes that will contribute to our knowledge about women's lives.

In the construction of the interview schedule I followed my conceptual categories with respect to the relations of power as outlined in the theoretical chapter. For the mothers I began with the daily experiences of women in the household and then asked them to describe their experiences with the Organisation. When I interviewed the paid workers I was interested in learning about their experiences with the Organisation; firstly their experiences in the workplace and those emerging from their relationships with other people, and then their views of the procedures of the IHC.

My previous experience with and knowledge about the Organisation contributed to the development of the schedule. I had, as previously stated, already carried out studies of this Organisation and the experiences of women who care for people with intellectual disabilities. I also read the background material about the Organisation such as historical records, the minutes of meetings such as AGMs, newsletters and special reports and publications.

I also spoke to five women on an informal basis in order to provide a pilot test before constructing my interview schedule. These women were not part of the study but were either mothers or paid workers who were (or had been) involved with IHC. These women helped me identify key questions and a method for asking these. To facilitate this process I discussed my theoretical ideas with them and after talking with them I subsequently modified and added questions to the interview schedule.

The final format of the schedule included a list of questions covering women's daily lives, their relationships with IHC and an exploration of the knowledge that gave meaning to these women's experiences.

When I phoned the women I asked them to set at least four hours aside. They selected the date, time and location of the interview. All of the interviews with the mothers were carried out in their own homes while those with the professional women were carried out either in their homes or their places of work. For some of the women alternative caregiving arrangements had to be organised. It was important to acknowledge the time the women were setting aside to talk to me and ensure that practical details like caregiving were organised so that they felt comfortable giving their time.

With the women's prior approval I taped the interviews and in this way I was able to listen to the women without being

concerned about taking notes. I found this to be extremely useful. The women usually forgot that the tape recorder was on and it was only turned off if women were sharing confidential information about themselves.

As well as the verbal communication I had with the women, these women also expressed themselves in non-verbal ways. These, and the nuances of the language, were sometimes extremely useful for determining the significance of the event they were discussing. The intensity of their feelings was illustrated in these non-verbal ways and included lighting a cigarette, playing with fingers, moving in the chair and talking softly. These contextual variables helped me understand further their experiences and the meanings the women attach to these. All the interviews were done in a quiet room with no-one else present. The women set it up like this. In many instances I obtained the impression that these women did not want anyone else to hear what they were saying and that they did not wish to be interrupted once they began to tell their story. In my view these arrangements have contributed to the authenticity of these women's stories.

Each interview was at least two hours in length and some were nearly four hours. This included the time I spent with the women socialising and talking about things that were not related to the interview. It was important to allow enough time so that I did not leave the women feeling that they had not fully discussed all their concerns. I was especially concerned to make sure the women had time to prepare themselves for returning to their daily tasks. This was necessary because a lot of the women shared some very painful experiences with me. But as the subsequent analysis will show these women had, despite the pain, continued to care and carry out their daily activities for many years.

It was important that I carried out the interview myself so I could get a total picture of the women's experiences and start to identify common themes. This was necessary because the

information these women shared with me has never been explored and written down in this way. I wanted to preserve the richness and diversity of these women's experiences and I believe that in this research this may not have been possible if others had helped me carry out the interviews. By doing the interviews myself I was able to more easily extract the common themes and make links between the women's experiences.

Wherever possible I undertook only one interview a day. If I did two, I did one in the morning and one in the evening. This ensured that I did not get so exhausted that I could not respond effectively to what the women were telling me.

The interviews were a sharing time with both of us actively contributing to them. I was aware that I had a responsibility to follow up on some of the information women were sharing with me. This entailed providing some practical details about the Organisation. I did not want to leave them feeling frustrated and confused because I had raised issues that had been painful and that had enabled them to talk about feelings they had been unable to resolve but were still trying to hide.

Because I have an intimate knowledge of the Organisation it was important to check that I was not making assumptions or conclusions based on my existing knowledge. It was essential to ask women to clarify their statements. I had to keep checking this throughout the interview by paraphrasing women's responses to ensure I had interpreted the words correctly.

It was also important to focus on the positive aspects of the women's experiences. I did not want the interview to become a time wherein the women felt as if they must relate all their horrible stories and criticisms at the expense of telling me about the good things they had experienced. It was also important to convey to the women that all of what they had to share was significant.

I was often asked what my opinions were on a certain matter. If

it was not possible to answer this during the interview I made a point of returning to it at the conclusion of the interview. I ran a feedback session at the completion of all the interviews where all the participants (except for three) came together as a group to discuss the findings. In this session, in order to preserve confidentiality I shared the common themes rather than detailed information about individual women. The feedback session was a valuable exercise as women were able to share their concerns and in some cases identify some strategies for dealing with these. Many of the women commented that they welcomed the opportunity to come together to share such concerns. As the analysis will show, it is often difficult for the women to come together as a group. Some of the women suggested that they should now meet more regularly in order to discuss the particular concerns identified in the process of sharing their common experiences in the feedback session.

The Analysis

The interviews were professionally transcribed and I listened to the tapes, checking them against the transcriptions. My analysis of the interviews began by extracting a number of themes. I asked two of the women who had helped in the construction of the interview schedule to read several of the transcripts and extract themes they felt were significant. These women were not interviewed but had some knowledge about the experiences of women who care for people with intellectual disabilities. My previous research and work in this area also helped me identify common and significant themes. The women themselves would often suggest that a particular experience was a common one for women who care for people with intellectual disabilities. There were in fact a number of common themes that emerged from the experiences women had on a daily level in the household and in their contact with the Organisation. In the feedback group session with the women I shared some of these themes in order to check my interpretations of the information.

It was interesting to note that several of the mothers found they had more to share about the Organisation than they did about the household. According to the women there were several reasons for this. Firstly, because so much of their lives were intertwined with the Organisation the boundaries between the household and the Organisation tended to become blurred. The Organisation became like a family, wherein the roles and activities of the Organisation reflected those of the family. Secondly, it was often very difficult for women to believe that the men they loved could cause them so much pain. Although these women believed that the things men did were not always intended to hurt women, it was still very difficult and painful to admit that the people you lived with and loved could be so unaware of your needs. For this reason it was often easier for the women to talk about the men who were more removed from their immediate daily experiences rather than about those with whom they lived. I hope I have adequately portrayed such feelings in my description of the women's stories as it was an important strand in their stories.

In writing up the analysis of the interviews I began with a description of the women's experiences. I did not edit any of these except to change people's names and the names of places. In dealing with key aspects of the women's experiences I tried to choose the quotations that were representative of these women. The analysis of the women's descriptions of their lived experiences follows the theoretical framework discussed in Chapter Two. I began with the women's daily lived experiences in the household and moved to an analysis of their relationship with the Organisation. The "technologies of power" were analysed at both sites.

In the process of carrying out the description and subsequent analysis of the women's experiences, I was mindful of feminist principles for developing theory and carrying out research. I attempted to show the ways in which the women had begun to

devise their own strategies for interpreting and changing their daily lives. As a researcher I tried not to take on the role of an expert who took down information in ways that further manipulated women's experiences (Klein, 1983). This research will have the most impact if it can be used by women to bring about some change in their lives. The analysis of the interviews will not provide a blueprint for change but rather a tool that can be used by women. It was in this way that I could give something back to these women. I was overwhelmed with the responses of these women to the research and their willingness to share their stories with me.

I believe that the experiences of these women must be told in a way that preserves the range and intensity of their feelings about themselves. The ways in which others have control over their lives and particularly their unflagging and seemingly boundless commitment to the people they care for and work with have not previously been told in such detail. Feminist theory and research emphasises the importance of retelling women's stories in order to correctly portray women's perceptions of their lived experiences. Many of the women were in fact telling their stories for the first time.

The stories of these thirty women can have significance for and contribute to a better understanding of the experiences of other women who care for people with intellectual disabilities. These stories may also in fact contribute and add to knowledge about other women's experiences in the household and with the organisations they are part of.

These women have made an invaluable contribution to the Organisation and to the lives of people with an intellectual disability. Now is the time to show this. I believe my research will assist this process by revealing and exploring the women's perceptions of their daily lived experiences.

PART 2: THE WOMEN'S EXPERIENCES

This section describes and analyses the women's experiences. I begin with a description of the mothers' experiences in the household. I describe their daily lives and the way power operates to maintain their current positions. I then describe the women's experiences with the Organisation. I discuss the experiences of the mothers and the paid workers in the same sections as the two overlap. In this description of the women's experiences a number of common themes will be introduced which will be analysed using the theoretical framework outlined in Chapter Two.

CHAPTER 4: WOMEN'S EXPERIENCES IN THE HOUSEHOLD

The Major Themes

I begin with a description of the mothers' experiences in the household. The household is a crucial site as this is where the mothers spent much of their time and it was here that they carried out most of the caregiving routines. The description of these women's lived experiences in the household will reveal how they may be isolated and kept apart from one another. This description will show how these experiences in the household are intricately linked to those in the Organisation with both influencing one another. A detailed description of the women's daily lives will identify the intensity, diversity and subtle effects of the power relations operating at this site.

The themes that relate to the physical experiences of the women will be discussed first. I then discuss those relating to the emotional aspects of women's daily lived experiences in the household. These, of course, will overlap, but some delineation is important as it assists the reader in their understanding of the women's experiences.

The themes that are central to women's experiences in the household are the daily routines and relationships of women; health; time; commitment; sacrifice; support; feeling grateful; feeling worthless and feeling ambivalent. I will now expand upon these.

The themes categorised within the physical experiences start with a description of women's daily routines and relationships. This provides a picture of what women's routines and relationships feel and look like; what they entail on a daily basis; and the women's interpretation of this. This leads on to a discussion of women's state of health including both the positive and negative aspects of women's health, that is, the high level of physical energy they have,

but also the tiredness and ill health these women may experience as a direct result of caring for people with intellectual disabilities. Following this the use and ordering of women's time is discussed. This includes a description of the long hours women spend waiting for and servicing others.

The emotional aspects of women's experiences begin with a discussion of the commitment women have to their child and family. It also includes a discussion of the sacrifices women make. Women may feel trapped, unable to determine and control what form their daily lives may take. They may forego certain opportunities in order to be with and service the child and other family members.

Women also talked about support which is, in itself, an ambiguous term with many meanings. The women's interpretation of this word is charged with a number of contradictions in that the needs of the women may clash with those of paid workers and others providing support. Professionals may, albeit unwittingly, encourage dependency from those receiving support. A number of conditions may be placed upon those women who require support, thus restricting their access to this. Women may have no part in defining what this support will be and in what form it will be provided.

Feeling grateful is another theme women discussed. They may be expected to feel grateful for any kind of support and service they may be given, even when this is not appropriate and does not actually meet their individual needs. This frequently made the women feel worthless, powerless, and unable to control their own lives. However, they felt ambivalent about this in that at times their situation was satisfying and had some positive aspects and outcomes. They did, however, point out that this did not happen often enough and much of the time they felt confused and frustrated about the unpaid 'work' they were expected to carry out for their child/adult and other family members.

These themes will now be explored in depth. I begin with the mothers' daily experiences in the household as this is where they spend most of their time. This is also where the relations of power may have the most impact. It may be difficult for women to remove themselves from the household and the technologies of power that operate there. In this section I focus on the mothers as it is they who live in households with people with intellectual disabilities. The paid workers' experiences are discussed if they are related to those of the mothers' experiences in the household.

The Daily Routines and Relationships Associated with Caregiving

I asked the women to describe to me a typical day. This included a detailed description of their daily routines and of the relationships they are part of. I wanted to discover what the relations of power feel like by understanding what happened to these women as they carried out their daily routines. This provided the context for understanding what caring was like for these women.¹

A Day in the Life of a Caregiver

Most of the mothers had remained at home to care for their child/children on a full-time basis. Very few had returned to the paid workforce. A number of the women had been engaged in voluntary or committee work for the Organisation. However, only one has had a position on an executive committee. Many had supported their husband/partners or other men in executive positions. When women were on a committee they very seldom took on positions on prestigious committees such as the finance and executive committees. Women tended to be placed on fundraising committees which required many hours of work but which were not part of making major decisions about the direction of the Organisation. These women had carried out their committee work in the form of organising raffles, annual appeals and other fundraising activities. Less than five of the women had

¹ See Appendix One for a summary of the women's personal characteristics.

attended a national executive committee meeting and very few had attended a national annual conference. Even when their child/adult left home most of the women continued to do some form of unpaid work for the Organisation.

These women also spent considerable amounts of time meeting with professionals about their children's needs. They spent many hours talking about and advocating for their children with people from the medical profession, educational authorities and auxiliary medical practitioners such as occupational therapists and physiotherapists. They then spent many hours carrying out the directions of these people, for example, implementing behaviour modification programmes which had been designed by psychologists.

From the stories the women shared with me I have attempted to describe what a typical day may be like for these women.

Morning Routine

When the child was younger most of the self-care tasks such as washing, dressing, toileting, feeding had to be carried out for them. These children may take longer than non-disabled children to learn self-help skills. Some will always need help with them or will need reminding that these tasks need to be carried out. Helping got more difficult as the child got older and harder to lift. The most common concern, when the women described self-care tasks and associated activities such as learning to help with the household routines, was that these children took longer to learn new skills. For example, toilet training may take many hours and it was difficult to give the proper attention to this when there were other young children in the household.

The women talked about the constant conflict between allowing the child to learn, but also getting the household self-care routines completed. They often felt frustrated and tired as they were continually trying to summon up the patience to allow the child to

learn at her/his own pace. They were always, it seemed, trying to balance the needs of the child with their own, and the needs of other family members. Women also talked about the difficulty of coping with the routines when other tasks become necessary, for example coping with menstruation, handling medication and coping with seizures. The mother was nearly always the family member who carried out and supervised the morning routines.

The Daily Routine

Most of the children/adults were sent to school or workshop facilities. Transport was usually arranged but at times this was not available. The women generally carried out some kind of voluntary activity for the Organisation during the day. For example, some visited the school or workshop and did work with the clients in these facilities. This activity took place at least once or twice a week.

These women also spent a lot of time visiting professionals to obtain advice about their child. This was generally a very stressful experience. They then spent many hours carrying out the programmes that were designed for their child. These added an additional task to the daily routines, for example teaching appropriate sitting behaviour at the meal table, teaching exercises for standing and walking, carrying out behaviour programmes. The women may have organised the family to help with these, but they usually had the final responsibility for ensuring that they were carried out. They often felt guilty for putting additional pressure on the family so did not ask them to help out. The women attended most of the meetings about their child, both within the Organisation and with other agencies, for example, meetings about the child's school activities. It was unusual for the husband/partner to attend with them.

The Afternoon and Evening Routines

Many of the women had concerns about the leisure time their child had to learn to use appropriately. The mothers were often left to "play"

with the child while other family members went to their leisure activities. It was improving but it was sometimes still a struggle to get the child accepted into mainstream leisure activities and transport and financial costs were often major barriers.

The evening routine was very similar to the morning routine with lots of time being used up in care-taking activities. The women described how this seldom changed over the child's life span and supervising or carrying out care-taking activities could continue for many years.

Many women talked about the feeling of always believing that they could be doing more for their child. For example, they should not just sit and watch television but they should talk to the child; they must not just prepare the meal, they must talk about this with the child; and they should always be thinking about the physiotherapy exercises they could be doing with the child. These are just some of the examples of how the routine of daily care-taking activities may make a woman feel that her job is never finished.

Some of the issues that women had fought for prior to the development of the IHC had now been resolved. Although many of the women now had some support and there was a variety of services available for their child/adult, there were still stresses and pressures that women were confronted with. For example, one of the major issues women had to deal with was balancing a career with caregiving tasks. Another primary issue was related to the feeling of never being able to provide for all the child's needs - the problem was not always the absence of services but rather whether women had the energy to access these services and carry out the programmes the professionals had offered them. It was still women who carried these out.

The Women's Feeling About Their Daily Routines

Despite the difficulty of their tasks women were still concerned about what they should do for their child/adult and how they could do

more for her/him. Even those women whose child/adult had left home still felt responsible and carried out repetitive routines when the child/adult came back to the household to stay for holidays and longer periods. One of the most common stories the women shared with me related to the repetition and the difficulty of the daily tasks they performed. Many of the tasks such as feeding, changing, doing therapeutic exercises and other kinds of therapy were extremely repetitive and these routines had to be carried out several times a day. Despite the repetition of these tasks, for example physical exercises, there may be little change in the child/adult. The rewards may be few and yet these repetitive tasks must continue in order to prevent the child regressing.

Many of the tasks such as lifting, changing, washing, cleaning up spills and other messes may be extremely physically demanding but must be done regardless of whether the mother or caregiver is feeling exhausted. Not only do these tasks take place in the home but after the mother has managed to get her child dressed and fed she may then have to transport this child to an activity. This can also be physically demanding if the child was non-ambulant and required to be lifted in and out of vehicles. Many of the women interviewed suffered from physical complaints which had been caused by the hard physical labour they must carry out on a daily basis.

Once the mother or caregiver had transported the child/adult to an activity they may have to stay with them to help in their educational or therapy programme. At this point they had to interact with others and this can be stressful as they often were criticised for the way they were "handling" their child.

When the mother or caregiver had managed to survive the day she must ensure that when she arrived home she prepared or organised the preparation of an evening meal and organised the household routines for other family members. She had to continually ensure that other family activities ran smoothly and that the child with a disability did not intrude on the lifestyle of other family members. My

interviews showed that it was primarily the mother who not only carried out the caregiving activities in the household but who, when being told to "have a break" by other household members, still had to ensure that there were clearly defined tasks outlined for everyone so that the needs of the child/adult could be met.

Mrs O, a mother, stated:

...the mother is really the one that looks after the handicapped children because the husband has to work. And then when he comes home tired from work he doesn't want to know how many times that day _____ wet on the floor or was sick or he had a row with the neighbour because of the kid or something else...¹

The following comments were typical and show how the experiences in the household were also present in the Organisation:

They're always in the caregiving roles. Direct hands on caregiving roles....I think it goes back to the traditional myth of women as being primary caregivers. The men in positions of power.

Um, I think mainly the men I've come into contact with within the IHC have been administrators or managers or executive staff, something like that, and it's the women who do all the hands on, all the middle management - not usually top management. But they're usually service orientated.

Mrs B talked at length about how her husband and the male members in the household would leave her to carry out the care of their child. She stated that men leave it to women because they know women will do the work for them:

¹ The quotes from the women have not been edited. Names and places have been changed in order to preserve the identity of the women.

The woman does too much and the man will leave it naturally. If someone else is going to do it they will always leave it, won't they? If my husband took over I'd leave it to him too.

There were many comments from the women that referred to the ways in which men could not cope with both the emotional and physical demands that a child with a disability placed on the family. They got too emotionally upset if they had to do therapy with the child or take them to activities. Typical comments were:

The father just didn't cope at first but he did come around slowly. However, I still think it, it's far harder for men to realise they have a handicapped child; they fathered it....Some fathers just refuse to be involved.

I don't think men face up to an IHC child like a woman or a mother does....I've heard of cases where it breaks up marriages...women are totally different than men. Men can shut it out, can't they?...

Many of the mothers referred to the fact that men would just refuse to be involved. Women didn't have this choice. They just had to cope. The paid workers also talked about how they had observed this behaviour in the households they visited.

When I asked the women who had helped them and what assistance they have had, comments such as: "Well, nobody because we did it on our own. We didn't need anybody else" were common. Similar comments were made such as:

No. I think you take what you're given and do the best you can with it. I don't think you wonder, 'Oh, I could've done that, or I could've done that.' That's never occurred to me...

I didn't expect anyone to help me, it's my problem...it would have been nice to have someone to mind him and the others while I went to the dentist and things like that...it would have been nice to do the shopping without any children....You just didn't ask.

Most of the mothers had hidden their feelings about what it was like caring for others. Mrs N, a mother, who has had a long involvement with the Organisation, stated:

I never sort of told many people or talked to other people about....I don't know why. I never did. I felt it was nobody's business but ours. I suppose I shouldn't have been like that and sort of talked with others - I might have got it off my back, but I never wanted to.

The paid workers understood the feelings of the mothers and often tried not to place additional expectations on them. Mrs K, who was involved in residential work, elaborated on this:

I mean, it's alright for us; it's our job and we go home and we can get away from it and have a break. Or we can share it among ourselves. Like some of us get on better with individual people here than others so we share the load. But for people at home with an intellectually handicapped person, getting the full brunt of that, 24 hours a day, it must be sheer hell. And somebody aren't made to cope with that. I don't know how I'd cope with that if I was a parent.

Another reinforced this view and commented that:

The Heads should remember that it couldn't keep going if someone didn't look after the child and make sure they were happy...

The men and others in the household leave caregiving to women and their own work gets done at the expense of the mother's lifestyle. This may lead to women experiencing problems with their health and well-being.

Health and Well-Being

This theme includes the ways in which the women's mental and physical health may have suffered. It also describes the level of energy women displayed for they not only get tired, they also have an overwhelming capacity to "keep going".

I will begin with a discussion on the energy level of these women. Women had the ability to keep "giving more" to their daily tasks. These women had cared for children/adults for many years and yet they had this unflagging capacity to "keep going". When asked what this felt like, many talked about the love they had for their child and the ways in which they derived satisfaction and pleasure from their work. Many women "live for the moment" and for what they can do for the child/adult.

However, keeping one's strength up is often difficult for women in that they may make many sacrifices. They often got tired and suffered illnesses that were directly related to the stress of caring for a dependent person. These people may always be dependent and the realisation of this often caused much distress for these women. They felt helpless and despaired that they were powerless to change this situation for their child/adult.

Women's mental health also suffered. This was true for both the mothers and for the paid workers:

I've tried hard to speak of my difficulties but I've kept a lot inside.

I think when I look back I was quite depressed.

I don't think I'll ever get over it. I think I've done as much as I possibly can to deal with it.

Women may be too tired to affect change in their lives. The women throughout the interview showed the feelings of tiredness in their eyes, by the ways they moved their hands and in the ways they sat. They commented on how they were scared that they would "never stop feeling tired". During this phase of the interviews there were often periods of silence where the women used the time to reflect on their past.

Despite their own tiredness the mothers would often protect other family members against stressful situations. They put the needs of others first and for some this behaviour had happened for many years. Some of the paid workers I interviewed were concerned that mothers had to be 'Supermums'. They appeared to understand the feelings of these women and tried not to place additional expectations on them.

Several of the paid workers had similar difficulties to those experienced by the mothers. This was especially relevant if they had been in the job for some time. They felt that they "must keep going and if you complain you may crack up..." Mrs C, a residential worker, suggested that this kind of work had similar pressures to that of the mothers. She felt the paid workers should support the mothers, but at times the paid workers really suffered too. She believed that group homes and workshops can be like households in that similar demands were being placed on women. She stated:

I really had to make an effort to do things on a social basis, to get out, meet people. And that was organised. A lot of spontaneity went out of that. I literally had to be efficient and organised. I did a lot of things on my own...like that anyway. I prefer to do that so that wasn't a problem. I think in many ways I become insular along the way too because of that, because of the hours I was working, the nature of the job. It can make you isolated and it can make you anti-social as well.

Mrs C talked about how tiredness and isolation can prevent women from lobbying for an improvement in their daily experiences. Others commented on how poor health can prevent women from changing their lifestyle, for example returning to paid work outside the home and organising additional support for the child. At times tiredness prevented women from challenging their partners to do more of the caregiving work in the household.

There were contradictions in the women's experiences. As I have described, at times women felt energetic and yet at other times they also felt an overwhelming tiredness.

The feeling of tiredness often made the women feel "out-of-control" and unable to change their situation. This feeling was reinforced by the fact that women frequently had to wait for others to give them time and support.

Time and Waiting

Women spent much time "waiting" for others. In their daily lives in the household they did, for example, wait for their child to finish their food, walk across the room, finish in the bathroom and wait for them to go to sleep. They also waited for others in the household to come home to "lend them a hand" or stay with the child so they could go out. The mothers and paid workers talked about waiting for others to see them such as doctors, teachers, social workers and psychologists. They also talked about waiting in queues at shops, banks and other public amenities. The frustration of this showed on the faces of the women and in their manner. They often stopped going to these places because "it's not worth the hassle" and the embarrassment of watching "your child scream" while you wait.

When women talked about their experiences in the community they related the difficulty of taking the child out in public and waiting

for people to help if they got into difficulty. Mrs M, a mother, commented on this:

I wish someone had come around and helped with...and the other children. I didn't feel able to go to meetings. You're sometimes ashamed of your child's behaviour.

The mothers also talked about how they waited for others to define what their activities should be. They talked about this with respect to normalization¹ policies and the move to integrate people with disabilities more fully into community life. One mother talked about the stress of knowing that your son/daughter "won't grow up" and that you "wait" for something that never happens. She believed that normalization policies would not change this. She stated:

They are still our children even when they grow up - we can't just shut off. I want him to be in a small home with his friends.

Some other typical comments about this were:

I think community living and normalization - again they worry me a little bit - they worry me as a parent because I wouldn't like people to take them too literally as far as my son's concerned. I think community living is fine providing there's a degree of supervision and protection.

Yes, I think it's probably happening. I think we've probably grown to be more aware that there's a need for it, that just putting people into the community isn't necessarily going to mean normalization's going to happen. The two don't necessarily go together.

¹ The IHC supports the philosophy and the policy of normalization which embodies the belief that people with intellectual disabilities have a right to experience the same lifestyle as their non-disabled peers.

Well, there's so much emphasis on getting everybody out into the community that I feel - you know, as I said before - you've got to be very realistic and realise that the community will only accept them so far. It's human nature.

These women were extremely realistic about the capabilities of their children/adults. For them their children will always require support. The passing of time will not mean that the intellectual handicap will disappear. The worry these women had for their children/adults never diminished. Mrs K, a mother, was concerned about this:

Yes, I am concerned, love, in a lot of areas. Again, love, probably this normalization. I think that is my biggest concern, as I think it concerns a lot of parents. I really feel that, from my feelings...it really is going too far...

Despite these difficulties and the frustration of waiting for others to provide them with help or ask for their opinion, women have a seemingly boundless commitment to their child.

Women's Commitment

Although women spent long hours caring for their children/adults, they generally did not have a negative view of this.

Many of the women talked about how it was important to ensure that the child/adult was happy and had a high quality of life. The daily tasks women carried out for their child/adult had a high priority for them. They derived much pleasure from watching the child/adult grow and learn and acquire new skills no matter how small these appeared to others.

Both the mothers and paid workers expressed this view. **Mrs G**, a paid worker, remarked:

Um, the last few years I think here, and seeing people - seeing the whole thing's worthwhile, seeing something for that - that you've done....As far as I'm concerned it's really seeing the people change and develop. Despite all the qualifications up there it is the giving, sharing and the caring on the daily basis that's the most important...giving of yourself and love and receiving it is the most tremendous thing that can happen.

The mothers and paid workers received their satisfaction from working alongside people with intellectual disabilities. It was the daily activities that brought satisfaction.

Despite the difficulty of the daily routines these women cannot be viewed as downtrodden, depressed or pessimistic. They also expressed feelings of happiness, joy, enthusiasm and hope.

In the interviews the women's commitment showed on their faces, especially when they were talking about the achievements of their child/adult. They had an incredible strength to "keep going". They had too, an ability to see the humorous side of a situation. They related many funny situations to me wherein they turned a difficult situation into one that could be laughed about.

These women had to change their lifestyle to cope with the demands of caring for a child with a disability. They described in detail what they had changed in their life, but they displayed no resentment toward the child.

Mrs O, a mother, commented:

...when she was little you couldn't leave a little wee three pound baby - she was five pound when she

came home at three months from hospital. But, oh, it does change your lifestyle. And then you know who your friends are and - well, I think the first time my husband and I went out together was when my older daughter was 17...There you are. Because my husband never had any parents and my mother lived in the South Island and she still does. So she couldn't. We didn't have any relatives handy. But no, it does. And then you find your - it's still the same today. We have mobs of visitors that we love because it would be lonely now we're retired and old, but it's very seldom you get asked out...but then we sort of manage it and not say anything...When I think back I had to sacrifice anything I could go to. Nobody else round where we lived had a handicapped child.

She continued:

It never occurred to me to seek out help because I was capable of caring for her and the others were adults, so it was all done within the home. We didn't need anybody. But there again it's not to say that people who've got younger children, you know, or frustrated with so many types of intellectually handicaps, and so many types of crippled people. Fortunately I've always been strong and had good health and sane and strong minded, that makes things - you get somebody that hysterical or you couldn't even manage...You have to be strong mentally and physically to do it yourself.

Mrs M talked about how it may be difficult to accept help:

I had a lot of help offered to me but I found it very hard to take it. I bet you hear that a lot! I got so centred myself on 'I'm going to cope with this' that I wasn't able to...

Despite this seemingly selfless commitment to the care of the child/adult women have had to make many sacrifices.

Making Sacrifices

Women sacrificed their own needs in order to ensure that the

household ran smoothly. They often protected other family members from experiencing too much stress. They felt it was their role to "make sure things ran smoothly." A typical comment was:

My husband was under a lot of stress and I felt too I couldn't give enough time to him and my other children. I tried to make it up to them. I wonder if they've got over it all.

These women managed to carry out a wide range of tasks in their attempts to "satisfy all family members". No medals for these women; they were hidden workers who really were responsible for "making things run smoothly". They generally did not question why their husbands did not take more responsibility. The women seemed to use the interview as an opportunity to talk about the sacrifices they had made.

Women often became so totally identified with the child that they always put the child's need first. Some of these women commented about how "the man" would not do this and that women had the strength to keep on caring even when times were hard and when the child was having difficulties. The mothers often used the word "I" and not "we" to show who had the major responsibility for the child/adult. They frequently stayed at home with the child so other family members could go out. Family activities such as "going to the beach" became difficult. It was often the man who looked after the other children while the woman stayed home with the child who had an intellectual disability.

Women felt guilty about not making sacrifices, for example, they felt they should give up their own interests in order to take advantage of the many options made available to try out new management techniques with the child. A number of the women suggested they did not feel guilty about having the child because it was now more acceptable to have a child with a disability. However, they felt guilty about not doing enough for the child in that the pressure was now for women to

make "the best of a difficult thing" by always trying to improve the child's skills.

Not only did women make sacrifices within the household by foregoing their wishes in order to allow others to meet theirs, but they also had often given up paid employment outside the home in order to be with the child. It was women who gave up their paid employment. None of the husbands in the study was the primary caregiver. Women felt "lucky" if their "husband helps". Several of the women had given up paid employment. Other women had difficulty leaving the household in the evenings and weekends in order to participate in other activities.

Women talked about this with respect to their need to begin to develop their skills in order to return to work once the child had left home or attended a centre full-time. The mothers had often invested all their spare time in the child and suddenly there was "a gap". This can be devastating for a woman especially when the skills she has as a caregiver may not be valued in the marketplace.

Women made sacrifices in other ways, for example, those who had to return to paid work for financial reasons were often expected to remain as the primary caregiver. This was also the situation for those women who did not have a partner. Mrs H, a mother, was concerned about women who were alone and who, out of economic necessity, had to return to work. She commented:

...I think one of the things I'm afraid of...it may sound stupid...if families are breaking up just through hardships how are we going to keep a family with an IHC person...

When the women talked to me about giving up paid work they struggled with their feelings. They really wanted to ensure that their child had the best possible care but at times their sacrifice could become unbearable. The pain of this feeling showed on their faces. Several said it was like feeling trapped in a situation that presented alternatives all of which required a "high price".

The women also talked about how many of these decisions were "out of my (their) hands" and that others determined the sacrifices they would have to make. Mrs G, a mother, talked about how it was difficult for women to be involved in activities outside the household. She suggested that sometimes women used their spare time to catch up and prepare themselves for their next task. It was rare that they could use this time to do things for themselves. Mrs G commented:

No, it's very, very difficult for the women to get involved, especially when they're little. Or even when they're - you know - in their teens, they still need a lot of attention and help. And I think that's when the mothers, more or less, should be getting involved. And then when they've gone off to bed I think all the mother wants to do is sit down and relax.

Women talked about how men did not consider what it was like for mothers and caregivers to make sacrifices. Mrs G, a paid worker, spoke about this:

Do you know, Robyn, sometimes I think we're so busy out there trying to make sure the community understands and gives - treats with dignity and gives respect, etc. etc. and we don't do it ourselves.

The sacrifices women made also intruded on their social lives. Many of the mothers commented about how they had difficulty finding others to care for their child. Even when they did find someone they worried about the safety and happiness of the child while she/he was away from home. It was generally the mother who organised the babysitting.

Some of the mothers did not go out to a social occasion without their child while she/he was living at home. When talking about this

particular aspect of caring for a child with a disability the women frequently alluded to the pain and the frustration of this. They did not display anger but rather expressed exasperation about how hard it was to get things improved. However, these women were not apathetic but instead they had found ways to cope with the consequences of the sacrifices they had had to make and they had found other ways to enjoy themselves. The difficulties women were faced with may be decreased if they had the support of others.

Support

Women talked about the difficulty of getting support from others in the household and extended family members, neighbours and friends. Support for these women meant emotional support and practical help. The mothers talked about how they had difficulty asking for support because they did not wish to "put them (others) out." They struggled on their own rather than "embarrass" someone by asking for help. Mrs H, a mother, commented about how she felt guilty about asking for help:

You know, most of the families - and some are under terrific pressure that cannot cope with any more than they're doing...And I did feel guilty. This is where pressures can come at times. And that always bugged me that I felt that way, that I should have thought differently.

Sometimes when the mothers have asked for help or complained about something that is happening they may be criticised. Their partner may not even support them in their "battles". Mrs H was the one in her household to ask for help. She often found this difficult:

I think it's often very difficult. But I think it's very difficult for me to ever complain. The one time when I did really have to make a fuss about something I didn't like what was going on with my

son, I actually let things slide for a long time before I really did complain. And it was because of the fact that I found it difficult to do so - because I knew the people personally...was complaining about too which made it difficult, and also because I was a....at IHC and I've known this from others' parents...it is difficult.

The women talked about needing individual support as well as attending support groups. Some have difficulty talking in groups:

I'm sure I had the chance to join a group but I didn't take it because I'm not a very sociable person...

The mothers talked about meeting someone who could become their friend and who would give support even before they asked for it because they tended to find it difficult to ask for help:

I think at the early times with your child you need a close liaison with someone who doesn't expect you to ask for it but is just there.

Mrs M, a mother, had got some support on an individual basis and she found this to be most helpful:

She was tremendous. I still look back now and I think if a person had someone like Mrs _____ you had everything on your side that possibly could have been...

The paid workers, both those working for the IHC and those working for other agencies, who had been the most supportive for the women, were the workers who were able to give practical help. The mothers want someone who would listen to them and they also wanted someone who could really understand the demands of their daily activities and provide some practical help to meet these demands.

Mrs G, in her comments about social workers and service staff (those running or working in IHC facilities) said:

Yes, they're very much practically orientated. They know what's happening out there to a large extent. They've got the experience and they're in a position to do things about it...

There was at times some confusion about the role of social workers and other paid workers whose role was to provide support. Some of the mothers felt that unreal expectations were placed on social workers by the Organisation, in that it was very difficult for these social workers to provide all the support women required. If the mother did not have a good relationship with her social worker she did not receive one-to-one support. Many women suggested that in the early years it was important to get support from other parents but they felt that the Organisation was not developing this enough.

Mrs F talked about the support mothers received "in the early days" of the IHC:

...it was marvellous really. The good that came with it. It didn't matter about the work. Nobody minded the work....We got together and had a sale. We started a second hand goods sale and we had a shop in Petone...

It might have been Even Stevens when we have the shop - when we had everybody at the meeting and everybody would have something to say. You met people and you realised what they can learn and what they can do...It may be that - we used to have day meetings as well. I haven't been to any day meetings. And now I suppose I won't be going because our people will be at _____.

The mothers were concerned that if support was not better organised they would not be able to continue to cope. Mrs C, a mother, commented:

And even more fundamental than that, I suppose, Robyn, families being allowed to say can they, in fact, survive effectively unless they get much more support than they're getting now.

Mrs C talked about how on the surface it appeared that help was help available but in reality this was not necessarily true. She said that women had difficulty identifying what help they needed:

...when you are right in the middle of it you need someone to give ideas about what is available. When you finally ring you want help. I was lucky because I knew what to ask for and what was available. I just wonder if in fact I would have got what, in fact, we have now got...

It was interesting to note that some of the women felt that the men did not get enough support. These women believed that women had the strength to cope but the men did not and so it was "them we should be worried about." As Mrs H, a paid worker, put it:

Well, I always feel sorry for a lot of them - the fathers, the parents of our kids - because I think they tend to be put into a very supportive role to...the mother and I don't think they always get the help they're looking for...The mothers do. Well, they get something. They tend to be the ones that everyone concentrates on. And when you speak to a lot of the fathers you're really in just as bewildering a situation, sometimes more so. And yet they don't always have the opportunity I don't think if actually talking about how they feel...

Another issue for some of the women was that if they were attending support groups they could have difficulty talking about issues other

than those that directly affected them. Some had opted out of groups for this reason. However, one of the most important functions of support groups had been to help women cope with feeling devalued and "being put down." The mothers and paid workers talked at length about these feelings. One such feeling the women related was how they were made to believe that they should feel grateful and lucky for receiving support and that the support should not be viewed as a fundamental right that they could assume would always be offered and readily available.

Feeling Grateful

The women may be kept in a continual state of hope for at times they received support from their partners whereas at other times they received none at all. They were often expected to "feel grateful" for any little piece of support they were given. Many of the women were "thankful" for some improvement in the child's/adult's situation and behaviour and were "grateful" for even small offers of help. They were determined to make the most of what they had and to do as much as they could for their child/adult.

The women spent little time reflecting on their difficulties and as one paid worker observed, they "just got on with it". Very few women complained about their situation and they did not usually complain about the stress the child/adult may be causing. One woman suggested that if women took the time to examine what was happening to them, they "may be overwhelmed with it and not go on."

Several women often hid the "bad things" and denied that their situation could be improved. Most of the women did not ask for help and they "kept on going." A number felt that they did not have a right to "ask for help." One woman commented that if "you are well enough to cope you should." They felt they did not need anyone else's help. Once women began to "hide things" or just "kept on going" it seemed to become harder to ask for help - the men and other

people in their lives just encouraged them to carry on. These women felt that they did not want to disillusion others by suddenly "giving in".

Not only did women feel they must "be grateful" and "thankful" for what little help they got and that they must not complain about this, they were also made to feel worthless.

Feeling Worthless

The mothers and paid workers described the long hours of work that was involved in caring for their child/adult. The mothers talked about the large number and difficulty of the daily tasks they carried out. Yet despite the intensity and frequency of the tasks they performed, some still felt worthless. Their husbands/partners would often criticise them and the ways they did the tasks. This could be done in very subtle ways. The mothers found it difficult to challenge their partners about this and usually blamed themselves if things went wrong. Typical comments included:

I sometimes don't cope...,
I find it very difficult...,
I couldn't tell him...,
It's hard really...,
He's got his problems too - I don't like to
complain.
His work is very busy and he has an important job.

These comments were accompanied by certain behaviours such as talking quietly, fidgeting and an expression of sadness. Sometimes the mothers told elaborate stories in order to convince themselves that their husband's/partner's work was more important and that they really could cope alone with the daily demands in the household. Some listed off the work their husbands/partners did and compared it with their work in the home, and in doing this they intimated that the husband's/partner's work was more difficult.

For example, they made comments such as "I can stop for coffee - he can't" as if to convince themselves that they had an easier job than their husband. They often talked about the times they did go out to social occasions as if to suggest that they should not complain as "things aren't too bad." None of the women were angry at their husbands/partners but at times their ambivalence emerged about whether in fact they should be the primary caregiver. However, this was usually followed by a comment such as "I shouldn't complain really." One particular comment summarised the feelings of these women: "You do it, you have to, you plod along on your own."

Many contradictions were identified by these women. The mothers talked about the incredible changes in the child, most a direct result of the work they had done for the child (doing exercises, managing aggressive behaviour, doing toilet programmes, carrying out feeding programmes) and yet they had difficulty identifying their strengths and their skills. Their ambivalence about their situation was clearly apparent.

Feeling Ambivalent - the Good and the Bad

Throughout these interviews I have discovered many contradictions. Some of the women felt that they had to be "Supermums" and some felt as though their contribution was worthless. At times they felt "unhappy" but these feelings remained "locked inside" because they believed they should not "complain". Some recognised that they often needed support in order to "keep going" and yet they thought that they must "carry on alone". The behaviour of their partners reinforced this because at times they could "help out" and be supportive. However, most of the time they left the household each day and expected the mother to carry on regardless of the difficulties she may be confronted with.

She carried the burden of blame if anything happened to the child. If the husband/partner did help it was usually with the non-disabled children. His assistance was infrequent, hence the mother could not plan when she could have "time off". She was the one who organised and carried out the routines for the child/adult.

However, in contrast with these feelings and despite the difficulties involved, the mothers had a deep love for their children. If the women's commitment wavered or they became depressed and thought they would be too tired to "carry on" they seemed to still find the strength to continue caring for the child. They had an overwhelming ability to derive enormous amounts of pleasure and satisfaction from the improvements the child/adult made. No matter how small these improvements, the mother was the child's fiercest ally and advocate. It was this optimism that enabled the women to not only cope with their situation but to bring about some positive changes. This was a common strand in their stories about the organisation.

It was difficult at times to find the appropriate words to describe the experiences of these women so I have allowed them to speak in their own words. It was in this way that their stories have emerged and retained their intensity. In the next chapter I will analyse the experiences of these women, utilising the theoretical framework I outlined in Chapter Two.

CHAPTER 5: AN ANALYSIS OF WOMEN'S EXPERIENCES IN THE HOUSEHOLD

This chapter analyses the experiences of the women and the dominant themes that emerged from their stories. One of the most overwhelming impressions I derived from the women's descriptions of their experiences in the household was the way in which situations existed that involved both positive and negative aspects and outcomes. Experiences were based simultaneously on both mutuality and conflict.

Accompanying this was these women's ability to "keep going" even when the situation was oppressive and when the technologies of power become extremely intense and hurtful. These women had been able to view the positive aspects of a situation and to "make the most of a bad thing" and they always had hope that a difficult situation could change and improve. Their husbands/partners could, for example, occasionally support them, do things for the child, show their love in a meaningful way and care for them if they got sick. Although for many of the women this happened infrequently the times when it did, helped them to "hang in." These women, regardless of the problems they had with their child, were expected to be "Supermum" - they suffered many abuses but they "keep going."

The theoretical framework outlined in Chapter Two provides a framework for understanding such experiences and themes that have emerged from the women's stories.

Within the household the technologies of power were the means by which power relations were maintained. These technologies include:

- the observation, examination and comparison of women,
- the use of knowledge to exclude women from certain activities,
- the use of language to provide meaning to women's experiences.

Because these technologies of power were administered by the people women lived with, those they loved and cared for, it was difficult to

detect power relations which were incorporated within these relationships. The nature of power relations were always changing and the technologies and their intentions masked in ways that hid their effects. I will reveal how these technologies operated and show how the women's activities were subjugated in ways that ensured that women would keep caring for people with intellectual disabilities.

Women's Daily Experience of Power

One of the most significant findings in my thirty interviews related to the ways in which the women's experiences had been hidden. Most of the women interviewed indicated, often with intense emotion, that they had never previously had the opportunity to discuss their feelings in such an open way. Because of the delicate balance of their lives, they seldom risked speaking of their experiences as they were often unsure of the consequences of doing this. They felt that once they had revealed their true feelings they may find it difficult to carry on their commitment. They were also unsure about who would listen and as they were often isolated from other women who had similar experiences, it could be difficult for them to seek out other women in similar positions who could support them.

Women in this study were expected to cope - a fact rarely, if ever, acknowledged and understood by their partners. There was an assumption that they enjoyed caregiving and had a choice about carrying out this role. Many of their partners were surprised when women talked about "feeling tired" and often pretended not to hear their cries for help. Mothers "feel guilty" for complaining because they did not want their child to suffer and if they "give up" who will care? They can become so totally identified with the child that even if they were offered help they were often unable to take it. They had been forced, albeit in subtle ways, to make the child their vocation. This was, of course, in the interest of men who did not have to participate in the care of the child and could carry on their own activities without interruption.

There was an assumption that women were happy and that caring for a child in the family was the 'natural' way to care for people who were dependent. Women's views of the situation were not valued and men in the household reinforced the view that women were carrying out their 'natural' role and the concerns of women were not sought out by these men.

What made it difficult to expose the power relations was that although women's tasks were arduous women enjoyed much of their work. They loved their children and derived pleasure from their role. However, women in the household were observed and compared in ways that ensured maximum utility was derived from their activities (Foucault, 1978) and in ways that resulted in them carrying out tasks that they no longer had any choice about performing (Irigaray, 1985).

Observation, Examination and Comparison

The observation, examination and comparison of women operated in subtle ways. In my theoretical framework I discussed how one of the ways that power operated to control women was to keep them apart from one another in a 'private' space. The household was such a place and the mothers described in their stories the difficulty of leaving the household either on a daily basis or on a more permanent basis such as returning to the paid workforce. The physical effort required to transport the child often prevented them from leaving their home. Not only did they have to organise activities for the child with a disability, but they would also be expected to be home in time to organise activities for other family members. Once the child/adult began to attend a centre or if they left the household for a short period, the women were often too tired to participate in activities outside the home. They may also just enjoy having an opportunity to be in the house alone.

This was encouraged by the women's partners and other people in the Organisation to be the most acceptable behaviour for women. Associated with this were the many sacrifices women have made in order to fulfil such expectations. In the description of the women's experiences I heard many stories about sacrifice. The mothers sacrificed their time, their own leisure pursuits and opportunities for paid employment. This sacrifice was often described by other people (such as their husbands) in euphemistic terminology. For example, these people indicated that it was the mothers who wanted to sacrifice their own needs and desires for their child because they loved her/him so much. Women were expected to perform this role, and this form of control over women was presented in very positive ways. Women were praised and given reinforcement for caring for the child and for fulfilling certain expectations. They were criticised if they did not do it. Hence encouraging women to care was done, as I described in the women's stories, in very subtle ways. It was in the interests of men to expend a minimum amount of effort to ensure that women would continue to care. Making women feel worthless if they did not sacrifice their own desires was an effective way of doing this.

Their husbands/partners and other people in the IHC watched these women perform their roles and commented on how well they did this. Although the mothers did at times become exhausted they persuaded themselves to keep going and this process was reinforced by other people in the household. Those who periodically came into the household would also encourage the mother to "keep going" and praised her for her selflessness, and for the care she gave to the child and other household members. This was, I argue, an extension of the role of the mother as her nurturing capabilities were highlighted in order to ensure that she would continue to care for the child with a disability (Dalley, 1988).

The contradiction for these women was that although they were often isolated from one another, when they did manage to meet other women these meetings could be stressful in that the mothers then compared

themselves with other women who were coping and tried to live up to some ideal standard. This process was very subtle and hard to detect and men encouraged women to compare themselves with other women. The mothers themselves often became critical of those women who did not make sacrifices for the child and who did not try to develop the child to her/his fullest potential. Women had many stories to tell about the ways in which women were "put down" if they did not maintain a certain standard. As with the other mechanisms this process functioned to maintain women in their current position and the women themselves had internalised the dominant view that women should be the primary caregivers and should live up to an ideal standard.

Even when they were working hard women could be "put down" and no matter how hard they worked they never seemed to achieve the ideal standard. Not only was the role of caregiving itself not valued, but also if women did not perform it adequately they would be criticised. Women were kept in a powerless situation as they were unable to determine what this standard was.

The observation and examination of the women's activities in order to ensure that they performed appropriately and were maintained in their current roles was linked to another effective mechanism for controlling women. This mechanism related to women's time and the way the woman's day was timetabled so that she would have little time for anything but caregiving activities. She was expected to go to meetings and to set up and implement special programmes for the child. She felt guilty if she did not do this. It was also hard keeping the child occupied while the mothers waited for meetings to begin. They described to me the increase in programmes that were now available to help the child learn more difficult skills. The move was towards more independence for the child/adult and the philosophy of normalisation encouraged families to allow their child/adult to be more independent and to participate in community activities. But in order for this to work the mothers were the ones who must take on the role of helping the child/adult become more independent. They

suffered much humiliation if the child did not succeed. Many of the women will never be free of this because the child/adult may never be totally independent. There was a demanding duality reflected in the women's stories. They hoped that the child would develop but to ensure this they had to make tremendous sacrifices, take on additional burdens, and use up more of their own time.

The organisation of women's time, then, is another effective mechanism for controlling women (Foucault, 1977). The women in my research not only had certain activities that they were expected to perform throughout the day but they often had to wait for others to either define what tasks must be done or to give them advice. In my study the women waited for men to make decisions and they waited for others to provide support and information. For example, they waited for doctors to make a diagnosis about their child. Another important factor about time is that the women also "waited on" men because they provided a supportive environment where men could carry out their activities. For example, they provided the sustenance so men could carry on with their important meetings and go to paid work each day.

The mothers spent a lot of time waiting and this waiting did, in fact, prevent several of them from becoming involved in activities outside of the home and away from the child. Not only did this place a tremendous amount of strain on the women, but it also resulted in frustration wherein a woman could become resigned to her situation and find little strength to change. The irony is that she spent so much of her time and energy lobbying for the child and had little energy left to expend on changing her own situation. When she did this it could be blocked in subtle ways like the creation of new 'rules' by men in the household or the identification of new activities the women had to perform. For example, women were expected to carry out more sophisticated programmes for the child/adult now that integration into the community for people with intellectual disabilities had become a goal. Some of the women in the study who had children/adults who had left the institution talked about this. At one time they had to wait to visit their child/adult

in the institution. This was stressful but they now had a different, no less stressful, pressure in that they had to "wait" on the child and develop appropriate programmes for the child. If they did not do this they felt guilty and inadequate.

Many of the women felt embarrassed about sharing their problems and blamed themselves for their inadequacies. They often did not have an opportunity to clearly identify what their feelings were and what caused these. Several of the women felt uncomfortable about attending "support groups" as these groups did not always "support" women but could, in fact, make them feel incompetent and inferior. If they did not compare favourably with other women, feelings of low self-esteem were reinforced. Moreover, clearly the very fact of attending could, for these women, suggest that they were not coping.

Very little of the work these women did was valued and the love these women had for their children was translated into an expectation that they would remain as the primary caregivers. This was reinforced by the activities women carried out and the way these activities were defined and ordered. The mothers in my study showed how on many occasions throughout their lives they believed that their most important role in the household was to service not only the child with a disability but also ensure that the needs of other household members were met. These other household members could not have continued their activities if the women did not carry out the duties of caregiving. The irony was that the women's role held little or no value. Hence the control of women by observing them and comparing them with others operated at many levels of the women's lived experiences.

Knowledge

Knowledge was used to reinforce the way the other technologies operated. In my theoretical framework I showed how the concept

"knowledge" can be used to describe how history is written, how social scientific research is carried out and the ways in which certain groups can use knowledge to control women. The use of knowledge was used in particular ways in the household, and in the analysis of the women's experiences in the Organisation I will extend this discussion.

In the theoretical section I discussed how events can be recorded in such a way that they function to maintain certain dominant myths (Grimshaw, 1986). The women in my research referred to this when they discussed the ways in which the books and other literature they read, and the films they watched, reinforced the view that they were the primary caregiver. This literature (both historical and current) also reinforced the belief that care should take place within the family and although the women I interviewed had a strong commitment to family life they emphasised the inequalities in the family. They had ambivalent feelings about this as although they derived much satisfaction from family members, at times the way the tasks were divided up in the household functioned to control women and restricted their choices.

As the women pointed out the books, magazines and films did not often mention the difficulty of caring for a child with a disability. They portrayed women as wonderful, selfless, caring human beings who wanted to perform and who were totally content with their roles and responsibilities. The formal literature such as books about working with children/adults with a disability and the history of services for people with disabilities also reinforced the idea that women would always be available to care for the child. The community care literature did the same and generally lacked analysis on why it was women who were the primary caregivers and the stress this placed on their lives. This was certainly true for the women in my research. When they discussed what was available to them to read and where they could get their ideas from most of the literature presented to them reinforced the current roles of women as caregivers. They had to seek out literature portraying alternatives for women but this was generally not readily available.

The women also talked about the ways in which the information and methods used by professional groups such as doctors, social workers, teachers and psychologists reinforced this view. It was generally the woman who had appointments with professionals and these groups had high expectations of women. For example, the mothers spoke about how information provided by these professional groups may be inappropriate and did not aid them in the carrying out of their daily tasks. These groups were not cognizant of nor took into account the real life experiences and circumstances of the mothers.

This information was often useful and added to women's knowledge. However, it was, at times, presented in complex ways that did not relate to women's daily activities. Several women cited the example of Individual Programme Planning¹ and the assessments associated with this. This was essentially a good idea as the Individual Programme Planning meetings aimed to involve the person with a disability and his/her family. What did happen however, was that meetings often placed additional pressure on the mothers because they had to carry out the training programmes and justify why they had or had not succeeded. Meetings required a large time commitment for the mothers. The information gained in the assessment may not be relevant for the person's daily experiences and it was also a frightening experience for women to have to justify their behaviour in a public meeting. They felt guilty and embarrassed if they did not agree with or had not carried out the goals outlined in the meeting. Some women talked about being pressured into agreeing with the paid workers at the meeting because "they know best". The reality is that if programmes designed to enhance the person's independent living skills fail, caregivers had to "pick up the pieces" and had very little choice in this. Women were concerned that

1 Individual Programme Planning was a system set up by the IHC to monitor the development of the child/adult. Families are asked to be involved in both the assessment of the child's/adult's skills and in the programmes that are designed to teach new skills.

information could be put in place to show how competent paid workers were and it could become so complex that the "average person" was overwhelmed. This was often difficult to challenge owing to the difference in status between the paid worker and the mothers.

Women at times had difficulty obtaining the skills they required to provide caregiving activities more effectively. The mothers in my research were being asked to provide an increasing number of complex tasks for the child/adult, such as the management programmes to manage and change complex behaviour problems. The mothers may however, receive no additional training to do this. Some of the paid workers referred to this also. Conferences, seminars and training workshops are usually directed at paid workers who already had some kind of formal training. It was difficult for direct caregiving staff and mothers to receive training that was relevant for the daily demands of their work and that incorporated the skills and knowledge they already had.

Much of the knowledge was derived from overseas sources and may have little relevance for the New Zealand situation. Both the mothers and paid workers were concerned that the specific information women had about caregiving was not valued. There were often no formal channels for sharing this information and certain groups of paid workers, for example psychologists, could in fact control and define the kinds of knowledge that was valued. They became "experts" and had the authority to define what was "truth" and what was "invalid". Research and related activities could also function to reinforce the dominant beliefs of this professional group rather than providing a method for critiquing and advancing existing knowledge.

Some professional groups used other kinds of technologies of power in ways that assured they had the authority to determine what activities caregivers should be involved in. Professional groups such as doctors, psychologists, teachers and social workers had techniques that they used to ensure that women carried out their tasks appropriately. These techniques did not necessarily begin as

oppressive because they could, in fact, be part of a strategy for helping women, for example teaching women to do toileting programmes. As Foucault argues, such strategies are generally not repressive but rather are productive in that they stimulate activity by encouraging women to carry out their role more effectively (Foucault, 1978). Their effects were for this reason difficult to detect, but did in fact place additional pressure upon women. Women had many stories to tell about how the programmes designed by teachers and psychologists began as useful and well meaning but over a period of time placed increased pressure on caregiving routines. Women often felt uncomfortable about asking questions of the professionals and felt inferior to doctors and others who were perceived as the "experts". These professional groups appeared not to understand what it was like for women on a daily level. The behaviour of these groups as I have described, albeit in subtle ways, frequently functioned to reinforce the belief that the woman should be the primary caregiver for the child.

As with the other technologies described, the function of the technologies of power associated with the use of knowledge, was to ensure that the dominant practices in the household were upheld. These technologies also functioned to perpetuate the devalued status of women in that while women supported the work of professional groups and were asked to carry out complex tasks they did not receive recognition for their ideas and knowledge. It was in the interests of both the professional groups and also the men in the household to minimise the status of women because there was always a fear that if women's work and knowledge were valued they may expect more rewards for this work, or even wish to move out of their role and cease caregiving.

Language

In the descriptions of the women's experiences in the household I talked about the ways language was used to "put us (them) down". The

women talked about how professional groups obtained status from the words and concepts they used. Both the mothers and paid workers became angry about this because they felt it was another way in which they were devalued. An example was the complex technical jargon used to explain assessment and intervention programmes for people with disabilities. Simple tasks were labelled in complex ways and although the phrases sounded meaningful when presented in a meeting, in reality they did not change the lives of people with intellectual disability and the people who cared for them. As described in the women's stories, this occurred with the introduction of processes such as Individual Programme Planning. Individual Programme Planning was described euphemistically and the mothers were persuaded that it would not only improve the quality of life for their child/adult but that it would also have benefits for them. However, in reality it could place additional burdens on the mothers because it was usually them who were asked to monitor the child's/adult's development.

Language was also used to mask contradictions and perpetuate myths. Women were labelled as "selfless", "emotional", "neurotic", "hysterical", "overprotective". Women were not only described negatively or portrayed in ways that did not adequately depict their activities, but certain characteristics were assigned a negative value. For example, showing emotion about one's child/adult was likely to be viewed as a weakness. The use of language reinforced the view of women as the "other" (de Beauvoir, 1972). Another term that had misrepresented women was the use of words such as "selfless" which had been used to imply that women enjoyed making sacrifices. They had to, however, cope with the consequences of being "selfless" and not become too "overprotective". Hence much of the language used embodied contradictions as the words used would be defined in ways that would fit the current practices but could have ambiguous meanings. The women, for example, may have been criticised for being "overprotective" but were also encouraged to be like this for it ensured that people with intellectual disabilities were cared for. The women were expected to take care of their every need and fight to ensure these needs were met.

Language then, as with other technologies of power, functioned to maintain the women in their roles and, as with these other technologies, it had both positive and negative elements. It can be a compliment to be called "selfless" but the compliment ceases to have an attraction if such a term is used to define the activities of what all women should be doing, and thus has the effect of minimising the women's choices and functions to maintain them in their current positions. I will extend this discussion in the analysis of how the Organisation used language to maintain the women's position as the technologies of power in the household and the Organisation reflect one another while functioning to reinforce each other.

CHAPTER SIX: WOMEN'S EXPERIENCES WITH THE ORGANISATION

This chapter describes the women's experiences with the Organisation. Some of these experiences are similar to those that took place in the household. As with the women's experiences in the household one can read from their stories that their experiences with the Organisation are not always negative. They had their stories about the difficult times but also they had stories about the joy, fun, rewards, and good times. Again I wanted to portray the richness and diversity of these women's stories by letting them speak and using their own words. I wanted to show that these women had strength and were not to be viewed as passive recipients of power relations because at times they had resisted these. The issue was not whether these women have had an influence on the Organisation but rather why this influence was blocked and sometimes even sabotaged and hidden from public view.

As I explained in Chapter Three, I felt that when the women were sharing their stories with me that they often had difficulty talking about their lived experiences. It was too painful and once they opened up they were scared that they couldn't cope with the feelings that would emerge. Many talked about this and cried with me. They shared many painful stories and for this I felt very privileged and honoured. I hope that I have been able to capture their stories in a way that correctly portrays the strength of these women and that this is a true reflection of what their daily lives were really like.

The Major Themes

A number of major themes have emerged from the women's stories. As with those described in the women's stories about the household they included both physical and emotional aspects. I also describe the

women's views about the changes in the policies of the Organisation and a detailed discussion of the women's attempts to bring about change is also provided.

The themes described are: A description of women's work for the Organisation, both paid and voluntary; the way women may be made to feel worthless; the women's view of the decision-making processes of the Organisation; the women's feelings about the way information was used by the Organisation; the women's view of the support the Organisation provided; the Organisation's expectation of work without rewards; the women's feelings about community care; the women's struggles and resistances; and the feelings of ambivalence the women experienced.

The first theme encompasses a description of women's daily experiences. This sets the context for the themes that follow as it provides the reader with an understanding of what the women's daily lives involved. These experiences and daily routines were the very activities that have generally not been written about in any detail and which consequently resulted in a misunderstanding of what the women's work involved.

Following on from this I describe the mothers' involvement in voluntary work. A detailed description of the women's daily household routines was provided in the previous section on the household. This is now extended to include a description of the work women did for the Organisation.

In the section on the household the women talked about feeling worthless. This was also a common theme in their stories about the Organisation. The women in this research had many stories to tell about the ways in which decisions were made by the Organisation. They felt that they were often excluded from being part of the decision-making processes. They had to work hard at finding out how decisions were made and often found it difficult to challenge this process.

This leads on to a discussion of the way information is used by the Organisation. The women did not receive enough information and there was not enough feedback provided by the Organisation. Much of the information was too technical and did not relate to their daily experiences and needs. The language used to define the women's activities is also mentioned in this section.

The women did not always get enough support from the Organisation. This concept is a complex one and as discussed in the section on the household it involved many layers. The women had difficulty asking for support for this could make them feel even more dependent. Because of the connotations attached to asking for support, it was difficult to ask for, and receive support even when they were desperate.

The women felt that they were always being asked to do more work and increasingly complex tasks without gaining any more status. Life did not get easier with the advent of community care - it would get harder and continue to get more stressful for women. The women had much to share about their thoughts and feelings of community care. They had spent many hours thinking about the implications of community care and this is reflected in the length of this section.

The next theme relates to the women's resistances and struggles. The women had not been passive but had found a myriad of ways to resist power relations. A number of the women had emerged as 'change agents' in these struggles and they shared their ideas about the roles they had adopted.

The final theme describes the ambivalent feelings women had. Life was not always difficult for these women and one must not leave these women feeling that life was one of total despair for they have had many good experiences and they were able to tell me about these.

Work With the Organisation

I asked the mothers and the paid workers to talk about the work they

did for the Organisation. This included a description of their key tasks and of their feelings about the relationships they had with others in the Organisation. I wanted to discover what the power relations felt like for the women. In this chapter I talk firstly about the work of the paid workers and then about the voluntary work the mothers carried out. I then describe in general, the experiences of both these groups and their views about the Organisation's policies and practices.

Let us firstly consider, as we did in the chapter on women's experiences in the household, what a typical day may be like for a paid worker.¹ This provides the context for understanding what caring was like for these women.

Nearly all of the paid workers had some kind of experience or qualification that had prepared them for their work with people with intellectual disabilities. All of the women had been in direct caregiving roles and many still remained in positions that required some caregiving functions.

All of the women commented about how difficult it was to get to the top management positions in the IHC. They felt that there was no planned career pathway and individual people often obtained promotion by knowing the "right person" rather than by displaying competence or having the appropriate qualifications. This was a major issue for some of the women who felt that it was difficult to become part of the "inner circle" and obtain the information and knowledge they needed to move into management positions. Many women were reluctant to "push for" promotion and did not actively seek out opportunities for advancement.

The positions the women occupied and the activities they carried out included direct caregiving positions, social work support positions, staff training and policy development positions, and management and coordinator positions. I will now expand on these.

¹ See Appendix One for a summary of the women's personal characteristics.

Direct Caregiving Positions

The paid workers in these positions worked with people in either recreational, vocational or residential facilities within the IHC or in the community. These women had similar experiences to the mothers in the study. The repetitive nature of the tasks was often stressful. However, the biggest stress came from not being able to make changes for themselves and for their clients. They felt that there was not enough contact with the decision-makers in that they often had difficulty influencing any changes in policy. They could suffer burnout as they worked long hours and worked with clients who had very complex needs. They often carried out their tasks with little direct preparation, training and support for these tasks.

The tasks included assessing clients' skill levels and planning and carrying out programmes to develop new skills. A large part of the day was spent in recording information about clients' programmes, with and without the client present. The major part of the women's time was spent in carrying out maintenance functions such as transporting clients and dealing with physical needs of the clients (toileting, washing, cleaning up spills, moving the client from one part of their environment to another, encouraging the clients' attention to their tasks). Another part of the day was spent in buying in supplies and organising the work or living environment for the clients. These staff were also expected to attend many meetings either about the client and their families or about the way their facility was run. A portion of time was spent in staff training, both providing it and receiving it.

Social Work and Support Positions

Paid workers in these positions provided counselling and support to families. They had very large caseloads but were still often expected to have a close relationship with all of the families on their caseload. These women were often asked to do additional tasks

such as supporting people who had moved to the community. They were concerned about the changes in responsibilities that the policies of community care had brought about. They had been in the past, largely responsible for only those people in the IHC facilities but now most of their work was carried out in the community and they spent considerable time liaising with other groups that could support the work of the IHC. Much of their time was spent in meetings about clients; supporting and counselling clients and their families; running therapy groups; and recording information about these activities.

Staff Training and Policy Development

These women believed they had more control than some of the women in other positions in the IHC because they could influence some of the policy of the Organisation. They felt they could influence the policy either through the writing of submissions or by changing the focus of staff training. They frequently took on the role of helping staff to critically examine the policies of the Organisation and the implications for practice. Some actively encouraged the development of support and study groups that helped staff understand and cope with the procedures and new policies of the Organisation. Some claimed that many of the positive changes in the Organisation had been initiated by the staff training they had carried out. However, these women felt that the Organisation's commitment to staff training was often unclear and that staff training was often the first service to be cut when funding difficulties arose. These women also believed that parents were not actively encouraged to be part of the training offered and to be involved in the development of new policy.

The frustration for the paid workers was trying to ensure that what was learned in the training or what was written in policy documents could have some positive implications for practice. Much of their time was spent in ensuring this happened and in being an advocate for parents' involvement in policy development.

Management/Service Coordinator Positions

The women in these positions managed and coordinated staff activities, developed policy and new services; responded to the needs of parents and other consumers; and monitored administrative functions including the financial aspects of the Organisation. These women referred to the uncertainty of their position. They believed that women had traditionally carried out the "behind the scenes" work and the direct caregiving tasks. Some of them claimed that men still believed women were in these positions not because they were good managers or coordinators but because they were lucky that someone allowed them to be promoted. They thought that men still believed that women should not take on management positions.

Some women observed that there was a conflict between the service and financial functions that the IHC expected managers to carry out. This was an ongoing tension for these women. They were constantly confronted with the dilemma of whether to focus on the financial efficiency of the IHC or the effectiveness and quality of the service provided. The two often conflicted.

The women also felt that the management style in IHC was based on competition and on a hierarchy that resulted in an elite group controlling the decision-making processes. Some women tried to change this to a co-operative style of management but found this was difficult to do in an Organisation that often met its goals by encouraging competition amongst its staff.

Several women claimed that it was difficult to reconcile the practice of encouraging staff to be positive with their clients when they themselves were given very little positive feedback.

A number of the women also felt isolated from other women in similar positions in the IHC and in other organisations. They were expected

to have an unquestioning allegiance to the Organisation and they often felt that their affiliation with other women who criticised this was discouraged. They were usually physically isolated from one another and could lose contact with the mothers and women in caregiving positions. They were frequently forced to adopt some of the practices of men within the Organisation in order to survive in their position, although they tried to maintain their links with other women in order to examine what was the most effective way of bringing about change.

Despite their difficulties the paid workers had made a commitment to working with people with intellectual disabilities. Their relationships with these people was often the factor that ensured that they stayed working for the IHC. Although these women were often devalued by the Organisation they had survived for many years and would be likely continue to do so despite the difficulties of their daily experiences and despite policies that were often in conflict with the realities of women and the people they cared for.

The Women's Feelings About Paid Work

This section extends the previous one and explores in depth women's feelings about the daily routines they carried out for the people they cared for and for the Organisation.

The paid workers had many stories to tell about the work they were expected to carry out. They talked about the different roles between men and women and the ways certain tasks were valued above others. The women were expected to carry out the caregiving tasks. Men often defined what these tasks entailed and what values should be assigned to them. There may be a hierarchy of values with respect to these tasks, that is, direct caregiving tasks were lower on the hierarchy than were management tasks. Many of the women considered that they did a lot of "behind the scenes work". They felt that this work was not valued and they were not given credit for it. "I am getting a

wee bit tired of being 'good old backroom boy', etc. etc. that will tend to pick up messes, sort things out."

These women could clearly identify the ways in which the carrying out of caregiving tasks impacted on their daily lives. Caregiving was about "getting your hands dirty", "being there day and night", "having no breaks", "going through pain with families". Management was about "being removed", "making decisions", "being up there", "going away and to conferences". Women pointed out the gap between the two types of tasks.

For those women who did eventually take on management positions, or who aspired to these, some felt "inferior" and not able to carry out the "management tasks", whilst others were sceptical about whether these jobs were as difficult as the men implied. A typical comment was:

...all the power positions are men. Maybe women don't want them and like what they are doing. Sometimes I wonder how hard management jobs really are.

The women commented that they felt that the IHC not only believed that men should be the people to have the management positions but that women should be there to "help them in these jobs". In some situations women appear to be there just "to help the men". Mrs D, a paid worker, remarked in her comment about committee work:

...within IHC nationally throughout the country, oh no, there's an incredible imbalance in favour of men. By and large I think the women in the Organisation help them.

This woman believed that women got to management positions because "men allow them to" and that these men could actually remove them at any time. They saw "jobs being contrived and prearranged for men who

were not necessarily more qualified than a woman". A typical comments which highlights this is from Mrs J who stated:

Yes, and I was very keen to be involved in her selection. It was interesting they let me. I mean, I said I want to be and they let me be involved, and maybe a while ago they wouldn't have. All I can say is I have seen, when there was a bit of a phase to employ people to middle management about two and a half years ago, and all these men came in with supposed middle management and they were all disasters. Bad for their branches; bad for their areas; and they had very few people skills. And I've always argued with...that you look for somebody with people skills and you can teach them the technical skill. And I firmly believe that....Yes. I mean, I think it's really fascinating that my predecessor was not keen on giving _____ the job. I think _____ is the ideal services coordinator. She gets on extremely well with the staff apart from one or two who object if she tries to push them. She's very mindful of the needs of people with intellectual handicaps. She's got a very good manner and she's hot on the philosophy. And she's got plenty of energy.

The women were often viewed as just a "token manager". Some had difficulty dealing with this and wondered how they could ensure that changes happened on all levels, not just for the women "who have made it". Mrs D, a paid worker, explained:

I have to wrestle with the conflict within myself that why I'm a manager. I think it was still a certain amount of tokenism that comes through from some - because we are pretty male dominated at the top. And I still think there is a certain amount, at the beginning I would say, more so than it is now, tokenism.

The experiences of these women showed clearly that men got promotions more easily than women and that the skills of men were more highly valued than women. It was assumed that men had better business skills than women and that these skills should have more value than

others. Even when women got into management positions they may not be part of major decision-making processes and were expected to "service" men's work such as always "taking minutes and sending memos out."

Some women claimed that the Organisation was at times run like a business and people treated like units of production. They argued that men got status from the IHC being viewed in this way in that they could then feel closer to their colleagues in the business sector. Some of the women believed it was getting worse with more voluntary agencies becoming like businesses. It was difficult to "break this down".

Many of these women were angry that men did not have experience in running services and that they often "messed up their job". The skills of women, for example working directly with people, were not valued. As many of the women commented, the management section of the IHC always focussed on the business and financial side of the Organisation and this, according to Mrs H, a paid worker, was part of the "old boys' thing".

Many of the women identified key women in management positions who had a services background and consequently seemed to have "more of an idea of what they are doing". This was relevant for all levels of management from branch managers to facility managers and also applied to committee members. These women believed that training programmes should be put in place in order to ensure that people in management positions knew how to manage services effectively:

I don't know how you re-educate those people who are in positions where they're putting up barriers. Take Branch Managers in IHC. They still don't have a training programme for Branch Managers. We're taking in raw people who have nothing to do with IHC more often than not, they're putting them in very influential positions and a lot of autonomy in many cases. So we need to start there perhaps. You've got the voluntary side of things, you've got

presidents and committees in the voluntary side of things who have never been trained or educated in what we're trying to do or how we're changing it, our philosophy (Mrs P, a paid worker).

Women wanted managers who had innovative and practical ideas about services and who knew how to manage people who worked in social services. Mrs G elaborated:

...All this heavy stuff, these managerial positions, the heavy stuff, must go. It must. They've got to be people taking over managers of homes with qualifications not just IHC but as I say, a brightness to do something different. It all depends on who's running the home. It must be a caring place, it's got to be. It's got to be caring staff...

Some women commented on the "coldness" of male managers and their failure to talk with and understand what services people and caregivers needed to do to make their work easier and more enjoyable. They believed that the service coordinators (those staff who have a direct link to the caregivers) should have more authority to make decisions and implement new programmes.

Some of the women were optimistic about things changing as women began to take on some of the coordinator-type positions. It was a slow process however as Mrs G pointed out:

Slowly. Since I've been in the last five years, yes. When I first started there weren't very many coordinator positions around. I think they do find barriers with people above them in trying to change things, make innovations within the system. It'll be a slow process.

The women felt that it was those in the service coordinator positions who could be the leaders in changing the current 'reality' in that they had either been caregivers or at least understood what these roles involved.

There was a mixture of optimism and pessimism. There were contradictions in that some women felt that the Organisation had, in some branches, changed its management style but there was still a concern about who would continue to question whether the Organisation had an ongoing commitment to this change. Women who did "make it to management" must, as many women commented, find ways to enhance the value attached to caregiving tasks both in the household and in the Organisation. Mrs J, a paid worker, believed that for this to happen the management style of the Organisation must first be changed. In her story she talked about "charismatic management styles" meaning that certain decisions got made because of a person's personality type rather than because there were clear and equitable guidelines to be followed. She stated:

...style of management I think is energy creating - a real positive thing. Because I think IHC could just, sort of, potter along without him. But it's also a bit chaotic and arbitrary decision-making - I find that a bit irritating....I think one of my most difficult times was probably about six months before I came into this job. I felt there was a bit of a lack of direction of where I was going and I think that's the problem with quite senior people in IHC, that the management structures above don't seem to - I don't think the whole personnel thing in IHC is very good and I think there's in many areas a problem of giving people direction and support while they're trying to do it. I used to find it frustrating to try and find out what was really wanted out of branches and there didn't seem to be a mechanism for trying to find that out.

She said that sometimes decisions seemed to be "ad hoc" and not written down - a few people have the 'power' to make lots of decisions and often it was difficult to find out about this process.

Another paid worker, Mrs M, suggested that she tried to do things despite management. However, she pointed out that management often:

came in and stopped things because they're too far removed and you sort of get back to basic management things if you want something to happen. I mean, you either just go and do it and have it successfully working by the time they find out, or you spend five years of blood, sweat and toil trying to get permission to do it or you present them with a number of options. 'I'd like to do this, this, I'd like to do this, you can either do it this way, this way or this way' and they'll choose one of them...

There were many comments such as these. I got the impression that women used this interview to explore their thoughts about their roles. There was some optimism however, in that the women had ideas for change such as "providing training and helping people to stay enthusiastic".

One woman felt that the only way the IHC could change was to make sure "they get training and stay enthusiastic". This must happen "at a base level at the coalface, and in middle management areas". It seemed to be happening in the larger branches - more "female branch managers and middle managers and men who are starting to understand." They were concerned that mothers should be kept up-to-date too and that ways should be found to ensure that changes are maintained.

Voluntary Work

Mothers had similar experiences to the paid workers through the voluntary work they carried out. The mothers had many stories to tell about the voluntary work they did. Most had been involved for many years - some helped set up the IHC. Some of the paid workers also did voluntary work at the beginning or end of the day and in the weekends. In fact, many talked about how this was an expectation of the Organisation. Staff were expected to have a selfless commitment to their work and not resent the time they gave to the Organisation.

The mothers discussed how they were expected to do voluntary work and often felt guilty if they did not have the time to do this. They participated in a wide range of voluntary activities and the Organisation relied on these women to do the tasks that aided in the provision of the services their children/adults attend.

Mrs G talked about the kinds of voluntary work women got involved with:

...we've always tried to help and now I serve on a Wednesday all day with the intellectually handicapped secondhand shop in _____. Clean clothes and sort clothes, and I clean the shop when it's my turn...And I took her over every morning and brought her back every night and very often helped out in the workshop when they were busy.

Providing transport and helping out in the workshop were major tasks for these women and even when tired many of the women "put in long hours" in voluntary work. It appeared that these women often felt more comfortable offering their help on this level rather than on formal committee structures. This perhaps perpetuates the myth that women could not do "such things". However, as one woman pointed out, women liked to be practical and "get things done, they don't talk, they get on with it - if a workshop needs a new item they go get it and don't just plan for it." One woman also suggested that they did practical jobs for specific facilities so they could "see where our money goes".

The women did a lot of the "practical tasks for committees". Mrs C, a mother, explained:

The women do a lot of more practical things, I feel. The men are often on committees about finance and things like that.

She continues: I'm not on a committee now and because I need a sitter at night it does make it

difficult. And I can do things - the womanly sort of things like bake cakes or knit booties or something - without going out of the house.

The women talked about their work and how it had changed. In the early days the mothers helped set up new services and worked in these. They were also on committees:

We have paid helpers now - they have committees now and they can find their words better - they plan things now.

If I can, I raise a little bit of money for the workshop and I buy something that she wants. Like, we bought a clock for the wall and some pictures that went in the foyer up there.

And I don't get talking the same probably. I still go to _____ for lunchtime duty.

I do the shop regularly.

However, many of the tasks the women carried out seemed to be on the fringe. The men got on the important committees and the women "bake the cakes". It was sometimes difficult for women to get to committee meetings. "It's difficult, if you are tired, to focus your energies on a committee meeting."

It may be difficult for the mothers to take on executive positions on committees, as many were worried that they did not have the skills required to do the job. Moreover, it was often difficult to switch roles from someone who was at home all day to a role where they were expected to attend lots of meetings and go to conferences, etc. They may not have had the time to do this or they may have felt they could not do it. Men often incorporated their committee tasks with the work they were doing during the day or with other groups they belonged to. Some women felt isolated on the committees as frequently they were the only woman on a committee.

Once a woman was on the committee the men may have made it very difficult for her to be an equal team member. The men may have asked

her to carry out "typical female tasks". Mrs I, a mother, told a very interesting story about this:

Well, I went to the committee meeting. I was put on. I went to my first committee meeting and when we got there the men sat down and said, 'Oh, it would be nice to have a cup of tea.' And one of the women got up and made a cup of tea.

I then went the next week, or month, whenever it was, I can't remember. It was sometimes once a fortnight, sometimes it's once every three weeks, sometimes, you know, it's been all different times. Anyway, I went to the next meeting and I realised that it was quite - I think there were only the two of us on - that it was quite obvious that I was expected to make the tea. And I had come from _____ where, in fact, we all shared when we were committees because I had been on committees since, you know, and I had been on the Social Services Committee in _____, you see. Where we all shared it and certainly you didn't get up, miss half the meeting making cups of tea for the men who then stopped the meeting, had a cup of tea and then got on with the meeting and you'd missed all the part. And if you asked a question they said, 'Oh, we've discussed all that.' So, before I had to get up to make the tea I said to them, 'I'm quite happy to make the tea tonight. I realise that this is expected of me. But next time I come I shall expect one of you to make it and I would prefer that we either have the tea before the meeting or after the meeting, because whoever goes out to the kitchen cannot possibly hear what's going on in here and the reason I'm on this committee is to know what is going on in the branch and to be involved in all the decision-making.

AND WHAT HAPPENED?

There was a deathly hush! Absolutely a deathly hush! And would you believe it, we never had a cup of tea from then on!

Many women believed that the way committees are organised must be changed but a number felt overwhelmed at the number of changes that were required to "make things better". They talked about how women were not necessarily making lasting changes because often if a woman

came off a committee she may not be replaced by another. Several of the women were concerned about this issue and the way women were "put down on committees". They were of the opinion that "they can still only go so far because the men are above them."

I discovered then that despite the frequency and intensity of voluntary work women did, they could still feel worthless. The paid workers also experienced this.

Feeling Worthless

There were numerous comments in the women's stories which showed how women may be viewed as the 'other sex' and their roles and activities devalued. These themes emerged when women talked about the decision-making practices of the Organisation, and when they gave their impressions of the mechanisms the Organisation used to maintain the status quo. All of the women talked in detail about the functioning of the Organisation. They were able to link this to their experiences on a daily level in households and in families.

Many women talked about groups of men forming an "elite" both within branches and on a national level. They commented that this group may make most of the major decisions. Sometimes these decisions were made outside formal meetings. One woman remarked:

...it's the Director, whatever he's called - the President, the Vice-President - and I would say one or two men who do have their ear, that I would name but would prefer not to, even if they don't - you're not going to.

Women may be treated badly by these men. **Mrs I**, a mother, who had been involved in committees elaborated:

Yes, I think the women on the whole, particularly the ones who go through as Presidents, are all excellent women but I think some of them don't in fact - aren't as assertive as they should be once they get to that point. They presumably are in their own branch or else how do they ever become President? But when they actually go to meetings and AGMs and that sort of thing, I'm always very sad at how few of them will actually speak out. And yet we meet them socially afterwards and they're all full of - bursting with ideas.

Women's activities may be observed and monitored closely by the IHC. If things did not work out well for the child/adult women often took the blame. The paid workers had an intense feeling for the mothers and a lot of respect. Most believed that women whether in the home or on the committees frequently got a "rough deal". It was generally the women who went to the meetings about the child and who were asked to run any programmes for the child:

Yes, um, mostly the mother but there were a number of meetings where both parents attended. But usually when both attended it would be the mother that spoke most.

The mothers ensured that their children/adults were receiving adequate care even when they had left home and were living in the IHC facilities where other people were responsible for their care. Women, it seemed, were never able to relax about whether their children/adults were getting what they needed. It was a lifelong concern. Yet despite this concern, very few women felt they had been given any credit for the work they had done.

It appeared to them that men were often valued for just being men, whereas women had to "prove themselves". Sometimes too, these men got to the "top very quickly" and took on key positions especially once status was attached to them, such as certain committee positions.

Men, according to the women interviewed, were increasingly removed from the daily reality of caring for people with intellectual disabilities because tasks associated with caring did not have a high value. Women did the "behind the scenes work" and were always waiting for men to make an important decision or finish a task so that they could then carry out their work. Because women may be viewed negatively and defined as being "emotional" and "aimless" their ideas were often not taken seriously.

Many of the women felt that their goals were more realistic, for example:

Women have had the model services. _____ is an example. She got it off the ground - the leadership has come from women when we are talking about actual services. Men aren't really interested in this - they have great ideas but forget about the practical details.

There haven't been so many outstanding men. I hope I'm not being too biased, but do they actually sit down and think they may have the wrong goals? Sometimes they are very narrow and single-minded.

There was a concern that some of the IHC's goals were too idealistic and did not take current conditions into account. However, if women brought this up they may be accused of being pessimistic. Their opinion was not valued. Mrs D, a paid worker, explained this:

I'm wondering if we shouldn't go back or slow down and be more practical - that they will learn but they'll learn slowly. I sometimes wonder if we haven't become too complicated for staff out there in the services and that - it's like, you know, three or four years ago, going and doing a valuation, where probably training became - I'd use the word 'a little bit more professional', but I question that word 'professional' compared to the rest of New Zealand where staff are running around with wonderful glossy programmes but are they doing

anything? And the standard of care was poor; the home was grubby, they didn't bath because there was a misunderstanding by staff saying, 'Well, they've got choices and rights and they bath when they want...'

One thing I do notice from parents, and I don't blame them, is that they've had so many - that with each successive generation bright upstarts come along and say, 'We should be doing this or that and the other' - they're just so unsure about the IHC. And they've been told so many different stories that they're a bit shaky and want to take things a bit slowly, sometimes start...patient. I wish we could wipe out some of the bad things that have happened to them.

This leads us onto a discussion of women's involvement in the decision-making processes of the Organisation.

Decision-Making Processes

Although the IHC was started by a group of parents and many people still called it a parents' organisation, some of the mothers felt they just "get in the way" and were not encouraged to take an active role in "things that matter". It seemed that in some instances the Organisation believed it should involve the parents but they really were a "bit of a nuisance". Decision-making processes often operated to exclude women and although some of the women felt they could challenge the Organisation's goals and practices, others were confused and believed they really were not involved and included in these activities. One of the paid workers pointed out that although it was not always essential that parents be actively involved in the Organisation, it was important for them to be included in decisions that would have implications for their daily lives. Many women claimed that they were "not informed, let alone being involved in decisions."

Mrs M, a paid worker, stated that one of her major impressions of the Organisation was that there were:

lots of confrontational kinds of situations between Branch and National...things to do with policy changes and stuff like that...unprofessional attitudes and bad communication both ways.

Women and their families could be totally unaware of "what is going on" and sometimes heard about the Organisation's activities from sources external to the IHC.

The women said that even if they were not aware of what was "going on" it was often better to "keep quiet and not make a fuss or rock the boat." Mrs N, a paid worker, talked about the frustration she experienced when waiting for decisions to be made and then waiting to be told about the outcomes.

...haven't actually got the power to do it. Where you need a signature on a document to proceed. Like, we have got a facility that we've got, that we're ready to operate, that we've got the staff, we've got the people. We're ready to go ahead and you sit around for two months and wait for a signature on a piece of paper. It's ridiculous.

Mrs I, a mother, had a similar view:

...I would like to know what's going on in IHC. I would like to be more involved at branch level without having to go on the committee - I think that's very sad that we're not involved...so that we could even know what they're thinking...

Women have to put a lot of effort into finding out 'what is going on'. We just don't have branch meetings. If you're not on the committee you don't know what's going on....I just don't get any information. The only reason I got it the first year after I left the committee was because I was in

the office doing voluntary work and I was on services. And the day I stopped that I haven't seen the minutes. I haven't had a newsletter other than the IH Review which is about the whole of New Zealand, and really it's all cut and dried by the time it's printed in there. It's all very well to say, 'Send us letters'. But you hadn't sat on that committee - I know it's all been discussed and they're on to something else now, and it's unlikely to be resurrected. So certainly in the 70s there was more involvement in the branch...

Many women believed that the Organisation's size contributed to the problems about decision-making and receiving information.

Mrs F, a paid worker, in her discussion on women's role, claimed that: "I don't think they often get the recognition, promotion, from New Zealand Committee, etc. that they need to..." She talked about a very small group making decisions:

Our very bureaucratic administrative and financial systems. It seems to get in the way of a lot of - I mean there's the pull between trying to get a centralised administration/financial system and quality service.

Women often found it difficult to confront the bureaucratic mechanisms of the Organisation and were made to "feel guilty" if they did this. They were given superficial excuses like "It's the way it has to be". It was a real concern for these women and many references were made about bureaucratic and complicated decision-making processes. "Too much paperwork, too many meetings, that's the problem. What about the people?" "There are not enough get-togethers; it's too big now."

It was my impression that for the older women something had been lost and they felt sad about this. It appeared as if "big" meant inefficient and impersonal. Some of the quality and closeness of people seemed to have been lost as the Organisation had grown. "We don't hear about things like we used to, it seems they don't have time for us." "They should ask us because he's still our son."

The women were frequently criticised for being "hypersensitive" if they challenged decisions. Mrs C, a paid worker, had seen this happen to women in the IHC:

...I think they're often informed of them when they're ready to be made or they have already been made. I don't think there's enough information prior - I think it often comes to crunch time before parents are involved. I don't think there's often enough emphasis or understanding that parents are often hypersensitive, perhaps over-protective and they are viewed as very vulnerable, and perhaps they do need a little bit more time. It's a big step for a parent of an IH adult who for years has worked on the basis that their offspring is going to need protection and guidance all their life, to suddenly be told...

Women may not have a chance to talk about these feelings. Mrs L, a paid worker, believed that not enough time went into discussing issues before decisions were made:

...You tend to sit round and get told what's happening and perhaps putting in the odd comment or answer a question - there really isn't time for discussion. This is why things get passed without us knowing because we do not talk about things often enough.

Mrs C, another paid worker, suggested that the knowledge women had was not valued and that the "grassroots" experience did not inform major decisions. Management seldom asked for the opinion of people working on a grassroots level. She commented:

...but then I think this is something that probably happens within the society too. There are people at ground level - and ground level I would say, the people within the facilities - aren't always asked for their opinions on how the facility should be

run, maybe, or if a new building is going up or perhaps how it should be - I think perhaps there's been some lack of utilising the experience and the knowledge of the people who are.

Mrs D, a paid worker, suggested there were not enough links between "services" and management:

I think if I was honest about it, I suppose the decisions are made by one or two or three people. I'd like to think with the Regional Directors in place - and they're the management team - that they're the ones that really should be making the decisions or making the decisions that need to go up to New Zealand Committee for consideration. But I still don't think there's enough link in that process with the advisory side of the Society...

These women emphasised the importance of decisions being made with "input from local people not just New Zealand Committee" because this is not representative of caregivers' opinions and experiences.

There was no point "elderly men making decisions" when they did not know what the daily lives of women were like. Women talked about how management did not always understand the interests of people with intellectual disabilities. They often ignored women's observations about this process. The women shared many examples of this. **Mrs O**, a mother, summarised these views:

_____ allowance has been cut down. This is what it is. And yet they go and buy all these houses. And that's where you find a lot of the people that gave to the intellectually handicapped, inasmuch as bowling clubs and Rotary and that sort of thing. In fact, I know a Mr _____ who visited - he was at _____ House but he's now at _____. Well, it must be a relative or somebody who cares for him - a couple. They worked very hard, Mr _____ did, to get a van up at the hostel and it was to be used for _____ and the residents to take them out. And about two or three months later, or a few months later they sold the van because they were starting this quarter off

the cost of taxis business, and Mr _____ was very angry. He said never again would he ever get their Rotary Club or whatever it was to do anything. If you give to the intellectually handicapped you give it to the welfare of the residents. You don't - all the handicapped people - children, adults or babies or whatever - you don't give it to them to buy a \$160,000 house in _____ or an \$80,000 section on the corner here that nobody had bought for a year - it's never been built on before. And then they've gone and done that. So that's where - at one time I'd have kept quiet about it - but now I don't damn well care. I'm too old!

One of the mothers, **Mrs C**, who had a long association with the Organisation believed that these issues were fundamental to the ongoing development of the Organisation and must be confronted.

She claimed that long range goals conflicted with the practical realities and that sometimes parents felt money was being spent in the wrong places:

...becoming property billionaires. But that money - they ought to beware - because that money's given to the intellectually handicapped - it's not given so the Society can become property millionaires.

A lot of the women were beginning to challenge these issues. They said they realised it was important to involve other women and to clearly identify what the issues were. **Mrs D**, a paid worker, suggested that women must continually challenge why decisions were "top-down". She stated:

There's a bit of a gulf between the hierarchy (as we call them - say, National Office or someone) and the people who are actually working every day with IH people.

The women related many stories that described the ways in which the Organisation tried to persuade women that they had chances to participate in the major decision-making process. A typical comment was:

They pay lip service to allowing feedback and I'm sure they say - 'We'll get them to do this, but as long as they do it the way we want it.' They say it's okay, they'll fit into our system, we know they'll see to that. If we criticise we get squashed on that because that doesn't fit in with the wonderful system that's set up for them.

Mrs C, a mother, who had been involved in the Organisation for many years suggested that it was hard to show how women were treated because people external to the Organisation believed that everyone belonging to the IHC had a consensus of opinion. She shared some personal experiences about the unfair treatment she received when she tried to challenge the Organisation. She wanted to slow the changes down because she was concerned that the Organisation had not fully thought out the implications of normalization and integration policies. **Mrs C** challenged the assumption that these policies would necessarily mean an improvement in the quality of life for people with intellectual disabilities. She was worried about the extra pressure this placed on women.

Another woman, **Mrs I**, a mother, had a similar story when she talked about her treatment by male committee members when she tried to challenge their dominant views. She remarked:

Well, unfortunately, I think it's made by a group of men at National. And this does disturb me because, as you know, I've sat on the Presidents' meetings, I've sat at the Services' meetings and, well, I would say on occasions it's been quite chauvinistic. Maybe not as bad at the end as it was at the beginning but one had to be - I think this is why I went so well prepared. And wouldn't open my mouth unless I had...

Yes, definitely. And if I put forward - I had to have - where a man could say something and it would be discussed immediately, if I put it forward there would be all the negative reaction before you would get a positive one, or 'Maybe perhaps we should be thinking about that'. And that was very obvious many a time...

Even when I was involved in Services and with the Presidents, I was quite sure that I still wasn't in that inner echelon.

Another woman, Mrs D, a paid worker, reinforced this view when she commented: -

I'd like to think it would get better for women. I don't know we'll ever see the day, as long as I'm a woman that there would be two women sitting at the table with me. I don't think - I think that would take a while for that to happen in the Society. But I know I'm different and I know I'm different when I sit on the management team. But I've always found that different because since I've been in IHC I've always worked for a man and I've never - it never ceases to amaze me what they consider to be a problem. I may see it as a problem but I don't concentrate on it. I'll deal with it or it'll go away and I can't spend hours over talking it through.

The women talked about how much work they had to do if they were to change the impressions the IHC had of them. This view is very clearly portrayed by Mrs I, a paid worker:

He said the only good applicants were women and he sounded as if he was quite regretful about that, whereas I was thinking, 'Oh good, one up for women!' I'm not a radical feminist but I certainly am a great believer in women's rights and so I felt that was good.

The comment by the male in this quotation suggested to Mrs I that women did not have the same kinds of abilities as men and for this reason they were not encouraged to be involved in the "inner echelons". Men encouraged the assumption that they were the only ones with the skills to carry out certain jobs. As Mrs I and other women have suggested this can be accompanied by the belief that men were the only competent decision-makers. Part of the process of changing this was getting access to information. The women talked about the difficulty in doing this.

Exchanging Information about the Organisation

The women discussed the need for ongoing information to do their job and to keep up-to-date with the changes in the Organisation. They talked about their attempts to get more information and how receiving information did not spontaneously occur. They often had to "beg for and fight to get it". Some of the women claimed that they got "put down" by the Organisation when asking for information and were not encouraged to be involved because they "ask too many questions". Many of the men, they suggested, supported the way things were at the present time as it was in their own interest to do so. For example:

...I think they really feel that what they're saying and feeling - they might have the chance to say it at committee level or at branch meetings - but I think they almost feel that they're being patronised, if you like. Okay, we'll have a branch committee and you can say what you like, but the feedback I get is that the decisions have already been made.

An important aspect of receiving information was being able to comment on it and pass this back to the Organisation as a form of feedback. This was, as the women described, not encouraged by the Organisation.

The written Philosophy and Policy of the Organisation (1986) stated that staff and parents should be encouraged to give feedback to the Organisation. However, many of the women commented that they were not encouraged to give feedback or identify any concerns they had. They may be "labelled" if they "complain too much". Committees were sometimes the only forum for bringing complaints but these were often inaccessible to women. Moreover, they may be threatening and overpowering in the ways they were organised. It may be difficult for women to challenge the so-called experts.

Mrs K, a mother, described her feelings about meetings:

...not always a great talker when it comes though to going to meetings where you have the likes of some of these for National or whatever who stand up and give all these, to me - great ideas forward and find it very difficult to argue against, which I don't think is always right what they're saying but I do find it hard to argue against them.

Many of the women claimed that the Organisation was not a big happy family and as one said: "The National Executive makes the decisions and tells parents what to do." She was very bitter saying that often the "Headquarters' actions" did not match their stated philosophy. For example, she elaborated in her comments about cuts in services:

cut out things like busettes [vans to transport clients in] but they buy property. We weren't asked. We never knew anything about it. People don't know anything about it. I went to a seminar once and when I got to speak they said, 'You've had your say. Sit down.' That's it...

She talked about how the information given out did not always provide a "true picture of what really is going on." Parents were often forced to change without any consultation. Sometimes change happened too quickly. This was the view of many of the women I interviewed. **Mrs D**, a paid worker, suggested that:

I don't think volunteers, parents and some staff agree with the changes but they may just accept it because they don't have a choice or understand.

She felt the size of the Organisation prevented these people being actively involved. She did not feel comfortable with leaving parents out and pushing them to change. She believed that a few years ago parents were involved, but now the Organisation had somehow left them behind and a number of parents were really frightened about all the changes, for example, normalization. New terminology and everything else the Organisation did today inhibited a lot of parents. "Particularly the parents that had sons and daughters who are 30, 35, 40, and I think still there in their 50s." She says they worried about the future; she wondered if parents had truly accepted change or because it was so big they had no option but to do so. This paid worker believed that because some professional groups could be viewed as "experts" everything they said was seen as "correct". This may not be so. Some professional groups, for example medical practitioners, appeared to reinforce each other by implying that what they were doing was "always correct". She felt the Organisation should be asking parents for their opinions, because "whatever happens" they are still the parents of that child. There were few opportunities for meetings and feedback on what the "experts" were doing. Typical comments were:

You usually don't see any instances where they give direct input. It's always very roundabout and often in negative ways. They're not asked, 'Right, we have an idea. We're going to do this, we're going to open a new workshop, we're going to do this. Would you like to come in and let's talk about it, let's tell you about what we're trying to do.'

They don't really know what's happening and what changes are about.

...They tend to get left out. They're left behind at the moment in what's happening, in the direction

IHC is going. There's not been enough discussion informing, letting them know what we're trying to do.

They're going to have to go to parents and explain things. They're still the parents, they want to know what's going on and they misinterpret what our philosophy is. I've discovered that quite a lot, quite a lot lately.

The paid workers who discussed how it was important to encourage and maintain parental involvement were not sure how this could be done:

I get into a bit of a problem area here, because I believe when you look at the Society as a whole, it has grown so fast, you're also talking about multi-million when you're talking about the money area. I believe that we're in a funny crossroads area and I'm not sure how we can retain - I believe it's important to retain that parent input but I'm not quite sure how we do it (Mrs N).

Others felt that a start could be made by providing more information and encouraging feedback on this information. Parents, as some of the paid workers suggested, must be involved in a very practical way and they must "see results - it can't be tokenism." For example, planning meetings for the child must be an honest discussion where everyone is involved and where there are positive and realistic outcomes. Parents wanted to "see results". They did not want idealistic solutions for their daughter's/son's problems. Some of the paid workers felt that this was beginning to happen. The issue for these women is how to translate these small changes into those that would influence the Organisation on a broader level. Mrs C, a paid worker, had hoped that the Individual Programme Planning process could contribute to this:

They're good. That's really good. And it's just beginning, I think, to gel. The people themselves are just beginning to realise that they can have a

say. We're not sitting around talking about them, we're talking with them. And I think the parents are just beginning to realise that they can have a definite input into that. I make sure that the parents all get a strengths and needs list for themselves so when they come to the meeting they're prepared - with their own ideas.

However, the Individual Programme Planning process would not work as Mrs C pointed out, if paid workers were not committed to seeing parents as equal partners in the decision-making process.

Several of the women pointed out that "training" should be given to staff in order to help them work with parents. Sometimes staff "just don't know what to do with parents, they felt confused too!" This would help facilitate more effective meetings where everyone felt involved in the process:

But I think you've got to have a good rapport with parents and know how to deal - public relations is a big part of this job and if you can't do that you might as well - I don't know if you can teach that - I don't know whether they should have courses on public relations and how to deal with parents, but I think it's very important. I've seen some awful blues made and I've seen some very good relationships grow up, so I think that's very important. But that's not - actually, I've never seen that come up as part of a seminar or anything. It's important (Mrs K, a paid worker).

When parents were not encouraged to have meaningful dialogue and were repeatedly "ignored" or "put down" they began to feel apathetic and worthless:

They just take over when they move to a group home. This is hard to take sometimes. They do all her shopping. I used to do that...but I just let it go on. Not a lot you can do... I guess I would like to know more about what's going on but I shouldn't complain - they are busy and I'm sure they're doing a good job...They told us about going to a job in

the community after they had discussed it. I'm not sure where that idea has come from...you know, moving from workshops.

Exchanging Information About Caregiving

The mothers considered that some of the information they were given was at times too complex and did not help them understand what was "really going on". Several mothers believed that some of the information given to them about their son/daughter and the activities they were supposed to be carrying out was too technical and complex. It did not help them to understand more fully their daily demands and activities. Rather than making a positive contribution to their daily lives it could make them more confused and consequently they felt more frustrated and "put down". For example, as I have described, the Individual Programme Planning (discussed in the section on the household) was initially designed to have a more effective way of monitoring the skills of clients and teaching new skills. Parents were to be involved in this process and invited to attend all the meetings. What happened in reality however, was that this process could be overwhelming for parents and place additional pressure on the mother who was generally the one who was expected to carry out the teaching programmes in the home. It also placed additional pressure on direct caregiving staff who were expected to teach clients more complex tasks without receiving any additional resources or support.

The women interviewed had another important point to make when they talked about their belief that learning from experience was as effective as learning from books. There were many comments about this and the types of information that was used by the Organisation. Mrs E suggested that much of what came from books was too technical and did not in fact contribute to and address the needs women had on a daily level.

The knowledge that often began as useful could also become so technical that it was overwhelming for parents and even some of the paid workers who had to use it. Some of the women felt bewildered and even hurt by this. They felt they had been betrayed by an Organisation whose original intent was to provide support and useful information for families.

Mrs M, a paid worker, describing in her story about the way new skills were now expected to be taught, observed:

...I don't suppose you can ever have too much information but if you could have - we almost have! - you know, it's all very well having all the technology and everything written down, and there's nothing wrong with that. I think it's good, but somehow we just need to convey it into practice a lot better and more - convey it into practice in isolated pockets but we need to get it into practice right throughout the services.

Mrs F, a paid worker, wondered whether professional groups developed knowledge in order to further their careers without thinking of its implications for women's lives. They were, she thought, concerned about using knowledge to show how "clever they are". She suggested that although it was the women who carried out the proposals of the professional groups and researchers their contribution may still be viewed as insignificant. She listed off many innovative programmes women had developed, for example, finding ways to make learning new skills easier for their clients or daughters/sons. These may not have entered the history books and social science literature but they had contributed to the quality of life of people with intellectual disabilities. These programmes may not get funding or support because they did not follow rigid social scientific criteria or uphold the dominant philosophies and current thinking of the Organisation.

Women also talked about the conferences that professional groups may run. These conferences may cost lots of money but may have little

relevance for the experiences of caregivers. They were an opportunity for professionals to share knowledge with other professionals but were generally inaccessible to other women.

One of the paid workers, **Mrs J**, suggested that some of the literature was too "formal" and did not have relevance for the New Zealand situation. She also suggested that information may not be adequately distributed or presented in a way that was useful:

Well, I don't think - I think a lot of the stuff that comes into National Office sits there, and I don't think it's disseminated well. I think the magazine has been quite good, but I think there's an awful breakdown between the good stuff that comes into National Office and what goes out to the branches, and that's appalling really because they're the people that have got to put things in practice. The other thing is that it's a matter of - some of the journals need to be interpreted for grassroots stuff.

The women talked also about the technical jargon used and as **Mrs C**, a mother, commented, how some people unwittingly used jargon to make caregivers feel uncomfortable. She said that some of the "professional people" she had seen "put down" her son and it hurt. She stated:

You know, that was quite hurtful to be told as a mother that she had - it was as if he was dead or something. She just stood there and assessed - what would be the word she used? Anyway, it just really grated that she had actually - instead of looking at him as a person.

Ms E, a paid worker, speculated whether all the phrases such as "normalization" and "individual programme planning" become cliches but may not really mean an improvement in practice. People assumed that concepts like normalization meant something good, but did they really?

To be helpful to caregivers some of the paid workers I interviewed wanted to provide information and in some instances training to parents that was meaningful and useful for understanding their child's/adult's behaviour. They valued caregivers' existing knowledge and used it as a base for developing further skills. I was impressed with the ideas that these women had about how the knowledge could be improved.

One of the ways they had begun to do this was to set up support groups for women to come together to discuss what support, services and information they required.

Support

The women also talked about their need for support. They tried to support one another because they understood what it was like to work long hours and make sacrifices for the people they lived and worked with. When talking with others the women began to reflect on their situation. They provided each other with support and shared skills. They valued the information they received from other caregivers and "hands-on" staff as this usually had more relevance for their situation than many of the theories they read about.

The women remarked on the importance of having support so that women could talk about small problems before they became major issues. However, this support could be hard to organise and "burnout" did happen.

I believe we lose a lot of good staff because they - and I hate using the term 'burnout' - but I think they sit for a long time, too long in an area and sooner or later it either comes to a blow up or they get cheesed off and they go.

They haven't got any better. They're getting worse because they've cut down on the staff...so you can't manage a home where there's so many severe cases.

Mrs C, a paid worker, suggested that new service developments can function to further isolate staff - for example, small residential and vocational units may mean that staff were often working alone. Support she believed must be given to these women. **Mrs L**, a paid worker, elaborated on this:

...And I believe that the smaller homes are doing this more and more. When you think that you've got - a mum out there with one intellectually handicapped person and everybody says 'Give her as much support as you possibly can. She must have lots of support.'

She continues: That's your mum out in the community with one intellectually handicapped person. But we are putting one manager out there with four or five IH people....No, I don't believe we are expecting too much of them. I believe that it's fine but we must put in the support.

Many of the women believed that support groups can be a way of involving parents in the Organisation's activities and stop them feeling so alienated:

In the past parental influence was more effective. The people in power were Presidents and Committee - they watched over us. Now only some of them have this power they are like staff. Many of the parents don't know what's going on, we're alienating them. We don't want emotives or parents to be unprofessional but they think staff are experts and won't listen to parents. This is wrong. I think we need more flexibility on a branch level so that they can decide how to work with parents.

However, some women believed that they had made their contribution and that support groups and other forms of support "Come with a price - you have to give something back":

Not very much at the moment because I haven't got a lot of time, as you can see. But over the years I have. I used to work with them up at the workshops when they were up in the smaller place and when my husband was well enough he'd come up too and we'd work up there. But now, I haven't had time to do anything that I want to do. My husband died six years ago and now I've got really involved in things that I want to do and have never been able to do.

Unless the younger ones put something into it, I'm worried. I've had my day - when you get to this stage in your life... Now I think they're finding it hard because young mothers go to work.

We've got specific things like the workshop, now people don't do this as much, we need to bring the young ones in again - they haven't got time to talk on committees or go to coffee mornings but some of the younger ones are starting to be on committees they're very good, better at that than us older ones.

We want a rest for a while.

Mrs J observed that the Organisation needed to acknowledge that many women now wanted a paid job outside the home and that they could not give of their time in order to receive support. She believed, as did other women, that at times the Organisation resented this.

Mrs I, a mother gave up paid work because she enjoyed being on committees and viewed this as an important role for her. However, she could financially afford to do this. As she pointed out, some women did not have this choice.

She was concerned though, that voluntary work with women in the IHC, did help women meet others who had similar concerns and interests. Now that some of the younger women went out to paid work they did not get this support. She believed these younger women had more difficulties than older women because they had to juggle caring for the child with paid work. **Mrs K**, a mother, reinforced this and stated: "It's us older mums who keep doing raffles and things but it

keeps us in touch and we get a lot of laughs from each other so I hope they don't miss out." Some women pointed out that there were times when they wanted to do activities and get support from outside the IHC. However, they often felt pressured not to do this by the Organisation:

I feel I can help myself by getting involved in other things. It keeps me sane and I also let other people know about IHC in this way....You don't see other parents volunteering for kindy for years - we have to give our whole life to IHC.

A few women felt bitter about this but most just "got on with it" and did not think about it.

It appeared as if my questions encouraged women to think about issues like support. They had strong views about these issues. Many of the women felt that a lot of the issues they were confronted with could be challenged if women could get together to give each other more support. Mrs O suggested that when women began to challenge the "status quo" the Organisation frequently discouraged them and this meant that it was hard for women to join groups that questioned the Organisation's practices. The Organisation also made these women feel very inadequate by comparing them with other women who did not ask for support or who were coping more effectively with their child's needs. It could be embarrassing asking for help and yet often when help was offered, women were so burnt out they could not accept it:

I had parents contacting me and crying, in tears, on the phone saying, 'But what can we do about it anyway?' You know, and the other feeling is, if they create they could get themselves disliked; they could have their person chucked out of IHC and there is nowhere else. They can't go anywhere else so there's a degree of fear too. It's like your child getting kicked out of school and there's no other school to go to...You can't. And if you kick

up a damn fuss they'll say to take _____ somewhere else. Although they say they won't, they will.

The women felt that they could get labelled as "stirrers" if they helped each other to challenge the Organisation. Sometimes women left because they had difficulty finding others who:

...feel the same as I do. I was told to have nothing whatsoever to do with _____. I wasn't to ring her or go to her for advice or anything. If there was anything I wanted to know or to clarify I was to go to him...

Some of the management take it very personally when women got together and offered some constructive criticism.

Mrs C, a mother, who had been involved with the Organisation for many years talked about how she had worked with women in support groups in order to improve the conditions under which women cared. She asserted that support groups can be used as a forum wherein new ideas could be discussed and analysed in depth. She talked about her efforts to organise groups of women and about how difficult it was to organise these because they took up lots of energy and time.

Mrs F, a mother, deliberated on the long years of involvement of women in the Organisation. She talked about women's activities as being the "bread and butter" of the Organisation and how the women used to support one another as they carried out these activities. Stories such as these enabled me to understand the strength these women had and how in small groups they managed to help one another cope with their daily experiences. These women believed it was essential that women became even stronger in order to challenge some of the new ideas the Organisation was putting forward.

Work Without Reward

I wished to capture the women's views on the current and possible

future roles of the Organisation and their understanding of some of the important developments such as community care.

Mrs D, in her comments about the way the IHC operated suggested that the Organisation expected women to do more work for less reward. She observed that:

I suppose, although they were difficult days when I look back in those early years, they were certainly much more challenging and much more rewarding and I don't think there are enough rewards for the challenges that are supposed to be lying ahead for us at the moment.

Mrs E, a paid worker, believed that the Organisation needed to re-think the way it expected women to carry out the work without looking at alternatives for providing services to people with intellectual disabilities.

Mrs E suggested that the changes made would be more appropriate if parents could be more involved. Parents should be helped by IHC to lobby for change. She believed the Organisation should ask them in what way services could be provided and funded so that additional pressure was not put on the women in IHC. She felt that the IHC did not fight hard enough for services:

...I think we're as slow as wet weeks. We worry too much about being nice and polite about things. I think we should kick up a much bigger fuss about things. And I think we should get intellectually handicapped people kicking up a fuss about it too. And their families, because they're going to be listened to a lot more than we are in some instances.

According to these stories, lobbying took place between the Heads of the IHC and those in the government. Many of the women believed that

the IHC was not radical in lobbying for resources because the government held the "purse strings". These women got frustrated because they could not lobby directly but had to do this through the processes outlined by the IHC. The women expressed their concern that funding and services were still organised on an ad hoc basis. Mrs D, a paid worker, believed that more funding must come from the government and then women would have to do less work, or at least get more money for the work they currently do. She stated:

...I think government has to - because I believe the pressure's now on branch managers - and since coming to management you're much more closer to that, whereas - and you get a much more overview, I suppose. But my concern is that branch managers are having more and more pressure placed on them today in respect of fundraising. So the money is playing a big role and I think it's causing concern.

She believed that the IHC only got money because certain people in management had the "ear of government". This view was also held by several other women:

It's silly that money depends on whether _____ is on good terms with the Minister. It's also not fair that _____ doesn't go back to the lower level like the Committee. They wouldn't have a clue sometimes how he gets the money.

Many of the women felt that the "days of charity are gone - we should just be a lobby group now and our services totally funded." There were mixed responses as to how the government should in fact be involved. Mrs B, a paid worker, suggested:

It's a two way thing. If you get more government involvement you get more paper. You have to conform to their ideas which are not necessarily the Society's ideas, not necessarily what the parents want for their child. Because if you're accepting -

I presume you need money to begin with anyway - if you're accepting their money then you've got to account for it. And it must be accounted for, spent in the way that they approve. If you did something that they thought was widely out of what they wanted it for, presumably the funding would peter out. So it is a two way thing, and while I know money is a big thing - we're always being told there's not enough money for this, that and the next thing - I still feel that maybe it's a better position to be in than to be dominated by government...And it really concerns me. I don't think government should have more of a role than is absolutely necessary because - it should only be a monetary role because - just listening to that guy - he's a really nice person - he's a really caring person, but he wouldn't have a clue. And I would say has probably never met an intellectually handicapped person in his life and he happens to be the Personnel Manager there.

Mrs C, a parent, was appalled at the way IHC had to get its money. She felt it was insulting for her and her daughter to have to fundraise. She retorted:

I think it's absolutely shocking. I think the fact that the IHC has to fundraise is an abomination...should be provided as of right. We shouldn't have to go out cap in hand and fundraise for it. I mean, it's our job - it's the IHC's job to make government aware and so perhaps if they're not aware then it's our fault.

It's a real concern for young mothers who want to go back to work but can't get money for babysitters and it worries us because who'll look after _____ when we're older and can't visit her as often. There's still not any surety about all this. You still have to fight. We've done it for years.

Mrs A, a mother, felt the same and remarked:

Well, I only wish the government would really back it almost completely. I mean, I think it's good that people have got to help a bit - it doesn't hurt. But as I say, I really think the Annual

Appeal should be wiped. I don't really think we should have to go knocking on doors. It's a thankless task and people have now got so many calls on their time, you know. I don't know how they'd do it - whether you could tax everybody so much, or the government, you know...It's embarrassing and degrading having to beg for money.

Some women suggested that an umbrella group like DPA (Disabled Persons Assembly) could administer funds. They believed present systems devalue people with intellectual disabilities and this may make their work more difficult. Women had spent years fundraising. Many of these activities were hidden and their total contribution was hard to measure. Some women were concerned about where the money actually goes. They were neither asked about their views, nor about how the money should be spent.

There was a very strong pressure on women to fundraise - they pressured one another because the Organisation assumed they would do it and made each other feel "guilty if you don't do it". Women, however, were beginning to feel "brassed off":

You often don't get credit for voluntary work. I've worked on it for years and I don't want to keep doing that. I'm finished. If I was in a job I'd be retired now. I just want to relax and have a bit of peace.

Sometimes women felt that the advertising used by the Organisation contradicted with what it was trying to do - "it is based on charity and poor handicapped people". One woman cited recent television advertisements to explain her point. Other women felt that even though big business may now give money it was still based on charity and they:

only do it to escape taxes; would they give it if they didn't have profits? We still have to be grateful. We should stop selling ourselves and

compromising. I think some of the things we do are sick.

The issues around fundraising and how the IHC obtained resources was of particular concern for the women I interviewed. It was connected with the ways women viewed the function of the government. The changing nature of State policies and how it supports (or does not support) the IHC was an ongoing concern. It kept these women in a situation of uncertainty because they could never totally feel comfortable with what would happen for their child/adult.

I discovered that although these women had spent long hours doing voluntary work and raising money, they were not always part of the groups that lobbied the State to ensure it would continue to subsidise the activities of the IHC. This was a major frustration for these women. They were also aware that if the State took more of a direct role in providing services they would still not have an opportunity to be part of the decision-making processes. Their involvement in fundraising and voluntary work gave them at least some chance of finding out what was happening in the Organisation.

Mrs C, a mother, pointed out that the IHC was now using big companies to help them fundraise and this may prevent women and others in the IHC from deciding on the image the IHC should portray, and what it should do with the money it raised. She suggested that it became like a big business where people with intellectual disabilities are treated like units rather than real people. She was worried that these practices were further alienating families.

The dilemma for women was how to maintain their involvement in the Organisation and be part of the processes that lobby the government for resources and services. Many women believed that the government should be more involved and that its relationship with the IHC required examination. They thought that other people in the community were of the opinion that the IHC received sufficient government funding, but the reality for these women was that this

money may not reach the families because it was also used to maintain the administrative functions of the Organisation. They knew that this funding and the government's provision of resources was always uncertain. There was still not an expectation that people with intellectual disabilities and the people who cared for them had a right to receive enough resources to ensure that they could remain living in the community. This theme was common in women's stories and was related to their stories about current policies such as devolution, deinstitutionalisation and community care.

Community Care

Most of the women told me that the interview with me was one of the first opportunities they have had to explore their feelings about current Organisation and State policies associated with community care. It was an area of much concern. For this reason I felt it was important to include many of their comments in full in order to preserve the richness of them.

The women were concerned about the policies of devolution, deinstitutionalisation and community care. They were concerned that these policies could make their lives more difficult. The IHC and the government were encouraging the community to take on the provision of more services. The women, however, argued that there may be no accompanying devolution of resources. Moreover, it was not clear to them who the community actually represented and whether this community would want people with disabilities as their neighbours. The IHC wanted to break its services down into smaller units and encouraged families to keep their children at home. This placed more pressure on women caregivers because there was an implicit assumption that women were able to care and that families were intact. It is important to emphasise that it was not community care as such that the women opposed. Indeed it was the women who had helped begin the IHC and its community services in order to allow people with intellectual disabilities to live in the community. What the women

were primarily concerned with was the way in which their years of unpaid work in caring for people with intellectual disabilities would continue to be exploited by the Organisation. They pointed out that community care was not necessarily care by communities but by women in households and Organisations. These women were either unpaid or underpaid. The women wanted recognition for their work and also wanted resources put in place so that community care would work effectively for all groups.

The women had many comments to make about current trends. The paid workers were supportive of the mothers' concerns. One woman, **Mrs F**, a mother, who had been involved in helping set up the IHC talked about how the government had provided institutions and had discouraged care in the community in the early part of this century. She said that now care in the community was the trend but she worried about people like her daughter who were getting older and needed lots of support.

Mrs D, a paid worker, talked about the ways in which the IHC had pushed for normalization¹ and how this was now being used by the State to give over more responsibility to voluntary agencies and to families.

Some of the women questioned whether the State and the IHC itself were guided by humanitarian concerns or if it was economic reasons such as saving money that directed policy decisions. They were worried that there was still not a fundamental belief that people with intellectual disabilities had a right to live in the community and to receive adequate support. These beliefs may be subtle and hidden. It may be difficult to identify the real aims of State policies.

¹ The belief that all people with intellectual disabilities have a right to experience the same lifestyle as their non-disabled peers.

There was also a concern that the policy makers had unrealistic expectations that did not take account of the practical issues related to "community care". Many of the women wondered about who the "community" actually were and whether they were ready to take on more responsibility for the care of people with intellectual disabilities. The women were concerned that they would continue to "carry the burden" if the "community" failed to provide adequate services.

A few of the women remembered what it used to be like before the IHC was established. Even after 40 years they were still arguing for services and so were sceptical about deinstitutionalisation and the availability of generic resources. The women had been called "over-protective" and "hysterical" but they knew what it was like for people who "don't make it". Many of them talked about the need for:

sheltered workshops and hostels for those who can't make it by themselves. There'll always be some that'll have to have these....There's not many of them employed, is there.... Only a few out there and you have to give a lot of support....I wonder if there's enough finance, Robyn, it's hard to say.

This concern ranged from pre-school children through to adults. Some of the paid workers felt concerned about those families who were worried about their children and what would happen to them once they left preschool. Mrs L, a paid worker, had some definite views about this:

Well, I don't think it's something that can be generalised. It frightens me a little bit that people go around saying everybody must be integrated; that normalization says they must do this, they must do that. I think that every child has to be rated on the state he's at and what is going to be best for him. We have several children here who, if they were integrated into normal

kindergarten, would sink, I really think. Not the ones who have behaviour problems, but the quiet ones. Where you have two or three staff for 40 children, the quiet ones are just left to be quiet. They might be just sitting in a corner or wandering around in their happy little world, not doing a thing constructive.

...And once more, maybe the quiet ones may miss out on that. Where somebody should be acting for them, but they haven't perhaps jumped up and down about it. What concerns me more is that people tend to jump on the bandwagons that we follow American programmes or American literature. And things that perhaps are falling apart in America are still being done here....We don't wait for the results. And everybody says about this marvellous public law act that everybody has to be included and that each area of the country has to kind of log in with a central authority what they're doing for each person. But we had somebody visit us one day who came over - I don't remember who he was - but he said they're running out of cash. The thing's falling apart. I think the IHC and government have to really look at the changes they are proposing to make sure this doesn't happen in New Zealand.

There was some concern that a total move to generic services (that is, services provided by agencies in the community, agencies which provide for all people not just those with intellectual disabilities) may be a backward step. A mother, Mrs M, stated:

Well, I could see it almost being phased out. The most difficult thing I think would be to keep tabs on everybody. Because within a couple of years here we could have most of these people scattered all over _____ and it would be a far more individual type of thing. I think we're beginning to because it's happening with people going out. And again this morning there was...because _____ had to be in about three different places at once. And that was only involving six different people...

The women were also concerned that in using generic services they may have to have contact with many more agencies. "I don't think they have thought all the practical things through." Some of the women

have had experience of "integration" and have some definitive ideas about it:

I would be concerned that they didn't have back-up if they needed it. I think perhaps we tend to be - we talk about normalization so much but we tend to forget that these people are intellectually handicapped.

Mrs G, a paid worker, observed:

Even though they're going to have different profiles than an IH person ten years ago, they're still handicapped; the brain damage is still there and I think even if they're out in jobs I would be concerned that they didn't have the security of knowing there was back-up there somewhere. But how you would cater for that many - probably mean that staff didn't ever come together in one place, or very seldom, but perhaps they would have a round - a circuit - they would have to do to support each case. If we want these folk to be able to compete in society in every area the same as everyone else we will have to work at it slowly. We've got to educate.

They could end up living a limited life; they have to be included.

I think we have seen with other groups how they suffer. I don't want my child to be like that.

These comments were common. The women were aware that people with intellectual disabilities could not be cured and they believed that this would mean that they would require continual support. **Mrs I**, a paid worker, explained:

....The idea that everybody can live in the community. I think that's going to be really difficult for a lot of families to handle. Some handicapped people are great within the family and great in the community. Others have such terrible

problems, behaviour problems, physical problems, I think, it's going to be really difficult for their families to keep them in the community....I don't really know how much the government is helping. I think sometimes they're cost cutting. Particularly by integrating them into the school situation, I think sometimes they might be better if they had perhaps a separate building in the grounds because they're not as grown up or as sophisticated as the other children. I think they do need a sheltered environment. I don't know whether it's a good thing, five days a week every week, you know.

These women intimated that the women in the IHC have had much debate about such issues. One woman suggested that the "people who make the changes have forgotten why they do - they want to push them out and forget the reason for doing it in the first place." In her story this woman described her feelings about the people who make the plans for the future. She believed that integration had become a catchword, "a bandwagon" and that people are really not thinking through what it means. It was her contention that the policy makers seemed to have an urgency to "get everyone out without thinking why they want it. I think it was to give them more choice but living in a doss house is not a choice."

Many of the women talked about how the policy makers "seem to forget they (their children) are handicapped - that won't go away." Ms L, a paid worker, argued:

...You know, if you're intellectually handicapped, for 99.9% of the people you will always be intellectually handicapped. You will not be normal because its the handicap that makes you not normal. Normal is without a handicap, isn't it? Although there's - I don't know that that's the average. Most people have got handicaps - Yes. Let's go as far as we can. Let's - as far as possible for this particular person and you might be able to get right up to S and I can only get up to B - up to B is the best possible for me whereas up to S is still being lazy for you. Yes, I believe it all comes down to the individual. So if you're getting tremendous support you can probably do wonderful things. I

might be capable of wonderful things but if I'm not getting the support I'm just going to sit at home and cry.

I like the small community homes we have because I think they get the support. Staff must have the support and the knowledge to carry out their job. Where are all the staff coming from to support people out there. We have to give more training - it will take a while to work through.

Several of the women questioned whether their daughter/son was "going to be any happier living independently. They were happy with their own." A number of the women felt that they were "put down" for feeling this way. However, they had real concern for their child's/adult's happiness and believed that living independently may not necessarily mean that people have more choices and are happier with their lifestyle. Mrs K, a paid worker, graphically described these concerns:

Yes, well, I went to the complex. I went there when it opened and I was horrified at the way that some of these people - they were put into these little houses - what do they call them? - flats. Semi-independent people and most of them didn't have any independence at all hardly. And it was very hard to see some of those people just literally struggling to cope in that first six months. Well, I felt some of them were living in absolute squalor there for a while because of the usual staffing difficulties, of course, but no way would I like to see people put into a semi-independent situation unless they're quite ready to go into it. I wouldn't like to see that again. I didn't like it at all. I mean, some of them, they couldn't cope with the cooking; they couldn't clean - the stoves were getting dirty; they couldn't cope with their washing and drying. And they needed far more support than they had. But I think a lesson's been learnt from that. We shouldn't push them.

Who wants to get them out there? Do they, or is it us?

Mrs I, a mother, also had many comments about integration and her experiences with it. She remarked:

I'd like to get education sorted out because I think that's in a real muddle. But I don't know enough about it to really say because I don't quite know where people are going and I can't stand what they are really trying to do....It originally started with the fact that all children should be educated and I agree with that. All children should go to school and I agree with that. But it's now getting to the stage where they are all being put into schools, any school regardless, just as my other children would be or any child, but I'm sure that in fact we haven't thrown out the baby with the bath water. And in fact, looking back, the special schools had the edge on them all - schools - in that they were staffed appropriately and looked at individual needs. If you have a good head teacher the children were certainly not held back in any way. That's not to say - I would hate to go back to having special schools built separate from everything else - but I think that we may still need to have a group or rooms or something on a site of a school where - certainly for three hours could be treated completely separately and people would go there, hopefully for no other reason than they needed help. Not because they were labelled because they were handicapped or anything else, but because they needed that extra help they couldn't get in the classroom..

Mrs K, a mother who had strong views about independent employment, expressed these:

You can only hope, that I feel that they will be happy, that life will be - they will be able to be as independent socially to be able to mix as far as is possible, but I always feel that they need each other. And this is what concerns me, going out to outside employment. And I know they always say the support will be there for them, but there are always some who miss out, I feel, somewhere along the line who could be very lonely.

I think all this is very good for those who can cope but what about the ones that can't cope?

Some of the women pointed out that the policy makers may not have thought about the problems that could emerge as a result of "our people living in the community, unemployment and violence - all these things." The women suggested that living in the community brings with it all sorts of problems.

There were many comments about the type and speed of changes in society and how it would affect people with intellectual disabilities:

I think it's the fast moving - I mean, we live in a fast moving society and most people out in the community are really having to grapple with that. They find it really difficult. The more independent you make the handicapped person the more they have to grapple with that.

Mrs L, a mother, elaborated further:

I think there could be barriers, particularly in the employment field. I have heard that _____ that had employed two or three IH young ones that the able bodied workers objected because there were able bodied people who couldn't get jobs and they didn't feel that IH people should have those jobs...

They have an influence on IHC. They - as the unemployment figure rises that's going to have dramatic effect on our people and I believe that we have to come to terms with that and the fact that there's unemployment doesn't mean that our people dip out any more than anybody else. But we have to realise that. We are entitled - our people are entitled - to a percentage of everything and their rightful percentage.

Mrs L was very concerned about services for the elderly and accessing quality care for her son. She was a solo parent and at times felt an

overwhelming burden in having "to do it all". She talked about the experiences with her son:

Well, I don't know what's happening. If they're kept living on their own, if there's anybody there to help if need be, because it's all sorts of things....Well, I think the ideal situation would be that if they could live in a situation like these retirement homes where they've got nursing staff available or social workers available to help them. _____ can manage most things on his own but things like cutting fingernails and toenails, he just wouldn't think about that. He might think about a haircut, but you know, they need a little bit of help in that direction. But other people can't get into these. He's so vulnerable.

Some of the women also talked about how legislation was not sufficient to ensure that things will change and become easier for people with intellectual disabilities and their families. Mrs H, a paid worker, explained:

Yeh, really makes a balls-up, and that's happening all over the country. Will it work because the legislation's there? Or will it work if the legislation comes in and the people down here make sure that the people who go in can cope with the job that they've been given, are given the support to continue coping - what will make it work? I think it has to happen at both levels - law changes don't mean it'll happen out there. Also sometimes you can do things without legislation - we've got the children in a normal kindergarten and moving on to schools without waiting for the Act to change. But there comes a point when you have to have a change in the law so it becomes widespread. But you still need these resources.

Many women talked about the importance of defining what the term "community" really means. "Who are they? Do they really want handicapped people? We'll have to do a lot of work in educating them. There's still prejudice."

One of the women was concerned that "society is going through a lot right now. Will they want handicapped people who are dependent and have lots of needs?" Her comment reflected the view of most of the women in that they were concerned that people with intellectual disabilities were not productive so may be able to "give very little back. Do we have to make them normal so they can live in society?" There were many comments about this. Mrs D believed that if "...we move slowly and carefully..." normalization could work.

Mrs I, a paid worker, however, was concerned about how schools would cope and remarked that:

...the schools concern me a little bit because I don't think our school system is coping with the problem of so-called normal kids in the classroom situations and here we are keeping other kids with real problems to assist them, and I'm not sure we're ready for it. I think we've tended to run before we can walk, that before they put kids in they should have been sure there were some people to deal with them, that the training should come of staff.

There were many comments related to the readiness of the community to accept fully people with intellectual disabilities. "The biggest barrier will be getting the community to accept but IHC must also realise it can't do it alone." Mrs M, a paid worker, reflected a common view because at times she felt optimistic about the changes but at other times was very concerned about them:

Well, I think we will get them into the community and in fact they are being accepted, and I do think that there is more acceptance generally in the community of handicapped people. And I do think that when we no longer have to say that they're going to be integrated, or they should be integrated - when we can accept that they are, just as presumably I don't have to think about whether or

not I'm accepted in the community - they might not like me, but I don't have to think about it - I think the day we cannot even think about the fact that some are handicapped and some are not is the day we're aiming for, but heaven knows when that will be.

The women felt there was still a lot of "ignorance about" and that extensive community education must be carried out:

We must not only prepare the person on their rights and responsibilities but must also prepare the community.

I'd have to think as an ordinary person not knowing about handicap how I'd feel about these people if suddenly they lived next door.

I'm aware that neighbours are important - they're an important contact when our people live in the community so they must be prepared.

Would the community help if my child was in a difficult situation?

Mrs M, a mother, expanded on this:

...I'm worried about violence that they're open to. _____ a couple of times has really become worried about - just recently when she was home - last weekend she said some boys in the subway asked her for money and she was scared. And she kept on going back to this and I said, 'Did you say anything?' and she said, 'I told _____' and I said, '_____ will come' and she said that _____ would come and help her.

One woman suggested that people may not introduce themselves to a person with a disability. Much work, she said, had to be done in order to prepare the community. She commented:

Am I going to sit down and invite them into my home and make friends with them?

They could be even more isolated if we don't tell the people in the community how to talk to our people.

I think it's something we've got to be conscious of. I think that's what parents are fearing.

Mrs K, a paid worker, had a similar view:

Yes, I think there's far more emphasis now of course put on getting them out into the community. But that's all very well and idealistic but I think what they should be looking at is more emphasis on getting the community to meet the IH. It's easy getting IH out into the community but an awful lot of people just don't want to know. I suppose it's human nature. They don't. They're very kind. They'll give a donation. They'll pay lip service. But when it comes down to the nitty gritty....I think in some ways it's a lack of understanding. A lack of knowledge. A lack of information. Where intellectually handicapped people are in the community, are making regular contact in the local shopping centre or the local factory, they're very well received and you constantly hear other people say, 'Well, I just didn't know. I had no idea.' Or, 'I was always a little bit scared of them.'

She had some alternatives, however, and said: I think it'll get better. I think again it's a case of more work. People who are involved in getting them into the community, whether it's through work or on a residential basis, they've got to do a lot more PR work, whether it's a matter of going round to your neighbour's or going up to the local shopping centre or talking to employers.

Mrs I, a paid worker, believed that professional groups need to be trained in the area of intellectual disability. She had some idea of how this could work in practice and stated:

Yes. As far as special classes go I think that if - I don't know who would pay for it and maybe that's

why it's not happening now - if OTs and physios could be included and actually visit the class on a regular basis and work with children who need extra physical help or specific help, I think if that could be sorted out then a lot more children would benefit from special education facilities that are available...I think it has been tried over the years but nobody's willing to pick up the tab. These services can become the difference between success and failure for these children.

Mrs C, a mother, wondered whether professional groups, other agencies and people in the community were aware of the daily tasks women carried out. She said that even with care in the community these tasks would still need to be carried out. She explained:

And you know, people could share their horrendous experiences and there are still such experiences. That hasn't changed. No, you know, the kid who dribbles and his nose runs all the time, and this is muddled up with his food and he vomits, and you know - it's all there still. That's what people are living with still.

Mrs O, a mother, had similar views to those of Mrs C. She believed that the practical demands of caring must be clearly identified so that appropriate community resources could be put in place.

The women's stories described how they had spent much time thinking about these issues. However, it was difficult for some of these women to encourage the Organisation to listen to their concerns. The women wanted a chance to discuss the alternatives and to clearly identify all the issues that were associated with the move to community care. They did not want a small group deciding on how changes could take place. They wished to speak for themselves and several of the women had begun to do this in their support groups.

Struggles and Resistances

The women I interviewed had some definite responses to the way the

Organisation was acting and they had some clear ideas on how change could take place. **Mrs I**, a paid worker, suggested:

Yes, well, I think it was originally set up as a parents' Organisation for the good of their children and this is quite a personal opinion. I feel it's now becoming so career structured that maybe the people it was actually set up for are only a little bit of the life of the person whose career it is. We, down here in the nitty gritty, are still working with children but there are a lot of people who are simply - say, administration and managers - and I know it's essential to have good administration in a big Organisation - but I sometimes wonder if they realise what is actually going on. If they would perhaps change some of their ideas, if they would spend a week in a workshop or a preschool or a residential establishment. If maybe that would change their thinking. I think the other way. Maybe there's not enough information passed on to them. I don't think we need to be consulted as to the running of the Organisation, but I think that maybe if they knew more about what we were doing, as I have just said, that they would perhaps change some of the things they were trying to do.

Mrs C, a paid worker, believed that men and people in authority should experience the daily activities of caregivers. She maintained:

I have never ever known a male in a position of authority or in an administrative position in the IHC come in and experience what life is like on a daily basis in a home. They are very brief visits, very brief occasions. Maybe half an hour.

Mrs E, a paid worker, suggested that more appropriate and effective decisions would be made if men could observe and also feel what it is like to care for people with intellectual disabilities. She said they would not then interfere with the good programmes "hands-on people" are carrying out.

Mrs N, a paid worker, believed things could change if people learned about "hands on nitty gritty stuff". She suggested:

...too many chiefs and not enough Indians. Too many people organising the policy but you need the people here doing the hands on nitty gritty stuff. And I still would like to see all these policy makers doing a lot of the hands on stuff. I'm afraid - not because I'm not really qualified - but because I've learned through experience and I think everybody should learn through experience. If they get lots of qualifications on the side or already have them, that's fine but unless you've had actual person-to-person experience and really get to know these people I don't think you're qualified to make the policy.

Mrs K, a paid worker, had a similar view and commented:

Well, what I would like to see is more of the people who make these policies and actually do some hands on work. I feel rather strongly about that. And then they might see things perhaps a little more realistically. I don't know whether that's just me or not, but I - well, it hasn't yet. But you often think, 'Oh, God, what are they going to cook up now?' you know. I don't mind. I just feel very strongly that people like administrators - whatever they call them now - branch managers - and anyone whose changing policy I like to see have a bit of hands on knowledge of the job. And I think that's important. If you were in a manufacturing business or something and the son took over the business, you usually find that the son had started off at the bottom and worked his way through. So that he knew what he was talking about.

Mrs D, a paid worker, believed that women must show by their actions that they can have a different way of doing things and encourage other women to do this too:

It's never been a conflict within myself. It may be a conflict with them and I consider that to be their

problem. I think I have probably, for a number of people in the management team - the other Directors or other people or the volunteers or President - I've earned a fair amount of respect from people that do listen. I have difficulty in being able to ration it out in my own mind about some of the decisions that are made hastily or that are talked about one day and it's changed the next, and I have that difficulty. I think there is still - and I suppose you get that in any national office - I think they're still very critical and judgmental and I don't believe there's enough - we're so busy telling staff or key people in branches to tell people that they're doing a good job. I still think that the branch management - managers, for example - take a lot of criticism and we don't spend enough time telling them that they're doing a good job. I think we still look on a lot of negative things and not enough positive things for people. And that worries me. That really does worry me. And I've got a different - I find that I'm different from men in their thinking and that's reinforced me since I've become a _____. I probably don't worry enough about things that they consider to be important.

There were conflicts about this however, as some of the women did not feel like "making a fuss". A number of the women suggested that they "hang in" because they enjoyed their work and this "makes up for" the bad times. Some of the women were of the opinion that it was not worth "making a fuss" because "you can get picked on" if you do.

Mrs N, a paid worker, suggested that caregivers may find it difficult to bring up issues and consequently things remained hidden. She tried in her coordinating role to provide a forum for discussion. She stated:

I believe we do, and I think we had a little issue not so long ago with the bank account numbers, which is a classic. I, some years ago, actually made a personal decision that if I knew there were rumblings in the background - because at that stage at our management meetings people would mutter in the background, they would never bring anything up at management meetings - if I knew that I felt there was rumbling in the background I'd give people an opening at the meeting by bringing something up.

The women also talked about how the women in the IHC may be given a few concessions to "keep them quiet" and in effect this prevented them from confronting the issues they were concerned about.

Some of the women commented that they may be given some individual support when they had a problem. This may improve their situation in the short term but it did not bring about any lasting change. **Mrs O** talked about her experience with this. Her problems were solved but other opinions were not sought and their difficulties were not resolved. She claimed:—

...there are no mechanisms that show...people coming together and many decisions are made behind closed doors...all these people sitting at National Office talking about this and that saying it's great, but to Joe Bloggs in this street and that house, sometimes it hardly reaches them at all.

Mrs M, a mother, commented that issues may be personalised and individual women "made examples of". She said it took her a lot of effort to find out whether other parents were having similar difficulties. She asserted that: "I got so carried away and really surprised myself how strongly I felt, and I rang some of the parents and...it was good..." Women may remain isolated from one another and often believed that it was their personal inadequacies that were the cause of their problems. This view, said **Mrs M**, is reinforced by the Organisation.

Mrs C, a mother, believed that women should not feel they must be grateful for what they got as this kept them in an inferior position. She contended that women must be clear about their rights and must not compromise these. **Ms F** reinforced this issue when she stated that "there were very seldom issues that went back to National Office to the people who make the decisions." She said that women discussed the issues among themselves but seldom brought them into the public arena for debate.

Mrs A suggested that the Organisation needed to have a "wider view" and determine what the implications of new developments could be. She believed the IHC may try to hide any difficulties by not identifying long range goals. She said that she would often say, "What's going to happen next?" and be told to "Stop thinking what's going to happen next." She related this in her story about integration and how people needed to look at the long-term implications of this policy. She also commented that "young women" had different concerns than older women. This may make it difficult for women to come together. She believed that groups of women did not develop spontaneously - having a child/adult with an intellectual disability did not mean that women would have similar opinions.

However, despite all the difficulties the women had in translating their individual problems into public issues which could be shown to affect women who care for people with intellectual disabilities, the women I interviewed did have some possible solutions. Some had already tried these out. I gained the impression that what will bring these women together will be the daily concerns they had around caregiving and the ways they had been treated by the Organisation. Mrs C, a mother, described her ideas for bringing groups of women together and emphasised that the immediate and personal concerns of women deserved as much discussion as the major issues. She emphasised that it was the common experiences of caregivers that were the factors that could bring women together. These could, as Mrs C suggested, transcend barriers of age and other differences. Mrs C had some very clear ideas about how she would organise groups of women and had in fact begun to do this. Ms B, a paid worker, had similar views. She advocated:

...Networking - and that goes back once again to staff strengths and identify what strengths they've got. Making them feel important and using that. And setting up those networks to do that so that they get more variety in their jobs. And the crucial thing is actually getting the staff working

together, networking together, and I think your support groups are really important. You shouldn't have to do that on your own because once you start having staff - like we did it - I mean, there was _____ and _____ and _____ and myself - we tended to form our own support group. But what happens is you end up separating yourselves...You've got to bring others in. And if they don't like what you're doing you can say to them, 'Well, why don't you take that idea? You put some thoughts on that and we'll get together.'

Mrs K, a mother, had some ideas about support groups:

Yes, they possibly could but I think IH can only go so far. I think parents must - and perhaps I'm saying younger parents - let's face it, I know how busy they are - but I still think they must become involved to a certain extent because as I always say, unless they come along, voice what they're needing, the likes of my age group do not know what the needs are. It's quite different to what it was when _____ was small, so therefore my age group can go along doing what they think is right and yet for the children coming on, it's probably not sufficient. But how does one know? They have to be informed and people have to want to come to these groups - it most probably should happen outside work if we're going to ask staff too!

She believed that the whole Organisation and the way it supported families had to be looked at. She wanted women to forget their differences so that they could "get something done". **Mrs G**, a paid worker, claimed that the staff she worked alongside refused to wait and got on with challenging decisions:

What happens is that people sit around and wait to be told from above, without passing on necessarily what they want, they sit and wait to be told what needs to be done. And I think that's the sort of historical thing - is that everybody in the end waiting till _____ says 'Yes'.

She suggested that the "hands on" people are generally those who knew what needs to be done "...and you don't go up and ask what needs to be done; you must always go down and say, 'What do you need?'" She intimated that those who are in "top positions" and understand the needs of the "hands on" staff should pass on "knowledge and the information and the methods" that "hands on" people "need to know" to change things.

Ms L, a paid worker, had been involved in support groups that had been successful in bringing about change. She felt there were still "too many blocks" and support groups could begin to "open up the system so it flows better". On a team there needed to be trust and an environment where ideas could be openly discussed and decisions examined and challenged. She talked about how working as a team could provide an environment for discussing new ideas and examining their implications:

It is important for me. I like to be able to bounce off my ideas. I might not change my idea but I can get - perhaps I can change my perspective just listening to myself giving it to somebody else. And I like to be able to have input into a team...

There was a group of women emerging who had become change agents in the sense that other women could go to them for advice and help in bringing about change. They had the ideas and knowledge that could bring about change for other women but they worked alongside other women to develop these ideas. They worked in caregiving positions or in positions where they could maintain their links with "hands on" staff and mothers.

I was impressed with some of the clear strategies these women had for bringing about change. For example, **Mrs B**, a paid worker, who had begun to do this claimed:

Women must do more brainstorming - I think they've got perception - they've got the vision. They are not afraid to make a decision because they know it may lead to more decisions or problems but it will eventually take us to where we want to go. We are used to action because we've had to really fight all sorts of things as women. We must be a lot clearer though and look at ourselves. We don't see it as a job but as a challenge and a commitment. We have a purpose even with all the frustrations. There's a purpose for being and doing.

She believed that women must try to get into senior management positions in order to bring about change. She said that although some women may decide to leave and work outside the Organisation, they could still work alongside women caregivers and other people who were trying to improve women's lives. Mrs B had made a personal commitment to bringing about change for women including staff and mothers. She was trying to look at changes in policy as well as in the jobs that women were currently doing.

Some of the women in this group talked about the importance of supporting each other so that they did not suffer from burnout. Working in a group could help women get some "refreshment" and a break from their struggles. Mrs C, a mother, discussed this in relation to "cell groups". She made some interesting comments:

And I think that's more important than another administrator, it's more important than another computer, it's more important than another social worker. I think that could be the key. Someone like _____ working right with small base groups and within a branch, even within a suburb, which might mean only three or four people. You know, it's the old theory, in a cell system, isn't it? It has always been found the most effective in any progressive movement. That's how any movement starts....And I think that's very, very real. I know it sounds - it's only doing what we did right at the beginning because, you see, there's a lot of scorn poured on some of the things that gave us strength at the beginning, such as we had one member in _____ who was a very skilled craftswoman and she used to get us together - get the people in _____

together - there would be about - right at the very beginning there would be - 12-15 of us would turn up and we specialised in aprons and we made aprons for an annual sale. There would be hundreds of aprons made. They were very beautiful, they were works of art. But the conversation all the time at a gathering like that was your child and what was going on at IHC.

She talked about how the IHC was started by groups of committed women and how it must never be forgotten that many of the services were begun by women. She gave several examples of these: Relief services so the women could have breaks away from the child/adult; Home Aid for support in the home; residential services for adults; and preschool services. It was her view that women often diminished the input they had in these changes. She believed that other women and herself had a role in beginning these "small groups" and linking their activities to the daily experiences of women:

....Probably in these small groups that you are able to talk with and to influence, out of them there may come someone who just starts another movement altogether. Or, sees a way of regrouping those who have some concept of why they're disappointed at present and where they should put their energies. I don't think it'll be done just by carrying on respecting the Society as it's structured now and hoping that you're going to break through. It just won't work....Yes, and I think that if I was working with staff I would encourage them to do that very quickly. That would be a part of the training I would give them.

Mrs M, a paid worker, believed that each Branch had to work out its "overall aims and philosophies", be "more creative" and accept that each region will be different and will need to respond to local needs. She pointed out that she had been involved with groups of women who were trying to ensure that legislation on a national level was put in place in local branches. She gave the example of the 28 days' relief provided by the government as often being insufficient in that not only were adequate relief services often not available,

but for some families 28 days was just not enough. Women who cared for children/adults who had special needs may have no access to relief services.

Mrs M had worked with another woman, Mrs D, to bring about some change in these areas. Mrs D believed that it was important to have clear goals about how services should be developed:

...I'll give you an example with our branch. We are very clear about where we're at as a branch. We're very much into a developmental stage; we've got definite goals that we've set to achieve within the next couple of years; and absolutely nothing to do with where we're heading and what we're doing is the pressure from National coming in that we should be splitting because branches are splitting. And it's got nothing to do with where we're at and what we're doing at all.

These women were trying to develop clear goals that they wished to achieve and they were trying to work in a collective way. The team members all had input into decisions. Ms L, Mrs N, Mrs O and Mrs H had also worked as a group to identify ways they could help other women bring about change. Ms L suggested that she used the group to "sort out ideas" and to prevent her from getting volatile and making incorrect decisions. The group helped her work out ways to confront difficult situations.

These groups of women helped each other develop clear strategies for bringing about change. However, as Mrs I, a mother, suggested they had to meet regularly and avoid being "put down" by management and executive groups on the committee. Women, she emphasised, should not "give in" to the dominant methods of carrying out the Organisation's policies if these in fact did not match women's aspirations.

In my interviews with these women they told me that there were groups which were bringing about some changes. The challenge for these groups was to link their struggles with one another and to keep these

struggles alive. Women had been actively involved in the Organisation over a long period of time. They believed that the issue was to ensure that their voices were heard and that their concerns were met. They, as Mrs D, a paid worker advocated, should have active roles in determining what form the Organisation could take and what its practices could look like. They must organise the way they wanted things done and not wait for others to tell them.

Feeling Ambivalent - The Good and Bad

As with the women's experiences in the household these women's lives and their experiences with the Organisation were a mixture of hard work and despair but also at times of joy and hope. It is important to convey this and also the ways in which women had begun to bring about change.

I want to end this section by talking about the optimism of the women. The women told me that the reasons they "keep going" were many. The main ones, as we have seen in their descriptions, were related to their relationships with their children/adults and the people they work with; their relationship with other women and their ability to bring about some change no matter how small it seemed.

As with their stories about the household the women's stories about the Organisation included a description of the "fun times" they have had with their children/adults. The mothers and paid workers have been able to bring about changes for these people and take much pleasure in watching them learn new skills. The women worked alongside other women as they did this and, as we have seen in the women's stories, they received much support and friendship from other women.

Working alongside other women has helped the women in my research bring about change and the belief that they could do this enabled them to "keep going". Life was not all misery for these women. The people that administered the technologies of power are the very

people that the women loved and cared about. The women lived and worked with these people and had many happy stories to tell about their lives with them.

My focus has been on the things that women wanted changed in the Organisation and the things that they had been unhappy about. A very powerful strand in the women's stories has been their feelings of ambivalence and the ways it had been difficult for these women to challenge the Organisation. I hope I have been able to adequately portray this in this section. I now take these themes and analyse them using the theoretical framework I outlined in Chapter Two.

CHAPTER SEVEN: AN ANALYSIS OF WOMEN'S EXPERIENCES WITH THE ORGANISATION

This chapter analyses the women's experiences in the Organisation. These experiences did at times mirror those that took place in the household and indeed there is, not unexpectedly, a reciprocal influence between both sites. The theoretical framework set out in Chapter Two provides the basis for elucidating the analytical categories for examining the technologies of power operating in the Organisation. These technologies are the means by which power relations were maintained. The following key technologies were identified:

- the observation, examination and comparison of women by the organisation;
- the use of knowledge to exclude women from certain activities;
- the use of language to provide meaning to women's experiences.

Observation, Examination and Comparison

Foucault (1978) suggested that organisations would use power relations in a productive rather than repressive manner and that the technologies of power would not be immediately apparent. Irigaray (1985) also examines the ways in which men define women's work and the value they attach to it.

The women I interviewed described the ways in which the Organisation defined the work they should carry out. Their work was devalued as caregiving tasks were given considerably less status than management positions. Men attempted to secure management positions for themselves because these were where the power was and where important decisions affecting the direction of the Organisation were made.

The women had many stories to tell about the ways in which men defined the work they did. Men attempted to derive the maximum utility from the women's skills. In so doing they tried to expend only a minimum amount of effort. The Organisation had certain key activities that it required carrying out, such as attending to the daily care needs of people with intellectual disabilities and teaching them new skills. The Organisation attempted to seek the most effective means for carrying out these activities. One way was to emphasise the 'natural' capabilities and predisposition of women toward caregiving. It reinforced the belief that women were the most 'natural' persons to care for people with intellectual disabilities and in so doing, tried to extend the 'natural' role of women to include the care of people who had many daily care needs.

There was evidence of this in the women's stories. For example, women talked about being encouraged to remain in caregiving positions. The move to management positions was made difficult. They remarked on the ways in which top management positions had more status attached to them and that these positions were nearly always given to men. The Organisation had a number of effective methods for ensuring that women remained in caregiving roles. Moreover, if they did move into management roles they were discouraged from taking on executive positions. Women were expected to do things like "write minutes" and "make the tea".

A most effective method was to observe women's activities. Foucault (1977) discussed the importance of observing individuals' activities in order to determine what work they could perform for organisations and for society in general. As I described in the description of women's lived experiences in the household, men in the IHC observed women's behaviour and defined the work women did in caring for others. As we saw in the women's stories, the necessity for women to carry out this work was continually emphasised. Observation is intimately linked to the examination and ranking of individuals (Foucault, 1977). For example, the women in the IHC had their work

routines examined by professional groups such as psychologists in order to ensure they included the appropriate activities for the child. The Organisation also tried to get this work done in the most cost effective manner. The women in my research were often asked to carry out highly complex tasks, tasks that professionals had been trained to do, in order to minimise the costs for the Organisation. Paid workers earned less than professional groups and additional support and resources were often not provided and thus this was an extremely effective way to keep the financial expenditure of the Organisation to a minimum.

The women talked at length about the ways in which their work was exploited. This work had been exploited over many years and with the current thrust and implementation of policies of community care the women would be further exploited. There was an assumption by the Organisation that institutional care (including large group homes) was "bad" and life in the community would always be "good" for people with intellectual disabilities. There was, according to the women interviewed, an absence of adequate debate over what made the community "good". It was likely to be low-paid workers in caregiving positions and mothers who would continue to carry the burden of community care. The women talked about how they were seldom consulted about what tasks community care would involve, how these should be carried out, and by whom. They were criticised if they questioned how the work within the Organisation was to be divided up. It was not in the interests of the Organisation to make their plans explicit but rather they continued to reinforce the dichotomy between men's and women's work and the contrasting values of this work.

In this research I demonstrated how the performance of women's work was monitored. It was not only the performance of their tasks that was monitored but the quality of the performance was also critical. Foucault (1978) argues that individuals will be criticised and even ostracised if they did not perform at a certain standard. They could be compared with others in order to ascertain whether they met the norm. However, not only will women have no part in defining what

this norm should be, but they will also be excluded from the processes which determined what value their work had (Irigaray, 1985).

The women in my research were often "played off against each other" and this was in itself a very powerful mechanism for preventing women from coming together to challenge the Organisation. Their work was compared with other women. Persistent criticism by the women about such practices resulted in some of the men ostracising certain women and encouraging other women not to associate with them. Some of the women had been publicly humiliated in this way and several of the men used tactics like labelling women as "stirrers" if they tried to challenge the dominance of men in management positions, why women had difficulty being selected for these positions, and why men still defined what constituted quality work.

It is important to note that the women were caring for a group of people who were in many ways devalued by the rest of society. Not only did this cause stress for these women but it also made it difficult for them to obtain support from outside the Organisation as others may not understand their plight. This at times made caregiving even more difficult to carry out.

However, men in the Organisation continued to emphasise the "good work" women caregivers were doing in an effort to imply that all women should be in this role. Clearly this was because it was in the men's interest to remain in management positions as this is where the technologies of power originated, and were administered and controlled.

Knowledge

In this research the term "knowledge" was defined as including historical documentation, scientific investigation and the application of knowledge by professional groups such as doctors,

lawyers, social workers and teachers. I begin with a discussion on historical documentation.

History, Grimshaw (1986) argues, is written in ways that may function to hide the experiences of women. The richness and diversity of women's experiences may be hidden. My reading of the formal history of the IHC, (Botting, 1972 and Riseborough, 1983) did not reveal the diversity and richness of experiences with the Organisation. I had no impression of what it really felt like to care for a person with an intellectual disability as only the major events were recorded and very little detailed description and analysis was provided.

The stories of the women I interviewed have revealed another level of the history of the Organisation. These women mentioned that they felt their experiences were not portrayed correctly and this was because it was not in the interests of the IHC to record any event or activity that did not reinforce the dominant view of the Organisation as being the correct one.

As I have demonstrated in the women's stories, if women's experiences were revealed in detail, this would upset the status quo because the oppressive situations women experienced would be exposed. For example, the women spent much time talking about the way the development of community care policies and practices had been recorded in the IHC official documents, such as the minutes of meetings. The difficulties the women may face as a result of these policies were not, according to the women's stories, considered in the historical and current documents of the IHC. It was not in the interests of the Organisation to do so, because those who develop policies such as community care must be careful not to reveal any negative outcomes from these. The aim of those men who control decision-making in the IHC was to ensure that the women would support community care by continuing, and extending, their role of caregiving. They would not only be required to continue caring for people with intellectual disabilities in the Organisation's facilities, but it was most likely that they would also have to

provide support to those people who moved from these facilities into the community. As the caregivers' stories have revealed, this would require additional work and result in working outside normal working hours. Hence, it was quite clear why the men who managed the Organisation were careful to record only the positive aspects of community living in their formal documents. It was not in their interest to indicate that this would mean more work for women with no accompanying increase in resources, support and monetary rewards.

Another aspect of history that was not adequately recorded was the contributions the women (mothers and paid workers) had made to the development of the IHC services. The long hours they had worked to provide new services and the achievements were not adequately portrayed. This aspect of history was obviously not viewed as central to the history of the Organisation and hence not a priority for recording in its historical documents. History was about those who had been involved in the major events as seen through the eyes of men. Thus, we have a history of major events which primarily included those activities carried out by the policy-makers of the Organisation. Another aspect to this is the ways in which men claimed the credit for the ideas of women, and as particular jobs took on more importance (such as certain committees becoming more central to the policy concerns of the Organisation) men would be appointed to these. It was not in their interests to show that women could be competent and able to "cope with" such jobs.

The serious shortcoming in the writing of the history of the IHC also related to the way research had been carried out in the Organisation. As several of the women commented, much of the research that was done focussed on the ways in which new policies could be implemented without researching the impact of these policies on women's daily lives. The women gave the example of Individual Programme Planning which was intended to benefit not only people with intellectual disabilities but also the families as they would be better informed. However, the women were generally not asked for their views on this programme and how it could be implemented effectively without increasing their work.

The fact that women had to carry out many of the programmes arising from better assessment methods with little additional support was usually not mentioned in the Organisation's documents about Individual Programme Planning. Nor was it made clear that women would be expected to attend the many meetings associated with Individual Programme Planning. The research examined whether there would be an improvement in the quality of life of people with intellectual disabilities but it did not talk about who would have the responsibility of ensuring this happened.

The women's knowledge about caregiving and the means to carry out their tasks more effectively was not acknowledged by professional groups who had the monopoly on certain knowledge and who were deemed to be the experts. A common example related to psychologists who had difficulty in not only sharing their knowledge but they also did not acknowledge that untrained staff and the mothers had some useful information to offer. This had the function of excluding women and making them feel worthless while simultaneously ensuring that through the use of knowledge such groups could continue to control the way decisions were made. There was an inherent ambiguity in this because although not sharing knowledge, these professional groups were asking the women to carry out some highly complex programmes for the child/adult. Both the mothers and paid workers commented on this. Despite carrying out these programmes, their status was not increased and they did not accrue the benefits that professional groups did. These benefits included an increase in monetary rewards, additional resources in order to carry out their work more effectively and the acknowledgement that they had developed improved ways for helping people with intellectual disabilities learn new skills.

This technology was linked to, and reinforced by, other technologies in ways that would contribute to the processes that secured and maintained the existing relations of power.

Language

Certain language was used by the Organisation to give meaning to the lived experiences of the women and to maintain the prevailing relations of power. As with the other technologies which have been examined, language did not at first appear to be oppressive and women themselves may have used the language without realising its effects. The men in the IHC found ways to mask its use and encouraged women to be participants in the way this technology of power was administered.

The women in the Organisation were encouraged to use certain key words to describe their activities. While at the outset these words appeared to have no function other than to factually describe an event, they would take on connotations that could indeed have negative outcomes. The term "care for" was a case in point because the men in the Organisation who made the policy would often talk about the need to "care for" people with intellectual disabilities. The fact that it was women who "care for" not only people with intellectual disabilities but also the men in the Organisation was cleverly disguised by the implication that "care for" must of necessity have positive connotations and outcomes.

The women's behaviour and activities were described in certain ways and key words would become cliches and remain unquestioned with respect to their use and definitions. Labels were used to describe the women's behaviour. The words used included "emotional", "hypersensitive", "hysterical" and "overprotective" and had a function of helping to secure and maintain the dominant group's use of women's activities. These words were, as described in the section on the household, used by those in the Organisation and by members of households with the consequence that the myths about women's characteristics were continually reinforced.

Not only were women labelled but language was also used to attach positive labels to certain practices that could have negative outcomes for women. Greene and Kahn (1985) discussed how certain

concepts and labels can be used to perpetuate myths about women's existence. My research showed that labels such as "happy family", "normalization", "quality of life", "community living" and "integration" were all used in ways that implied that the practices associated with these were always positive. Let us take the phrase "happy family" as an example of how many of the men in the IHC used this phrase to define how the Organisation should and in fact did operate. There were a number of levels to this. There was an assumption that women were part of a large "happy family" - the IHC. It was assumed that the Organisation acted like a "family" and cared for them. The women were encouraged by those who ran the Organisation to go to this "family" for help if things were proving too difficult. They were encouraged not to go outside the "family" if they had problems and were criticised if they did. This concept could mask the differences between "family" members, that is, those who were part of or worked for the IHC. It also hid the negative practices that took place in this so-called "happy family". Another aspect related to the use of the word "family" was that the term reinforced the dominant belief that care for people with intellectual disabilities should take place in families and with this it reinforced the belief that women were to be the main caregivers.

This was an extremely subtle process and it was not until I had critically examined the women's stories that I began to realise that the belief in the "family" as the dominant mode for organising the care of people with intellectual disabilities was continually reinforced by the IHC. The Organisation reflected and extended the practices of the household and in turn the Organisation influenced what happened in the household. The "happy family" concept can be extended further than just a phrase that at a cursory glance appeared to be a positive label and concept. It reflected how families (and the Organisation) were structured with the "man at the head" and the ways in which certain roles and tasks were divided up. This, in turn, was reinforced in other ways, for example, by groups such as professional groups who met only with the mother when they were discussing the child, for they assumed it was her role to oversee the care of this child.

As Foucault (1977) points out, the various technologies of power operate to support each other with the overall effect being to uphold the dominant view. I have demonstrated this by analysing some of the ways the organisation had used certain technologies to maintain the status quo.

These technologies are inextricably linked to one another and I have explored this by describing some of the ways language can be used as part of a process that defines and interprets women's activities. This very act is intimately related to the way women's work is devalued as language and is an extremely powerful mechanism for reinforcing the current social practices of the Organisation.

It is important to emphasise that because these technologies were subtle and at times hidden, it was difficult for women to determine how they were actually operating. Because individual men in the Organisation did not always consciously set out to oppress women it was difficult to expose the power relations. The "subjection" of women was part of a complex process, the purpose of which was to ensure that the goals of the Organisation were met. However, because power relations are so tenuous and forever changing their nature and form, there were times when the women could use this to their advantage in order to bring about some change. It is to a discussion of this that I now turn.

CHAPTER EIGHT: WOMEN'S RESPONSES TO THE RELATIONS OF POWER

Thus far the analysis of the women's experiences has concentrated upon discovering the ways in which their lived experiences were structured. In this chapter, the focus of the analysis alters in order to elucidate the mechanisms that determined how change that would benefit women could arise.

The theoretical framework outlined in Chapter Two explained some possible ways for bringing about a significant improvement to women's lives. However, this can create the impression that if a certain 'blueprint' was followed change could come about relatively easily and have benefits for all women. For the women in my research this was certainly not true. They were not always aware of the significance of the changes they were bringing about as often they did not have time to reflect upon their circumstances and to plan how change strategies could be implemented. The practices these women wished to confront were so much part of their lives that not only the identification of these but also the means to change and overcome them was difficult to identify. To change these practices women have had to challenge the very structures they are based upon and this process takes much time and energy.

Despite constraints and difficulties the women had, through hard work, brought about change for themselves. I would not like to give the impression that it had been easy for these women to effect this change. However, nor would I want to convey that their lives were always miserable. It was important to capture the richness and diversity of these women's lives, the many levels of experience they have had and the ways their responses to power relations have been able to be re-examined and re-negotiated.

In this discussion I will outline a number of phases in the process of change for these women. The first phase is to understand the

nature of the women's oppression. This was one of the reasons why in my research I began with a description of women's daily experiences. This enabled me to obtain an understanding of what forms of oppression were present in the women's lives. I argue that any analysis must begin with an understanding of the immediate effects of oppression before it can be linked to a global form of oppression.

Women's individual needs have to be met before they can become part of and contribute to major struggles. For example, in my research women described how it was important in the interim to ensure that they received adequate relief and financial support on a daily level. Once a woman's emotional and instrumental needs were met she could begin to examine the inequalities and how these arose. Some "stop gap" measures had to be used before women could get on to fighting the major issues. The women talked about this with respect to receiving support and having time out from their children/adults. It was difficult for them to think about how their lives could improve when they were so involved in coping with the recurring demands of their daily caregiving routines.

When women discovered a space to think about and reflect upon their situation there were a number of strategies they could use to help in this reflection. In my research I wished to determine whether Irigaray's (1985) concept of "mimesis" could be used to explain and understand the strategies women had begun to use in order to work at exposing the relations of power present in their lives. Some of the women I interviewed had begun to do this. They did not label it as such but they intuitively acted out their roles in order to expose oppression. When women use "mimesis" they continue to act out their roles and carry out their daily routines and tasks. While they are doing this they try to "stand back" from their position in order to examine the power relations and the ways in which they may have become oppressive. Several of the women cited a variety of examples of how this strategy was working. The paid workers talked about how they tried to meet with one another in order to evaluate what social practices were operating to control them. Some of the

mothers used their support groups to do this and in these groups they talked about what was happening on a daily level and tried to understand why certain events were taking place.

"Mimesis" is a useful tactic as it can help women identify what roles they wish to retain and which require transforming. Several of the mothers and paid workers referred to this aspect of "mimesis". Although they enjoyed caring for people with intellectual disabilities the difficult part was coping with the pressures of the Organisation and the expectation others placed on them. Not having choices about their roles and how they were defined, were important issues that were being confronted by these women.

There can, however, be a problem with "mimesis" as women may in fact identify so strongly with a role they may have difficulty removing themselves from their daily situation in order to analyse it. I demonstrated how the women required the support of other women to ensure they overcame this possible difficulty. Another difficulty was that physically and emotionally women could become so exhausted and overwhelmed by the daily demands that they did not have the energy to look at what was happening to them. They could also choose not to because it was too painful. Several of the women cited examples of this. They had difficulty becoming involved in a process of social change and challenging current structures especially when they felt their actions could harm their child/adult.

Because women had been used in certain ways for long periods it was often difficult for them to transcend their daily routines and look at themselves. They could become so enmeshed in their role they might not be able to believe there were any alternative ways of existing. They could lose their own identity in the child/adult and have difficulty viewing themselves as someone who could have some control over their own daily lives and existence. Many of the women had experienced these feelings. This, I argue, was one of the reasons why it had been difficult to bring about lasting change.

Although these women were at times unwittingly practising the tactic of "mimesis" they showed in their stories that what was required was a process that could sustain this and could allow them to act and reflect on their situation continually. Some of the women did this in the groups they formed with other women. In these groups they were exposing and analysing the power relations and the ways in which they were oppressive. The function of these groups was for women to support one another in their daily routines but at the same time they were used as places wherein women could identify the common themes of their oppression.

The next phase the women were involved in included the process of challenging the power relations in order to transform them. The women had to do more than just reveal the sites and practices of their oppression for these will not spontaneously disappear. Careful analysis and critique of power relations must occur and in my research I showed how the women in the IHC were doing this in a number of ways. They were attempting to make their concerns more public. This was sometimes difficult because it seemed easier to deal with one's own situation rather than worrying about the circumstances of other women.

Individual women could have found personal ways of getting their husbands/partners to take more responsibility for caregiving or some of the paid workers could have found ways to "work the system". The women on committees and in management positions did at times find it easier to support the "status quo". A lot of effort had to be expended in order to keep alive the struggle for all the women in the IHC and extend personal changes in ways that would benefit other women.

Part of the strategies in the phase of challenging and transforming power relations is to find a common issue to be brought into the public arena for debate. When a group of women are working to bring about change it is important to choose an issue that they can all relate to. Because the Organisation was currently examining its role

in relation to its own and the government's policies in respect of community care there were numerous issues that needed to be confronted. These issues were complex because there are both good and bad aspects of community care.

Several of the women were focussing on issues related to community care and were attempting to reveal the implications of current community care policies for the daily lives of caregivers and of people with intellectual disabilities. They were trying to show how current policies associated with community care not only had repercussions for the lives of people with intellectual disabilities but also for the people who cared for them. The women were having to decide as a group whether it was worth challenging these current policies and structures in an effort to show how these were impacting on the lives of women. It was often very difficult for women to make a commitment to those groups who were bringing about positive change for women when such an action could have negative outcomes for their personal lives. The women could be made to feel very uncomfortable if they attempted to challenge existing arrangements as their families and members of the Organisation may try to marginalise them even further. Involvement in an organised struggle had been a learning process for several of the women as prior to coming together with other women in the IHC, they had not been involved in any previous organised strategies for change. They may not have ever challenged their family members or the Organisation on a sustained basis. They spoke about being concerned that they may be viewed as being too radical and this had often prevented them from joining "groups of women" who were labelled as "feminist". These women wanted minor changes but were concerned about the implications of any major changes. However, despite these concerns, I found all of the women I interviewed to be extremely tolerant of one another and willing to make allowances for those women who were uncertain about joining groups that were fighting an issue in ways that could present some difficulty for them in their personal daily lives.

The next phase has been for women to decide when it was the right time to challenge the issues they had identified. In my research and in the case of community care the women had just begun to identify when and how they could bring this issue into a forum for public debate. They cited the example of consultation because they were attempting to challenge the Organisation about the process of consultation. Although the Organisation had told them they would be consulted on any issue relating to community care, in reality this did not happen. Women could, however, use this promise to push decision-makers and planners to outline how consultation should take place and how the needs of women would be addressed and considered.

Many of the women talked about the importance of using community care as an issue to bring about some change as they felt that women should determine the pace of change and what its outcome should look like. Clearly the implementation of the policy of community care affected all caregivers and it is important to propose some alternative strategies for making programmes such as community care work effectively for all groups.

Laclau and Mouffe (1985) illustrate the importance of less powerful groups being able to take advantage of the "seeds of change". They emphasised that in order to do this groups must not only have a "strategy of opposition" but also a strategy that outlined the construction of a new social order. With community care, for example, women had begun to talk with one another about how services in the community could be organised. However, it was difficult for them to keep this process active and keep moving towards more appropriate services, because at the same time they needed to continue in their daily routines. These routines often exhausted them thus making it more difficult to bring about change.

Again it is important at this point to emphasise the vulnerable nature of any change process as it does not happen in a logical fashion and women do not spend all their spare time systematically planning a 'struggle'. The women in my research, for example, moved

in and out of groups that were organising for change. This may help to explain why it takes many years to bring about any lasting change. Despite assurances to the contrary, the men in dominant positions in the Organisation tried to ensure any change that would jeopardise their positions did not come about. They sought ways of interfering in and stopping the change process.

One of the ways of ensuring the change process is systematically organised and that change is sustained is to utilise the skills of those individuals whose function it is to oversee the change process (Gramsci, 1971). Gramsci calls these individuals 'intellectuals'. This term has however, several connotations and for some women it may imply an elitism that could negate the efforts of all women in bringing about change. Although Gramsci (1971) and Foucault (1980) in their discussion of the term 'intellectual' did not imply an elitism, in my research I used the word 'change agent' because I believe this more appropriately describes the role of women who take on this role.

These 'change agents' did not necessarily work as a group but worked alongside women in the household and in the Organisation to help identify how change could take place. They did not provide a 'blueprint' for change, but rather had ideas that they shared with women and they helped women articulate what it was they wanted to change. The women did at times come together as a group to fight a particular issue but again this was difficult because they also had to carry on their daily routines and activities.

The women I call 'change agents' were both mothers and paid workers. In the interviews they identified themselves as 'change agents' or were identified as such by the other women in the research. A key factor in my research was to discover how these 'change agents' evolved and emerged. These women had a variety of experiences and backgrounds and they usually became a 'change agent' after being involved in an issue such as getting better relief services and then staying on to fight for other issues alongside other women.

Some of the women had come from other organisations where they had also been 'change agents'. At least a third of the women in my research placed themselves in the category of 'change agents'.¹ They worked alongside other women, and they shared their knowledge and their skills, providing stability and continuity for any change that was taking place. They carried out their usual roles at the same time as being a 'change agent' and did not come together to form an elite group that forced change on other women.

The women were at different stages in their commitment to change and had differing views on how this change could be effected. Many referred to the conflict between achieving small changes for a few women, at the expense of bringing about lasting change for all women. Sometimes they had brought about change at an individual level but had been unable to encourage women to move on to further challenge the system. This often resulted in minor reforms being won on an 'ad hoc' basis but not necessarily benefiting all caregivers.

An example of this is the twenty-eight days relief provided each year to families. This appears to be, on the surface, an excellent way of ensuring that women would be able to get breaks from the daily caregiving routines. However, in reality, this does not always happen as it is often difficult to obtain access to the appropriate relief services necessary to meet the needs of the child/adult. A number of the women talked about the necessity for having more than twenty-eight days relief. Once they had taken their twenty-eight days they had to pay for this relief themselves and for some women, this was not possible due to financial reasons. The 'change agents' identified these concerns and they explained how these kinds of changes could be problematic as they could in effect make caregivers

¹ This figure may appear to be somewhat high. However, it must be pointed out that all of the women interviewed had been involved with the Organisation for more than five years. They had an extensive and intimate knowledge about the issues confronting the IHC. This accounts for their commitment to bringing about change.

"feel grateful" for a minor change but reluctant to fight for further changes in case they lost what they had already achieved.

An important role for the 'change agents', and a key phase in any change process, is to help women identify what alternative systems they wish to put in place. Several of the women were doing this as they had set up programmes that could be used as ideal models for other women to use when appropriate. Alternative ways of managing the Organisation was an example of this. Some of the women who had been in management positions had begun to test out non-hierarchical and collective ways of making decisions and offered some very practical ideas for doing this. They ran seminars on team work and shared decision-making, they shared responsibilities in their job and they tried to involve households in the decisions about their child/adult in order to show the ways in which knowledge and skills could be shared. Another group of women ran meetings to talk about women's issues and were organising seminars for discussing current issues. Clearly change must be practical and relevant to a woman's situation. Ideas for change must be specific and rooted in daily experience and must also encompass clear strategies for challenging why the daily experiences of women take the form they do, such as why women are the primary caregivers and why this is not valued.

Those women who were forming groups for bringing about change had to continue to build their group's membership and make the changes relevant for all women. In order to encourage those who had not usually joined groups adequate reasons must be given as to why change would benefit women. 'Change agents' had worked hard at defining how groups for bringing about change could be formed. 'Change agents' did not spontaneously form themselves into a group - they too must find ways to come together. The issues were not always clear and the women in the IHC, as do other women who are fighting for change, have to continue to find the time and the space to plan and reflect on the change they are engaged in.

I have a feeling of optimism. Change has taken place despite enormous barriers. Women have resisted power relations for many years so there was no reason to believe that they would cease doing this. The task now is to translate these personal resistances into struggles that could benefit other women who care. These struggles must be taken up by feminists and be recognised as important as all other women's struggles. This and other major issues confronting these women will be discussed in the final chapter.

CHAPTER NINE: CONCLUSIONS

This dissertation has explored the experiences of a group of women who care for people with intellectual disabilities. It has described and analysed the daily lives of these women and examined the perceptions and the meanings the women used to explain and understand their daily lives. My intention has been to capture women's perceptions about their daily lives in order to reveal and explore the relations of power these women experienced. I began with the immediate effects of this power and showed how the daily experiences of these women were related to the forms of oppression that were experienced by women in general.

The relations of power were explored and analysed at two key sites - the household and the Organisation. The household was where the mothers carried out much of their daily routines and the Organisation was where these experiences interacted with the public realm and where the paid workers carried out their work. Ideas and concepts developed by Foucault and Irigaray were used to develop a theoretical framework for analysing the themes that emerged from the women's lived experiences. This included the identification of a number of technologies of power including the observation, examination and comparison of women, the use of knowledge to control women's activities and the use of language to provide meaning to and interpret women's lived experiences.

I was particularly concerned with examining how an understanding of the gendered culture could be used to analyse and explain how power relations influenced and controlled women's lives and in so doing I took the view that an exclusively economic stance was too limited for this purpose. Indeed, it was an understanding of gender relations that helped me illuminate the ways these women's lived experiences had been defined and interpreted.

An understanding of systems of patriarchy and the ways in which the gendered culture was constructed has been fundamental to the writing of this dissertation. Such a perspective had not previously been used to critically examine the experiences of women who cared for people with intellectual disabilities in New Zealand. Although our understanding of the position of these women must take into account other forms of oppression such as economic factors, I argue that it was the differences between the ways men and women were perceived that were the major sources of oppression for the women in this research. The women I talked to did not belong to the same economic classes, however they had similar experiences with respect to the ways in which they had been treated by men. An understanding of the gendered culture helped me understand why women's reality had been hidden and devalued. The women wished to discover why their work was not valued and why it was the men who were in positions of authority in the Organisation and who defined and interpreted the Organisation's practices. Although this view is espoused I do not deny however, that future research can explore further the relationship of patriarchy and class.

As discussed in Chapters One and Two, women's experiences are diverse and from these emerge a number of strands of feminism that have different ways for defining the nature of women's oppression. This research has examined women's existence from a radical feminist perspective. One of its primary aims was to examine the non-economic forms and aspects of power. This should not detract from the important contribution other perspectives can make. These perspectives can also contribute to our knowledge about women's lived experiences.

Feminist theory informed the way I carried out this research. I was concerned with revealing the experiences of women who care for people with intellectual disabilities and providing alternative ways for interpreting these experiences. I argued that the experiences of women had not been adequately examined in the social science literature. Not only are women's experiences in general relegated to

the periphery of social science investigation but the lived experiences and daily lives of women who care for people with intellectual disabilities has not been a priority for in-depth analysis by mainstream social scientists and even feminist researchers. In carrying out this research I aimed to reveal the richness and diversity of the lives of women who cared for people with intellectual disabilities.

The women in my study experienced oppression in a number of ways. These related to the ways in which their contributions and work were devalued and was also directly linked to the fact that the group of people these women cared for were also devalued. For some of the women this factor had made them even more determined to change their current situation. They not only struggled to bring about change for themselves but they struggled to change the conditions for the people they were caring for.

In order to reveal the immediate effects of power on women's lived experiences and to create a picture of what life was really like for women who cared for people with intellectual disabilities, I began by describing the daily lives of the women. This process inevitably led to an examination of whether the frameworks and systems we have for explaining women's reality are relevant for the experiences of groups such as women who care for people with intellectual disabilities.

Feminist theory not only influenced the content of what I studied, that is, my decision to examine the power relations affecting the experiences of women who cared for people with intellectual disabilities, but it also informed the way I carried out my study. I did not want to, for example, retrieve the data I required and offer nothing in return to these women. As I have demonstrated, the research process can contribute to the change process because by describing their lives women can identify some common experiences of oppression.

I believe that the recording of the women's stories and the subsequent analysis of these was a very effective mechanism for revealing the power relations that the women experienced. In order to facilitate this process I carefully examined the relationship I formed with the women during the interviews. They shared some intimate details about themselves and I had a responsibility to treat their stories with sensitivity. The stories were described in ways that revealed the richness and diversity of the women's lives. In seeking to comprehend their daily lives I found it necessary to always acknowledge the intensity and the amount of work the women were doing. I recognise that for these women life was not always miserable and that the positive elements of their lives were also important to capture. In so doing I provided an opportunity for these women to identify some of their achievements.

Major Themes

In order to begin to critique the ways women's experiences had been interpreted and the ways in which power relations had operated, I identified a number of key themes. The themes addressed were examined in the two sites of the household and the Organisation and related to both the physical and emotional aspects of the women's lived experiences. The themes common to the household did, in some situations, reflect those in the Organisation and vice versa.

Private and Public Worlds

The themes can be briefly summarised here by examining some key ideas and concepts that were common to these women's experiences. One of the most significant of these was the way in which women did at times feel they were "locked" in the household and consequently had difficulty emerging from this private realm. They were not able to influence the ways in which decisions were made by the Organisation and there was also an assumption that the private world of the household and the public sphere of the Organisation were separate

with neither influencing the other. In my description and subsequent analysis of the caregivers' experiences I illustrated how these two realms interacted with one another. The activities of the Organisation did impact on the lives of women. The household was not a haven wherein women were free to carry out their activities in ways that were not influenced by what happened in the Organisation. It was shown that in general men controlled the Organisation and also had a key role in determining the way household roles and routines were structured and allocated.

Power relations pervaded the most intimate spheres of women's lives. The men they loved and lived with were part of the relations of oppression. Certain roles for women were defined by the Organisation and these were upheld by members of households, that is, their partners and husbands. The women who cared for people with intellectual disabilities had carried out many of their activities in the private realm and had not been given credit for the work they had done. When they did enter into the public world and attempted to make some changes in their lives they were often ostracised and criticised for upsetting the status quo. They frequently had difficulty trying to organise for change because the myths about caregiving that controlled and gave meaning to their lives was so entrenched that it was hard to imagine another reality.

These findings lead to a re-examination of the relationships between the private and public sphere. This debate has been articulated in current feminist literature both in New Zealand and overseas (Cox, 1987). My research has shown that this dichotomy between the public and private can mean that we misrepresent and at times even fail to recognise the complexities of women's experiences. This dichotomy has been used as a global concept that is often utilised without thoroughly examining the diverse implications for women's daily lives. The precise effects of power may not be clearly identified. The roots of women's oppression will not be understood if we are not explicit about what we mean when we speak about the private and the public realm. An example from this study illustrates this.

I showed in my analysis of the women's stories that it may be assumed that because services for people with intellectual disabilities improve, it naturally follows that women also have an improved quality of life. It was not, as demonstrated in this research, ascertained why women remained the primary caregivers. The fact that new technologies for people with intellectual disabilities may actually result in more work for women was not revealed.

The Organisation also failed to recognise that these women did not have access to and contribute to the decision-making processes. These women may have no input into deciding what form these services should take. The household was clearly not a haven; moreover, although the public sphere influenced what happened in the household it was apparent that the exchange of information was not reciprocal. As was shown, the women had difficulty obtaining information in order to participate in decision-making processes.

Another pertinent example related to the belief that once women moved from the household to the Organisation and joined committees or took on management positions, they had in fact entered the public realm. It was assumed, albeit at times unintentionally, that these women would be able to have a significant influence upon decision-making processes. This presented a contradiction because although at times the women felt involved in the major decision-making processes for the most part they were excluded from this activity.

In this research the Organisation could not be viewed as a public realm wherein women's influence and contribution was valued. It was for many women still a private world. The power relations may have been more subtle and difficult to detect than those in the household but the power relations continued to hide and devalue the experiences of women. I have attempted to reveal this contradiction as I believe it is a key element of current feminist thought and requires further study. The ways in which the so-called private world of the household and the public world of the Organisation interrelate and influence women's lives must be further researched and analysed.

Mutuality and Conflict

Another key organising principle emerging from the themes and related to those already described was the ambivalent situations women found themselves in. The descriptions of the women's experiences and the subsequent analysis captured women's perceptions of these situations.

The women often felt uncomfortable in challenging those who at times helped them in their work. The women's partners and the men in the IHC occasionally supported and assisted women in their work. However, these men retained the ability to control how the routines in the household and Organisation were to be structured. It was difficult for women to challenge those people with whom they had shared many happy times. This made power relations seem even more pernicious and created even more dilemmas for the women.

It was difficult for the women to believe that the people they lived and worked with could also be their oppressors. If caregivers did challenge the "system" it could hurt their children/adults as those who controlled the Organisation could make it difficult for women to gain access to the services they required. It was frequently too much of a risk to challenge the power relations because such challenges, while they could eliminate the negative aspects of women's roles, could also endanger the positive aspects of them.

I have defined this contradiction as mutuality versus conflict. The women were always experiencing ambivalent situations and this was used by the Organisation to ensure that women would keep on caring. The Organisation and the men in the women's household relied on the women's commitment to keep them "hanging in". Women were simultaneously subjected and supported. The relations of power were not always obvious and did not always appear intentional and

punishing. They were in turn intertwined with relationships that were congenial.

In my interviews with these women I found the contradictions between mutuality and conflict to be always present. Many of the women had difficulty labelling themselves as an oppressed group. Although they could describe their experiences of oppression it was often too painful or they were unaware of how to link this to other forms of patriarchal domination. The nature of this domination was always changing and was difficult to detect. Although the women had found many ways to resist these power relations it was at times difficult for the women to organise these resistances into planned strategies for change that could be sustained.

I believe that these experiences may be familiar to other women. As Foucault (1978) suggests the very intensity of power relations is represented by the ways in which they operate in extremely diffuse and subtle ways. The situations of mutuality and conflict the women experienced are one manifestation of this. This has an impact on the ways in which women have had to organise the change process.

Bringing About Change

An exploration of the process of change and how this can take place is a critical aspect of feminist research. In my study I have identified what changes the women were involved in and discussed the strategies they were using to bring about this change. I explored a number of elements of the change process and these were connected with the theme of mutuality versus conflict because change has both positive and negative elements. The caregivers were often in contradictory situations in that what could begin as a positive change could, as a latent consequence, make their lives more difficult. Related to this were the difficulties they had in determining the pace and nature of this change and the hard work that they had to do in order to bring about change that would benefit

themselves. Spending long hours carrying out strenuous caretaking routines meant that for many of the women they did not have the energy to join in the struggle for change.

Associated with this, and again an example of the ambivalent situation of these women's lived experiences, was the ways in which any influence these women have had on the Organisation's development had been ignored or misrepresented. Women have had a key role in beginning many of the services in the IHC and yet the written history did not adequately portray this. This history also portrayed women as taking on certain roles, for example the caregiving role. The women found it difficult to change the social structures and processes that functioned to reinforce these roles; roles that did not allow women to have choices about the work they chose to carry out. The men in the Organisation and the household tried to preserve the existing regime of relations and meanings. They emphasised the "natural" role of women as caregivers and the presumed "inevitability" of this role. They challenged women who tried to disrupt this. I have shown that the men in the household and in the Organisation defined what work had the highest priority and what form women's work should take. Caregiving work was generally the lowest paid in the Organisation and in the household unpaid. Women had difficulty breaking out of this role and when they did manage to move into positions that had a higher status they could be excluded from many activities such as being involved in major decision-making processes. This was one of the key areas that the women in my research had begun to challenge. Not only did they want caregiving tasks valued but they wanted to choose whether or not they should be the ones to carry these out and what value should be attached to these. They wished to challenge the boundaries between their public and private worlds and examine why caregiving was the activity that pervaded and dominated the lives of the women - both in the household and in the servicing functions they carried out for the Organisation.

My research has shown that for change to occur for these women they need to continue to be aware of and incorporate into the change

process the diverse experiences other women have had. I have attempted to reveal and capture the extent and variety of issues confronted by the women who cared for people with intellectual disabilities. I also identified the common themes that were part of caregiving experiences. To extend this one must go further and not only reveal the hidden history of women but critique the structures that have defined this. This is necessary in order to reconstruct those frameworks that have provided meaning to women's experiences. Alternatives for these women and the ways these can be linked to the experiences of women in general must be defined.

For me this is an ongoing process which must begin with an understanding of how patriarchy operates to control women. Hence, my interest was to examine how power relations operated in the daily lives of women. The key principles of feminist theory emphasises the importance of moving from this understanding and explanation, that is, in this research how the gendered culture determines these relations, to a situation where one can deconstruct these frameworks and build alternatives. My research was aimed at not only understanding the caregivers' lived experiences but also linking these to wider structures and events in order to find some possible ways that change could occur for these women.

Several of the women were beginning to link their experiences to those of other women. For them their struggles were once largely concerned with obtaining adequate services for their children/adults. They now wanted to ensure that they themselves had control over what their lives would be like. This was a difficult task as many of the women had been self-sacrificing for years. I illustrated how the women who had become 'change agents' showed how change must happen at all levels - in their daily lives, in the structures that controlled their lives and in the knowledge and language that was used to define and interpret these women's experiences.

The interviews provided an opportunity for the women to talk and reflect upon the change they had been involved with. The interviews

proved to be useful for helping the women understand and analyse not only their experiences but to link these to the troubles experienced by other women in similar positions. Encouraging women to take the opportunity to meet with others and reflect on their experiences was a powerful mechanism and one that can continue to be used by these women as it can help to understand the fragmenting effects of the Organisation's and household's practices.

Community Care

The process of bringing about change includes finding an issue that is common to all women. In this research one of the major issues was that of community care. The issues surrounding community care encapsulate and bring into focus the way in which power relations had operated to control women's lives and had determined what their work would entail. Community care is an extension of the belief that women are the 'natural' caregivers and because they give birth to the child and love the child their role should be extended to ensure that they remain as the primary caregiver (Dalley, 1988). It was at times difficult to detect the mechanisms men had adopted to ensure that women did nearly all of the caring for their child and how paid workers remained in caregiving positions which had a lower status than the management positions in the IHC. What had been a situation of convenience for many years in the household and in the Organisation had become extended even further in order to put into place the policies of community care.

I explored how certain practices such as the use of the words "happy family" functioned to hide what the word family really meant and in so doing, tended to imply that the current way of organising people's activities in households and in the Organisation had equal benefits for all members. The concept of "family" was used to imply that care should take place in "families" and that women had to continue to provide the majority of care for the child/adult. There was no analysis by the Organisation as to whether families could cope and

were in fact still intact. The Organisation also acted like a "family" in the sense that it encouraged the women to bring any issues they had to the "family" to be solved rather than go outside to other people for support. Thus, the theme of caregiving and how it related to the policy of community care has been a very significant and powerful one in this research.

It is difficult to determine exactly how much work is entailed when people with intellectual disabilities move from sheltered workshops and the IHC group homes to ordinary jobs and residential accommodation in the community. Not only is the work in the household hidden but so is the work done by many of the paid workers. The paid workers were treated in many ways like mothers in the household as they carried out extra hours of voluntary work in addition to their paid duties. This is unaccounted for in a productive sphere that does not have adequate frameworks for detailing the economic contributions of women (Waring, 1988).

These women had a life of struggle. The good times they had with their children/adults and the people they worked alongside were at times overshadowed by the effort they had to put in to establishing services; the energy they had used to ensure that they had input into decisions that determined how these services were run; and making certain that these services were not eroded and diminished in their quality. Despite the work women had done to develop the IHC so that they themselves had "a break" from their caregiving routines, they have had to struggle to ensure that they were informed, and part of, the decision-making processes of the Organisation.

Community care will be the site of another struggle for these women. The needs of these women have been, because of these policies, put in opposition and competition with the needs of their children/adults. The women did not necessarily want to stop the current changes but to control the pace of this change. Changes for other groups does not always mean a positive change for women. Although the women agreed with continuing to try to improve the quality of life for people with

intellectual disabilities, they also believed that this should not be at the expense of other groups. Women's needs should not be sacrificed for the very people they love and have a commitment to. The Organisation had used the unpaid and underpaid work of women to put its policies into practice. For many women current community care policies would continue these trends.

The battle for women is to find the energy to continue their struggles against such policies. It is difficult for women to find a place of their own wherein they can act and reflect on their struggle and if necessary change its direction (Irigaray, 1985). Community care and its implications can be an issue that brings women together as a group because this policy will affect many groups of women. Women who care for people with intellectual disabilities may have the same concerns as other women who care for dependent groups. It will be women who will be expected to continue to carry out the tasks associated with caregiving.

Future Research

My aim in this research has been to reveal some of the issues confronting women who care for people with intellectual disabilities by describing the work they had carried out in their households and in the Organisation. The focus has been to tell women's stories so that alternative ways of explaining and understanding women's experiences can be developed. For this reason, my aim was to not only reveal and analyse the power relations, but in so doing to acknowledge the many significant achievements and milestones these women had brought about in the development of the IHC.

I wished to contribute to the process of discovering new ways of describing and understanding these women's reality, as this process is an important part of the struggle to transform the current reality for these and other groups of women. Thus, it is in this way that this research can have relevance for other groups of women. The

themes about caregiving and women's work can contribute to an understanding of how society views the caregiving role. This is intimately related to the ways in which families are constructed and roles and activities within those families are defined and allocated. The issues about who will do the caregiving and what value will be attributed to this are common for all women as women continue to be the primary caregivers in households.

In this research the work of Foucault and Irigaray provided one particular framework for exploring and understanding the power relations the women experienced. These conceptual tools and their subsequent extension were invaluable because they provided a mechanism for understanding the "infinitesimal" technologies of power and the ways the gendered culture determines how the women's lives would be structured and interpreted. I believe that future researchers could use these frameworks as a means to determine not only how the daily lived experiences of women who care are organised but how other women's lives are structured. These frameworks have provided a point of departure and have connected with the way I view feminist theory and research and the role of gender in understanding women's experiences. The technologies of power were used as a tool for making sense of the information women shared with me and for increasing our understanding of their lived experiences. The challenge for others who wish to carry out research about women is to take these tools and extend and modify them so that they can continue to contribute to an understanding of women's experiences.

Our knowledge and understanding of the experiences revealed in this research can also be extended by using both quantitative and qualitative research methodologies. For example, one can function to measure the amount of caregiving work done by women and the nature of this work; whereas the other, as with my research, can capture and help us understand women's feelings and perceptions about caregiving and the meaning given to this work. This is based upon women's lived experience and the relationships they have with others. An understanding of gender will continue to help illuminate the

diversity of women's caregiving roles and activities and how these are structured. Women's reality and the ways in which this differs from and is controlled by the activities of men must continue to be revealed and analysed in the social science literature.

The themes that have emerged from this research such as those outlining the nature of the private and public sphere and the relationships of mutuality and conflict women experienced require further theorising and extended research. Different aspects of feminist thinking can be used to further our understanding of how patriarchal systems control women's lives. For example, the issues of class and ethnicity and their relationship to gender deserve attention.

It will also be important to continue to carry out research that explores the ways in which women's lives are affected by policies of community care. This requires further examination with respect to the changing composition of families and the ways in which feminist thinking is challenging social understanding of the "family" and the role of men in the "family". This has relevance for both women who care and for women in general. An in-depth examination of the lives of younger women in the IHC and in similar organisations would be a useful extension to the present research as these women are experiencing the full impact of current community care policies.

In carrying out this research feminist theory and methodology provided a way for moving from understanding and evaluating women's lived experiences to a situation where it could be shown how these experiences and the meaning attached to these can be transformed. Although the women who care for people with intellectual disabilities have unique experiences that derive from the daily routines associated with caregiving, similar experiences are present in the daily lives of other women. Relationships and solidarity with other women must be strengthened if these women are to have a role in defining what their future will be.

APPENDIX ONE: THE PERSONAL CHARACTERISTICS OF THE WOMEN

The following provides a brief summary of each woman. All efforts have been made to preserve the identity of the women.

The Mothers

1Mrs A 50-55 Married.

Full-time mother. Has an adult aged 25-30 who has a moderate intellectual disability and was living away from home. The adult lived in a large institution for a number of years but now lives in a group home and stays with the family regularly (at least once every month). Mrs A has been an active volunteer for the Organisation.

Mrs B 45-50 Married.

Full-time mother. Has three adults aged 20-30 who are all living away from home. They have an intellectual disability ranging from mild to severe and associated medical problems. They all lived in a large institution for a number of years but now live in group homes and visit the family regularly (at least every two weeks).

Mrs C 60-65 Living alone.

Worked full-time most of her married life. Her child had died but Mrs C remained an active committee member and at times a paid employee of the Organisation.

Mrs D 65-70 Married.

Worked part-time most of her married life. Has an adult aged 30-35 with a severe intellectual disability living away from home but who visit regularly (at least once every month). Mrs D has been actively involved in voluntary work.

1 All of the women will be called Mrs in the interests of confidentiality.

- Mrs E** 50-55 Married.
Worked part-time and full-time most of her married life. Has an adult aged 25-30 who has a moderate intellectual disability with complex medical needs and who was living at home. Mrs E was actively involved in committee and voluntary work.
- Mrs F** Mrs F passed away in 1987 (two months after the interview). She was a founding member of the Organisation and was actively involved in voluntary and community work all her life. She cared for her adult at home until she was no longer able to carry out the daily caregiving routines.
- Mrs G** 65-70 Married.
Full-time mother. Has an adult with a severe intellectual disability living at home and attending a sheltered workshop. Mrs G has been actively involved in committee and voluntary work.
- Mrs H** 45-50 Married.
Worked part-time and full-time most of her married life. Has an adult aged 25-30 with a moderate intellectual disability living at home and attending a sheltered workshop. Mrs H was actively involved in committee and voluntary work.
- Mrs I** 50-55 Married.
Full-time mother until a year ago when her intellectually disabled adult aged 20-25 moved to a group home. Mrs I is still active in voluntary and committee work.
- Mrs J** 65-70 Living alone.
Full-time mother living with an adult aged 45-50 who has a severe disability and who attends a sheltered workshop. Mrs J is still actively involved in voluntary work.

Mrs K 60-65.

Full-time mother. Has an adult 25-30 with a moderate intellectual disability living at home and who attends a sheltered workshop. Mrs K is actively involved in voluntary work.

Mrs L 45-50.

Full-time paid work. Living alone with an adult aged 20-30 with a moderate intellectual disability and who works in an independent employment situation.

Mrs M 50-55 Married.

Full-time mother. Has an adult aged 20-25 with a moderate to severe intellectual disability living away from home but who visits regularly (at least every two weeks). Mrs M is actively involved in voluntary work.

Mrs N Aged 50-55.

Full-time mother aged 25-30 with an adult with a moderate to severe intellectual disability living away from home. The adult has lived in a large institution for a number of years but now lives in a group home and visits the family regularly (at least once a month).

Mrs O Aged 65-70.

Full-time mother. Has an adult aged 25-30 with a severe intellectual disability who lived at home until recently but now lives in a group home. The adult visits the family regularly (at least every two weeks). Mrs O is actively involved in voluntary work.

The Paid Workers¹ .

Mrs A 45-50.

Works as a Residential Coordinator. Has worked for IHC in the residential field for nearly 10 years. She has no formal qualifications related to residential work.

Mrs B 30-35.

Has now left the IHC and moved to a position in another agency. During her employment with the Organisation Mrs B was involved in residential and vocational work. She worked for the IHC for over five years. She is a trained teacher.

Mrs C 30-35.

Has now left the IHC to go overseas. During her employment Mrs C worked as a residential worker and as a manager of a group home. She has university qualifications related to this field of work.

Mrs D 55-60.

Works in a management position and has been in a variety of jobs in the 14 years she has worked for the IHC. She is a trained teacher.

Mrs E 20-25.

Has now left the IHC but prior to this worked in both office and residential work. She has no formal training related to her work in the IHC.

Mrs F 35-40.

Has worked for the Organisation for nearly 10 years. Employed in a staff training position and coordinator of services. She has a university degree related to her work and is a trained teacher.

¹ Two of these women are currently employed in senior management positions.

Mrs G 55-60.

Has now left the IHC to go to another agency. While working with the Organisation Mrs G was in a direct caregiving role. She is a trained nurse.

Mrs H 40-45.

Has worked for the Organisation for nearly 10 years and is now in a management/coordinator position related to children's services. She has a childcare qualification.

Mrs I 45-50.

Has worked for the IHC for nearly five years and is now in a management/coordinator position related to children's services. She has childcare qualifications.

Mrs J 40-45.

Has worked for IHC for nearly five years and is now in a management position. She has university qualifications related to her work.

Mrs K 50-55.

Has worked for IHC for over five years in residential work and is now in a management position. She has no formal qualifications related to residential work.

Mrs L 40-45.

Has worked for IHC for over five years in community support services. She has no formal qualifications.

Mrs M 35-40.

Has worked for the IHC for nearly 10 years and is now employed in a services coordinator/training position. She has university qualifications related to her job.

Mrs N 50-55.

Has worked for the IHC for nearly 10 years and is now in a middle management position. She has childcare qualifications.

Mrs O 55-60.

Has worked for the IHC for over 10 years and is now in a middle management position. She has no formal qualifications related to her work with the Organisation.

APPENDIX TWO: QUESTIONS FOR PARENTS AND PAID WORKERS

1. When did you become involved with the IHC? (Parent)
When did you become involved with the IHC? (Paid worker)
2. What happened that caused you to join the IHC? (Parent)
What happened that caused you to join the IHC? (Paid worker)
3. Tell me about your involvement in the IHC. What do you do? Is it like you thought it would be? (Parent)
Describe it -

Tell me about your involvement in the IHC. What do you do? Is it like you thought it would be? (Paid worker)
Describe it -
4. What were you doing 10 years ago? (Parent)
When you joined? Now? (Paid worker)
5. What was happening to IHC 10 years ago? (Parent)
When you joined? Now? (Paid worker)
6. What for you has been one of the most significant experiences in your involvement with IHC? (Parent)

What for you has been one of the most significant experiences in your involvement with IHC? (Paid worker)
7. What do you think has been one of the most significant experiences for IHC? (Parent)

What do you think has been one of the most significant experiences for IHC? (Paid worker)
8. Tell me about a typical day in your life and the things you do with your son/daughter? Now? Ten years ago? (Parent)

Tell me about a typical day in your contact with people who are intellectually disabled. And the things you do with them Now? When you joined IHC? (Paid worker)

9. In your experience what has been one of the most difficult times? Happiest times? (Parent)
- In your experience what has been one of the most difficult times? Happiest times? (Paid worker)
10. Who/What has been the most help to you in caring for your son/daughter? Now? Ten years ago? (Parent)
- Who/What has been the most help to you in learning about people with intellectual disabilities and working with them? Now? When you joined? (Paid worker)
11. Tell me about the involvement of your husband and other family members in the care of your son/daughter? Now? Ten years ago? (Parent)
12. Who in your family goes to meetings about your son/daughter and other children? (Parent_
13. When you meet with the family who is usually present? Now? When you joined? (Paid worker)
14. Do you meet with other women? Who are these women? Now? Ten years ago? (Parent)
- Do you meet with other women? Who are these women? Now? Ten years ago? (Paid worker)
15. What do you do when you meet? (Parent)
- What do you do when you meet? (Paid worker)
16. Tell me about the involvement of women in the IHC? (Parent)
- Tell me about the involvement of women in the IHC? (Paid worker)
17. What do professionals and staff do to you when they are helping you with your son/daughter? Now? Ten years ago? (Parent)
18. How does this feel? (Parent)
19. What would you like them to do? (Parent)

20. What are you supposed to do with families when you meet with them about their son/daughter? Now? When you joined? (Paid worker)
21. How does this feel? (Paid worker)
22. What would you like to do? (Paid worker)
23. When you are having a difficulty with your son/daughter or need support who should you go to for help? What happens? Now? Ten years ago? (Parent)
24. Who do you go to? What happens? Now? Ten years ago? (Parent)
25. When you are having a difficulty or need support in your work who should you go to? What happens? Now? When you joined? (Paid worker)
26. Who do you go to? What happens? Now? When you joined? (Paid worker)
27. Describe the dominant feelings about yourself and your situation. Now? Ten years ago? (Parent)
Describe the dominant feelings about yourself and your situation. Now? Ten years ago? (Paid worker)
28. In what ways have you changed your lifestyle since having a son/daughter with a disability? (Parent)
29. In what ways have you changed your lifestyle since coming to work for IHC? (Paid worker)
30. In hours how much time in a week would you spend on IHC related activities? Now? Ten years ago? Your husband? Now? Ten years ago? (Parent)
31. In hours how much time in a week do you spend on IHC related activities outside working hours? (Paid worker)

32. What things do you like to read about intellectual disability?
What stands out for you? (Parent)

What things do you like to read about intellectual disability?
What stands out for you? (Paid worker)

33. In the last ten years what sort of information about people
with intellectual disabilities has been the most exciting for
you and what has been of the most use to you? (Parent)

In the last ten years what sort of information about people
with intellectual disabilities has been the most exciting for
you and what has been of the most use to you? (Paid worker)

34. What would you like to learn about intellectual disability and
things related to this? What will bring this about? (Parent)

What would you like to learn about intellectual disability and
things related to this? What will bring this about? (Paid
worker)

35. What do the following words mean to you? (Parent)

assessment
advocacy
IPP
Normalisation and community living

What do the following words mean to you? (Paid worker)

assessment
advocacy
IPP
Normalisation and community living

36. Of the exciting things you read/hear about do you see them
happening around you? (Parent)

Of the exciting things you read/hear about do you see them
happening around you? (Paid worker)

37. If not, what do we need to know or do to make them happen?
(Parent)

If not, what do we need to know or do to make them happen?
(Paid worker)

38. Describe how the IHC is set up? What are its goals? Do you
like these goals? Do you think they reach these goals? Now?
Ten years ago? (Parent)

Describe how the IHC is set up? What are its goals? Do you
like these goals? Do you think they reach these goals? Now?
Ten years ago? (Paid worker)

39. Tell me what happens when decisions are made about people with intellectual disabilities in the IHC? What person/people make(s) most of these decisions? Now? Ten years ago? (Parent)

Tell me what happens when decisions are made about people with intellectual disabilities in the IHC? What person/people make(s) most of these decisions? Now? Ten years ago? When you joined? (Paid worker)

40. Do you meet with these people? Now? Ten years ago? (Parent)

Do you meet with these people? Now? Ten years ago? When you joined? (Paid worker)

41. What happens in these meetings? What are these meetings like for you? Now? Ten years ago? (Parent)

What happens in these meetings? What are these meetings like for you? Now? Ten years ago? When you joined? (Paid worker)

42. If you do not attend meetings what/who keeps you up-to-date with what's happening? Now? Ten years ago? (Parent)

If you do not attend meetings what/who keeps you up-to-date with what's happening? Now? Ten years ago? When you joined? (Paid worker)

43. What does the Government do to help you? IHC? (Parent)

44. What does the Government do to help people with intellectual disabilities? IHC? (Paid worker)

45. Have you read the Philosophy and Policy statement of the IHC? What for you is one of the most important aspects of this? If you haven't read it what other ideas do you find exciting? (Parent)

Have you read the Philosophy and Policy statement of the IHC? What for you is one of the most important aspects of this? If you haven't read it what other ideas do you find exciting? (Paid worker)

46. Whose ideas do you find exciting? (Parent)

Whose ideas do you find exciting? (Paid worker)

47. What words are used to describe people with intellectual disabilities and their families? Now? Ten years ago? (Parent)

What words are used to describe people with intellectual disabilities and their families? Now? Ten years ago? When you joined? (Paid worker)

48. What do you think this feels like for a person with an intellectual disability? What does it feel like for you? Now? Ten years ago? (Parent)

What do you think this feels like for a person with an intellectual disability? What does_it feel like for you? Now? Ten years ago? When you joined? (Paid worker)

49. Are any other groups described in the same way? (Parent)

Are any other groups described in the same way? (Paid worker)

50. Do you think they have similar experiences to the person with an intellectual disability? (Parent)

Do you think they have similar experiences to the person with an intellectual disability in their family? (Paid worker)

51. What do you think is one of the most difficult things for a person with an intellectual disability to deal with? Now? Ten years ago? In ten years? (Parent)

What do you think is one of the most difficult things for a person with an intellectual disability to deal with? Now? Ten years ago? In ten years? (Paid worker)

52. What do you think a typical day will look like for people with an intellectual disability and their families in ten years? (Parent)

What do you think a typical day will look like for people with an intellectual disability and their families in ten years? (Paid worker)

53. What would you like it to be like? (Parent)

What would you like it to be like? (Paid worker)

54. What can you do to make this happen? (Parent)
What can you do to make this happen? (Paid worker)
55. Who can help you with this? (Parent)
Who can help you with this? (Paid worker)
56. What things are the people who are making decisions doing now to make this happen for you? (Parent)
What things are the people who are making decisions doing now to make this happen for you? (Paid worker)
57. What do you think will be one of the most difficult things for you to deal with in ten years? IHC? (Parent)
What do you think will be one of the most difficult things for you to deal with in ten years? IHC? (Paid worker)
58. Has anything happened in the last ten years to bring about some change for people with intellectual disabilities and their families? (Parent)
Has anything happened in the last ten years to bring about some change for people with intellectual disabilities and their families? (Paid worker)
59. What happened to bring these about? Who/what started them? (Parent)
What happened to bring these about? Who/what started them? (Paid worker)
60. Were you involved in any of these changes? (Parent)
Were you involved in any of these changes? (Paid worker)
61. What else was happening in New Zealand? (Parent)
What else was happening in New Zealand? (Paid worker)
62. Were any other groups involved in these changes? What did they do to help and to help you? (Parent)
Were any other groups involved in these changes? What did they do to help and to help you? (Paid worker)

63. Did anything happen to stop these changes? (Parent)
Did anything happen to stop these changes? (Paid worker)
64. What would you do now to make sure they happened? What will be the biggest barrier to overcome? (Parent)
What would you do now to make sure they happened? What will be the biggest barrier to overcome? (Paid worker)
65. What person/group will decide the future for you and your family? (Parent)
What person/group will decide the future for you and your family? (Paid worker)
66. What do you think will be the best thing that could happen for you and your family? (Parent)
What do you think will be the best thing that could happen for families? (Paid worker)
67. What will you do to make this happen? (Parent)
What will you do to make this happen? (Paid worker)
68. Have you ever been involved in a research project before? What was it like? What happened? (Parent)
Have you ever been involved in a research project before? What was it like? What happened? (Paid worker)
69. Any other comments or experiences you would like to share with me? (Parent)
Any other comments or experiences you would like to share with me? (Paid worker)

We made it! Thanks a lot.

BIBLIOGRAPHY

PUBLISHED SOURCES:

- Ayer, S and Alaszewski, A (1984) Community Care and the Mentally Handicapped. Croom Helm, Sydney.
- Balbus, I D (1986) Disciplining Women: Michel Foucault and the Power of Feminist Discourse, in Benhabib, S and Cornell, D (Eds) Feminism as Critique. Praxis International, Cambridge.
- Baldwin, S and Glendinning, C (1983) Employment, Women and Their Disabled Children, in Finch, J and Groves, D (Eds) A Labour of Love. Women, Work and Caring. Routledge and Kegan Paul, London.
- Baldwin, S (1985) The Costs of Caring: Families with Disabled Children. Routledge and Kegan Paul, London.
- Ballou, M and Gabalac, N W (1985) A Feminist Position on Mental Health. Charles C Thomas, Springfield, Illinois, USA.
- Barrett, M (1980) Women's Oppression Today. Verso Editions, London.
- Barrett, M and McIntosh, M (1982) The Anti-Social Family. Verso Editions, London.
- Barrie, C (1987) The Personal is a Political Construction, in Sites, No.15, Spring, pp.68-75.
- Bell, C and Roberts, H (Eds) (1984) Social Researching: Politics, Problems, Practice. Routledge and Kegan Paul Inc.
- Benhabib, S and Cornell, D (Eds) (1986) Feminism as Critique. Praxis International, Cambridge.
- Bernstein, R (1976) The Restructuring of Social and Political Theory. Blackwell, Oxford.
- Boshevkin, S (1985) Women and Politics in Western Europe. Frank Cass, Great Britain.
- Bowles, G and Klein, R D (1983) Theories of Women's Studies. Routledge and Kegan Paul, London.
- Braidotti, R (1986) The Ethics of Sexual Difference: The Case of Foucault and Irigaray, in AFS, Summer, 3, pp.1-13.
- Bright, R W and Wright, J M C (1986) Community-Based Services: The Impact on Mothers of Disabled Children. Paper Presented at AAMR Conference, Brisbane, Australia.

- Brook, E and Davis, A (Eds) (1985) Women, the Family and Social Work. Tavistock Publications, London.
- Brookes, B, Macdonald, C and Tennant, M (Eds) (1986) Women in History: Essays on European Women in New Zealand. Allen and Unwin/Port Nicholson Press, Wellington, New Zealand.
- Bryson, L and Edwards, (1988) A Gender, Social Control and Community Services, in Australia and New Zealand Journal of Sociology, Vol.24, No.3, November.
- Burton, C (1985) Subordination: Feminism and Social Theory. George Allen and Unwin Australia Ltd.
- Butler, J (1986) Variations on Sex and Gender: Beauvoir, Wittig and Foucault, in Benhabib, S and Cornell, D (Eds) Feminism as Critique. Praxis International, Cambridge.
- Carnoy, M (1984) The State and Political Theory. Princeton University Press, New Jersey.
- Cousins, M and Hussain, A (1984) Michel Foucault. Macmillan, London.
- Couzens Hoy, D (Ed) (1986) Foucault: A Critical Reader. Basil Blackwell, Oxford.
- Cox, S (Ed) (1987) Public and Private Worlds. Allen and Unwin, Wellington, New Zealand.
- Croft, S (1986) Women, Caring and the Recasting of Need - A Feminist Appraisal. Critical Social Policy, Summer, 16.
- Dalley, G (1988) Ideologies of Caring. MacMillan Education Ltd, London.
- Daly, M 1978 Gyn/Ecology. The Women's Press, London.
- David, M (1985) Motherhood and Social Policy - A Matter of Education. Critical Social Policy, Spring, No.12.
- de Beauvoir, S (1972) The Second Sex. Penguin Books, England.
- de Lauretis, T (Ed) (1986) Feminist Studies: Critical Studies. Indiana University Press, Bloomington.
- Delphy, C (1984) Close to Home. Hutchinson, London.
- Donzelot, J (1979) The Policing of Families. Pantheon Books, New York.
- Duchen, C (Ed and translated by) (1987) French Connections. Hutchinson Education, London.

- Eichler, M (1980) The Double Standard: A Feminist Critique of Feminist Social Science. Croom Helm, London.
- Eisenstein, H (1984) Contemporary Feminist Thought. Unwin Paperbacks, London.
- Eisenstein, H (1980) The Radical Future of Liberal Feminism. Longman, New York.
- Evans, J et al (1986) Feminism and Political Theory. Sage Publications, London.
- Ferguson, K E (1984) The Feminist Case Against Bureaucracy. Temple University Press, Philadelphia.
- Femia, J (1981) Gramsci's Political Thought. Clarendon Press, Oxford.
- Finch, J (1984) Community Care: Developing Non-Sexist Alternatives, Critical Social Policy, Spring, 9.
- Finch, J (1984) in Bell, C and Robert, H (Eds) Social Researching: Politics, Problems, Practice. Routledge Kegan Paul, London.
- Finch, J (1986) Research and Policy: The Uses of Qualitative Methods in Social and Educational Research. Falmer Press, England.
- Finch, J and Groves, D (Eds) (1983) Labour of Love: Women, Work and Caring. Routledge and Kegan Paul, London.
- Firestone, S (1972) The Dialectic of Sex: The Case of Feminist Revolution. Granada Publishing Ltd, London.
- Foucault, M (1971) Madness and Civilization: A History of Insanity in the Age of Reason. Tavistock, London.
- Foucault, M (1973) The Birth of the Clinic: An Archaeology of Medical Perception. Pantheon Books, New York.
- Foucault, M (1977) Discipline and Punish: The Birth of the Prison. Translated by Alan Sheridan, Vintage Books, New York.
- Foucault, M (1978) The History of Sexuality, Vol.I: An Introduction. Translated by Robert Hurley, Pantheon Books, New York.
- Foucault, M (1980) Power/Knowledge. Selected Interviews and Other Writings 1972-1977, Gordon, C (Ed), Harvester Press, Brighton.
- Freire, P (1985) The Politics of Education. Bergin and Garvey Pub Inc, Massachusetts, USA.

- Friedan, B (1963) The Feminine Mystique. Delacorte Press, New York.
- Furman, N (1985) The Politics of Language: Beyond the Gender Principle, in Greene, G and Kahn, C Making a Difference, Feminist Literary Criticism. Methuen, London.
- Glendinning, C (1983) Unshared Care: Parents and Their Disabled Children. Routledge and Kegan Paul, London.
- Glendinning, C (1986) A Single Door and Social Work with the Families of Disabled Children. Allen and Unwin, London.
- Goodnow, J (1986) Topics, Methods and Models: Feminist Challenges in Social Science, in Women, Social Science and Public Policy. Goodnow, J and Pateman, C (Eds), George Allen and Unwin, Sydney.
- Gorz, A (1982) A Farewell to the Working Class. Pluto Press, London.
- Graham, H (1983) Caring: A Labour of Love, in Finch, J and Groves, D A Labour of Love: Women, Work and Caring. Routledge and Kegan Paul, London.
- Gramsci, A (1971) Selections from the Prison Notebooks. Hoare, P and Nowell Smith, P (Eds), Lawrence and Wishart, London.
- Greene, G and Kahn, C (Eds) (1985) Making a Difference: Feminist Literary Criticism. Methuen, London.
- Grimshaw, P (1986) Women in History: Reconstructing the Past, in Goodnow, J and Pateman (Eds) Women, Social Science and Public Policy. George Allen and Unwin, Sydney.
- Gross, E (1986) What is Feminist Theory? in Pateman, C and Gross, E Feminist Challenges. Allen and Unwin, Sydney.
- Gross, E (1986a) Irigaray and Sexual Difference. AFS, Autumn, 2, pp.63-77.
- Gross, E (1986b) Philosophy, Subjectivity and the Body: Kristeva and Irigaray, in Pateman, C and Gross, E Feminist Challenges. Allen and Unwin, Sydney.
- Guess, R (1981) The Idea of Critical Theory: Habermas and the Frankfurt School. Heinmann, London.
- Harding, S and Hintikka, M B (Eds) (1983) Discovering Reality. D Reidel Publishing Co, London.
- Holter, H (Ed) (1984) Patriarchy in a Welfare Society. Universitetsforlaget, Norway.

- Humm, M (1986) Feminist Criticism. Harvester Press, Great Britain.
- Illich, I (1983) Gender. Marion Boyars Pub Ltd, London.
- Irigaray, L (1985) Speculum of the Other Women. Cornell Uni Press, New York.
- Irigaray, L (1985) This Sex Which is Not One. Translated by Catherine Porter with Carolyn Burke, Cornell University Press, New York.
- James, B (1982) Feminism: Making the Private World Public, in Shirley, I (Ed) Development Tracks: The Theory and Practice of Community Development. The Dunmore Press, Palmerston North.
- Jay, M (1984) Marxism and Totality. Polity Press, London.
- Jessop, B (1982) The Capitalist State: Marxist Theories and Methods. Robertson, Oxford.
- Joll, J (1977) Gramsci. Fontana Paperback, Great Britain.
- Jones, A R (1985) Inscribing Fertility: French Theories of the Feminine, in Greene, G and Kahn, C Making a Difference: Feminist Literary Criticism. Methuen, London.
- Kelly, J (1984) Women, History and Theory - The Essays of Joan Kelly. University of Chicago Press, Chicago.
- Keohane, N O, Rosaldo, M Z and Gelpi, B C (Eds) (1981) Feminist Theory: A Critique of Ideology. University of Chicago Press, Chicago.
- Klein, R D (1983) in Bowles and Klein (Eds) Theories of Women's Studies. Routledge and Kegan Paul, USA.
- Kristeva, J (1980) Desire in Language. Basil Blackwell, Oxford.
- Laclau, E (1977) Politics and Ideology in Marxist Theory: Capitalism, Fascism, Populism. NLB, London.
- Laclau, E and Mouffe, C (1985) Hegemony and Socialist Strategy: Towards a Radical Democratic Politics. Verso Editions, London.
- Land, H and Rose, H (1985) Compulsory Altruism for Some or an Altruistic Society for All? in Bean, P, Ferris, J and Whyness, D (Eds) Defence of Welfare. Tavistock Publications Ltd, London.
- Marchant, H and Wearing, B (Eds) (1986) Gender Reclaimed: Women in Social Work. Hale and Iremonger, Sydney.

- Maas, F and Sach, S (1984) Community-Based Services for Children and Families. Institute of Family Studies, Melbourne, Australia.
- Marks, E and de Courtivran, I (Eds) (1981) New French Feminists. Schocken Books, New York.
- Middleton, S (1988) Women and Education in Aotearoa. Allen and Unwin, New Zealand.
- Mills, C Wright (1970) The Sociological Imagination. Oxford University Press, New York.
- Mitchell, D R and Mitchell, J W (1985) Out of the Shadows. Department of Education, Wellington.
- Mitchell, J (1971) Women's Estate. Pelican Books, London.
- Mitchell, J and Oakley, D (Eds) (1986) What is Feminism?. Pantheon Books, New York.
- Moi, T (1985) Sexual Textual Politics: Feminist Literary Theory. Methuen, London.
- Moi, T (1987) French Feminist Thought. Basil Blackwell, Oxford.
- Moore, S (1988) Labouring for Love or Sharing Community Care. Paper presented at IASSW Conference, Vienna, July.
- Mora, G and Van Hooft, K S (Eds) (1982) Theory and Practice of Feminist Literacy Criticism. Bilingual Press, Michigan.
- Morrison, A, Beasley, D and Williamson, K I (1986) The Intellectually Handicapped and Their Families. Research Foundation of New Zealand Society for the Intellectually Handicapped, Wellington.
- Mouffe, C (1979) Gramsci and Marxism Today. Routledge and Kegan Paul Ltd, London.
- Munford, R (1986) Better Services for People with Intellectual Disabilities, New Zealand Social Work, Vol.11, No.2, October.
- Nicholson, L (1986) Gender and History. Columbia University Press, New York.
- Oakley, A (1981) Interviewing Women: A Contradiction in Terms, in Roberts, H (Ed), Doing Feminist Research. Routledge and Kegan Paul, London.
- Offe, C (1980) An Interview with Claus Offe, in Keane, J (Ed) Contradictions of the Welfare State. Penguin Books Ltd, England.

- Pascall, G (1986) Social Policy: A Feminist Analysis. Tavistock Publications, London.
- Pateman, C and Gross, E (1986) Feminist Challenges, Allen and Unwin, Sydney.
- Phillips, A (1986) Patriarchy at Work: Patriarchal and Capitalist Relations in Employment. Polity Press, Cambridge, England.
- Phillips, A (1987) Divided Loyalties: Dilemmas of Sex and Class. Virago, London.
- Poster, M (1984) Foucault, Marxism and History. Polity Press, Cambridge.
- Pratt, J (1983) Reflections on the approach of 1984: Recent Developments in Social Control in the UK, International Journal of the Sociology of Law, No.11, pp.339-360.
- Pratt, J (1987) Power and Resistance in the Social: The Critical Theory of Michel Foucault, in Sites, No.14, autumn, pp.3-16.
- Rabinow, P and Dreyfus, H (1982) Michel Foucault: Beyond Structuralism and Hermeneutics. Harvester, Brighton.
- Reiger, K M (1985) The Disenchantment of the Home. Oxford University Press, London.
- Rimmer, L (1983) The Economics of Work and Caring, in Finch, J and Groves, D (Eds) A Labour of Love: Women, Work and Caring. Routledge and Kegan Paul, London.
- Roberts, H (1981) Doing Feminist Research. Routledge and Kegan Paul, London.
- Roper, B (1988) Marxian Methodology and Feminist Theory: Towards a Materialist Conception of Herstory in New Zealand, Sociology, Vol.3, No.1, May, pp.14-32.
- Rowbotham, S (1983) Dreams and Dilemmas. Virago Press, London.
- Ryan, A (1984) Constructing 'Stable, Happy Families': Sterilization and Abortion in New Zealand, in P Crisp et al (Eds) Working Papers on the State, Vol.2, Sociology Department, Massey University.
- Segal, L (Ed) (1983) What is to be Done About the Family? Penguin, Harmondsworth.
- Segal, L (1987) Is the Future Female?: Troubled Thoughts on Contemporary Feminism. Virago Press, London.

- Shearer, A (1980) Handicapped Children in Residential Care: A Study of Policy Failure. Bedford Square Press, London.
- + Sheridan, A (1980) Michel Foucault: The Will to Truth. Tavistock, London.
- Showstock Sassoon, A (Ed) (1982) Approaches to Gramsci Writers and Readers. London.
- Singh, N and Wilton, K (1985) Mental Retardation in New Zealand. Whitcoulls, Christchurch.
- Smart, B (1983) Foucault, Marxism and Critique. Routledge and Kegan Paul, London.
- Spender, D (1985) For the Record. The Women's Press, London.
- Stanley, C and Wise, S (1983) Consciousness and Feminist Research. Routledge and Kegan Paul, London.
- Summers, A (1975) Damned Whores and God's Police - The Colonization of Women in Australia. Penguin Books, Australia.
- Ungerson, C (1983) Why Do Women Care? in Finch, J and Groves, D (Eds) A Labour of Love: Women, Work and Caring. Routledge and Kegan Paul, London.
- Ungerson, C (Ed) (1985) Women and Social Policy. Macmillan Press Ltd, London.
- Urry, J (1981) The Anatomy of Capitalist Societies. Macmillan Press Ltd, London.
- Walby, S (1986) Patriarchy at Work. Polity Press, Cambridge.
- Walker, A (1983) Care for Elderly People: A Conflict Between Women and the State, in Finch, J and Groves, D (Eds) A Labour of Love: Women, Work and Caring. Routledge and Kegan Paul, London.
- Walker, A (1982) Community Care: The Family, the State and Social Policy. Oxford, London.
- Waring, M (1988) Counting for Nothing. Allen and Urwin, Wellington, New Zealand.
- Wearing, B (1984) The Ideology of Motherhood. Allen and Urwin, Sydney.
- + Weedon, C (1987) Feminist Practice and Poststructuralist Theory. Basil Blackwell Ltd, Oxford.

Wilson, E (with Weir, A) (1986) Hidden Agendas. Tavistock Publications Ltd, London.

Wollstonecraft, M (1972) A Vindication of the Rights of Women. Joseph Johnson, London, 1792; reprinted Miriam Kramnick (Brody) (Ed), Penguin Harmondsworth, Middlesex, 1978.

UNPUBLISHED SOURCES:

Botting, R W S (1972) An Oral History of the IHC.

Caldwell, C (1984) Truby King and Seacliffe Asylum 1889-1907. An essay submitted for degree of BA (Hons) in History, University of Otago, New Zealand.

James, B (1985) Mill Wives: A Study of Gender Relations, Family and Work in a Single Industry Town. Unpublished Ph D thesis, University of Waikato.

Ministerial Task Force on Social Welfare Services (1987) Review of Social Welfare Services, September.

Munford, R (1983) Foster Care for Handicapped Children. Unpublished MSW thesis, University of Calgary, Alberta, Canada.

Munford, R (1986) Shared Care - A Wellington Pilot Project. New Zealand Society for the Intellectually Handicapped (Inc), Wellington.

Munford, R (1987) Who Cares? Working with Women who Care for Children with Intellectual Disabilities. Pending publication, in Craig, W (Ed) Working with Women.

New Zealand Society for the Intellectually Handicapped (Inc). Copies of Meeting Minutes 1972-1987. Includes New Zealand Committee, Services Committee and Special Working Parties.

New Zealand Society for the Intellectually Handicapped (Inc). Annual Reports of the New Zealand Society for the Intellectually Handicapped (Inc): 1972-1975, 1984-1988.

New Zealand Society for the Intellectually Handicapped (Inc). IH Reviews 1972 to 1987. Magazines published by New Zealand Society for the Intellectually Handicapped (Inc). National Office, Wellington, New Zealand.

New Zealand Society for the Intellectually Handicapped (Inc). (1984) Constitution and Rules.

- New Zealand Society for the Intellectually Handicapped (Inc). (1986)
Philosophy and Policy. Published by New Zealand Society
for the Intellectually Handicapped (Inc).
- New Zealand Society for the Intellectually Handicapped (Inc). (1986)
Induction Manual for Midland Region, IHC.
- New Zealand Society for the Intellectually Handicapped (Inc). (1986)
Conference Proceedings, September.
- Riseborough, A (1983) The IHC Society: The First Twenty-Five
Years. Unpublished BA (Hons) paper.
- Royal Commission on Social Policy (1986/87) Submissions and Working
Papers from Royal Commission.