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**COMMUNITY CARE OF SEVERELY HANDICAPPED CHILDREN AT HOME:
A 'MOMENT' IN THE ORGANIZATION OF WOMEN'S WORK**

BY

ANNE BULLOCK, B A.

A thesis submitted to
Graduate School of Social Work
The Faculty of Graduate Studies and Research
in partial fulfillment of
the requirements for the degree of
Master of Social Work
School of Social Work

Carleton University

Ottawa, Ontario

June 3, 1986

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ABSTRACT

This thesis examines how the use of the term community to describe the care of severely handicapped children at home organizes a course of social action that expedites the fiscal and administrative priorities of 'the state'. These priorities include a reduction in expenditures for institutional care and the 'repatriation' of the children to the community.

Data for research is drawn from interviews with women who care for their severely handicapped children at home, from provincial government documents that describe and organize this form of care, and from the writings of academics and other 'experts' whose ideological conceptualization of 'community' serves to mediate the work practices of the provincial government and the women providing care.

Findings indicate that the common understanding of 'community' shared by the women and by the provincial government represents one stage or 'moment' in which the work of women in the family is organized to complement the priorities of 'the state' mentioned earlier.

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INTRODUCTION

"...the notion of community implies the existence of a network of reciprocal social relationships which, among other things, ensure mutual aid and give those that experience it a sense of well being".

The Seeborn Report

"In the ideal community brotherhood, love and harmony replace conflict and competition; purpose and meaning replace alienation; sharing and collective responsibility replace private hoarding of goods; and family warmth and intimacy replace isolation. Relationships are loving; work is meaningful; and behaviour is self-fulfilling".

Rosabeth Moss Kantor

Community care, according to Alan Walker (1982: 4), who draws on the work of Abrams and Bailey, "is the provision of help, support and protection to others by lay members of society acting in everyday domestic and occupational settings which corresponds to the notion of care by the community". It is only one aspect of 'social care' which includes all forms of services and treatment in institutions and elsewhere, other than medical care and direct cash support. Community care is thereby distinguished from other forms of social care, including institutional care, institutional treatment and community treatment (Ibid.). It can also be distinguished from certain forms of 'private' community care organized and operated for profit by individuals or groups. The community care referred to in this paper is also 'private', since it occurs in the home, but in this case the term private is used

in contradistinction to the 'public' care provided by the state rather than 'public' in the sense of 'market' (as in the case of profit-making enterprises).

It is difficult to think of community care in the home as being organized, since the intimate connections implied by home or family life seem the antithesis of the more formal arrangements associated with care in hospitals or other specialized facilities that are operated for that purpose. The fact that certain forms of community care in the home are implicit in state policy also goes unremarked, as we simply assume that it is 'natural' for families to look after 'their own', although the existence of formally organized, state-funded care facilities of every description belie this fact. Walker (1982: 4) points out that state policies on community care reinforce these taken for granted assumptions about the benefits of care in the home by promoting the idea that families or other informal social networks composed of neighbours or friends are capable of looking after dependent people; and that such arrangements are preferable to institutional care, making a more explicit requirement for families to assume care unnecessary. These ideas, Walker states, obscure the fact that community care in the family relies primarily on the unpaid labour of female kin (Ibid.).

When the term community is used to describe care of severely handicapped children at home, Wilkin (1979: 65) argues that it seems to be a "means of winning approval for the policies (of de-institutionalization) rather than a means of achieving the ideals of community in practice". For example, certain assumptions about 'the community' and 'the family' are implicit in official statements about care of retarded children. These statements "are based on models which are rarely made explicit and which are also static, and therefore fail to take account of changes in family structure and the attitudes and expectations of the individuals who comprise families" (Wilkin: 1979: 28). Although considerable stress has been laid on the fact that family relationships are a critical factor in the decision to seek long-term institutional placements for severely handicapped children, little attention has been paid to the importance of the practical aspects of the organization of care within families in 'the community' (Wilkin 1979; Glendenning: 1983). Wilkin reports that the few studies that have devoted even a small amount of attention to the organization of this form of care indicate that the mechanics of providing it on a day to day basis are an important element in the decision to seek long-term institutional care. For instance, Hewitt's (1970) work, cited in Wilkin, indicates that the fathers of children admitted to long-term care were more likely to be described as non-participants in child-care and housework than fathers of the children who remained at home.

It can be argued that community care of severely handicapped children, resting as it does on static assumptions about the 'structure' of 'the family', relies on certain assumptions about the work women do in the family. The use of the term 'community care' does not tell us anything about the work required to make it a reality or who does that work. "The activities of daily living, the ordinary child-care and domestic work, are what constitute the nuts and bolts of community care and they are carried out by individual family members" (Wilkin: 1979: 43).

The difference between the way community care is understood and/or conceptualized - as being a more natural and hence beneficial arrangement for the family as a whole but, especially for the child - and the struggles involved in providing care on a day to day basis, even when the family is anxious to care for the child at home - appears to be ideological. That is, there is a disjuncture between the lived experience of caring for the child and 'beliefs about' such care. As I will show, the very fact that there has been a concerted effort on the part of the government to deal with the 'problems' of this form of care indicates that it is not easily organized or carried out, despite the persistence and pervasiveness of ideas to the contrary, and therein lies the problem. The desire on the part of the government and families alike to remove the impediments to home care of severely

handicapped children have taken precedence over any consideration of the impact that care of the child has on the mother who is usually the primary care-giver. Moreover, the focus on solving the problems presented by this form of home-care obscures its relationship to the larger social, economic and political context of which it is a part, for example, why it is that women do this work rather than men, or why the government itself has taken an interest in promoting community care in the home. To illustrate this problem in a more concrete way, I will describe the personal experience that prompted my interest in examining community care as an ideological concept.

My Point of Entry into the Problem

In 1980, I set up a respite care program for families whose mentally and/or physically handicapped children lived at home with them. This program and others like it, funded by the Ontario Ministry of Community and Social Services (referred to in this paper as COMSOC or the Ministry), make arrangements for short-term relief for the family from the on-going care of the child. Previous work with parents of handicapped children left me aware of the difficulties they had trying to find people to look after their children - either to give them "time-off", or in the event of a family emergency. Although the nearest

provincial retardation facilities offered the option of short-term placements, families made little use of the service. It was difficult to schedule placements on short notice and families were concerned about the effects of an institutional placement, however brief, on children used to living at home.

Community-based parent-relief programs are supposed to eliminate such difficulties. A body of research on these programs promotes them as an essential element in helping families 'cope with' or 'adjust to' the difficulties of care (Moore and Seachore: 1977; Cohen: 1979 et al.). Studies indicate that scheduling regular time off for care-givers can alleviate the stress and exhaustion that often go hand in hand with meeting the needs of severely disabled children, thus reducing the likelihood that a long-term institutional placement will be required for the child as a result of 'family breakdown'. Parent-relief programs have come into their own in Ontario over the last few years. The one I was involved with was one of 32 funded in 1980.

The impetus for this funding initiative was directly related to a provincial policy for de-institutionalizing retarded persons which was formally implemented after 1974, although it had been operating informally for several years before that. In the case of children, de-institutionalization was part of a shift in government policy, identifiable from the

1950's on, to keep children with their families wherever possible. It reflected a growing belief that care in the family was less disruptive and more 'therapeutic' than either foster care or institution care when problems related to the child's care were seen to require intervention by agencies such as Children's Aid Societies (Ontario Ministry of Community and Social Services: 1983(b)). De-institutionalization of retarded persons has been summarized by the Ministry itself (Ontario Ministry of Community and Social Services: 1983(b)) as follows:

- (1) the systematic depopulation of provincial retardation facilities;
- (2) the restriction of new admissions to those same facilities;
- (3) the creation of community-based services and programs.

The last consist of the provision of alternative accommodations such as group homes; the development of various training/therapeutic programs that increase the retarded person's capacity for independent living or enhance the ability of the individual's family to meet that person's special needs; and, finally, the creation of parent relief programs that function solely to alleviate or lessen the difficulties of this form of care for the family.

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The program I set up was well received by families in the mainly rural area it served. My concern about the program and community care in general grew, however, the more I saw of the demands that care for the children put on their mothers. In some instances, the emotional, physical and financial costs to the women involved were so great that they seemed to be deprived of the very quality of life they were seeking to provide for their children. I began to sense a relationship between what I saw of the women's work and the taken-for-granted assumptions about 'community', 'the family' and 'care' that permeated the parent-relief program objectives and those of other community support programs. It became more and more clear to me that giving 'families' 'time-off' from 'care' did not address the underlying causes of stress, family breakdown, or the resulting institutionalization of children that Parent Relief programs were created to alleviate.

I began to feel that community-based parent-relief programs shifted the focus from an analysis of the context in which care of handicapped children took place (and who provided that care) to one in which solving a particular problem associated with this form of care - the stress and exhaustion of care-givers - took precedence. I became conscious of the disjuncture referred to earlier. My understanding of community care, the understanding of the local association for the mentally retarded (who sponsored my program), the understanding

of the government who funded it, and the literature on which the solutions for the 'problems' of care were based bore only the most superficial resemblance to 'the real thing'.

When I tried to share my thoughts about this apparent contradiction with the women involved, they indicated that the difficulties they experienced were a small price to pay for having their children at home. They argued that the benefits of community care outweighed its difficulties, and had to be balanced against the meaning of a life-time of incarceration for any human being however handicapped. It was difficult to counter this argument, yet I was not satisfied. While I believe that retarded people should have the opportunity to live in the least restrictive environment possible, and that the material and emotional supports to facilitate this should be freely available, I am also increasingly concerned about the way in which these opportunities are being provided, through reliance upon women's unpaid labour in the home. Why should the major responsibility for making community care a reality fall to women, and how is it that the often unacceptable conditions of the care-giver's work take a secondary position in the overall enterprise of making community living a reality for the children involved? The idea that community care in the home is the best form of care, appears to me to be part of a complex set of ideological practices central to the work of professionals, academics, employees of the state, and so on

which shapes the common-sense notions of 'community' and even of 'care' that most of us share and assume to be natural.

My point of entry into the problem does not lend itself readily to posing 'traditional' research questions - those which test the validity of certain hypotheses about people or situations in relation to previously determined variables. I want, instead, to pose questions about how this particular situation (care of severely handicapped children at home) has been socially organized:

- (1) How its meaning has been determined historically by individuals who are located within a material context that is inseparable from their 'ideas' about community;
- (2) How the attributes which the term community has acquired make it useful for managing certain social courses of action - in this instance a provincial policy of de-institutionalization for retarded people and the 'problems' associated with community care as a result of that policy;
- (3) How the term community has been incorporated into a variety of administrative processes, including those of the government, which organize everyday life

without posing any threat to the social relations of capitalism; and; finally,

- (4) How the use of the term community to describe, promote and legitimate care of severely handicapped children at home organizes women's work there in a way that promotes and legitimates their exploitation and oppression generally, and in the family in particular.

I also hope to show that a critical analysis of 'community' such as this is of special importance to social workers involved in directly supporting or facilitating 'community' care in the home. It seems to me that there is little chance of attaining the 'ideals' associated with community care unless we are willing to recognize its fundamentally 'gendered' nature and the contradictory, even conflictual relations this gives rise to in a capitalist society like our own.

Organization of Thesis

The following summary by chapter provides an indication of the content of my work, as well as its general organization, which differs somewhat from the standard organization of a thesis-research paper.

In Chapter One, I identify and discuss the terms and concepts integral to this work, for example, 'care' and 'the state', as well as the relationship of these to an ideological understanding of community. The remainder of the chapter is devoted to setting out a conceptual framework for a feminist materialist analysis of ideology as 'ruling practice'.

In Chapter Two, I describe how I carried out my research, selected the data, developed criteria for analysis and so on. I also show how my method of proceeding is a constitutive part of the conceptual framework. As well, I include a brief feminist critique of knowledge/science and a short discussion of the implications of this critique for feminist research.

In Chapter Three, data from interviews with mothers of severely handicapped children provides some understanding of: (a) the day to day work of care; (b) what factors influenced the decision to keep the child at home; and (c) 'who' or 'what' can be identified as 'community' in the women's lives. This chapter, beginning with the women's experiences, provides the basis for the subsequent chapters, as it orients and roots my analysis in a determinate position which is socially organized. The women's experience serves to alert readers to the disjuncture between the concept of 'community care' and the experience of providing community care, and the necessity for learning more about its origins as well as how its textual

mediation provides for the state's interests, often at the expense of the family's interests - especially those of mothers.

I examine in Chapter Four, selected works on community from 19th and 20th century sociology and point out how these ideas have been incorporated into social work practice. I pay special attention to the understanding of 'the family' and women's work during these periods, and the social, economic and political context that gave rise to these. I will also show how 'the search for community' in the 19th century was informed by that same context, and served as a basis for 20th century work on community which conflates it with the family. I will argue that the conceptualization of community by its male authors relies implicitly on a particular understanding of the location and value of women's work. This conceptualization has served to buttress the intimate, supportive and integrative aspects of community, the very attributes that make it such a powerful descriptor of care at the present time. We can begin to see how women's work is integral to the idea of a particular form of social organization identified as community, but how the understanding of that work as 'natural' renders it invisible within that social organization.

Chapter Five takes the form of a brief history of care of retarded people generally, and in Ontario in particular. This

chapter sketches in the position of the Ontario Government with regard to community and institutional care during the last century as well as the part played by 'families' in recent years in influencing government practices in this regard. My intent here is to show that de-institutionalization and community care were not imposed unilaterally by the provincial government. In fact, an ideological understanding of community made it possible for families and government to assume their interests in community care were similar when, in fact, those interests were prompted by very different concerns.

In Chapter Six, I return to textual analysis, and examine a variety of government documents. This analysis shows that although community care of retarded people was understood as 'natural' by 'the state' and families and, therefore, beneficial, its implementation in the form of de-institutionalization policy served state financial and administrative interests, and provided for state intervention into family life. This ideologically mediated intervention organizes women's work as care-givers so that they are brought into a particular 'ruling' relationship with the state and other experts. This relationship limits their life choices as well as imposing arduous mental and physical labour on them.

I return in Chapter Seven to the experience of mothers in order to show some instances of the effects of ruling in their

lives; for example how their work in caring for their children intersects with and becomes a resource for work in other state-funded services such as health and education, and how care-givers are continually intensifying their efforts/labour in order to make community care for their children fit 'the ideal' in the face of social service cut-backs.

Chapter Eight takes the form of a brief discussion about the issues raised in this analysis, with particular reference to the re-organization of work generally according to the constantly changing requirements of capitalism and the effects of this for women.

My research involved reading in a wide variety of areas - care of handicapped children, womens' work in 'the family', analyses of the most recent fiscal crisis of capitalism as well as the subsequent 'cut-backs' in social welfare spending. Rather than attempt to summarize this material in a single chapter, I have elected to incorporate it into each section as appropriate. The presentation of my data - either from informants or from texts - is not confined to a single chapter either, but is used in a particular sequence to show how the lived experience of community care feeds into both theoretical work on the subject and the practical application of this work in developing solutions to meet the needs of outside interests, such as those of the government.

I THEORETICAL FRAMEWORK

TERMS AND CONCEPTS - THE 'PIECES' OF THE PROBLEM

Introduction

In the first section of this chapter, I will discuss terms and concepts used frequently in this work such as community, care, ideology, the state and normalization, with the intention of showing the difficulties of taking any of them at 'face value'. The discussions are condensed and do not address thoroughly the complexities that emerge from 'problematizing' these terms. I feel, however, that the attempt to set these out, even in abbreviated form, points up how the definition of terms or development of concepts has political implications. Such activities delineate an area of struggle - one that has importance for women in general and for those caring for disabled people in particular. I will elaborate on many of the ideas set out in this section in subsequent chapters. Given the impossibility of a simultaneous discussion of the understanding of these terms, I have set them out individually in what seems to me to be a logical sequence.

The second section of this chapter sets out a conceptual framework based on the work of Dorothy Smith. Smith considers ideological construction to be a distinctive feature of the ruling process of capitalist society at the present time - a method of thinking through which 'ruling' is actually

accomplished. Her theoretical work posits a method of analysis to determine empirically how and where ruling takes place.

Community

As Dehli (1983) points out, over the last ten to fifteen years, 'community' has become an important political catchword on the 'left' and on the 'right'. In the case of de-institutionalization, the use of the term community to describe a preferred form of care, living accommodation or treatment outside the confines of the state-funded care facilities we associate with 'the institution', has advanced quite contradictory aims. On the one hand, care of institutional residents in the community serves conservative interests, as the de-population of institutions necessarily reduces the expenses connected with their operation and maintenance. This move is pleasing to those committed to an overall reduction in government expenditure, especially in the area of social services (Scull: 1984). On the other hand, the substitution of community care for institutional care has also been supported by more liberal factions since it holds the promise of providing or restoring to individuals their 'rights' to full citizenship and the opportunity for a 'better quality of life'. Neither is believed to be attainable within the institutional setting which tends to 'de-humanize' residents.

Somewhere at the heart of the matter lies the belief that community care or living is always 'good'. The fact that the term can be marshalled in the service of radically different interests, as mentioned, or why this might be so, goes unaddressed.

The desire to explore the properties of the social formations we call 'community' so that they can be defined 'once and for all' has occupied the energies of a diverse group of thinkers who share little in common except that desire. Although there have been periods when community has not been viewed as a particularly useful or beneficial form of social organization, for example during the Age of Reason, (Plant: 1974; Nisbet: 1966) it is usually associated with a number of positive attributes (Plant: 1974; Nisbet: 1966; Effrat: 1974).

Community as a term or notion is seen as describing a form of social organization characterized by a high degree of personal intimacy, emotional depth, moral commitment, social cohesion and continuity in time (Nisbet: 1966). Moreover, the notion of community implies the putting away of self-interest in favour of the interest of the group (Nisbet: 1966; Plant: 1974; Hardy: 1981). The debates about what community is have tended to centre on its characteristics, while neither the assumption that it exists as a feature of society nor how it came to acquire this status has been questioned. The emphasis

on its positive, even romanticized attributes tends to downplay the possibility that 'the community' can also have less positive effects for some of its members (Wilson: 1982).

Nisbet (1966) points out that the 'nomenclature' of the family has been used to define and explain the social organization known as community. He takes this as a given, as do many sociologists, without considering how such linguistic practices might affect women. If, as Nisbet suggests, 'family' and 'community' have been conflated, then the use of the term community could easily pass over or render invisible the work of women in the community, as has been the case with the term family. It is only in recent years that systematic studies - undertaken for the most part by feminists - of the labour required to produce 'family life' have demonstrated the centrality of women's work in the family. The significance then for women of joining the terms 'community' and 'care' should be obvious. While 'community care' in the home can indeed be of benefit to dependent people, its organization at the present time also produces contradictory effects for care-givers. Our understanding of community care - derived from a particular understanding of the location and value of women's work - makes it difficult to uncover how the work of care-giving is socially organized or the physical, emotional or financial costs that can accrue to the women involved.

Care, Dependence and Women

Although the need to care and be cared for is an integral part of the way societies reproduce and maintain themselves, the responsibility for it, the manner in which it is carried out and the value accorded it varies by society (Finch: 1983). In our society, most forms of care are provided by women, whether these involve tending or looking after the physical needs of another or offering another person 'moral support', encouragement or interest (Ibid.). It is taken for granted that this work ebbs and flows in terms of the demands it makes on women. It is also assumed to be 'part and parcel' of being a wife or mother and in some sense epitomizes 'family life' even though the work that it entails goes unnoticed or is considered inconsequential. It is also central in women's paid work as nurses, social workers and so on.

The care and maintenance of disabled people appears to have become an increasing problem for 'the state' in capitalist society as the changing forms of work alter the availability and ability of the members of such societies to look after people who require long-term care. Indeed, as I hope my work will show, 'the state' has had to devote more and more efforts in the past 150 or so years to organizing care for these individuals. The criteria for state-funded care or support has changed through the years so that it now includes those who

have no means of financial support although they are mentally and physically fit for work - redundant workers for example. 'Care' in a variety of forms is what the present day welfare state is all about (London Edinburgh Weekend Return Group: 1980). Since most paid and unpaid care can be considered 'women's work', it seems reasonable to assume that 'the state's role in its organization will affect women.

While state-funded care in hospitals and asylums represents one attempt at a solution to the dilemma, the care of dependent individuals continues to be thought of as a 'family responsibility', and not without good reason. There is evidence to indicate that this is where the majority of dependent people have lived and continue to live (Moroney: 1972). McIntosh (1979: 169) points out that the care of 'incapable' people in the home is in the hands of women and is more widespread than often realized. The changing relationship of the family to capitalism has very much affected the work of women there - contributing to their economic subordination inside and outside of the home and dependence on the waged work of men which is more highly valued. It is possible to see how providing long-term care at home has a special significance under these conditions, since the requirement to care for dependent people must be met in some fashion, whether at home or elsewhere. The fact that care-giving in the family is understood as the 'natural' work of wives or mothers obscures

this important point. Since the ability to care is assumed to be in-born in women or the expression of a particular female morality, the effects of long-term care arrangements on them have often gone unquestioned - even by women themselves. Moreover, the relationship between the work women do as care-givers in the family and their material subsistence in the family (Graham: 1983: 24) also goes unremarked.

When these material arrangements are coupled with the value-laden moral and social connotations of care (Alan Walker: 1982: 5), the implications for women stand out more sharply, especially during times when there is a need to reduce the expenditures of state-provided care. An increased reliance on their unpaid work to maintain a steadily increasing number of physically, mentally and, perhaps even economically dependent people presents an attractive and 'natural' alternative to paid care. The use of the term community to describe this form of care seems highly significant as it implies that there is an interest in and shared responsibility for the work of care beyond the confines of the family, as well as a growing number of the community's members who need to be cared for.

Although 'care' is not the subject of this thesis, I want to provide some sense of how feminists have attempted to grapple with both the theoretical and practical significance of care in women's lives. This discussion is important in

establishing the centrality of care to women's experience and, thus lays a foundation for an analysis of the disjuncture between an ideological understanding of care described as 'community care' and the lived experience of providing that care.

Care - Women's Nature or Women's Work?

Some feminist analyses of care consider it a manifestation of women's nature. Others argue that care is the work 'assigned' to women in capitalist and/or patriarchal societies, and that it advances the interests of both at the expense of women's equality in all areas of life. Both positions have been summarized by Hilary Graham (1983), and I will draw on her work to set out the main points of each framework. This abbreviated version does not capture the richness of Graham's arguments, but I hope it will serve to indicate the parameters in which any discussion of care in the community can take place, as well as the complexity of the questions 'care' raises for women, both in terms of what it means for the kinds of work we do, and our understanding of it in relation to being female.

The belief that the ability to care is part of women's nature is posited on the argument that care cannot be reduced

to a labour process. Instead, its significance is seen to lie in its inseparability from femininity and womanliness. Horney (1932) and de Beauvoir (1972) have argued that the intimate relationship between caring and femininity should not be understood as the outcome of the sexual division of labour within the family, but rather as the organizing principle upon which 'femininity' and notions of 'the family' are based. In other words, caring is one of the categories which serve to distinguish the sexes from each other - caring becomes the defining characteristic of women's self-identity and their life-work; 'not caring' becomes a male characteristic.

Jean Baker Miller (1976) and Nancy Chodorow (1971; 1978) have used these ideas somewhat differently. Jean Baker Miller believes that the subordinate position of women in a male-dominated society gives rise to a 'psychological predisposition' to care which becomes a survival tool for women - one that makes them indispensable to the men on whom they must rely for material support. Chodorow suggests that caring marks one of the boundaries between men and women that is embodied in the distinction between 'being' - the other-directed but essentially passive nature of femininity - and 'doing' - which represents the self-directive and active nature of masculinity. She also states that the caring role is not reproduced directly through male domination, but by women themselves through the mother-daughter relationship. In caring

for children, women recreate the personality types we associate with masculinity and femininity, that is, daughters learn to be care-givers from being with their mothers. Chodorow points out, however, that the sexual division of labour and women's responsibility for child-care are linked to and perpetuate male dominance.

The perspective that care is women's work is based in the belief that care is part of the relations of reproduction in capitalist society. Reproduction and/or reproductive labour used in this context includes the whole process from conception, through birth, to the point of personal independence of the child and involves all aspects of nurturing and socializing children performed (usually) by their mothers (Clark and Lange: 1979). Assuming that reproductive labour, especially in the form of care, reproduces capitalism on a daily and generational basis, questions are raised about the understanding of this work as a 'natural' ability of women when it extends far beyond the ability to give birth or nurse; and how the assumption that women are 'natural' care-givers has been extended to include the care and/or nurturing women provide not only to family members, but to others as part of their paid work. It is argued that the relationship and value of care to capitalist forms of economic organization, especially when care is understood as 'natural' to women and because it occurs in the family, contributes to its being seen

as something other than work. This view of care as something other than work carries over into paid work where it is reflected in low salaries (Breugel: 1978; Hartmann: 1979, 1981).

Each of the frameworks - caring as women's nature and caring as women's work - advance our understanding of care, but neither is complete. Care is neither a totally subjective experience nor one in which women are completely powerless against 'external forces'. It is mediated in a variety of ways, and, as Parker (in Graham: 1983: 20) points out, we cannot really understand the meaning of care until we examine the institutions most centrally involved in its organization - 'the family', 'the community' and 'the state'. This is vital at the present time when:

"A woman's experiences and identity as a carer are increasingly moulded not through her involvement with the able-bodied members of the immediate nuclear family but through the services she provides for the sick, the elderly and the handicapped."

Moreover care of dependent people is not in the exclusive domain of 'wives' and/or mothers. Unmarried women are also expected at times to assume care-taker responsibilities. Townsend's study (1963) of old people in Britain, for example, indicated that unmarried daughters were much more likely than

unmarried sons to assume care of their elderly parents, and any discussion of care should take this into account.

The models of care which focus on its 'psychological' elements point up why or how women acquire certain beliefs about the significance of being a care-giver. An approach emphasizing personal subjectivity shows that ideas about being a good care-giver are often inseparable from the notions women have about 'womanliness' and 'femininity'. The fact that women can feel unsexed when they think they aren't caring/nurturing enough is a case in point. To posit the idea, however, that the ability to care is a female trait (or tendency) teeters on the edge of biological determinism. It is that very understanding of women's lives and work as natural that underpins the unequal social, political, and economic arrangements that work against women's interests in the first place. Women have been given the task of conserving the very values that legitimate female privation (O'Brien: 1981). Furthermore, the distinction between 'being' and 'doing' tends to obscure how gender is socially constructed, and does not provide an adequate basis for understanding how care 'becomes' women's work and/or why it should be considered so unimportant when its benefits to (any) society are obvious. As Graham (1983: 20) so aptly puts it, "what counts as caring is determined as much by who does it as by what is done."

Analyses of care as work, in which care is understood as a critical component in the maintenance of capitalist societies like our own provide a view of the labour-intensive nature of care (which tends to be downplayed in the approaches stressing its origin in women's nature) and of the benefits of having the costs of care subsumed in 'the family wage' paid to men. These analyses also make clear that in the course of providing unpaid care for others who are dependent, women become dependent themselves - the effects of this dependency sometimes not apparent until they find themselves without a male provider, for example, in the event of his death.

Although this framework makes clear how care is related to market processes, it too can verge on determinism by taking a rigid view of the economic value of the work and/or the understanding women have of it. Although care most assuredly is work, the relationship that women have to those they care for within the family is not the same as the relationship that workers in factories, for instance, have to their work. At the same time, there are aspects of the organization of care in the family that appear to be analogous with paid work. To assume that women only care for their families - whether any member is 'dependent' or not - because they are duped into it or are powerless to do anything about it does not give adequate recognition to the fact that caring is one way people have to show their love or concern for someone else, and which seems

capable of transcending the more 'instrumental' relationships so characteristic of capitalism. Overly deterministic views of 'the state' and/or capitalism also leave unanswered the many questions that arise about how the work of care, organized to have benefits to the state and capital, can appear perfectly acceptable and, in some cases, preferable to institutional care in the eyes of care-givers themselves.

Toward an Understanding of Care

We need to place our understanding of care in an historical context that takes into account both its public organization, that is, how 'the state' intervenes in the provision of care to dependent people, as well as its private organization in the family-household. For example, we need a materialist understanding of the emergence of certain 'dominant ideas' about care at various points in time and their effect on government policies that support custodial care on a grand scale as well as community care. In a sense, this is what analyses of de-institutionalization are about, yet I think we also need to see also how this 'public' aspect of care is related to the (private) work women do as care-givers in the family.

Historical analyses of womens' work (Lewis: 1986) indicate that it has changed in the family through the years as the organization of economic forms themselves have changed, and given rise to different kinds of work generally. Current standards of appropriate child-care, one major form of care, have, for instance, only evolved in the last century. In many respects these standards are a sharp contrast to earlier child-care practices. The changing material context in which women provide all forms of care is clearly shaped by economic considerations. At the same time, neither their attitude toward care, nor that of 'the state' as it organizes certain aspects of care is the result of economics alone, but of an interplay between the shape that economics gives to care, the needs people themselves identify around care and how both are incorporated into various state policies that implicitly or explicitly organize care.

Care also forms an integral part of what we recognize as 'community life'. Womens' paid work often involves them in caring for people in 'community' agencies as nurses or social workers. As well, women take on volunteer work in many of the institutions considered to be the 'backbone' of community life - in churches or schools, for example. Women also devote considerable time and energy to organizing and putting on social events that bring people together. These activities, ranging anywhere from providing coffee after a meeting to

organizing much more elaborate events, provide opportunities for people to discover shared interests or needs which, in turn, form the basis for a shared perception of 'community', but one in which the work that encouraged such social contacts fades into the background. I would argue that the understanding many women have of the various kinds of work they do in the community as their 'natural' responsibility to support or care for others, even when it exacts a great personal cost, is best understood as being ideological.

Ideology

The term ideology was first used at the beginning of the 19th Century by the French philosopher de Tracy to refer to the study of ideas. It has come to be more popularly understood, however, as a set of ideas justifying particular interests - a system of interdependent ideas held by a group or society which reflect, rationalize and defend its particular social, moral, religious, political and economic institutions and commitments (Theodorson and Theodorson: 1969). As well, it is usually taken for granted that holding to a particular ideology involves the repudiation of other ideological frames of reference

Marx gave 'ideology' special prominence in his work. He defined it as a system of ostensibly logical ideas that served the vested interests of a dominant class - the most dominant ideology in a society being that of the ruling class. His work provided the foundation for subsequent analyses of the relationship between ideology and the subordination of certain groups or classes, by 'the state' as the agent of ruling class interests. Among the most noted are those of Gramsci and Althusser. The work of each offers an explanation of what ideology is, how it is reproduced and who benefits from it.

According to Abercrombie (1980) Gramsci developed a theory of ideology as hegemony. He argued that the state did not use force to maintain its rule except in special instances. Instead, its ideas, values and definitions penetrated every level of life in a variety of ways. Institutions like the education system engineered the consent of subordinate classes in their own domination. In this way, subordinate classes were systematically taught to see their interests as identical with those of the ruling class (Corrigan and Leonard: 1981: 100). Gramsci's work lends itself to over-emphasizing the passivity of those who are ruled as well as the power of those who are dominant (Ibid.).

Louis Althusser argued that ideology was an imaginary form of reality representing the relation of individuals to the

mode and relations of production (Abercrombie: 1980). Like Gramsci, Althusser believed that ideology was the main 'mode of domination' in capitalism. Although his work allows for the possibility of resistance to 'ideological state apparatuses', its structuralist/functionalist interpretation of both the state and ideology itself tends to be static (Griffith: 1985).

The work of both relegates the majority of people to a passive position where they are "done to" by individuals, events, or institutions beyond their control. Struggles waged by the working class, and/or other groups to get their needs met contradict the picture of a monolithic and rigid state or ruling class. It would seem to be more to the point to ask how people, whatever their class location, sex, or race, take an active role in creating and/or reproducing dominant ideas and how such efforts can give rise to contradictory effects in their lives.

Neither Gramsci nor Althusser treated as problematic 'the effects' of state or ruling class ideology in women's lives, although 'the family' was identified as one of the main sites of ideological reproduction. Feminist analyses of ideology (Mitchell: 1971; Wilson: 1977) have shown how the excessive valuation by 'the state' of a certain form of the family and the relationship of its members to each other can contribute to the economic subordination of women as well as to other forms

of oppression in their lives. There is a possibility, however, that the reification of 'ideology' and 'the state', on the basis that it is a bastion of male supremacy will be perpetuated. While it is clear that men do occupy the most important positions in the state, and that women have not as a rule benefitted from state policy that touches on 'family life', this situation has not evolved in any straightforward way. The reduction of state organization to patriarchy alone does not account for the contradictory organization and practices of the state, or for the wide range of outcomes that state policy can have on women's lives (Lewis: 1986). Moreover, this approach tends to downplay the active role women themselves have taken in these developments (Ibid.). An historical understanding of the organization of care in the family illustrates this point.

Ideology, State and the Family

Zaretsky (1982) states that the colonial, patriarchal family in the 'new world' was considered the natural provider of care to the poor, physically infirm and so on. There was virtually no distinction at this time between the authority of the state and the authority of individual men as heads of families. In the 18th century, the authority of the state 'flowed' into the family through the authority of the father.

The shift from this 'patriarchal' arrangement between the state and families coincided with changes in the social structure brought about by the changing dynamics of capitalism.

The increasing ownership of private property, especially by bourgeois families, gave rise to a kind of buffer zone between them and the state that served to limit intrusion by the state into their affairs (Zaretsky: 1982). State practices took the form of non-intervention, of a laissez-faire approach, reminiscent of its dealings with the market itself (Zaretsky: 1982: 198). Working class families became more vulnerable, at least in principle, to state organization of their lives as they had no property to protect them.

Zaretsky (1982) identifies a number of factors that contributed to the separation of women's work from general economic processes, its identification with a particular form of work and organization of the family in the 19th century and its 'spread' to the working class. These were trade union protectionism, middle class reform movements, early urban liberalism and early feminism. Each contributed to the re-constitution, re-structuring and even creation of the family as a private economic unit supported by a male wage, although this was not necessarily intended. For example, child welfare legislation as well as union reform served to squeeze working class women out of their jobs although these reforms attempted

to improve the material conditions of their lives, and were generally accepted by working class women (Lewis: 1986).

The ideals of bourgeois family life came to be accepted as the norm for all family life, and these included an emphasis on the caring role for women. According to Sennett (in Harris: 1983: 164), "'the family' was elevated as the seat of moral virtue, of truly human relationships...". Subsequent state policy, concerned with the reproduction of workers, was articulated through 'the family' as it embodied these ideals although it was women's work that made the attainment of those ideals possible. This understanding was not in any simple way imposed by 'the state'. It drew on the notion presented in the work of philosophers and sociologists which supported the proposition that family and locality constituted the last remnants of 'true community' (Sennett in Harris: 1983). Thus, community and family were, in some sense, the same thing for the state, but its activity was based on the common ideological understanding of 'family' and 'community' of the time rather than on one it invented for its own purposes.

In the case of care of retarded people, the local or central state has never had a single solution for how best to maintain this particular group. Sometimes the 'economics' of the situation have produced moves to collectivize care, at other times to privatize it, as is happening at present (by

describing it as community care). Both alternatives have the potential to affect the family and the work of women who care for retarded dependents. At the same time, however, certain 'beliefs' held by families, including the women in them, about what constitutes 'good' care or where it can best be provided can have an effect on government activity. What must be borne in mind is that these effects in turn, can be contradictory, as adequate material resources or emotional energy to care for a severely handicapped dependent at home are not evenly distributed among care-givers. Simply attributing these effects to a male-dominated 'state' or 'ideology' does not aid in our understanding of how the situation came to be organized so that even when the provision of care is very difficult - and more so for some women than others - women have struggled in recent years to ensure that the family will continue to be the major site for care, especially when children are involved.

The Welfare State and Capitalism

"The notion of a distinct political sphere is...peculiar to capitalism" (Gough: 1979: 40). An appreciation of the role of the state in a capitalist society, as well as how it goes about its work requires an understanding of the 'basics' of capitalism itself.

Class society is not unique to capitalism. Slave and feudal societies were also organized on the basis of class. According to Gough (1979: 18) the productive activity of slave societies was undertaken by people who had no rights or freedoms. Their very bodies were owned by their masters. In feudal society, serfs laboured for nobles with the understanding that nobles owed them specific obligations in return. In both cases, the extraction of surplus labour was direct and obvious.

Within capitalism, most goods and services are produced as commodities to be sold, that is, exchanged for money which, in turn, is used to purchase more goods. The dominant class owns the means of production. For example, the capitalist purchases machinery, raw materials and labour to make a commodity. At the end of the process, he sells what has been made and makes a profit. Workers sell their labour power to the capitalist and receive a wage in return which provides for their subsistence. They are not 'forced' to work and their wages are not forever fixed; their employment and remuneration are determined by 'the market'.

Capitalism is premised on the freedom of the individual worker to exchange his/her labour power with any capitalist (presumably for the most money). The notion of a fair day's work for a fair day's pay obscures, however, the fact that the

worker does not receive his full entitlement, as the capitalist keeps the profits. Thus, the worker's labour does more than provide for his/her own subsistence. It also provides for the subsistence of the capitalist and gives rise to a host of different structures of social relations that isolate workers from capitalists, or treat them as individuals with mutual rights or obligations (London Edinburgh Weekend Return Group: 1980: 56, emphasis added).

Since the extraction of surplus labour in capitalism does not rely on the coercive mechanisms of slavery and feudalism, and since the market provides capitalism with its own momentum which is beyond the control of any agent or class (Gough: 1979: 39), the separation of economic and political processes is to be expected. In fact the individualism of capitalism - the belief that people are free and equal to pursue their own ends - requires a separate structure to represent their common interests (Gough: 1979: 40).

Marx and Engels suggested that the economically dominant class was also the ruling class. According to Gough (1979: 43), however:

"What distinguishes Marxist theory is not the view that a particular class dominates the institution of the state (though this is the normal state of affairs), but that whoever occupies these positions

is constrained by the imperatives of the capital accumulation process."

At the same time, the separation of the state from economic processes suggests that it does not simply 'rubber stamp' the desires of one class. Within these constraints, there is some room to manoeuvre around competing strategies and policies. While the state serves the long-term interests of the ruling class (by intervening to maintain accumulation) it must also contend with struggles initiated by the working class to get its interests met (Corrigan and Leonard: 1978: 94), thus the state reflects much more than the 'status quo' (Ibid.). State services also reflect those struggles and contradictions. Even when they have been created to help or support, state services are usually coercive and can involve people in bureaucratic nightmares that turn out to be worse than their original problems. On the other hand, state services have made the lives of most people a bit easier by providing health care and pensions. For many, many women, state benefits are the only means of financial support available to them, and a great number are employed in state-funded agencies or institutions. This 'double-edged' experience of the state has prompted numerous analyses by women in recent years (Wilson: 1977; Land: 1978; Barrett: 1980) which attempt to come to terms with the positive and negative effects of these developments.

Corrigan and Leonard (1978: 96) argue that the welfare state is the universal type of state in contemporary capitalist societies. The welfare state - a product of struggle that involved gains and losses for capitalists and the working class - raised the standards of health, education, housing and so on for the working class. It also provided subsistence for the aged, the unemployed and so on. Earlier notions of 'less eligibility' which typically involved the segregation of dependent individuals from the general population by coercive and/or punishing means, in work houses for example, were supplanted by the belief that each person had the right to minimum subsistence provided by the state. This amounted in some ways to a return to the much older practice of 'outdoor relief' in which dependent people were supported wherever they happened to live. Gough (1979: 44) provides the following definition of the welfare state:

"The use of state power to modify the reproduction of labour power and to maintain the non-working population in capitalist societies."

He goes on to point out that the welfare state is the institutional response in advanced capitalist societies to the two activities basic to any society - the reproduction of a working population and the maintenance of the non-working population. Since 'the family' plays a major role in both

activities, the welfare state represents a new relationship between the state and family.

Women have a particular relationship to the welfare state. Zaretsky (1982) notes that the welfare state was the product of the single-issue movements, such as early feminism, referred to earlier. The unexamined assumptions of each of these movements concerning capitalism and/or the relations between the sexes, especially with regard to paid work, became incorporated into the reforms of the welfare state. In particular, the welfare state preserved the family as an economically private unit (Zaretsky: 1982: 195) based on a bread-winner male and dependent female primarily responsible for rearing children and keeping the home - and who, more recently, is increasingly assumed to work outside the home as well (Zaretsky: 1982: 215).

According to McIntosh (1979: 163) state policy bolsters the family-household so that the needs for income and care are met within it. Even where the state recognizes the need for collective consumption - in meeting the needs of the sick or disabled - it does so through ideology that "retains a definition of these needs as properly belonging to the family" (Ibid.). Thus the organization and practices of the welfare state both rely on and legitimate the unpaid, privatized work of women in the home - an important point in the organization

of certain forms of community care as mentioned earlier. As Barrett and McIntosh (1982) observe, an analysis of the ideological organization of the family is also an analysis of the ideological organization of the state. The normative understandings of ideology bring the work practices of families and 'the state' closer and closer. This means an increasing amount of state intervention into women's lives.

The Welfare State and De-Institutionalization

Scull (1984) rightfully questions why the well-developed 19th century critique of institutions failed to direct the course of institution care toward community care at that point. He argues that the material support for community care was not in place until a much later period - with the advent of the welfare state in the 20th century.

During the 19th century, the only forms of state-provided welfare were collectivized - work houses, institutions and so forth. Care of dependent people had developed in this form in order to discourage those capable of earning a wage from any thought that state care would provide a better standard of living (Scull: 1984). Changing ideas about the treatment of the poor, mentally ill and others, as well as the economic changes of the 20th century coincided in the welfare state.

The belief that every individual had the right to minimum subsistence not only made receipt of state income acceptable, but a reality under these circumstances. The requirement of the state to segregate special needs groups became less of a necessity, although entrenched ideas about the danger to society of certain groups like the insane and retarded, or the necessity for them to receive 'treatment', served to justify their continued care in institutions (Scully: 1984; Rothman: 1980).

Growing demands from the public for more institution care, as well as the sharp rise in costs associated with the operation of institutions during the 1950's and 60's, the result of the unionization of institution workers and so on, and the growth of expenditures of the welfare state generally during this period contributed to a need on the part of the state to reduce costs. Although the process of de-institutionalization did not occur in any simple way, the possibility, at that point, of care for dependent people outside the institution system presented not only an attractive but feasible alternative to the costs of collectivized care which involved greater costs to the state overall.

The impact of social service spending on state budgets has been significant since World War II, and is due not only to the expansion and improvement of services, but to the fact that

the associated costs have risen faster than the average price level, forcing even greater expenditures in order to maintain the same service in real terms (Scull: 1984: 138). This has been due in part to the labour-intensive nature of the social service work funded by the state.

The most recent downturn in the economy, which began in the 1970's and which has had a definite impact on government spending, is not an isolated event. As the authors of In and Against the State (1980) explain it, the antagonistic relation between capital and labour which drives capital to increase its exploitation of labour is responsible for the downturn. This action expresses itself paradoxically in a tendency for the rate of profit to fall. Capitalists begin to withdraw their capital from investment when this happens, bringing about unemployment and a fall in wages. Thus an economic crisis is merely a clearer or more obvious expression of those antagonistic relations that are there all the time.

Such crises are not limited to the 'economic sphere'. They represent a crisis of the entire social structure which can only be resolved (for capitalists) by restructuring social relations in a way that makes it possible for production to continue (London Edinburgh Weekend Return Group: 1980: 64). Making these changes not only increases the rate of workers' exploitation, it requires a "major transformation of social

relations" (Ibid.). This not only means negotiating with workers to get them to accept new conditions in the paid workplace; it can (and has) involved a restructuring of state social services. Gough (1979: 40) notes that under these conditions we can expect pressure to develop for reprivatization of parts of the welfare state, that is a switch from direct state provision of services to public subsidisation and purchase of privately-produced services. Concessions given in one area, then, result in "tightening up" in another.

"All this involves too a restructuring of family relations, as women are often the first to be made redundant, as the cuts in hospital and other social services throw back caring responsibilities on to the home, where they fall primarily on women as the increased stress and tension at work and out of work take their toll on our 'private lives'" (London Edinburgh Weekend Return Group: 1980: 64).

Although the fiscal crisis of the welfare state and its relationship to de-institutionalization and community care is an extremely complex one, the need on the part of the state to reduce its expenditures cannot be underestimated. On the other hand, the efforts of families to influence the government with regard to de-institutionalization cannot be minimized either. These actions have been rooted in their own knowledge and experience of institutional or non-institutional care, as well as in the advice of 'experts'.

A Note on De-Institutionalization and Normalization

Families caring for severely handicapped children at home may attach a meaning and significance to that care which goes beyond their personal situation; they think about what they do in relation to a particular understanding of retarded people as a special group who have been denied access to 'mainstream society'.

The basis for this understanding seems to be derived from two main sources: (a) The work of Erving Goffman (1961) and others which related the de-humanizing effects of institution life to the organization of 'the institution' itself; and (b) The philosophy of normalization developed by Wolf Wolfensberger (1972), which offered a 'blue-print' for integrating marginalized groups, especially the retarded, into a 'normal' life. Both perspectives rightfully exposed the worst forms of institution care (Dalley: 1983) and validated or confirmed in a formal way what many families had learned, through bitter experience, about institutions. On the other hand, the implications of these critiques, that care outside the institution was necessarily better, tended to discourage any serious attempts to re-organize institutions, and also minimized the difficulties of providing a decent quality of life elsewhere. Community care and institution care came to

symbolize the best and worst forms of care respectively (Dalley: 1983).

These writings had special implications for the care of retarded children. The depiction of the institution as an unstimulating and uncaring environment supported other 'expert' work on the importance of the mother-child bond and the irreparable damage to children who experienced maternal deprivation (McIntosh: 1979; Riley: 1983). I will discuss later in this paper how these ideas were promoted, and some of their effects on the organization of mothers' work. I mention them at this point - normalization in particular - because it provided a new conceptual scheme and vocabulary for mental retardation (Simmons: 1982). Not only did this new understanding affect profoundly the aspirations of families with retarded dependents, it was to become, as I hope to show, one way for the Ontario government to 'understand' retardation and provide for the care of retarded people in 'the community'.

Normalization in this context means the utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors which are as culturally normative as possible. In other words, retarded people could become more like non-retarded people if they had the opportunity to take part in the 'normal rhythms' of life with non-handicapped people (Wolfensberger: 1972). This view

emphasizes the importance of focusing on the strengths of the retarded person - rather than his/her disabilities.

Dalley (1983) has challenged Wolfensberger's notions of 'normal life' from a feminist perspective in that the nuclear family is assumed by Wolfensberger to be the normal and ideal place for the handicapped person to live. An analysis of his major work Normalization (1972) reveals Wolfensberger's uncritical view of family life, and is one example of how an ideological understanding of the family and community became inextricably connected to de-institutionalization and community care.

The belief that home-care in the community would serve the interests of retarded people better than care in large impersonal institutions did not originate, of course, with Wolfensberger. One of the things that set his work apart was its reliance on an expanded notion of citizenship and the belief that retarded people have the same right as anybody else to participate in society. His unproblematic understanding of 'community' provides for this belief. The exploitative and/or oppressive relations upon which capitalism depends, and which make true equality impossible to achieve, are thus obscured.

The strong sense of 'moral responsibility', perhaps a feature of ideology, that families have toward providing these

opportunities for their children seems to be an integral part of the decision to care for the child at home as I will show in later chapters. There is certainly nothing 'wrong' with the idea of a severely handicapped child growing up in a 'normalized' environment which, for children in our society is understood to mean residing with their biological parents. On the other hand, abstract and reified notions of 'family' or 'community', provide for an understanding of normalized care for these children that does not take into account that care of the child is work rather than a 'natural' process, and that normalization will have effects for somebody besides the child.

Normalization theories place the care of retarded people in an historical context that takes account of the social construction of deviance. They also point up how the vested interests of 'experts' can perpetuate segregated care which is not in the best interests of the retarded person, although 'expert' advice is given with the best of intentions. These theories do not, however, examine the interplay of these 'beliefs' - about deviance or its control or treatment - with the changing economic context.

PUTTING THE PIECES TOGETHER

Overview

I have found Dorothy Smith's work useful as a conceptual framework for examining the ideological construction of community and women's lived experience of it. Smith (1973, 1978, 1981(a)) building on the work of Marx and Engels considers the work of ideological construction to be a distinctive feature of the ruling process in capitalist society - a method of thinking through which ruling is actually accomplished. In the article "A Peculiar Eclipsing", Smith (1978) sets out her view of ideology as a method of proceeding which organizes society in a particular way, structures our understanding of it (and the consequences of this for women). She argues that in our society ruling gets done in words or symbols on paper. The work of administration, government and management is communicative work as is that of organizational and political processes. Certain images, vocabulary, concepts, and abstract forms of knowledge are integral to the practice of power in this form.

Smith argues that how we think about ourselves, one another and society itself is given shape and distributed by specialists occupying positions within a ruling apparatus which organizes capitalist society. She uses the term 'ruling

apparatus' to better express the complexities of the prevailing organization of power relations. The ruling apparatus is composed of a complex of relations among the state, managerial and administrative processes, institutions, professions, the media, etc. all of which draw upon the work of academic, cultural and professional discourses which enable them to articulate and reproduce class relations as well as co-ordinate the general social processes of capital (Smith: 1981 (a), emphasis added).

Smith (1978) points out that women have been excluded from producing the forms of thought, images and symbols in which thought is expressed and ordered.

"There is a 'circle effect'. Men attend to and treat as significant only what men say. The circle of men whose writing and talk was significant to each other extends backwards in time as far as our records reach. What men were doing was relevant to men, was written about by men for men. Men listened and listen to what one another said" (1978: 281).

Women have been involved in the development of capitalism as much as men but their work has been of a different kind and location. The questions, solutions, themes, styles and standards of looking at the world do not include women's experience. It seems reasonable to assume then that the concepts and discourses through which state activities are accomplished (ruling practices by means of documentary

discourses) can have special effects for women. These activities are based on knowledge that ignores women's experience or re-frames it according to the requirements of government personnel, various specialists, professionals, and so on. This applies whether women are on the 'receiving end' of this knowledge, for example as clients of state-funded programs or services or whether, as state employees, they draw on such understandings - as social workers or teachers for example - and 'pass them on' to female clients or students. The appropriation and containment of women's work practices in this way is one instance of how women 'produce class'. I will return to this idea later in this section.

Sociology as 'Ruling' Work

Sociology has played a major part in the work of conceptualizing social phenomena (Smith: 1972(a)(b), 1981(a)). The development of 'community' as a unit idea of sociology is a case in point. This conceptual work, as I hope to show, is done in a way that facilitates the development and administration of policies and programs as courses of action. Such processes structure the relationship between those whose task it is to keep society operating smoothly in the interests of capital, and those whose actual experience may be seen to require management in order to bring it into line with ruling

interests. Problems that arise out of such relationships are dealt with by means of practices based on the ideological understanding of experts at the conceptual level rather than on an understanding of the particular events that occasioned those difficulties in the first place (Smith: 1979(b)).

The practice of sociology externalizes everyday experience and creates a new understanding of it (Smith: 1972(a)(b), 1974(a), 1977(b), 1979(a), 1981(a)). In the process, certain aspects of experience are eliminated. This work, drawn on by various aspects of the ruling apparatus, organizes what happens in people's lives so that it may be fitted into categories that facilitate administrative or financial priorities, and also provides a way to think about lived experience. Smith states (1981(a)) that the work of the ruling apparatus (in part, at least, undertaken by sociology) complements the economic relations of capitalism. Just as the economic relations of capitalism are organized as abstract relations between things (such as commodities and money) so conceptual work transforms concrete experience into categories that are actionable in bureaucratic, professional or managerial modes (Smith: 1981(a)).

The abstract form of communication used in texts, various reporting and accounting systems, and so on relies on discrete terms/concepts to codify, categorize and ultimately standardize

experience, thus providing a common means of expression and understanding among those who rule, which becomes, in effect, the means of ruling (Smith: 1972(a), 1978, 1981(a)).

"The ordinary forms in which the features of our society become observable to us as its features - mental illness, neighbours, crime, riots, leisure, work satisfaction, stress, motivation, etc. - these are already constructed, some as administrative products, others by our sociological predecessors" (1972,(a), emphasis added).

In the process, certain aspects of actual experience are "dropped out", transformed or "glossed over". Neither the work processes of those who construct such terms or concepts nor the social relations in which the process occurs are visible.

Figure I (based on Gillian Walker: 1986) sets out what this process might look like for the term community.

FIGURE I

The Concept of a Social Relation(s)

Conceptualizing lived experience in this way limits our understanding of how events at the local level are tied into requirements and practices arising outside of it - and how this work ties the two together. Smith (1972(6), 1974(b), 1979(a), 1981(a)(b)) uses the concept of social relation(s) to uncover where these practices and requirements originate and how they are incorporated into the daily activity of the local setting, although they are not immediately visible there as requirements or practices. She defines a social relation (1981(b): 7) as "concerted sequences or courses of social action implicating more than one individual whose participants are not necessarily present or known to one another".

The following illustration used by Smith develops this idea more fully. It shows how the actual and immediate organization of the everyday world can be examined so that its connection to an extended organization of social relations is made visible, that is, how the subject's world is determined, shaped and organized by social processes beyond that world.

"Goods are made; they are brought to the market-place and exchanged for money; they may pass through a sequence of transactions ending up with the purchase of that good by its user. Different individuals enter this sequence of action at different points. When a child goes to the store for candy, her action enters her into that social

relation. The concept of social relation enables us to conceive how actions beginning from where we are and with our goals and intentions are or may be articulated to social relations to which our own particular goals and intentions are irrelevant. The child buying candy intends that - she's going to eat it. Yet her act is bound up into and depends upon the social relations of a complex division of labour and completes the sequence which fully realizes the commodity" (1981(a): 22).

Smith argues that this concept of social relations does not objectify the individual's activity as separate from themselves and does not create a purely external relation between subjective and objective (1981(a): 22). The social relations are a part of the individual's actual practices and thus the individual is integral to the process.

The way in which work processes come together in social relations is not always, according to Smith, consciously intended. "What becomes conscious and planful is structured by ideological practices which are constituents of social relations" (1981(b): 26). Figure II (based on Gillian Walker, 1986) shows how community and care as ideological terms might be taken up, circulated through various levels of society and fed back again, both into the conceptual practices that give rise to them in the first place, and into the original situation that was seen to require definition or explanation.

FIGURE II

What remains obscure in this process are the social relations/ conceptual practices which are already embedded in the term when it is used in everyday life and which serve to bring it into being in a particular way.

"When concepts are detached from the relation in which they make the world of living men observable, they become a means of operating selectively upon it and sorting it out in ways which preserve the ideal representation. Ideology can be viewed as a procedure for sorting out and arranging conceptually the living world of people so that it can be seen to be as we already know it ideologically" (Smith: 1974(a): 45).

Ideological Practices and Community

Most of us pay as little attention to where our understanding of "community" comes from as we do to the notion of care. Community is just 'there' a constant feature of our understanding of society. The process by which we come to this understanding is both informal and on-going. It comes from a variety of sources, such as T.V., popular literature, school as well as our personal experience of it. It is possible to see, however, how all of these ordinary ways of learning and thinking about it are connected to the work of the textual discourses referred to where 'community' is developed as a conceptual category by those who study community in specialized areas such as sociology or social work.

Textual discourses, words or images which exist on a fixed material form without their speaker's presence, identify the characteristics of 'community' so that they become recognizable to people as such. They mediate our understanding of community, that is, form a kind of bridge between the lived experience of it and ideas about it. This work is ideological because, as mentioned earlier, it transforms concrete activities to fit certain conceptual frameworks which, in turn, become actionable categories for government, professions, and so on in extra-local discourses and, finally a 'moment' in a social relation which mediates in the situation I have described, certain forms of care in the home.

'Community' takes on a life of its own as scholars and a variety of specialists exchange their ideas and theories about it. Such an exchange, described by Foucault as a conversation, can be seen, in this instance, to determine what aspects of community are worthy of investigation and what aspects are not. "Community" becomes a phenomena to be investigated. It is reified in the process and its features determined. This creates an entity which stands in for and/or obscures and organizes, the unpredictable, untidy, local world in which we experience the daily condition of our lives, and makes over or transforms the lived experience into an idea or series of ideas about it. We can then understand community in terms of morality, cohesiveness or its intimate character, as mentioned

earlier. This provides for a way of organizing and administering the 'local' by the local and central state.

The Position of Women

When we try to understand what textual discourses on community might tell us about women's experience or understanding of it, we are faced with a further problem. Critiques of community point out that its conflict-free, homogeneous and benign nature are contrary to the experience of many of its members, yet the experience or activities of women in 'the community' have been ignored, in spite of the fact that women's involvement there is accepted or even taken for granted by most people (Dehli: 1983; Mayo: 1977).

The relegation of women to the sidelines in the discourses on community, when their involvement in the various aspects of 'community life' is anything but peripheral, raises questions about the processes which give rise to their absence. It further suggests that use of the term community to describe care could have special effects for them. The centrality of male thought and experience in textual discourses on community cannot simply be understood as biased or incorrect. This would imply that getting the facts straight or inserting the female point of view would rectify an oversight when, in fact, the

exclusion or marginalization of women in those discourses reflects the different kind of work women do in a capitalist society like our own, and the different location of that work from the location of men's work.

Smith considers 'gender' and 'class' to be inseparable. She argues (1983: 2) that capitalism itself gives rise to the notion of separate gender and economic relations.

"It is only within capitalism that we find an economic process constituted independently of the daily and generational production of the lives of particular individuals and in which therefore we can think economy apart from gender".

The social relations that women experience are already organized, and they are not separate from social relations involving men. Smith points out that women must be included from the outset in all aspects of any investigation of those social relations since they are a part of them.

"For we are addressing the reality of a world which is put together as it is in the actual activities of actual individuals and in that world women are really present" (1983: 3).

Smith (1983: 3) points out that women are in class, part of class and class struggle as much as men and that the task of research is to show how gender relations are "an integral

constituent of the social organization of class". At the same time:

"There is a division then. It is a division which in fact aligns men in this respect on the other side in class struggle, that is on the side of the ruling class" (1977: 52).

Analyses of the relationship of domestic labour to the labour-power sold as a commodity by the worker according to Smith (1983: 10) points up the importance of a work organization 'behind the scenes' which appears as a personal service to the individual worker but that is indispensable if that person is to sell his/her labour power to the capitalist. Over the years, that privatized relation has been consolidated as one in which the individual worker is 'produced' through his wife's domestic labour.

"Hence the social form of the individual as worker is, like the wage, an appearance which conceals an actual relation between the domestic labour done largely by women in the home and the individual wage-earner and the productive process" (Smith: 1983: 10).

Smith (1983(a)) considers in her work how the form this personal service to the worker takes differs among women. For instance, the work of women whose partners own the means of production or who belong to managerial or professional groups takes on a different character than that of working class women. In addition to meeting the everyday emotional and

physical needs of family members. 'middle class' women are actively involved in producing 'class'. Their work as mothers, for example, in preparing their children for school by teaching them certain skills ahead of time, or by reinforcing and adding to what they learn in school is vital to this process. This on-going work, although generally understood as an expression of their 'natural' interest in or love of the individual child, has a significant impact on the child's educational career and life chances which, in our society, are more and more linked to success in school.

Although in earlier periods this work was originally the exclusive concern of middle class women who had the material resources and time to do it, it was taken up by working class women as well (Lewis: 1986; Wilson: 1977). This was due initially to the efforts of middle class women who promoted the study of child care and domestic science among working class women and later to the efforts of women in the rapidly expanding and predominantly 'female professions' like social work (Wilson: 1977; Brandwein: 1982). The education and training of women as mothers, however, also coincided with the work of experts such as sociologists and psychologists.

"Mothering thus became tied to the recommendations of authorities who spoke either directly or indirectly through mass media, through courses and through government pamphlets and bulletins" (Smith: 1983(b): 10).

The understanding women have of their work as mothers comes not only from their own experience then but from the understanding of experts in various disciplines. This is an important point in this research since the care of handicapped children is seen to present problems that require expert help. Community support programs can be seen as one of the critical points at which the work of state-funded specialists and the work of women who have a handicapped child intersect. These 'outsiders' have a special relationship with the mothers of the children. They have specialized knowledge that can make care of the child easier. The circumstances in which the knowledge is imparted, for example the objectives of those programs as well as the material resources the mother has at her disposal to care for the child or put the knowledge she has been given into practice, can serve to organize the care-giver's work in different ways. At the same time, an ideological understanding of community care that shapes the work of mothers and experts forges a powerful link between them.

SUMMARY

I have discussed briefly the major terms and concepts that will be used in this work as well as a conceptual framework for an analysis of the organization of care of

severely handicapped children in the community; how the ruling apparatus and families come to understand care in 'the community' and 'family' in the same way; and how this shared understanding can have special effects for women during times of financial restraint brought about by changes in economic forms. I have also argued that families with retarded dependents place special importance on providing a non-institutional living environment for them. The ideological understanding of terms like 'community', or, 'care' can be seen to provide for the management of care of dependent people in accordance with extra-local administrative priorities.

Abstract, ideological understandings of these terms make them recognizable and/or applicable in a wide variety of circumstances although they seldom reflect the particularities of lived experience. It is this quality which renders them useful in managing the interests of the central or local state.

In Chapter Two, I will discuss the importance of developing a materialist method of analysis to make these processes visible. I will also describe how the research for this paper was organized and carried out.

II METHODOLOGY

INTRODUCTION

The aim of my research is to show how the understanding of a traditional community, developed in the 19th century, persists (at least implicitly) in the theoretical and empirical work on the subject at the present time; how that understanding has been built upon and how it has been taken up by the state in recent years. I hope to make visible in this work how an ideological understanding of community used to describe certain forms of care provides for a course of action that has particular effects in the lives of women who care for their handicapped children at home. It is not my intention to establish a cause and effect relationship between the texts, the lives of the women I have chosen to examine and the difficulties they experience in providing care to their children. I do hope, however, to show how the textual material is implicated in the organization of these care arrangements as well as the women's understanding of them.

The organization of community care is of special significance for social workers in that our immediate need to help people solve the problems in their lives often obscures or downplays the theoretical underpinnings of the very support we offer. If we want to make the issues of gender, class, or race explicit in our practice, then we have to become more

knowledgeable about the implications that an unquestioning acceptance of terms like 'community' or 'family' can have for ourselves and the people we work with. Moreover, since women make up the majority of clients in social welfare programs as well as the majority of front line workers, our understanding can shed some light on how the state organization and practices affect our lives. According to Smith (1979(a)) the standpoint of women is a determinate position from which society may be known, because it locates a subject who begins in a material and local world. An analysis of the organization of women's lives not only reveals how our subordination and oppression is socially organized, but provides a way of seeing how subordination and oppression operate generally.

Research that takes the standpoint of the subject is not simply a 'new' or 'different' approach. Making explicit the material location of both researcher and subject represents a challenge to knowledge as we know it. Feminist scholarship, in particular, has challenged as well as expanded our understanding of the social construction of knowledge. It has also offered a critique of science in particular.

FEMINIST CRITIQUE OF KNOWLEDGE/SCIENCE

It is not possible in this paper to do more than set out very simply the premises on which this critique is based. According to Eichler (1985: 26-27) feminist scholarship accepts and extends four central conceptions of sociology of knowledge:

- (1) that all knowledge is socially constructed;
- (2) that what is accepted as a dominant ideology is the ideology of the ruling group;
- (3) that there cannot be such a thing as value-free science (and it is debated what constitutes objective science in contradistinction to value-free science); and
- (4) that the perception of people, including their insight into the workings of society, varies systematically with their position within that society.

These statements, Eichler argues, can be turned into specifically feminist propositions.

- (1) knowledge has been, so far, constructed by some men for the benefit of men;
- (2) the dominant ideology, including the dominant approaches to sociology bolster and maintain patriarchy;
- (3) social science in general has so far largely been the handmaiden of sexism; and
- (4) women and men have a different perspective on society which stems from their different positions within that society and which will continue to be of crucial significance for as long as a sex structure continues to be of crucial importance within society.

FEMINIST METHODOLOGY

The feminist critique has given rise to considerable discussion about the development of research methods that can ground the research process in women's experience and validate that experience (Stanley & Wise: 1983; Oakley: 1981; Jacobson, 1977). As well, this work has been concerned with minimizing the 'distance' or power imbalance between 'researchers' and 'subjects' which seems to epitomize the issue of how knowledge is used, that is, the distinction between knowledge about and knowledge for (Eichler: 1985). For women, the creation of knowledge for can be seen as political in that the more we understand our lives and the processes that shape them, the greater the possibility of changing their more oppressive aspects. Therefore, the empowerment of women is typically an implicit or explicit tenet of feminist research.

Up to this point in time, feminist research has tended to rely on qualitative rather than quantitative research methods which are often coupled with concrete social action (Eichler: 1985). Among the existing methodologies in sociology, feminists have drawn most heavily on ethnomethodology and Marxist analysis (Eichler: 1985). Ethnomethodology begins by affirming the validity of personal experience. This approach lends itself well to learning about and understanding the everyday experience of women, of which we know little. Marxism

has provided a framework for a materialist analysis of women's oppression.

Neither of these methodologies can be seen as complete in itself. While ethnomethodological approaches are useful in providing detailed accounts of lived experience, they cannot account for its organization in capitalist formations like the one we live in, since that experience is shaped by individuals/ events outside the purview of the local. There would be, for example, no way to analyze the construction or reproduction of ideology as a ruling practice originating beyond the experience of the research "subjects".

'Strict' Marxist frameworks which equate all forms of oppression with economic exploitation, in the paid workplace, have not been able to explain how the oppression of women clearly goes beyond the literal interpretation of the wage relation or why most capitalists are men (Armstrong & Armstrong: 1983; Barrett: 1980). Moreover, as mentioned in the previous Chapter, they tend to over-simplify how the interests of dominant classes and/or the state become 'ideological', and resort to idealist explanations for how subordinate people/ classes come to understand their lives ideologically.

Smith (1974(b)) suggests a way to think about research and a method of proceeding with it that is grounded in the

local or particular context but that takes account of the wider social, political and economic organization of which that experience is a part, as well as how it is mediated by ideology in a particular way.

As mentioned in Chapter One, Smith identifies the conceptual practices of certain disciplines like sociology as playing a major role in the construction of ideology. She suggests (1974(a): 41-42) that ideology is created in the following way from research: the responses of individuals at an interview are recorded as 'data'. The 'data' rarely includes the conditions of the interview situation or the part played by the person carrying out the research. The data is then arranged to yield particular information and is manipulated statistically to find its central tendencies. The resulting aggregates, based on the information supplied by real people, out of the totality of their experience, is attributed instead to various abstract agents such as "society". Smith, (1981(a): 22) states:

"The language of social science is the language of the institutional process. Its conceptual practices are of the same order and have indeed contributed to it. We cannot therefore vest in it ~~the~~ depend upon its analyses and naming to organize our inquiry."

Smith argues that the task of the researcher is to unravel the "mysteries of the problematic". That is, to

discover how it is socially organized prior to the appearance of the researcher on the scene. Smith (1981(b): 26) makes the following specific suggestions for doing research:

- (1) That an analysis should be made of the ideological procedures that are an integral part of social relation(s) and which articulate work processes to institutional functions;
- (2) That a generous notion of work be used to allow the researcher to see how people actually produce their everyday world (and also how that everyday world is organized and sustained by institutional processes);
- (3) That the concept of social relations (described earlier) be used to make visible the articulation of everyday work to extra-local sequences of action. An analysis based on social relation(s) provides a means of looking at local work practices (and people's experiences of them) in relation to the generalized and generalizing relations of economy and ruling apparatus.

This approach does away with distinctions based on where work is done, a critical factor in research on women, as it shows that all work is interrelated. This analysis also provides a way to examine the systematic construction of ideology as a constituent of those work relations which enables people to recognize and 'produce' them in a certain way which, in turn, facilitates the co-ordination of the institutional processes of the ruling apparatus.

The generalizability of research 'results' is not an issue because the local experience is understood as an integral

part of the wider context. "The problematic of the everyday world arises precisely at the juncture of the particular experience with generalizing and abstracted forms of social relations organizing a division of labour in society at large" (Smith: 1981(b): 10). Since the social practices are already organized, social organization may be seen to recur because the social and material relations that are explicated generate those practices as the same (Smith: 1974(b)).

The ability (usually through education) of the researcher to provide an analysis of lived experience sets her apart from her research 'subjects' (Smith: 1981(b)). Her work feeds directly or indirectly into the work of government, professions and so on who can draw on it to accomplish ruling, as described in Chapter One. The knowledge and experience shared by research 'subjects' with the researcher becomes a resource for ruling as it is typically circulated among those whose work orders society in some way. For this reason, it is important for the person doing research to locate herself as well as her 'subject(s)', so that the material, determinate context of all participants is made clear, for those contexts are not necessarily identical, even when all parties are women.

COMMUNITY AS IDEOLOGY AND WOMEN'S LIVES - A FEMINIST MATERIALIST ANALYSIS

The lack of prominence of women in 20th century theoretical and empirical work on community can be traced to 19th century sociology where traditional (feudal) communities were thought to embody certain personal relationships between people within a specifically defined area (Lofland: 1975). These relationships were understood to be the same as those of 'the family' which, it was assumed, engendered the strongest bonds between people. According to Lofland (1975: 147) the 19th century understanding of community "abstracted a particular empirical reality...one bounded within a spatially contiguous area in which relationships, social organization, culture, etc. occur...community is some place". This view states with an understanding of community as a place but also as an experience of closeness or connection with others, and has persisted up to the present time. It has been, especially evident in the sociology of the family (Lofland: 1975). In this area of study, family and community functions have often been explicitly traced in terms of the family's involvement with or isolation from 'the community'. The existence of 'community' and 'family' have been taken as 'givens' and research has proceeded on this assumption.

The settings for research on community have tended to focus on places where women are absent, such as Whyte's Street Corner Society (1955); research on the family has tended to treat women's experience and work there as unproblematic, if not invisible, as in the case of Parsons (1954; 1956). If we assume that women's work is crucial in producing family as well as the more intimate aspects of 'community', then an analysis beginning from their experience/work can provide insights into how an ideological understanding of 'family' and 'community' articulates that work to the requirements of 'the state' to manage the social relations of capitalism.

Shifting the site of research on community to those places where women are present in it, is an essential part of learning about their work there and how certain aspects of 'community' or 'family' operate. Such a shift cannot explain, however, how women come to be in that location in the first place (rather than men); how the work they do there is articulated to work arising elsewhere; or how women come to understand what they do in relation to an ideological view of community. In other words, it is also necessary to examine the social relations (as Smith defines them) in which women's work in the community is embedded.

Textual discourses, especially sociology, social work and psychology produce a changeless view of women's lives and work.

The theoretical and empirical work on community does the same thing. Moreover, the failure to locate the practice of sociology or even social work within the ruling apparatus obscures how both can be used to facilitate certain institutional processes at the local level, as when the term 'community' is used by government to describe, promote or explain the work of caring for dependent people in the family.

DATA - GENERAL

It is necessary to use a variety of data in order to provide a feminist materialist analysis of the ideological construction of the term community: its use as part of a ruling practice; the understanding mothers of severely handicapped children have of it; and the effects it produces in their lives (work) as care-givers. The data exists in the form of texts which conceptualize community by means of the processes described, as well as in documents prepared by the state which draw on the former work to administer 'community' according to its needs. The experience of women, in this situation caring for their handicapped children in the 'community', can also provide data as that experience is rooted in the particularities of the material world in which they live. Therefore, it is possible to examine the effects of textual work in "real life" situations.

An analysis of care of severely handicapped children at home should take into consideration how we "know" what we know about community and/or family care. An ideological understanding of community takes for granted that the same inter-personal dynamics and roles considered appropriate in the family apply for community. It does not give consideration to the material conditions that give rise to these roles in the first place. An ideological understanding of community provides for understanding of the terms by both government and families, even though the two groups do not in fact have the same things in mind when they use the term. For government, 'community' and 'family' become categories to expedite their affairs. For parents of mentally handicapped people, the terms touch the lives of individuals they know and care about. The concern on the part of families and others that an examination of 'care' that focuses on care-givers necessarily jeopardizes the already precarious social position of retarded people is logical given the treatment of retarded people in the past and even at the present time. On the other hand, this exclusive and selective focus may not serve the best interests of retarded people or their families as it can limit our understanding of how retarded people and those who care for them come to be oppressed in this society. Even normalization, which offers a positive way to meet the needs of retarded people, relies on an implicit assumption that family and community life are positive for everyone, without considering

how these 'benefits' are rooted in and integral to a material world in which inequality is much more necessary to its operation than equality is.

To do full justice to this analysis would have required far more extensive research than I could do in the time available to me, and with limited financial resources. As well, the research would have far exceeded the usual scope or requirements of a master's thesis. I have chosen instead to focus on what appear to me to be the crucial points along the way in the transformation of lived experience into abstract categories that provide for the co-ordination or implementation of a particular course of action expressed in government policy; the effects of this course of action on the work of women caring for a handicapped child at home; and, finally, how the 'women's' experience feeds back into the conceptual work that organized it in the first place. I believe that my research does indicate how community care of severely handicapped children is organized. Perhaps more important, it shows how to go about making a materialist analysis that has, among other things, a special relevance for social workers.

I would argue that the issues raised by this research provide a useful way for social workers to think about the relationship of theory and practice, our location within a complex of institutional processes and the implicit or explicit

effect of our work on the lived experiences of the people we work with. Making these processes visible not only locates us within the ruling apparatus, but should serve to make us more sensitive to the ways in which we can oppress clients, even when this is unintentional. At the same time, this analysis makes it possible to see how we are also oppressed by 'the system'. We can then begin to see how and where social workers and clients together might struggle against the divisive and oppressive relations of capitalism, which as Manicom (1985) states, are 'shot through' with gender.

In order to make this analysis, there is a need to establish the following by means of the data. The kinds of data are described in a general way and will be taken up in more detail later in the chapter.

- (1) Determine community as lived experience. This data, provided by care-givers, allows us to learn about community care of severely handicapped children, on a day to day basis, from those who bear the major responsibility for that work. It is necessary to establish the character of this work and locate it in a material, determinate context as well as find out what care-givers think about it. This information tells us about the organization of care of the children at the local level. It's very 'ordinariness' forms the starting point - the 'mystery' to be explained - because the work of care prompts questions about why the women care for the children in a particular way and whether they have total control over it and so on. By learning how the women do their work, who it brings them into contact with, whether they receive financial support and so on, the complex nature of care and its connection to a wide variety of institutions such as schools or hospitals begins to emerge, as does the disjuncture

between what they think about care in the community and what they must do to bring it about;

- (2) Trace the origin (or determinates) of community as notion. This is done by examining textual work to discover when and how the term community has come to be used, and the circumstances in which this took place. In other words, showing that the term has been historically constructed;
- (3) Trace the construction of community as ideology. This will also be done by using textual work from sociology and social work. Again, the emphasis is on the historical, material context, but will also focus on how the conceptual practices of sociology served to "work up" the notion of community so that it becomes useful in other areas besides sociology, for example, in social work;
- (4) Show how this ideological understanding makes possible community care as a ruling process. This data comes from government documents on care of retarded people, especially those on the advisability of community care, as well as those that order it in a particular form.

DATA FROM CARE-GIVERS

This data is based on 21-1/2 hours of taped interviews provided by five women caring for their severely handicapped children at home, as well as logs kept by the women which record their activities on a particular day. The interviews focused on the following: (a) care of the handicapped child; (b) the womens' paid and unpaid work; (c) who helped them to look after the child; (d) whether they got time-off from care; (e) their involvement with other agencies, institutions, professionals and so on; (f) the decision to keep the child at

home; and (g) what they thought of or about community care for their children.

Sample

Originally, I planned to have a sample of six women. There were three criteria for selection: (1) that the women were presently caring for their mentally handicapped children at home; (2) that the children cared for were at least 5 years of age; and (3) that the children could be considered to have severe handicaps in mental development. The third criteria was established on an informal basis, that is, the children were identified by their mothers as being severely handicapped and displayed learning deficits that I could associate with severe mental handicap. I used this informal approach to establishing the child's disability rather than the use of formal assessments for the following reasons: the women are aware of the children's disabilities and, it seemed unnecessary to have their judgments corroborated by an external source; at a practical level, the process of getting a hold of such documents is very time consuming and would have involved a great deal of extra work for the women who, as 'parents', would be required to initiate the process for 'release of information' from various agencies that hold the children's assessments on file.

By requiring the children to be 5 years of age or more, I hoped to avoid some of the confusion that might arise around the similarities in caring for very young (dependent) children, whether they are handicapped or not, since there are clear expectations in our society about the kinds of self-help skills a child can perform by the age of five, for example, self-feeding, toileting, or dressing. The inability of a 10 or 12 year-old child to do these things cannot be easily equated with the inability of a much younger child to do the same things. As well, care of older severely handicapped children shows that their care, instead of decreasing as they grow older, actually becomes more taxing. Not only can physical care become more of a burden, childish or unusual behaviours are less tolerable in public and sometimes are difficult to cope with and create more work at home.

I decided to arrange the interviews in the area where I had set up the parent relief program for the following reasons: (1) that was where I had become interested in the issue of community care of severely handicapped children; (2) I felt some of the women I had worked with there would be interested in taking part in research about care at home; and (3) I would be able to draw on my knowledge of the 'community' the women lived in, the history of care of retarded people there and development of services for them. As well, I felt my previous relationships with the women had resulted in good rapport

between us, and that this would be helpful in the interviews, as I would not be a total stranger to them.

I did not contact the women directly but made arrangements instead for an individual who has worked with families in the area, both in paid and voluntary capacities, as an advocate and case co-ordinator to do this. I trusted this person's judgment both in approaching the women and understanding the criteria I had set out. I made use of a 'third party' because I felt that approaching the women directly myself might leave them feeling pressured to agree to take part even if they were reluctant to do so for any reason. Having an intermediary, gave the women an opportunity to refuse without having to say 'no' directly to me. This was important not so much because the women would be concerned about offending me, but because they take very seriously anything to do with their children, and might feel 'guilty' for not taking part in research concerning any aspect of the child's care. (Initially, the women found it very hard to believe that it was their lives I was focussing on!).

The contact person informed me that six women had expressed an interest in taking part including two whose children were not severely handicapped. I then contacted each of them by telephone to explain in more detail what the research was about and what taking part would entail for them.

2

MICROCOPY RESOLUTION TEST CHART
NATIONAL BUREAU OF STANDARDS
STANDARD REFERENCE MATERIAL 1010a
(ANSI and ISO TEST CHART No. 2)

in the way of time and information. My initial feeling was to reduce the sample to the four women whose children were most disabled, however, one of the women with a less handicapped child was quite interested in taking part, and pointed out to me that I might be creating a distinction in how care is organized where one does not exist. That is, that women caring for handicapped children have much in common beyond the daily work of care. This seemed to be a reasonable argument and this woman also took part in the study. Where her experiences as a care-giver differ substantially from the experiences of the other women, this is noted.

As will become apparent in subsequent chapters, the five women form a very homogeneous sample. The striking similarity between them in areas like education, what their partners do for a living and so on, was not intended. The fact that these particular women volunteered to take part in the research is significant in itself. Their participation, as I hope to show in the course of my work, raises questions about what mothers care for severely handicapped children at home, and why. As well, the fact that these women were involved with the case co-ordinator/advocat who acted as my intermediary suggests an understanding of care in which the benefits of certain kinds of services or the importance of access are already accepted. While these attitudes may have developed in the process of working with this individual, the similar material situations

of the women suggest that this is not the total explanation. While it would have been desirable to have a more heterogeneous group, for example, one that included sole-support mothers whose economic situation is often more precarious, the fact that these women are not represented does not detract from the overall issues raised in this paper. By learning how the women in this study care for their children as part of the extended and organizing relations of capitalism, the question of how other women do this work is constantly raised.

Data Collection

This aspect of the data was collected by conducting individual interviews, using the same open-ended interview schedule for each woman (see Appendix A). This was done to facilitate discussion of the subject matter and to ensure that the same areas were covered in each interview. Every interview was tape recorded so that I could participate fully without having to take notes. As well, the tape recorder was less of a distraction in the situation than my constant writing would have been.

The shortest interview lasted 2-1/2 hours and the longest were six hours. Four of the interviews were divided into two sessions in order to accommodate the women's schedules and yet

allow them to take as much time as they needed to answer each question fully. Each of the women was also asked to keep a log for one day (from the time she got up, to the time she went to bed) and a form for this purpose was given to each and explained (see Appendix B).

The interview schedule focused on the areas already mentioned and was based on one developed by Nissel and Bonnerja (1982) for a study of family care of the handicapped elderly in Britain. The Nissel and Bonnerja study focused on how providing long-term care affected (or not) paid employment for care-givers; the physical-environment in which the care-giver works; how the decision was made to care for the elderly person at home; what daily care consisted of; how care fit in with other on-going work that the care-giver does in the home; who helps the primary care-giver; and the amount of leisure time care-givers have. The authors also devised a log which showed how care is carried out in conjunction with other work each day.

There are similarities in the 'mechanics' of care for the frail elderly and severely handicapped children. Care is usually organized into a daily routine and involves assistance with physical care. Both groups have a high incidence of physical disability, such as deafness, blindness and/or medical disorders. Both groups require supervision, although the

degree and amount can vary. Owing to the specialized needs of the dependent person, it is often difficult for care-givers to make time for leisure activities or care may interfere with the care-giver's ability to engage in paid work.

There are also a number of factors that make these two kinds of home care quite different. For one thing, an elderly person's dependence is expected and comes at the end of life. Although caring for a frail elderly individual can go on for years, it is, in some sense directed toward making that person's existence as comfortable and pleasant as possible for a limited period of time. In the normal course of events, the care-giver would be expected to outlive the person cared for. In the case of handicapped children, the work of care is not only of concern in the present, but extends into the foreseeable future. Here, it is not only more likely that the person being cared for will outlive the care-giver, but that care itself might be more than 'custodial'. As well, care of a handicapped child could be expected to begin when the care-giver is much younger than she would be if looking after an elderly person and, perhaps, impede her own goals - for example in paid work - in a different way than if she were older.

It is possible to see then how the attitude of the care-giver and the focus of her energies would vary, depending upon the age of the person being cared for. As well,

government policy around the two forms of care could be expected to differ. The total number of severely mentally handicapped people in the population is very small. The number who are children (under 18) smaller yet. However, some of the basic issues around their care at home, rather than in institutions, raises some potentially serious issues for the state to deal with. For example, the provision of desperately needed child care or other services to families with handicapped children at home (especially mothers) could set precedents for all women caring for children. On the other hand, a life-time of institution care, estimated to be in the range of \$40 to 45,000 per year is a costly proposition for the government. The issues around care of the aged, though just as serious, do not involve the provision of life-time caring arrangements.

With these things in mind, I modified Nissel and Bonnerja's work to account for the day to day work the women do, but also for their relationships to the various services and programs that facilitate and/or organize care of the children at home in the community. Presumably these services/programs comprise some of the key connections between various aspects of the ruling apparatus and the work the women do and vice versa. While studies of the daily routines of caring for handicapped children exist (Wilkin: 1979; Glendenning: 1983), this work rarely touches on the effect of these institutional

contacts for the women. For example, the time spent making appointments with physicians or therapists; the time spent in waiting rooms waiting for those appointments and so on.

Furthermore, in Ontario, the system of applying for financial support for the child's needs - Handicapped Children's Benefits and Special Needs Agreements - can be assumed to require a particular kind of abstract work on the part of the women.

They must be able to 'think' about their children in the same way the government does in order to access needed resources.

We should be able to see this in the the preparation of detailed requests and the organization of pertinent supporting information to make their case, thus demonstrating empirically how an ideological understanding of community mediates between the priorities arising out of de-institutionalization policy and those of care-givers.

With these ideas in mind, I took the wider definition of work suggested by Smith which involved encouraging the women to be very specific in talking about what they did. For example, if they said 'I went to a case conference', I tried to get them to break this statement down into its component parts: did this mean re-organizing other paid or un-paid work? Hiring a sitter for other children? Did they have tasks to do arising out of the meeting, like carrying out a special program with the child? and so on.

It seems reasonable to assume that the emphasis on 'normalized' care of the child, (see Chapter One) also introduces a different dynamic from that of care for the elderly. Normalized care shifts the custodial focus - meeting the person's basic physical and emotional needs, - to promoting independence which is believed to enhance the quality of the child's life. While a normalized environment may indeed be of benefit to the child, trying to ensure it can present real difficulties for the mother. In order to appreciate what this means in terms of the women's work, it is necessary to learn something about the child, whose own strengths, weaknesses, moods and so on impose yet another structure on care - one that is unique and intensely personal for the mother.

To facilitate the discussion of this aspect of caregiving, I drew on the work of David Wilkin (1979) who did extensive research on home care of severely handicapped children in Britain. Wilkin developed a detailed questionnaire to establish the abilities, and behavior of the child with a view toward relating these to the decision to seek long-term institutional placement. While his questionnaire is designed to generate quantitative data, its general organization was useful to me. Wilkin's study points up how the child's handicaps impose their own structure on what the mother does, and how possible (or not) normalized care is given particular disabilities. For example, the ability to perform basic life

skills, such as walking independently, the ability to express basic needs to the mother and so on.

In my work, I encouraged the women to think about the details of providing normalized care. When a mother said she dressed the child, we attempted to break this down - how long did it take, what did she actually do (dressing an older child typically involves heavy physical labour such as lifting; it also, however, is an activity that the mother attempts to involve the child in so that he/she can learn from it. Thus, very 'ordinary' work turns out to be physical, emotional and intellectual!).

The Interviews

The women were interviewed in their own homes at a time of their choice. While this arrangement spared them a certain amount of inconvenience, I was aware that the time they spent with me made inroads into their normal schedules. Grocery shopping or laundry were put on hold. Even though I already knew four of the five women, I could sense that my visits prompted certain extras - they mentioned tidying up before my arrival, or preparing lunch for their children ahead of time so that this did not interfere with the interview. This is exactly the sort of work women do that, in being understood to

be a 'matter of course', relegates it to a category outside the general understanding of work where it becomes invisible and/or natural. (It is important for women carrying out research with other women to bear this in mind and understand its implications for our work!)

I began the interviews by reviewing with the women what we were going to do and explaining how I planned to incorporate what they said into my work. We also spoke about the immediate purpose of my work - to fulfill an academic requirement. As well, I spent some time sharing my own biases about women's work generally and about their particular situation. I tried to stress to them that they were under no obligation to agree with my views and that I would make clear in the paper who 'owned' what opinion. I asked for their permission to tape the interviews and explained my reasons for wanting to do this. I told them we could shut the tape off at any time and that if they wished, I would return the tapes to them after my work was completed.

I stressed to the women that thinking about the details of their work or even talking about these in the way that we were going to - examining it in detail and trying to figure out how it was organized and how that organization fit in the larger scheme of things - might not only be a new experience, but one that would generate information useful to them in their

dealing with the Ministry of Community and Social Services, School Board and so on. In other words, the research might prove helpful to them in making changes in their relationships with these bodies. To that end, I offered to make my finished work available to them.

We also discussed the possibility of keeping a log. The log was divided into hourly segments where the women entered their activities - it showed time, the kind of activity, where it was performed, who was with them, whether or not they were doing anything else at the same time and what the handicapped child was doing at that time. The idea was to get a sense of the 'rhythm' of their work overall with all family members. The decision of whether or not to keep a log was left up to the women, as I was reluctant to impose additional demands on their time and energy. Only two of the five women completed them for one day. As part of the interview schedule, however, I asked each woman to "tell me about yesterday" from waking to retiring, thus I did cover the rhythm and kind of work that form a 'typical' day with each of them. The two logs merely enhanced that information. The women who kept them did so on a Saturday or Sunday so that I could get a sense of their weekend activities.

Method of Analysis

As the sample was so small, I correlated the 'data' descriptively, the response of each woman to each question, in order to rate similarities and differences. I did not do this, however, until I had immersed myself in each woman's story by transcribing it and then reading it over and over. At times this seemed inadequate and I returned to the tapes. Hearing the women speaking was a constant reminder of what can 'get lost' on paper - hearing the background noises of their children, doors slamming or telephones ringing on the tapes epitomized for me the rootedness of 'womens' experience in the concrete and particular.

Presentation of Data

The names of the people and places mentioned have been changed to ensure confidentiality. What the women say is unaltered. I have used ellipsis only where there was substantial repetition. Those portions of the interviews included in this paper were selected because they expressed particularly well the points being made. Where only one statement is used this can be taken to mean that the other women said much the same thing. Where the women had different experiences, these are included. At other times, even when

there was substantial agreement, I have included a number of comments for emphasis or to show the subtler differences in their experiences. I found it difficult, almost painful, to make decisions about what portion of the women's stories to include. Having to select some aspects and omit others in the interests of producing a thesis does require 'de-contextualizing'. In the process, some of the richness and impact of their experience is lost, despite my attempts to preserve that richness.

The description of the city of Lakewood and Union County is based on my own insights gathered from living and working there for a number of years. It is a personal opinion. The account of services and programs in the area, on the other hand, represents 'the facts'.

DATA FROM TEXTS

Community as Notion and Ideology: Sociology and Social Work

The intent in these sections is to provide a brief historical perspective on the meaning of the term community before it began to be used technically to provide for a course of action involving care of dependent people. I will attempt to show that an ideological view of community grew from a

critique developed by 19th century philosophers and sociologists of their own society. The critique was based on notions of the 'naturalness' and 'morality' of community which were predicated on certain models - the Greek polis and life in pre-capitalist or early capitalist societies. The models paint a picture of the position and work of women in those societies which was understood and incorporated into the 19th century work on community in a particular way.

As an analysis of the original accounts of polis or early capitalist periods could easily form the basis for several theses. I have chosen, instead, to examine some secondary sources on both. My aim is to provide some sense of why these social formations came to be looked upon as models for community, and the possible implications of this for the connection of certain attributes to the term, especially as they might affect women.

In considering the development of community from notion to ideology, I will look at selections from the 19th and 20th century sociological discourse. In particular, the work of Auguste Comte who is known as the 'father' of sociology; the work of Ferdinand Tönnies whose typologies of *Gemeinschaft* (traditional community) and *Gesellschaft* (contract society) stood as the authoritative work on community for many years, and continues to inform some aspects of writing about or

understanding of community; and finally the work of Talcott Parsons whose well known and highly influential work on 'the family' relies at some points on a conflation of family and community. I will also establish the connection here between the sociological work on 'community' and its incorporation into social work practice.

All of the above will be examined with the following criteria in mind: how is community defined? what was the larger material context in which the work is located? what does the work say about women's lives/work vis a vis the understanding in our own time of 'community care'. My objective is to show in select instances how the conceptual work of sociology lends itself to or provides for an understanding of community as a reification; one which ignores or reframes the experience/work of women. Whether the individual authors intended this or not becomes secondary to understanding the process itself which produced the work, and the possibility of it being used in different ways for different reasons. That is, how in a later period it could be incorporated into the administrative and fiscal practices of the state which expedite the accumulation of capital over the long term.

Community as Ruling Process: Government Documents

This data is drawn mainly from a range of government documents such as policy papers and commission findings on care of retarded people, especially those dealing with community care, as well as regulations governing access to 'community' support. It includes also news releases prepared by the government on care of severely handicapped children 'at home'. This material will be considered according to the same criteria set out for community as notion and ideology. I will attempt to show why this is ruling work, how its use draws on the 'working up' of 'community' in sociology, and how the documents are implicated in organizing the women's work.

I am aware that from a positivist perspective my choice and use of data may appear biased and highly selective. Smith's social organization of knowledge research posits a world socially organized before the researcher enters the picture, and in which the researcher attempts to discover how 'found' social phenomena are organized. In contemporary corporate capitalism there are distinctive modes for ordering social behaviour: texts of various kinds, specifically identifying texts which order specific acts is not random, and focusing on one or two examples rather than doing an 'exhaustive' review does not constitute 'bias'. Selection is part of the

investigative process. Showing how a selected text does 'work' as part of a course of action shows its relevance.

As a woman and social worker, I am increasingly concerned about the effects of certain social policies for women which, even when they serve our interests or needs over the short term, tend in the long-term to perpetuate our economic subordination and oppression. In order to make an analysis of these arrangements, we must examine capitalism itself - not only as a form of economic organization, but as a dynamic process that also produces specialized ways of thinking about ourselves and society; these have important consequences for women in a world where we do not occupy the same place as men. My work attempts to show empirically how these processes provide for and shape the lives and work of the five women who took part in this study. It, thus, adds to our knowledge of how women's oppression is socially organized by 'real people' and events in everyday life.

SUMMARY

I have set out in abbreviated form the feminist critique of knowledge/science as well as the implications of this for developing feminist research methodology. I have also tried to point out both the value and limitations of ethnomethodology

and economic Marxist frameworks for feminist research, and have discussed a method of proceeding which builds on the best of both frameworks.

The Chapter also includes a statement of how I proceeded with organizing and carrying out my research, which draws on textual work as a source of data as well as interviews with women caring for handicapped children at home.

In Chapter Three, the lived experience and understanding of community care of severely handicapped children is described by the women I interviewed.

**III LIVED EXPERIENCE: CARE OF SEVERELY HANDICAPPED
CHILDREN AT HOME - PART I**

INTRODUCTION

Alan Walker's discussion of community care (1982) indicates that the term covers a wide range of work done by different people under a variety of conditions. It can be considered informal when it refers to efforts of family, friends or others who take it up because they have some personal reason for doing so. Informal care-givers are not paid for their work. They may have training to do the job but that is not usually their main reason for providing care. Informal care is quite distinct from formal care which is performed for a wage by individuals trained for that purpose who are connected with a service or program, often state funded. Finally, there is quasi-formal care. This care originates in an organized program that makes use of volunteer or low paid workers (low-paid here can also refer to receipt of honoraria rather than a wage). These individuals may be trained or not depending on program requirements.

Care of severely handicapped children at home usually involves all three kinds of care-giver, however the mother's work in caring for the child is central. The other categories of care-givers could not do their work if mothers did not do theirs, as mothers provide for the child's basic maintenance. Their designation as informal care-givers is a misnomer. It makes what they do sound easy or relaxing - more like a

recreational activity than the demanding work that it is.

'Informal' certainly doesn't convey the idea that this particular care would be of any monetary value. This dominant understanding of care in the family as 'natural' and not like 'real' work has a silencing effect. The work of care is, in the background; something taken for granted and rarely noticed unless it is missing. Even care-givers, although readily admitting that what they do is not easy, tend to lose sight of the larger picture of which they are a part.

The use of the terms 'informal' or 'natural' to describe the relationships of individuals, families, groups or communities to care of severely handicapped children has important implications. It assumes that those relationships are of a different character than those of the more formal world of work, associations of business, and so on; it also minimizes the economic disparity between people or families. In the case of 'the family' it also minimizes the economic disparity among its members. The communicative work of specialists and government uses the terms family and community to describe a preferred setting for care, but the labour required to bring about 'community care' or 'care in the family' remains invisible in these descriptions.

The remainder of this Chapter is devoted to 'hearing' what mothers of severely handicapped children have to say about

their work. By beginning from this point, the work comes to the foreground and forms the basis for questions about its organization as part of a course of action on the part of the government which will be considered in subsequent chapters.

THE SETTING

The city of Lakewood seems in many ways to be a perfect community. It is small (population approximately 20,000) and located in a particularly scenic area of the province; the pace of life is slower than that of larger centres and many of the problems associated with living in a more densely populated area - traffic jams, higher crime rates and so on are less prevalent. Lakewood is 'family-oriented' and people who live there often describe it as a good place to raise children. It is the largest centre in a mainly rural county. Two larger cities are located about an hour's drive away. Life in the area can be characterized as conservative. A high value is still placed on conformity to traditional roles for men and women as well as on the idea of helping one's neighbours. The latter appears to be rooted in the rural tradition of the area and is directed toward helping people 'get on their feet' or become self-sufficient. Natives of the county pride themselves on being able to 'take care of their own', and have tended to view the increasing organization of their lives by 'the state' with alarm and also anger. For example, the creation of a

county board of education in 1969, which did away with dozens of small local school boards, was vehemently opposed and continues to provoke criticism.

Life-long residents of the area say there were very few changes in Lakewood until after World War II, when the location of a number of large industrial plants there generated an influx of 'strangers' who had new ideas about the quality of education, social services, and so on (most of the plants hired managers and specialists from elsewhere). Many of the people in the area who earned their livings on small mixed farms began to supplement that income by working in the factories, or got out of farming altogether although they continued to live in the country. There are still some large and prosperous farms in the area, but they are in the minority. Farming is no longer the backbone of the county, the way it once was. At the present time, unemployment is high as the factories (mostly assembly work) cut back on production.

Medical services in the area are not highly developed. Two small general hospitals serve the city and surrounding area. Neither offers a full range of medical specialties. For example, if the services of a neurologist are required, it is necessary to travel out of the county to a larger centre. A provincial psychiatric institution, also located there, offers limited out-patient and short-term service for adults. The

de-population of this institution has also contributed to unemployment in the area.

Specialized social services such as family counselling are limited. In recent years, Union County has been described as 'service poor', especially by Lakewood residents. The Children's Aid Society and Board of Education have been the typical routes for families into the service system, that is, through the needs of their children. The Ministry of Community and Social Services operates a small sub-office which oversees the provision of Family Benefits Allowance, Handicapped Children's Allowance and vocational rehabilitation services, but direct supervision of COMSOC funded programs in Union County is the responsibility of the area office located in a neighbouring county.

Services for the Retarded

Specialized services for retarded persons outside of those provided by the Board of Education, which operates three schools for retarded children, were virtually non-existent until the late 1970's. Even now, families have only a limited number of options. There was, until 1983, a mental retardation unit for adults at the Lakewood Psychiatric Hospital operated by COMSOC. Some personnel from the unit provided service in

the community in the form of a behaviour management team that visited families on a regular basis. Program staff, in effect, taught parents how to teach basic life skills to their children, enlarge the child's repertoire of behaviours or eliminate troublesome behaviour. As well, staff was available to carry out certain psychological or behavioural assessments. In 1982, the residential adult unit was closed by the Ministry and the residents re-located in a number of communities. The behaviour management team remained intact and continues to provide community-based service funded by COMSOC to children and adults.

The local Association for the Mentally Retarded first applied for COMSOC funding for children's services in 1980 when it assumed responsibility for setting up the parent relief program.

Families are entitled to 21 days or 504 hours of out-of-home relief in a year. Relief is arranged by matching mentally handicapped children with other families in the area who are willing to provide short-term care for them. The matching process is involved, as it must take into account the child's special needs as well as the ability of individual relief providers to meet them. When a suitable match seems possible, both families spend time getting to know each other. The

child's mother teaches the 'relief mother' how to look after her child.

The child's family can use their time allotment as they wish - use all three weeks at once, take it by the day or weekend and so on. If the match works out, the child returns to the same relief provider each time - the aim of program staff is to go through the matching process once only, thereby cutting down on it's work as well as that of the child's mother, who is so essential to a successful match.

Relief providers are paid an 'honorarium' of \$20 per 24-hour period. The rates and rules of payment are set by the Ministry. The child's family pays 20% of the total cost of each relief period and the Parent Relief Program pays the remaining 80% out of program funds set aside for that purpose.

The main objectives of the program are:

- (1) To promote family unity by lessening the emotional stress often seen in parents of mentally and/or physically handicapped children;
- (2) To prevent the institutionalization of mentally and/or physically handicapped children, which occurs as the result of stress or other family needs, by regular use of respite care;
- (3) To allow children to follow established routines while in respite care, as well as providing them with the opportunity for further social development through new learning experiences;

- (4) To provide training and other resources to relief providers so that they can effectively meet the needs of the children in their care; and
- (5) To acquaint the community with the needs of such children, and their families, so that it can respond with increased sensitivity to those needs.

(Taken from Union County Parent Relief Program Objectives: 1980)

In 1982, the Association opened a 5-bed residence for severe and/or multiply handicapped children. This decision was the subject of considerable debate among association members as the commitment to operate the residence represented a major undertaking for a group of people who were not 'experts' in administration, although all of them as parents had considerable knowledge of the needs of handicapped children. The main impetus to go ahead with the residence came from the fact that COMSOC was providing one-time funding for such projects across the province. To take advantage of this, an association had to have a proposal 'on-line' by a certain date. Failure to submit a proposal meant forfeiture of funding. Ministry guidelines stipulated that three of the five beds be filled by children from Union County who were living in mental retardation facilities. The other two places were reserved for children living with their families, but whose needs might be better served by an out-of-home residential placement. The residence also contains two beds held open for scheduled respite or unscheduled emergency care.

The circumstances under which the group home was set up are a good illustration of the sorts of problems local associations must contend with as service providers: (a) the pressure to take advantage of Ministry funding put a closure on potentially fruitful discussions about local needs and how these might best be met; (b) the funding itself provides for only a very few children and/or families - particularly when you take into account that the children admitted to the residence could be expected to live there until they reached the age of 18. Moreover, the preference given to 'repatiating' children from institutions, however positive in itself, ignored the needs of families whose children were living at home. As a member of the Admissions Committee for the residence I was aware, for example, that there were at least six families whose children might have benefited from such a placement - where each child clearly met the admission criteria set down by the Ministry for severity of handicap - yet only two of them could use the program.

Also of interest here is the fact that it took the Association nearly a year to find a location for the residence. Each time it became known in a neighbourhood that there was a possibility the residence would be located there, homeowners took legal action to stop the project. This is an interesting comment on the willingness of 'the community' to care and will be dealt with in more detail later.

Aside from the services for children provided by the Association, one of the hospitals sponsors an infant stimulation program. The children are also seen in the physiotherapy, occupational therapy and speech therapy departments of the hospitals. Generally speaking however, these departments have a limited capacity to handle the more specialized programming the children require. It is not a slight exaggeration to say that families in Union County who have a severely handicapped child can spend half their time on the highway just taking the children to larger cities for necessary examinations, consultations and assessments. Besides the difficulties involved in travelling with a disabled child, there is considerable time lost from paid and unpaid work as well as the necessity of providing a substitute organization to cover for the care-giver's absence.

THE ACTORS - WOMEN, CHILDREN, 'FAMILIES'

ADZie

Angie is 30 years old and has lived in the area for nine years. She has 3 sons - ages 6, 5 and 2 and was expecting her 4th child in a matter of days at the time of the interview. The two oldest boys are severely handicapped, and both are 'legally blind' and attend a school for retarded children. After separating from her husband, Angie was a 'single parent'

for 3-1/2 years. She remarried a year and a half ago and her 40 year-old husband is an executive with a large company based in Lakewood. He travels a good deal in his job and when he is in town often works 12-hour days. Angie works full time as director of nursing at a geriatric facility an hour's drive from home. Her major concerns at the time we met were making arrangements for the care of her children while she gives birth and after in the period when the needs of the new baby will take priority. She and her husband have seats on a recently-formed community board set up to administer the operation of the few out-of-home living options that currently exist in the area for retarded adults and children.

Louise

Louise is 39 years old and has lived in Lakewood for 5 years. She has three children ages 14, 9 and 5. Her 14-year old daughter Susan is severely handicapped. Her husband is an accountant in a large chemical company in the area, and it was his job transfer that brought the family to Lakewood from the Maritimes. Adjusting to the re-location has been difficult for everybody, Louise says they miss relatives and the more 'neighbourly' lifestyle of Atlantic Canada. All of the children are in school although the 5-year old only goes half-time. Louise suffers from rheumatoid arthritis and when the disease flares up she has problems looking after Susan. She is concerned about her long-term ability to care for her

daughter and worries a great deal about what will become of her. At the time of the interviews, Louise was trying to plan summer activities for Susan.

Louise is not working outside the home right now. Before moving to Ontario she was employed as a supervising elementary school teacher - a job she enjoyed - and hopes at some point to return to paid employment, preferably on a part-time basis. She has been involved in many community activities involving retarded people, for example, speaking to local service groups and teachers about the needs of mentally handicapped people generally and also what it is like to raise a handicapped child at home.

Mary

Mary is 41 years old and has lived in Lakewood for five years. She has two daughters aged 11 and 10. Both are in school full time. Cathy, 11 years old is severely handicapped and not able to walk by herself. The family also came to the area as the result of a job transfer. Mary's husband works for an insurance company and manages its Lakewood office. Although the family now live only a few hours drive from their old home, where most of their extended family are located, they don't get back there very often as Cathy dislikes the car and becomes very fatigued on a long ride. A recent re-organization of Bob's work requires him to be away from home for days at a

time. He has little chance to be with Cathy, much less help out with her care. He has decided to quit his job and open his own insurance agency in a small village in the northeast part of the County hoping that an office in his home will enable him to spend more time with the family.

At the time of the interviews, the Green's were building a home in the village and expected to move within three months. Mary has mixed feelings about this. On the one hand she is pleased that Bob will be able to give her more support with Cathy but on the other hand, she knows it will be some time before this happens, as establishing the agency will certainly take Bob's full attention at the outset. Mary said that just thinking about the move, finding appropriate services for Cathy and getting the whole family settled in made her feel anxious and exhausted although the process had not even begun.

Mary is a nurse but has not worked full time since the children were babies. She does not foresee a time when she could return to nursing, given the care Cathy requires, but she does plan to do office work part-time in Bob's agency once it is operating. She has been involved in a wide variety of community activities for handicapped people including membership on the Board of Directors of the local association for the retarded.

Iris

Iris is 39 years old and moved to the area about seven years ago with her husband. She has a 16-year old son and a 13-year old daughter Patti, who is severely handicapped and who also suffers from a serious, although presently well-controlled seizure disorder. Patti attends school. Iris' husband is a pharmacist in one of the city hospitals and he also works one evening a week at a drug store. Iris is employed full-time as a chemical technologist in a large pharmaceutical company located in town. Like the other women, she also manages to do her share of work in the community. At present she is involved in setting up a Citizen Advocacy Program for mentally handicapped people. She states that there are times when she wishes she didn't have to take on so many causes, but feels she has no choice as she has to fight for her daughter's rights. At the time of the interviews she reported that life was on an 'even keel'. She had just completed plans for Patti's summer program. Up to a few years ago there was a recreation program laid on for the children. The program no longer operates. Instead, individual funding must be applied for on behalf of the child and a program devised for his/her needs. Although there are resource people available to help parents do this planning, and an individualized program can benefit the child, it is a much more complicated process than enrolling the child in the old program was.

Doreen

Doreen is 40 years old, was born in Lakewood and has lived there all her life. She has a close relationship with her mother and brothers and sisters. She has two sons ages 20 and 18. Her daughter Judy, 16, although mentally handicapped, is independent in self-help and social skills. Doreen's husband Mike was also born in Lakewood. He is the proprietor of a tobacco and novelty store on the main street that has been in his family for many years. The store is considered something of a local institution. Doreen has worked part-time in the store as a clerk for the past 5-1/2 years. Before that she worked on the recreation staff at the psychiatric hospital. At one point her job involved her in helping discharged patients settle in 'the community'. She is passionately committed to the idea of community living but knows it is easier to talk about than put into practice. She hopes that her own efforts as a member of the local association and a variety of other advocacy groups will help to bring the institutional system to an end.

Doreen recognizes that Judy's independence frees her from some of the more demanding aspects of day to day care that are basic to the other women's routines. She argues, however, that 'the bureaucracy' makes it difficult to get Judy's needs met since she does not fall into a high-priority group - that is her disabilities do not require institutional care.

All of the women are aware that the government plays an important and more obvious role in their lives than it does in the lives of families who do not have a handicapped child at home. They have to depend on the Ministry of Community and Social Services to provide many of the special resources vital to their childrens' development as well as certain forms of financial support (both will be discussed in detail later). At the same time, their relationship to the Ministry is marked by frustration because of the way they are dealt with. In many ways the women are quite cynical about COMSOC's efforts to provide 'community care'. Their first hand experience leads them to believe that the Ministry is more preoccupied with 'dollars and cents', than it is with the quality of life for retarded people.

There is no recent history of unemployment among the women's partners. The men could all be considered above-average wage earners. While ownership of a house or car is not necessarily proof of financial security, it seemed consistent in this instance with a sense the women conveyed of not being totally preoccupied with 'making ends meet'. The women did not see themselves as affluent, yet they often stated in the course of our conversations that they felt fortunate to be spared the stress that comes from not having a steady income, and the effects this would have on trying to provide for children whose special needs are often expensive. In the cases of Angie, Iris

and Doreen, the second salary is a help in meeting these costs. Fortunately for them, all of the women in this study have education/training in fields where women receive better wages. Louise and Mary, who are at home full-time contribute to the family income in other ways - making clothing for their children or doing jobs around the house that would be 'expensive' if purchased, such as painting.

Each family owns its own home, and all are tastefully furnished and well maintained. The women have washers, driers, freezers, and so on - the sort of equipment that is considered more and more a necessity for running a household but which, in fact, many women do not have. All of the women drive and have easy access to the 'family' car or have one for their own use - an important resource in light of the limited public transportation in Union County and their need to travel with the handicapped child as mentioned earlier, as well as run other errands or get to and from a paid job.

Although the daily work of care related to the child merits a study in itself, I was interested in seeing how the women combine it with the 'ordinary' work that women do in the family - handling the demands made on them by their partners and other children for emotional and physical support. Each member of the family requires food, clean clothing, an environment that is habitable, and so on. Making these

'ordinary' and taken for granted needs a reality involves the organization of a whole range of work processes that not only ensure the day-to-day existence of individual families but that ties those families into the work processes in the wider society, for example those of schools or of employers. Children are expected to arrive at school clean, fed and dressed appropriately. Men are expected to arrive on the job rested up enough to do their work. The presentation of children and men to the outside world so that they conform to such expectations is 'women's work'. How women go about this work is determined not only by the size of the paycheque(s) that come into the house or personal standards of consumption but also by a host of accepted standards, regulations and so on that do not originate with the family (Smith: 1981(b)).

The more affluent a neighbourhood is, for example, the more necessity there may be to maintain certain standards of upkeep and some of these may be enforced by zoning or other municipal regulations that are, in turn, connected to county or provincial requirements. Even the fact that families have some disposable income for leisure or recreation activities has a bearing on women's work. They may be responsible for planning such events, according to what is 'done' in their group. For example, in a working class neighbourhood children may teach each other to ice skate while in a more 'middle class' neighbourhood they may be expected to have skating lessons

which not only have to be paid for but scheduled, child reminded to go and/or be taken to and so on - tasks usually performed by mothers.

For middle class women in particular managing, as Smith (1973) has described it, an imaged order that does not originate with them, becomes an important part of their work, and one which they refer to in a variety of ways. "Thus it becomes a constraint over all, a measure against which all may fail, a necessary divergence between how they are measured and how they are" (Smith: 1973: 24). This imaged order extends to raising children so that they will be able to take their 'rightful' place in the middle class. The fact that this work is presented as 'mother love' places women in a double bind. What is understood as 'best' for the child is based on an imaged order rather than the particularities of the situation. If women do not 'produce' the child in accordance with the image, this becomes proof of their failure, or a lack of love (Smith: 1973: 29). This referencing women do to an external order is also evident in the lives of the women in this study and occurs in a particular way with regard to the handicapped child. Although the child may be limited in his/her ability to live a 'normal' life, the women structure the children's lives so that they can be as 'normal' as possible even when this is very difficult to do, and they judge themselves on how well they do this.

It does not require a great deal of imagination to picture how difficult it would be to provide care for a handicapped child without some of the resources that these women have at their disposal. Moreover, their education and training enable them to understand the directions of various specialists, in addition to being able to relate care of their own children to the broader issues of normalization and de-institutionalization. Many women might not find these ideas relevant much less have the resources to implement them.

Despite the obvious difficulties of looking after the children, the women were convinced that care in the home was best for the child, because it meant being with 'family':

MARY

"Cathy has always been with us...I guess I just always felt she was ours, our responsibility... I remember an aunt telling me, 'maybe she belongs with her own kind'. I said to her, 'who is more her own kind than us? We're her family'. I just could never understand that, especially Cathy who needed so much help, how could she get along with other people?"

DOREEN

"Judy has always lived at home. I just don't think there's anything the same about institution or group home care and care at home. It just devastates me to think of a child being dumped in a place other than a home -- whether it be their own home, a foster home or an adoptive home -- but a place where there are parents, siblings, extended family -- I guess that's why when Judy was born, it just wasn't a consideration. There's this child we made and who I carried and gave birth to -- there

just wasn't even a thought she wouldn't come home with us."

ANGIE

"Basically I think handicapped children need to be with their own family. They need to be with their mother and dad".

The women believe that (all) children belong with their families, and their idea of a family is "traditional", as witnessed by their emphasis on two parents - one male and one female. They also feel that family life is even more critical for a handicapped child than a non-handicapped child because only the family can love that child unconditionally and provide the support and encouragement necessary for full physical, social and intellectual development, no matter how limited that development might be. As the previous statements indicate, providing this environment is understood as a family responsibility although, as I will show later, it is not shared equally by all family members or, indeed, by the community.

It is clear that a particular understanding of 'the family' is integral to the process by which it becomes a logical, humane and progressive course of action for the state to support families in caring and that this view of family affects the way women think about what they do as care-givers (as well as the actual work of caring). This view also grounds the understanding of various professionals, and government personnel, who are involved in providing services that support

care in the family. Not only are families and their relationships taken as a 'given', they symbolize our most cherished values. The attribution of these positive (even moral) characteristics to the family results in a strong normative connotation when the term is used to describe certain kinds of care, because it is taken for granted that such care will be superior to care given elsewhere. Care in the family is thought to be informed by a special set of ideals that set it apart from the more instrumental (contractual) relationships that exist 'outside' the family.

IRIS

"(In an institution or group home) you always have to behave under somebody else's laws, whereas here (at home) as a parent, even though you do set up laws and Patti is bound by them, it's because we love her rather than we're paid to take care of her".

Women's lives have been intimately connected with the affective relationships thought to be unique to the family. The emotional, physical and financial costs to women involved in meeting the standards of selflessness and dedication required of care-givers are usually minimized or ignored because they are seen to be natural or inborn, even by women themselves.

Iris' comment epitomizes the belief that care is a labour of love and, as such, is a striking example of how women's work

gets devalued or minimized (by placing it outside the economic relations of capitalism) and the implications of this for women as care-givers. Her comment also reflects, however, the knowledge the women have that care at home in the community is better than care given elsewhere at the present time. The following statement by Louise about the eight weeks Susan spent in an institution several years ago speaks for itself.

"Originally she was just going (into institution) until the baby was born and I got back home...but she fell (there) and had a concussion...by the time she got over that she took pneumonia...then she had another fall...we brought her home finally with a severe infection that was highly contagious because we thought if we didn't get her out, it was going to be the end of her".

The impact of that experience has not lessened over the years. Louise talked about existing options, including the Association's children's residence, this way:

"When the group home opened, I went up and looked it over...I'm not happy with it (staffing arrangements, program, etc.). When I think of Rideau Regional Centre and the stories I hear from there, it makes shivers run up and down my spine. Really, I think I'd just struggle on forever - I think I'd rather do real damage to myself than have her in a place like that. I know it's not good for me and it's really not good for her to always be so closely connected with me, but I can't put her into any of those situations I know are available here".

Louise's comments are not unusual. In fact it was just this sort of experience that generated parent advocacy around the closure of institutions.

When it came to what 'community' meant to them, the women were somewhat less clear, and some of the contradictions of 'community' surfaced:

DOREEN

"It's a real contradiction that just because you're present in a community that you are a part of it. Still most aren't, most people with a handicap aren't a part of the community that they physically live in..."

I asked Doreen what that meant for her.

"I guess if it's one thing we're trying to do, it's make a community more competent. Unfortunately it's a group of people who have to hammer away at making that community more competent. (Mentally handicapped) people just have to stop being isolated and start being accepted and start being a part of it."

LOUISE

"Not only do you have to do all the things at home -- answer all the major physical and health needs, but you also have to do all this planning and community awareness and putting all the things you want into place."

Louise went on to say:

"I think most people don't know anything about community care of the mentally retarded because they don't have a handicapped person living at home."

Day to day care of a severely handicapped child gives rise to a routine series of tasks which Bayley (in Glendinning: 1983) terms 'the daily grind of care'. While the care of any dependent child contains certain elements of routine, it differs from other service work that women do in the home such as housework. Anne Oakley (in Glendinning: 1983), points out that child care is productive in that a successful mother works herself out of a job over a period of time. Housework must be done over and over. Glendinning argues that the distinction between child-care and housework becomes blurred in caring for a disabled child. Prolonged dependency means that the care-giver carries out an essentially repetitive set of service functions that can be physically taxing, mentally exhausting and despiritingly monotonous. On the other hand, what appears onerous to the outsider, may not seem so to the mother precisely because she has developed a workable routine for herself (Glendinning: 1983).

Severely handicapped children often do not acquire basic life skills until long past the 'usual' time for doing so or they may never master them. Basic life skills here include the ability to move about independently, feed, dress, bathe oneself and attend to toileting needs. The degree of assistance the

child needs to perform these tasks is one way of establishing the character of this form of care as work. It should be noted that, with the exception of Dpreen's daughter, none of the children could express themselves verbally although there was a differing ability among them to understand what was said to them or to make themselves understood. Deficits in communication mean the woman must be constantly on the alert to signs that indicate a change in the health or mood of the child. As well, the children require almost constant supervision or stimulation. Some sit and stare off into space or engage in pointless (and annoying) activities like tearing paper. Others are more physically active and need to be protected from dangers that they are unaware of - falling down a flight of stairs, wandering away from home and so on.

The following comments give some idea of the children's abilities, which are clearly inconsistent with their chronological ages. We also get some idea of what looking after them involves.

Mobility

LOUISE

"Susan walks and gets around well but has to be walked to the bus in the morning and cannot go outside alone - she's not aware of dangers or might wander off".

MARY

"Cathy cannot get around on her own. She can stand up and walk sideways around a table or counter but she loses her balance and can fall easily. We walk her by holding her from behind and she takes steps and shows us where she wants to go".

FeedingANGIE

"Both needed to be fed until about a year ago. Now one is pretty well independent (with reminding, cuing and a little hand-over-hand) and the other one requires a fair amount of assistance".

MARY

"Cathy spoon feeds. She uses a sloped dish. She does pretty well. She can almost finish her meal herself. You have to watch her - sometimes her spoon gets turned upside down and she doesn't realize - things like that. With a glass, she can handle it but might stick her fingers in it just to get attention, but she can pick up a glass and drink from it if she wants to, but you have to be at it - you can't just give her her meal and leave her - you've got to be right there".

DressingANGIE

"My children require total care in dressing right now".

LOUISE

"Susan co-operates with dressing but cannot button buttons or zip zippers or fasten her bra. She is learning to pull up her pants and take her boots off. I do the major dressing and undressing (AM and PM). It takes about a half hour in the morning to get her ready".

IRIS

"Patti needs a lot of assistance. She tries but no matter if its her socks, pants, blouse - everything

gets piled on top of her head. She will put her arms through when you say push and she knows where her head goes, and if you ask her to stick out her feet, she puts them out so you can get her shoes on. She takes things off better than she puts them on, but she still needs a lot of help".

Bathing

ANGIE

"The boys need total care".

The fact that the boys are blind means added complications:

"The oldest got introduced to a shower a couple of weeks ago. Up to then we could hardly get him into a bathtub - he was petrified of the tub and getting his hair washed - there were great screaming sessions...now he's learning to take a shower with his dad".

IRIS

"Patti does not have a true body concept and only washes the front of her body - that's the only part she sees and knows about. If you said 'wash your nose', she couldn't. Because of her seizures, I never leave her alone in the tub".

Toileting

LOUISE

"Susan isn't really toilet trained if toilet trained means being able to know when you need to go and attend to your needs in the bathroom".

ANGIE

"The boys need total care and are in diapers most of the time".

MARY

"Cathy can indicate when she has to go and that's just terrific. Before that she was going every hour. I couldn't stand her being wet...like I'd do anything to avoid that. I'd take her (to the

bathroom) every 10 minutes. Now she's much better. She goes every 2-1/2 hours. There's times when she still wets at night. We just went through about 3 weeks of it...."

IRIS

"Patti clasps her hands to indicate that she has to go. If she has accidents they're usually my fault because I haven't paid attention to her...."

The women also try to teach the child life skills as they do the activity. While any independence the child gains from learning how to take even a minor role in dressing, feeding, and so on reduces the women's work, this is not the sole motivation they have in training the children. The inability to do any or all of these things sets the child apart from others and reduces the likelihood that he/she will be able to take part in activities away from home without one-to-one attention. For example, not being able to find and use a bathroom or take off a jacket or boots limits access to recreation programs. This reduces the child's sphere of experience and also means their mothers have to spend much more time with them than with non-handicapped children who go out to play on their own or take part in other activities. As well, this lack of independence can curtail family outings. Something as simple as visiting a shopping mall or having supper out become major undertakings or else are given up altogether because of the difficulties involved.

The need for the child to gain some degree of independence, places considerable pressure on the mother. The following comments indicate the difficulties they have trying to be teachers in the midst of competing demands on their time. They also show how hard the women are on themselves when they feel they have neglected this aspect of their work.

LOUISE

"There is a sense of pressure. Sometimes even when I'm getting her dressed in the morning, I know that she can pull up her own pants, but sometimes I just plain do it because I don't have time to wait any longer. I do it and then later I think: 'there, you did that for her again - you just waited on her again - you didn't make her do it'. Sometimes I feel I let the school down a bit because that's a program they have".

MARY

"I do think she has the ability to do some of her own dressing. It's just the thing of starting it. Like it's to start something and know its going to take 2 years - its almost easier not to start...I talked to them at school about getting (teaching) her to put on her sweater...I know we should be working on this but all those things just exhaust me to think about it".

IRIS

"I'm not sure with dressing and bathing, how much lack of independence is my fault for not teaching her more because of course, its a lot easier and faster to do things for her rather than teach her. Maybe a lot of the things she doesn't know are because I haven't taught her or haven't had time to teach her...I just don't take time now because I've got two other people to help through their lives and a household to run".

When I asked the women about the most difficult aspects of day to day care, their responses touched on a number of issues. The 'mechanics' of looking after the children's needs appeared to be of less concern to them, however, than the overall 'context' of care in which they interact with the children and/or other people.

ANGIE

"I think not having the things that normal parents take advantage of...when you can't even get out to get groceries, get to the bank, go have your hair done, or take your other little boy out for a walk - there's just nobody to help".

LOUISE

"There's nothing she can do to entertain herself in her spare hours...there are times when she doesn't really have anything to do and I keep thinking 'if only there was just something that you would do...so that I didn't have to entertain you all the time...there must be something I should have you doing or be teaching you that would be useful to you if only I knew what it was'".

MARY

"I guess its not so much any of the things we've talked about, what's really hard is trying to help her amuse herself or put in her time. As far as those things of caring for her - they're just routine now. It's just seeing her sit - she's not interested in anything...so that's what's really hard and the fact that she doesn't walk. I think even if she could walk around and break stuff up it would really be better than seeing her sit".

IRIS

"Because Patti is different - walks different and behaves different - it's hard to go out and be just one of the crowd. People turn around and look - they're deferential to you - I don't mind the

preferential treatment (opening doors, etc.) but it still makes Patti an object. I have to fight more for her rights, for what I think she deserves. I spend more time than I would like away from my family - lobbying, going to meetings and I really resent that...a lot of it is confrontation which you really don't need on top of everything else".

Doreen's remarks point up the kind of careful negotiating she does with other people and with Judy so that Judy has the opportunity to develop all of her abilities.

"Judy is caught in a kind of unique situation in that she is so capable. Sometimes I don't know - I don't know personally what other families go through - she doesn't need that much physical care because she is so capable (and yet handicapped) and it's a lot of work to make sure that people are having expectations for her. Making sure she lives up to them and not letting her slide, and yet not having too many expectations for her...Finding that balance is difficult and yet I've always pushed her to get to her full potential and make sure that's realized. It's very difficult to be sure that you're including Judy in that process all the time and that she's not being excluded from the kinds of decision-making that sometimes you go ahead and do - you think you know what's best for her and there are so many people thinking they know what's best for her!"

Paid Work Versus Unpaid Care

The decision to seek paid work or not was based on a number of factors for all of the women, but care of the child was a central issue in one way or another for everyone except Doreen.

ANGIE

"...a lot of people ask me why I work and why I'm not at home. I'd love to be at home - not full time - certainly I have a career and I've worked very hard for that ... but I can't financially afford to stay home and keep my kids living with me."

LOUISE

"I would like to work again, I'd like some kind of part-time work, I really would. I really enjoyed working."

MARY

"It just all seems too tiring (to return to nursing) I guess. When I'm in hospital, like when Cathy is sick, that's when I miss it - when I'm right there with it - but I just can't foresee going back."

IRIS

"The reason I work, more than anything else, is I like to be out in the community. I really don't need to work financially. Initially when I went to work, I felt Patti was being stifled by her mother! She needed to be away from me and I needed to be away from her, and it really did us both a lot of good."

DORÉEN

"I don't really see myself going back to work full time, but then I don't really plan my life ahead more than a week or so at a time. It would depend - a lot depends on the business now and what Mike decides to do with that..."

Balancing a double day of labour is particularly difficult for Angie.

"It's not easy organizing a schedule at work and a schedule at home because you feel as if you're torn in the middle between the needs of the people

you're looking after and the needs of the family - it's pretty tough sometimes".

Both Angie and Iris consider themselves fortunate to have employers who are understanding about unavoidable absences due to appointments for the child (all five women stated that they had the major responsibility for dealing with the many specialists who treat the children or advise on their care). At the same time, their remarks indicate the lengths they go to make up for 'lost time'.

IRIS

"If Patti is ill, I have a work ethic to the fact that I will not use my sick days for Patti's sick days. If she's ill, I take a day without pay because I don't think it's fair to the company to do that".

Louise and Mary, at home full-time, have the opportunity to intensify their labour when everybody else is out. By doing that, they and other family members have more chance to relax on weekends. The other women use weekends as a catch up time - even Doreen whose job is part-time. "I usually try to get a whole lot of running around done that I can't get done during the week".

The women were quick to point out, however, that handicapped children 'give' as much to the family as they 'take' in terms of care.

MARY

"I could talk all day I guess about the pleasure and satisfaction Cathy gives us. She's taught us so much - like Cathy's love is just there all the time. She's taught us a lot. I think about accepting other people - I think just about the priorities of life too... we're content being at home..."

LOUISE

"When (Susan) learns to do something, it's such a sense of accomplishment. With the other kids, they almost learn to do things by themselves, but with her, every little thing is with your intervention! You can see you've been patient or done something and this gives me a great boost. I think too we have a better family life - we have a better marriage - than a lot of people. The younger children are more sensitive and practical...they've given up a lot they normally wouldn't have."

IRIS

"Patti is a joy!"

WHO IS THE COMMUNITY?

I tried to find out who the community was and whether the women could count on 'the community' for support. I began with the family (often considered the basic unit of community and the model for all other forms of it), but also looked at extended family, friends, neighbours, and so on, as well as the formally organized, community-based parent relief program to see whether any or all of these aspects of 'community' actually supported the women in their work and/or whether they felt supported by any of these. The definition of 'support' was

left up to the women, that is, it could mean anything from being involved in helping her with daily care such as dressing; amusing the child; teaching the child; accompanying the mother and child to appointments and so on. I also tried to ascertain whether this support occurred on a regular basis and whether or not the women had to take the initiative in seeking it. It was clear that the women made a distinction between concrete help and 'moral' support. Both were important to them.

The Immediate Family as Community

It seems logical to assume that the women would get the most support from those closest to them. A great deal of the work on the family in the past, for example that of Parsons, translated the division of gender into roles (Thorne: 1982). "The language of roles conveys not only a sense of fixed and dichotomous, but also an image of separate but equal" (Thorne: 1982: 8). This framework passes over the complexity of lived experience in families. For example, some studies assume a harmony of interests among family members which obscures a more complete understanding of the allocation of tasks, experiences of work and leisure, the giving and receiving of nurturance, decisions about employment and so on. Feminist critiques of the family have stressed the necessity of differentiating the experiences of family members and point out how women's

experience of the family has been buried by the use of overarching, homogeneous units of analysis. The emphasis on love and consensus as the basis of family relations, not only over-simplifies the 'personal' aspect of family relationships, but gives little importance to how wider social, economic and political issues shape the context in which the relationships are negotiated.

ANGIE

"...(my husband) travels a fair amount...I'm on my own a considerable amount during the week... He is very supportive emotionally and financially..."

The absence of Angie's husband during the week means he does not routinely help with household chores or child-care.

"Basically what happens is I come home from work and I have three kids very anxious to spend some time with me and so we spend some time together until about seven. I have a husband who comes home and we have supper and then I usually have all the laundry from that day, all the dishes from that day - anything that has to be done. John is very good, its just his days are very long. I guess I find the end of the day harder because I've worked all day and I'm tired. John is seldom home before seven and he starts his day before seven. Usually by the time he's coming in, the kids are just about ready to be tucked in. He gets them tucked in, spends some time in their rooms with them, gives them their medicine while maybe I'm getting our supper started or throwing in a load of laundry. I don't want to make it sound as though John doesn't share, I guess there's so much that has to be done with the home - its huge - and lawns etc., that he does all that.

IRIS

"I do most of the chores although the guys do help out. (My husband) still needs prodding about helping with things every once in a while, but generally they're both very good... but the brunt of it falls on me, I'm the organizer...I still end up doing a lot of the actual physical things".

MARY

"Bob and my other daughter help. She needs prodding but she's pretty good. Bob is really good on weekends, he won't go off and leave me with Cathy. He'll help with the dishes, make up the beds...and he'll run around and tidy up in the morning".

DOREEN

"I have the responsibility for these things. We've worked through these things...although Mike doesn't get involved in a lot of this stuff, he's always been really supportive. He's close to the kids and whenever I've had enough and really had to pull back, he's been there. Between the two of us, there's never been anything we haven't been able to handle".

To say the men do not help would be inaccurate. However what they do is determined by other commitments - their work comes first and depending upon the demands, they may actually have little time available to help out. Angie and Mary's husbands are often away from home during the week, and Doreen's husband works every Saturday until two o'clock in the afternoon.

Most of non-handicapped siblings were younger than the handicapped child and could only make minimal contributions to on-going care such as playing with the child. The women look forward to the time when those children can help. If Iris'

16-year-old son is any indication, other children in the family can be considered an important source of support. Although the women were anxious for this help, they were also reluctant to over-burden non-handicapped children. Louise said she did not want to see Susan's brother and sister 'caught up' in caring for her, as she is at the present time, when they are adults. Her comments point up Louise's awareness of the limitations that being a full-time care-giver place on her.

"I don't want them to feel she's so much their responsibility that they would have to have (her) in their homes...be responsible for her total care. Right now I think she is my responsibility and it is my job to make sure that she is taken care of but I don't want them to feel that".

The centrality of care in the women's lives cannot be stressed enough. In contrast, their partners were free to make a choice about doing this work, even when they were at home and available to do it, and even when the decision increased the women's work or limited their freedom to go out. One striking example involved physical care of handicapped daughters who had reached or were approaching puberty. The men involved had all routinely helped with bathing and toileting when the girl was younger. The onset of menstruation and other signs of sexual maturity caused a marked change in the amount and kind of support the women received from their partners.

LOUISE

"My daughter is not able to care for herself when she menstruates. When she's having her period, I just never go out in the evening or anything like that because that's one thing my husband really draws the line at. I could go out - he says he'll look after her - but I don't go".

MARY

"She needs help bathing. Now that she's developing more, my husband wants to do less things for her - like he doesn't bathe her (anymore). I guess he would do this if I was away, but I just don't be away on a night when she needs it".

IRIS

"Patti has not started to menstruate yet... although her brother and my husband help with toileting now, the brunt of her hygiene, of course, is going to fall to me as bathing and showering do now".

The ambivalence the women feel about having to take on more work or having their freedom curtailed is apparent in what they say. At the same time, they defend their partners by arguing that the withdrawal of support is a logical outcome of normalized living for retarded individuals; that it would be inappropriate for a father to bathe a non-handicapped daughter that age. While reluctance to do this work can be taken as an indication of an awareness of certain cultural proprieties, the same 'awareness' does not apply to women when the situation is reversed to the care of a sexually mature son. Although Angie's sons are still quite young, she takes for granted, at least by implication, that she will continue to care for their personal needs as they get older.

"Progress is slow when it's there. So basically I have got two toddlers and I will have two toddlers for a long time to come".

Extended Family as Community

The term is not used here in the more formal sense of a particular family form. It refers to kin with whom the 'nuclear families' of this study have contact and on whom they might conceivably rely for some help in looking after the handicapped child. For example, the child might spend time with grandparents, aunts, uncles and so on. The existence or not of such support networks has been the subject of continued debate among sociologists who specialize in the study of 'the family'. Parsons' (1954; 1956) arguments about the functionality of the nuclear family were partly based on the idea that the occupational mobility requisite in industrial societies separated family members from each other. This enforced separation was, in turn, countered by the self-sufficiency of the nuclear family. Others such as Young and Willmott (in Morgan: 1975) argued that at least for some families, the extended family support system continued to thrive.

As far as this study is concerned, there appears to be some truth to both premises. Four of the five families had

become separated from kin because of work considerations related to male partners. In the case of Doreen, where this had not happened, extended family played an important support role. She mentioned, however, that she regards this close relationship as unusual, even among her friends who also had extended family close at hand. Doreen says she has no hesitation about asking relatives to take care of Judy now and then. While Doreen's extended family might be just as willing to look after Judy if caring for her presented more work, the fact that she is capable of looking after herself does make these arrangements much less of a problem than similar arrangements would be for the other women.

Mary pointed out that her difficulties around getting support from relatives had less to do with the physical distance between herself and them than it did with the concerns she had about the ability and/or physical stamina of relatives to care for Cathy.

"My one sister had Cathy for awhile. I think she was exhausted. Her oldest was 12 then - she had little ones too - but she said they were less work (altogether) than Cathy. I think it's the care of her. Like I'm sort of built up. I'm used to her all the time...but somebody who hasn't been doing it...they find it very hard".

Angie, Louise and Iris felt that living closer to extended family would be of benefit. Mary's experience, however, raises

some question as to just how much support they would be able to rely on. When the women spoke of extended family, they invariably referred to female relatives and, thus, to support provided by other women.

Friends, Neighbours, or Acquaintances as Community

The emphasis on finding support networks in the community outside the family has become an integral part of facilitating community care (Collins and Panacost: 1976 et al). It originates in evidence that most people turn to informal supports rather than formal systems of help, and that the bulk of social problems are dealt with by these informal helping networks. Although the social work literature on helping or support networks distinguishes between types, it tends to rely on a particular understanding of family and community in which it is possible for the networks to operate. For example, they are thought to exist apart from the paid work setting. This, of course, implies that women are central to them. As more and more women enter the paid labour force, however, the idea becomes less viable.

The women in this study tended to make a distinction between neighbours and friends, even when their friends lived in the same neighbourhood. All of the women except Doreen said

they did not know their neighbours very well, despite the fact that they had resided at the same address for a minimum of one year and, in most cases, for much longer. This was not too surprising coming from Angie and Iris since they are away at work all day, and are caught up in a multitude of tasks when they are home. However, Louise and Mary reported much the same thing. None of the women considered their relationships with neighbours to be of much support in caring for the handicapped child, although there might be reciprocity in caring for non-handicapped children.

MARY

"They're nice but...I guess I wouldn't say they've been of any assistance. I think they would help if something happened, but I have never left her with them or anything like that. I would have a hard time to do it because they don't really know her (care routines)".

Friends offer both concrete and moral support. Louise has contact with her closest friend while Susan is at school.

"I think there will come a point when Susan will be at home during the day and I think that will be the time when I'm more isolated... because now when I want to go for a walk in the morning I can call Shirley. We have time to do this. We talk and hash over our kids, talk about what's bothering us, sort of supporting each other..."

For Angie, friendship has at times been a real lifeline in helping to take the boys to hospital or other appointments.

"I had a very good friend who moved and I miss her dearly. She always used to come with me to the hospital when I was raising the children on my own".

Support from other acquaintances was not extensive either. Louise has managed to find time to be active in church since moving to Lakewood. As well, the entire family, including Susan, attend weekly services. Sometimes Susan gets restless during the service or after when the congregation get together for a social hour. Louise comments:

"I think lots of times they say to themselves, 'somebody should be giving her a hand'...but they also say to themselves, 'please don't let her ask me', and that's the way with community".

A Community Support Program

The women were in favour of the idea of out-of-home relief and were generally satisfied with the care the children received when they were with their relief families, yet they cannot depend on the program in all situations. One reason for this is that families providing relief must be in agreement about when the child comes to stay with them. This means they provide relief at their convenience rather than at the convenience of the women. While relief providers are not insensitive to the women's needs - they usually have good reasons when they refuse to take a child and the women

understand this - the women cannot plan or look forward to holidays in advance. As well, capable and willing relief-providers are not easy to find.

LOUISE

"Sometimes (out-of-home relief) is not as available as you'd like it to be".

MARY

"Our parent relief has fallen through every summer".

Mary found the twenty-one day limit on out-of-home relief stipulated by COMSOC to be more anxiety-producing than reassuring.

"We don't use the program that often. We're entitled to 21 days but when you know you've only got 21 days you're afraid to use it for fear you'll need more later on".

In Angie's case, out-of-home relief is provided at the Association's Children's Residence. She prefers that the boys not be separated which makes it virtually impossible to find a relief provider in the community. She is satisfied overall with the arrangements at the residence but must book the relief beds well in advance as they are in almost constant use. Thus, Angie too is constrained around when she can actually make use of out-of-home relief.

The women cannot count on support from any of the forms of 'the community' described here to any extent. They must depend on the good will and ability of individuals and have little control over the amount or quality of help they receive, even from members of their immediate families. Their partners cannot be seen as contributing equally to care of the handicapped child, other children or housework although some of them attempt to help out as much as possible. Neighbours, friends and extended family are helpful by times but, are not always readily available or are limited by their ignorance of the child's needs. Even the formally organized parent-relief program cannot always be depended upon.

The women continually made allowances for the minimal help they received from others. They made these allowances in terms of the great mental and physical cost of being a care-giver, ignoring the fact that these same costs applied to them. When I pointed that out, they agreed but then countered with the fact that caring wasn't quite as tough for them because they were used to it; or by pointing out how the people who didn't support them had some special reason such as extreme fatigue. There could be many reasons for this stance, some of them quite practical such as not having the time or energy to negotiate the issue with the other person or the difficulty in training somebody else to do their work. On the other hand, a particular understanding of community which is synonymous with

'the family' and its traditional "roles" was clearly a referencing point for the women as was the notion of normalization.

LOUISE

"I'm sure when I'm 60 years old, I'll wonder where all these years went to. But to me, whether its caring for Susan, the other two or Glen (husband), I don't know, I guess these are the things we choose in our lives. To me, having made the choice, its made and it's done...having chosen to have Susan at home - I'm sure 14 years ago I didn't know what work would be involved...I may work harder than a lot of my friends or neighbours and they may not understand it, but I think maybe they could do the same kinds of things if they had to and, given the choice, probably a lot of them would. I still don't think we can stop making our community aware of these things, or our government feel they have to make the best life possible for our handicapped people..."

SUMMARY

It is possible to sense in the women's stories the faint outline of a form or shape to their work that extends beyond the confines of their own homes into the City of Lakewood, Union County and even beyond. We are given hints when they speak about the company's their husbands work for being re-organized, when they worry about "letting the school down", when they talk about services and programs that don't quite meet their needs. We also begin to understand why caring for the handicapped child at home is so important to them, because

children need to be with their families, who care for them out of love, but also because out-of-home settings do not give as good care, and thus do not present a viable alternative. We can also see that 'the community' in various forms does not support the women.

In the Chapter Four, I will examine the development of community as notion and ideology in texts from sociology and show how these understandings have been incorporated into social work practice.

IV TEXTS FROM SOCIOLOGY AND SOCIAL WORK:
WAS COMMUNITY EVER 'THERE'?

"We can trace the concern with community to the same source as the breakdown of particular feudal or feudal style relations and the emergence of social relations based on a wage economy".

Gillian Walker

INTRODUCTION

Although I am examining the development of community as notion and ideology in texts, this is not simply another topic in a history on how community has been conceptualized. The aim of this Chapter is to explicate the differences between an ideological account of 'community' and an experiential account of 'community' as a set of practices. Thus the question: was it ever there as it has been and still is portrayed in those ideological accounts.

The Notion of Community

Both philosophers and sociologists, the latter beginning their work in the 19th century, were attracted to the attributes generally identified with the term community - a sense of locality, identity of interests, a sense of belonging and shared cultural values (Plant: 1974). The community that formed the reference point for this work was a composite image drawn from two main models: the polis of Periclean Athens and

the village life of late feudal or early capitalist times in Europe (Plant: 1974; Nisbet: 1966). The emphasis in the 19th century work on the return to an older, simpler way of life, typified by the societies referred to, reflected the desire of these writers both to understand the causes of the upheavals and massive social organization engendered by the industrial revolution, and to find a "cure" for them (Plant: 1974; Walker: 1986(b)).

Earlier, these same attributes of community had been regarded in a much less positive light by men like Hobbes, Grotius, Hume and Bentham. They argued that the ascriptive relationships of community limited the possibility for individuals to change their lives by improving their economic position, social status and so on. Marx, in a later period also offered a critique of the community which will be discussed later in the chapter.

The belief that 'community' represented an ideal form of social organization, and one preferable to the social organization of 19th century urban life in particular, coincided with the development of sociology as a specialized area of study (Nisbet: 1966). Although philosophers like Schiller and Hegel wrote about the loss of community, it was sociology that elevated the notion of community to a unit idea, perspective or methodology for measuring the presence of social

organization and determining its "health" (Nisbet: 1966). This textual work on community drew on a variety of sources in which the models themselves were described. The important aspects of each are discussed below.

The Polis

The polis was the basic social unit in Ancient Greece. In its earliest period, the polis was a small, independent, self-governing body. There was little difference between the nobility, landowners, and other people. Each polis was composed of a variety of inhabitants and work was mainly agricultural (Encyclopedia Britannica: 1979). The strongest social connections were kinship-based although there was no term in the language for 'family' as we know it (Humphreys: 1983). 'Oikos', the opposite of polis, referred to household effects. Powerful families attracted numerous dependent people who lived with them and offered their work in exchange for protection (Britannica: 1979). The polis had three forms of ruling- king, council, and assembly of male citizens. The latter represented the interests of the general population. During this agricultural period, aristocratic women moved about freely in society; their household economic activities were regarded as important and in carrying out their work, they supervised slaves and other labourers (Murray: 1980: 44).

Over the centuries, as the society became more urban, there were changes in the ruling mechanisms of the polis. Its representation became less participatory. Membership became hereditary and the governing processes more formal (Encyclopedia Britannica: 1979). During this period, Murray (1980: 44) notes that the participation of women in the public life of the polis began to decline, and that they were increasingly confined to the household. "Urbanization saw the increasing exclusion of women from athletics, politics, drinking parties and intellectual discussion".

The household or oikos became less of a primary social connection. For example, young boys were taken from the household and educated separately for their future roles as citizens. Adult men spent their time in the company of other men. Women were regarded as the property of their husbands (Murray: 1980: 169).

What is known of the polis through its literature, history, drama and so on presents its life, especially the Periclean period, in an idealized and romanticized form that went unchallenged by later scholars (Frost: 1971). It is only in more recent years that a critical eye has been cast on the period. Generally, philosophers and sociologists before the twentieth century viewed the social organization of the polis as unitary, participatory and egalitarian. They did not take

into account that participation in polis life was limited to a select group of men (Murray: 1980); that there were extreme social divisions such as slavery (Murray: 1980; Frost: 1971); or that it was sexist (Humphreys: 1983; O'Brien: 1981; Clark and Lange: 1979).

Clark and Lange (1979) point out that the accounts of the polis assumed the existence of another set of relations - those of the household - but since the accounts were produced outside that domain, they did not consider explicitly the relationship between the two. Thus distinctively political units and distinctively social relations were not only understood to be outside 'the family' but between men.

The study of women's lives in antiquity has been difficult owing to the fact that what is known about them comes chiefly from the writing of men (Humphreys: 1983). "We have no account of a woman's life as a continuous biography" (Humphreys: 1983: 33). The lack of material is not simply an accident of source preservation. Writing, with very rare exceptions was a male activity. Therefore the understanding of women presented in the written work of the period not only represents the views of individual male authors but also the cultural conventions of the time (Humphreys: 1983). As O'Brien (1981: 140) puts it, "Not least of Greek achievements was the definition of humanity as man".

The Traditional (Feudal) Community

The period of late feudalism or early capitalism was also one of face-to-face relations although these were organized differently from those of the polis. Castles, manors and early towns provided the social organization through self-sustaining households. There was little geographic mobility. Class for both men and women was based mostly on ascription and was hierarchical. There were few ways to better one's position although the Church, a major source of wealth, power and prestige offered that possibility to some men and women. Feudal relations created a strict and binding hierarchy (Bullock and Walker: 1984).

Obligations in the society were mainly military, agrarian or religious. In return for fealty, nobles protected people in times of war and provided for their welfare through land grants, pensions and so on. Those who did not belong to the society by marriage or birth or who forfeited their positions through madness, leprosy, disability, crime ('outlaws') were cast out and left to roam outside the more populated areas.

Women were important at every level of society. Aristocratic women exercised considerable authority in their work and managed large estates and farms (Stacy and Price: 1981). Women in labouring classes often worked outside the

household in a variety of trades, as traders, or worked the land with men (Stacy and Price: 1981). Although women took an active and visible part in the work of the time, they were subordinate to men within the household. Marriage especially provided for the subjugation of women and male control over women's productive and reproductive labour (Burstyn: 1983: 5). Marriage laws were originally encoded by the church but in the transition period between feudalism and capitalism came to be a state concern as well, especially in the area of property relations. According to Wemple (in Stacy and Price: 1981) in the first feudal age, the family was very important, and the key to power was the control of landed property through private ownership or fief. Daughters as well as sons shared in the property or fief and some women, in this way, were able to exercise considerable power. By the twelfth century, however, institutions outside the family were being created to administer public affairs. "As the impersonal machinery for government was developed the women were excluded" McNamara and Wemple (1974: 115 in Stacy and Price).

There was little differentiation between 'living' and 'working' as production was an integral part of household life itself. There does not appear to have been a notion of 'community' distinct from society. The only social groups that existed apart from it, other than those formally excluded, were based on function, for example monasteries or guilds. Even

within those groups, daily life was not conceived of as being divided between 'working' and 'private' life (Bullock and Walker: 1984).

Freedom was understood as a release from bonds or obligations, rather than a matter of individual or personal right. Concerns of life revolved around the sacred rather than the secular. The point of human existence was seen to lie outside of and beyond the immediate world (Plant: 1974). The theologian Thomas Aquinas stated for example that "man (sic) does not belong to the political community with the whole of his being or with all that he is" (In Plant: 1974: 22).

Use of the Models in the 19th Century

In both the polis and feudal society, "forms of social organization and social relations were mostly visible, evident and knowable in their entirety" (Walker: 1986(b): 8). The social relations of both societies were clearly oppressive to some of their members, but the reasons for this were also 'knowable'. "Under such systems people's understanding of their lives is congruent with their experiences" (Walker: 1986(b): 9).

The 19th century sociologists proceeded on the assumption that the face to face relations of the earlier societies could be re-created in their own time by producing the right conditions. They tended to romanticize these relationships without taking into consideration how their own society differed from the earlier ones they so admired. The increasingly fragmented and differentiated world in which they lived could never produce the same social relations of the polis or feudal 'community'. Nineteenth century society was based on another mode of production in which wage and commodity relations obscured exploitation and promoted individualism. The 19th century writers made certain inferences from the models, based on their own understanding of the world, and incorporated them into their understanding of community.

- (1) That community was separate from the household and therefore distinctively social and political in a way that household/family relations were not;
- (2) That the community denoted reciprocal relationships which benefited all of its members equally;
- (3) That community meant men since they dominated in the organization of (1) and (2).

In other words, they considered the earlier social formations which they identified as 'community' to be 'unproblematic', especially in terms of the underlying work organization that produced them. They took exactly the same approach in analyzing their own society and the combination of the two

provided for the development of an ideological understanding of 'community' that was quite distinct from the lived experience of it during this period.

COMMUNITY AS IDEOLOGY - THE 19TH CENTURY

The names of Comte and Tonnies are familiar ones in sociology. Comte is credited with being the 'father' of sociology. He gave the discipline its name and attempted to systematize its work processes by means of the positivist method which he devised. According to Nisbet (1966), Comte considered 'society' and 'community' to be synonymous, and used the terms interchangeably. Comte also rejected the belief that the individual was the principal actor in society. He argued instead that the 'individual' was, in effect, the sum total of his/her social roles and could not be understood apart from the social processes that shaped those roles and experiences. He attached special importance to 'the family' in this regard. His major work, The System of Positive Polity (1967 (1851)), tells us about society/community and the position of the family within it.

Ferdinand Tonnies occupies a special place in sociology as a result of the publication of his book Gemeinschaft and Gesellschaft (1957 (1889)). In this work, the 'traditional

community' and 'contract society' were developed by Tonnies as 'ideal types'. Although he did not intend the typologies to be prescriptive (1957: 263), they became a standard for measuring the presence or absence of community in a variety of contexts beyond the one Tonnies described.

"Through this typology, the momentous historical transition of nineteenth-century society from its largely communal and medieval character to its modern industrialized and politicized form has been taken from the single context of European history in which it arose and made into a more general framework of analysis applicable to analogous transitions in other ages and other areas of the world" (Nisbet: 1966: 71).

Comte

Comte's prescriptions for society were his prescriptions for community (Nisbet: 1966: 55). His observations about the family reveal his belief that community and family were also inseparable. Comte assumed that the family had certain major functions and that these could be categorized as either moral or political (Nisbet: 1966: 60). The moral function of the family was to socialize children to take their place in the wider community (Comte: 1967 (1851): 157). Socialization referred to teaching children three things: (1) respect for superior authority; (2) a sense of solidarity and awareness of others; and (3) an understanding of the fusion between

"attachment, veneration and ~~love~~" (as seen in marriage)
(Ibid.).

Comte's analysis of the family as a political entity dealt with the relationships between its members. He argued that the family exemplified the essential elements of all human authority which have been developed in political society (Comte: 1967 (1851): 163). For example, the legal act of marriage set a seal of approval on relationships in which one person is subject to another. Just as 'political' harmony required the obedience of citizens to the government, so a family could not function if a woman did not obey her husband (Comte: 162). In Comte's view, a husband should provide for his wife and thus make it unnecessary for her to work. This arrangement freed wives for their 'real' work of providing a haven for husbands from the rigors of public life. As Comte (p.174) put it, women's work was to save man from "the corruption to which he is exposed in his life of action and thought". At the same time, he observed that it is "public life that enables private life..." (p. 305), meaning that men create society/community and that the work women do in the home or family merely supports men's work. Although Comte (p. 172) stated that "woman is the real centre of the family" their elevation by him to the position of moral or affective head of the family downplayed their material contributions to family

life, or the connection of that work to mens' work. Moreover, he considered the organization of bourgeois families only.

Comte's work was a reflection of the social and economic arrangements for bourgeois families of the time as well as his own position in that world. During the early 19th century, the bourgeois-patriarchal family, served as the vehicle for transmitting and/or consolidating capital (Harris: 1983; Smith: 1983(a)). The head of the family, as husband or father, acted as the main agent in these transactions. Fathers arranged marriages for their daughters that were intended to increase family holdings. The male children from these alliances ensured that assets would be kept in the family. Thus the control of womens' sexual and childbearing activities were crucial in advancing capitalism at that time.

The social changes of the late 18th century, however, made some inroads into these arrangements. The French Revolution, for example, legitimized the idea of greater personal freedom for everyone. Harris (1983: 146) states that during this period social life and family life in particular were increasingly characterized by individualism expressed as a greater demand for personal autonomy as well as a corresponding respect for the individual's right to privacy and self expression. The effects of these ideas could be seen in the granting of more freedom to children and in a de-emphasis on

the patriarchal relations within the family, that is the legitimization of patriarchal authority through marriage and an emphasis on its more personal or affective side. This new understanding of marriage and family life resulted in an increase in divorces after the French Revolution - a development which Nisbet (1966: 60) states was of great concern to Comte.

Comte's bias is clear. The society/ community he envisioned required a return to and/or bolstering of the bourgeois-patriarchal family, which, in turn, could serve as norm of family life for all members of society. His work is based on the idea of a society/ community that has two spheres. An impersonal economic or political sphere which is in the purview of male experience, and a more intimate sphere where women as wives and mothers bind the two spheres together so that the *raison d'être* of the larger society/community - men's work - is advanced by women's work. A woman's proper (ideological) understanding of her (subordinate) role also advanced the 'ideals' of political harmony, solidarity and obedience to (male) authority in the 'community'. Thus, Comte incorporated the three main points from the polis and feudal society already identified.

Tonnies

By the time Tonnies wrote Gemeinschaft and Gesellschaft at the end of the 19th century, social, political and economic conditions had changed substantially from Comte's time. In the intervening years, a number of writers had attempted to explain the changes through the use of typologies (Nisbet: 1966: 72-73). Typologies, or ideal types, are a method of classification based on abstract categories for analyzing individual or group phenomena (Theodorson and Theodorson: 1969). The differences noted between the ideal types can then be conceptualized as a discrete phenomenon or as a gradual continuum. Gemeinschaft and Gesellschaft provided the latter kind of analysis.

Gemeinschaft, translated from the German means community. The family is the foundation of all Gemeinschaft unions as it joins people together by blood, neighbourhood and friendship. The other associative aspects of Gemeinschaft are derived from these and include common work and beliefs. "The authority of the father is the prototype of all Gemeinschaft-like authority" (Tonnies: 1957 (1889): 253). Gesellschaft denotes society, but Tonnies used it in a more specific way to describe a form of social organization characterized by a high degree of individualism, impersonality and the notion of contract. Gesellschaft is based on volition and interest rather than

feeling and emotions and typifies the modernization of society - the development of corporate economic enterprises and the moral relations derived from them. "Authority", Tonnies (1957 (1889): 254) wrote, is based upon a free contract whether between individuals, as service contracts or by agreement of the many to recognize and place a master or head over them and to obey him unconditionally".

Gemeinschaft presented a picture of pre-capitalist life and Gesellschaft presented a picture of life within capitalist society. The typologies described the changes wrought by capitalism as evolutionary. Tonnies believed that society had already progressed to the fourth of four possible stages - from unions of Gemeinschaft to associations of Gemeinschaft to associations of Gesellschaft. The second and third phases represented the growing individualization of human relationships as a result of economic change. The last phase, unions of Gesellschaft, represented the attempt to recover the communal security of the earlier stages through state intervention - for example, by means of various welfare provisions. Tonnies (1957 (1889): 78) argued that this stage of Gesellschaft was entirely dependent upon the state to regulate its social relations.

In many ways, Tonnies' Gesellschaft provided an accurate description and analysis of late 19th century life, especially

in large cities where the working class could barely provide for its own subsistence even when all family members worked. He was also correct in identifying the growing importance of 'the state' in regulating or remediating the tendency of capitalism to destroy or waste labour power as it accomplishes accumulation. The working conditions of men, women and children during this period, as well as the effects of these on family life, have been well documented (Hewitt: 1958). As well, this period has been identified as critical to an understanding of how the work of bourgeois and working class women changed and gave rise to notions which persist to the present time about women's roles in paid and unpaid work (Zaretsky: 1982).

Nisbet (1966: 77) notes the strong moral connotation of *Gemeinschaft*. The traditional community was associated with all that was good - love, loyalty, honour and friendship. *Gesellschaft*, in Tonnies eyes, since it lacked the fundamental or 'natural' basis of *Gemeinschaft*, was less humane. The morality of traditional community was derived from Tonnies premise that 'natural' will, out of which *Gemeinschaft* evolved, was female; while the rational will of *Gesellschaft* was essentially male (Tonnies: 1957 (1889): 103). Tonnies elaborated on the mental processes and affective states associated with each will, as well as the different kinds of social organization they produced. The unions and associations of *Gemeinschaft* were based on liking, habit and memory which,

In turn, give rise to kinship, neighbourhood and friendship. Gemeinschaft was epitomized by the family, village and town, and its main occupations were home, agriculture and art. In contrast, Gemeinschaft relationships were motivated by special interest, especially those based on exchange or labour. The city was the setting for Gesellschaft, and its predominant forms of work were trade, industry and science.

Tonnies' view of traditional community took no notice of difference based on class or gender. Although it is now generally accepted that Gemeinschaft life was greatly idealized, the understanding of women and their work in it not far-removed from the dominant ideas about women at the time Tonnies wrote. The description of Gemeinschaft work as natural, a calling and its own reward, helped to perpetuate those ideas. Tonnies used 'the community' to diagnose the harmful effects of urban-industrial society (Plant: 1974: 24). 'Community' meant for him fixed modes and hierarchies of status and/or power based on shared traditions and values. Community was thus static orderly and conservative (Plant: 1974: 24).

A Note on Marx and 'Community'

Marx did not favour a return to the traditional community, the relations of which he held to be hierarchical

and rigidly oppressive. He saw the demise of traditional community as a necessary condition for the development of capitalism which, in turn, would give rise to a world-wide community of workers. As well, 'the community' might play a limited part in advancing socialism - an idea elaborated upon more by Engels (Nisbet: 1966: 67).

Marx stated his views clearly in 1853 when he wrote about the effects of British occupation on traditional communities in India. He acknowledged the social disorganization produced by the occupation but also cautioned against romanticizing social relations that had served to limit the development of individuals in those communities.

"We must not forget that these little communities were contaminated by distinctions of caste, and by slavery, that they subjugated men to external circumstances instead of elevating man into the sovereign of circumstances, that they transformed a developing social state into never changing natural destiny" (Marx: 1853 in Nisbet: 1966: 68).

While Marx correctly identified the more oppressive aspects of traditional community, he did not take into account how the social relations of community might be particularly oppressive for women. That is, since their work and experience were subsumed under that of men, the social transformation he envisioned would not benefit them, as long as family life in

which their work consisted of personal service to individual men, was a building-block of that community.

COMMUNITY AS IDEOLOGY - THE 20TH CENTURY

The 19th century understanding was carried forward into the 20th century. I will set out below what the transformation of community from 'notion' to 'ideology' appears to have embodied:

COMMUNITY AS NOTION

1. Community separate from the household and distinctively social and political.
2. Community denotes reciprocal relationships from which all of its members benefit.
3. Community means men since they dominate in the organization of (1) and (2).

COMMUNITY AS IDEOLOGY

1. Community separate from the household and distinctively social and political but women seen to create its affective relations. Men increasingly separated from the local and particular by their work.
2. Community denotes reciprocal relations but these are organized by gender, i.e. men and women play different "roles". Women's relations material.
3. Community means men and women but men continue to dominate in the organization of (1) and (2).

As Elizabeth Wilson (1982: 42) notes, "the view of village 'community' and urban 'society' as mutually incompatible migrated to the sociology of the family...". This is essentially correct although Wilson does not explain how that happened. I have attempted to show how textual work does not simply represent a set of ideas. It co-ordinates local historical processes that are separated from each other and thus organizes, or provides for social organization. Peoples lives are mediated by textual work, even as their lives are the subject of that work.

I am not, of course, suggesting that the textual work on community created a lesser position for women in the community. When looking at the 20th century discourse on the subject, it is important to bear in mind what had been happening to the understanding of womens' work in the home from the late 19th century on, mentioned already. The view of motherhood as a 'career' in this period was the result of the writing of 'experts' in a number of areas. As well, women themselves, especially middle class women were anxious that the 'unique female' qualities associated with motherhood be recognized as an important force for 'good' in the world. Middle class women were active in promoting the study of children and domestic science, and passed these ideas on to working class women (Lewis: 1986: 10).

Functionalism

After World War II, the welfare of the child was linked more and more to the character of family relationships. The concept of familial roles in which the man was the breadwinner and authority and the woman played the part of nurturer and subordinate was represented as psychologically beneficial for both children and parents (Smith: 1983: 11; Riley: 1983). Motherhood became a challenging and all-engulfing activity (Ehrenreich and English: 1979: 209). This work was understood as private, that is, separate from the public sphere of men's economic activity, as can be seen also in policies of the welfare state during this period.

Sociology and social work played significant roles in these developments - sociology providing the theoretical framework and social work the application of it. In both areas there was a further conflation of family and community as the result of functionalist theories of society. This theoretical perspective dominated sociology after the Second World War. Functionalism accounted for social organization on the basis of a model of the interaction of the component parts of society and the relationship of the individual to these (Morgan: 1975). Since functionalism presupposes a necessity for consensus and integration toward which all of the parts are directed, the model concerns itself with order (Ibid.). Nowhere is this more

evident than in the work done in sociology of the family. Although the usefulness of functionalist analysis has been challenged in recent years, it has remained the dominant perspective in the sociology of the family (Morgan: 1975: 19).

In functionalism, the individual's life is understood in terms of roles: role theory has played a key part in the development of social theory in general and in the sociology of the family in particular (Morgan: 1975: 54). There are two main schools of thought. The first emphasizes roles in terms of positions in the social structure, the way in which these positions are articulated into the social system and the way in which individuals are selected for or socialized into these roles. The second approach focuses more on the actor in the role. Both perspectives emphasize the constraints on human conduct and have an affinity for functionalism. Neither role theory nor functionalism examines the historical source of such constraints and (thus), the possibility that roles (or society itself) can change (Morgan: 1975: 54-55).

Parsons

Talcott Parsons is frequently represented as the modern theorist of the family (Morgan: 1975: 25). He attempted to organize and analyze a wide range of topics associated with the

family within the functionalist perspective. Parsons' idea of functionalism admitted to the possibility of change for the family (to the extent that this served the wider system). He argued that while the family had lost some of its past functions, it had acquired new ones adapted to the requirements of industrial society. Morgan (1975: 26-38) identifies the major themes in Parsons' work on the family as follows: (1) the functions of the family; (2) its relative isolation; (3) its structure; (4) the socialization process within the family; and (5) sex roles. I will consider these in a general way as they relate to his understanding of community and the implications for women in the family and in the community.

Parsons and Bales (1956) conceptualized the changing functions of the family in two ways. First, by assuming that the family was virtually without function in terms of the wider society: (a) it no longer operated as a productive unit; (b) it was not a significant unit in the political power system; (c) it was not a major direct agency of societal integration as, for instance, schools were. While members of the family continued to participate in society according to their roles as workers, citizens, and so on, they did so as individuals rather than as members of a family contributing to society in the above three ways. The second point, arising out of the first, posited the idea that the family functioned on behalf of "the personality" rather than on behalf of the family as a unit in

society. Its major tasks were the primary socialization of children and the stabilization of adult personalities.

Elsewhere Parsons (1954(b)) argued that since the kinship system of the (American) family had no clearly marked out rules of descent, involved the establishment of new households and was rooted in the marital relationship between husband and wife, the chief obligation of the spouses was to each other and their children. He considered this arrangement well-suited to the needs of modern industrial society where the demands of "occupation", constituted its most powerful determinant.

Parsons derived the functions of the family from Bales' work on small groups. Bales' research suggested that: (a) some people take on a leadership role in groups while others take on more subordinate roles; and (b) that groups are also differentiated on the basis of function (activity). Goal attainment and the adaptation aspects of the group process were designated as instrumental activities while the management of the integrative and tension aspects of the group were identified as expressive activities (Parsons and Bales: 1956). Parsons attempted to show in his research that the nuclear family reproduced these specialized functions in the form of female expressive roles and male instrumental roles.

Parsons had been developing a theory on sex role structure for many years. This analysis is crucial to his

argument concerning the changing functions of the family; it assumed that male/female 'roles' based on the instrumental/expressive axis replicated the biological divisions between the sexes (Wilson: 1982).

Parsons' (1954(a)) argued that there was little difference in the treatment of children except when it concerned "future" sex roles. Girls learn their future adult roles earlier than boys because they see what mothers do and model the behaviour. Boys do not have the same opportunity, as a father's work requires him to be absent from home most of the time. Parsons (1954(a): 90) pointed out, however, that boys would not necessarily profit from watching their father's work as this work was 'abstract' and beyond their understanding. (This comment is indicative of Parsons' middle class view toward mens' work - working class mens' work is not abstract - and also indicative of his view that womens' work was 'natural'.)

Parsons saw little difference in education of the sexes either, up to the level of graduate or professional study, where the focus was more immediately connected to a career and was determined by individual ability or 'class'. He believed that the small number of women who went on to advanced study was due to the fact that higher education was not useful to them in their roles as wives and mothers. There were, however,

positive benefits in a liberal education for women as it enabled them to generate and perpetuate "generally human patterns and values", particularly in "informal social life" and in the realm of "community participation" (Parsons: 1954(a): 92).

The distinction in sex roles became fully realized in adult life. Men got jobs and women took on "a domestic pattern with marriage and the arrival of children" (Parsons: 1954(a): 94). A man's self-esteem and public reputation were contingent upon his ability to earn a living and provide income and class status for his family. The 'pattern' for women differed in that most did not work after marriage or, if they did, took up work that did not place them in competition with their husbands (Ibid.). Career women, according to Parsons, were usually unmarried. When married women combined career and family, it resulted in a "profound alteration in family structure" (Ibid.).

A woman's fundamental status in an urban setting was that of "her husband's wife, the mother of his (sic) children and, traditionally the person responsible for a complex of activities in connection with the management of the household, care of the children..." (Ibid.). Parsons concluded that the structuring of adult sex roles was rooted in the "inter-relations of the occupational system and the conjugal family"

(1954(a): 95)... He theorized that the emphasis on male occupational status was the principal cause of strain in sex role structures. Women were deprived of the opportunity to be partners in a common enterprise with their spouses, and the boundaries of their lives became those of the family itself, and the informal social practices associated with it. Household management was a "pseudo-occupation".

Parsons correctly identified women as the casualties of modern capitalism in that their former, more obviously productive, role in the family had been eroded. Their new roles did not compensate for the loss of status associated with their earlier roles. Parsons' believed that women sought other means of fulfilling themselves, among them the cultivation of cultural interests or the cultivation of interests in "humanitarian obligations in community welfare situations" (1954(a): 97).

Although Parsons' was clearly referring to 'middle-class' women going out of the home to do 'community work', his discussion illustrates how he built on the earlier textual work on community. He argued that the work women did in 'the community' was of benefit to society generally. First, men had little time or energy for 'community' owing to the demands of their work. Second, men were more likely to devote themselves to work-related activities and organizations rather than to

more humanitarian ones, unless their prominent position was used to add status to these efforts (1954(a): 97). Parsons noted that men are devoted to things that divide the community rather than to those that unite it (1954(a): 98). Women, on the other hand, were more closely tied to the local residential community and were more apt to be involved in matters of common concern to its membership.

"It is understandable that many of these orientations are most conspicuous in fields where through some kind of tradition there is an element of particular suitability for female participation". (1954(a): 97, emphasis added).

He elaborates on this:

"...women who take obligations to social welfare particularly seriously will find opportunities in various forms of activity which traditionally tie up with women's relation to children, to sickness and so on" (1954(a): 97).

Once again, Parsons' perceptions are accurate, however his presentation of these as inevitable is problematic. This view of 'Womens' work and experience 'at home' and 'in the community' provide for a particular understanding of women's lives as static and also outside the sphere of mens' work and experience. He never questioned why women's work in the community should take the form of care for those who were dependent.

LOUISE

"My daughter is not able to care for herself when she menstruates. When she's having her period, I just never go out in the evening or anything like that because that's one thing my husband really draws the line at. I could go out - he says he'll look after her - but I don't go".

MARY

"She needs help bathing. Now that she's developing more, my husband wants to do less things for her - like he doesn't bathe her (anymore). I guess he would do this if I was away, but I just don't be away on a night when she needs it".

IRIS

"Patti has not started to menstruate yet... although her brother and my husband help with toileting now, the brunt of her hygiene, of course, is going to fall to me as bathing and showering do now".

The ambivalence the women feel about having to take on more work or having their freedom curtailed is apparent in what they say. At the same time, they defend their partners by arguing that the withdrawal of support is a logical outcome of normalized living for retarded individuals; that it would be inappropriate for a father to bathe a non-handicapped daughter that age. While reluctance to do this work can be taken as an indication of an awareness of certain cultural proprieties, the same 'awareness' does not apply to women when the situation is reversed to the care of a sexually mature son. Although Angie's sons are still quite young, she takes for granted, at least by implication, that she will continue to care for their personal needs as they get older.

3

MICROCOPY RESOLUTION TEST CHART
NATIONAL BUREAU OF STANDARDS
STANDARD REFERENCE MATERIAL 1010a
(ANSI and ISO TEST CHART No. 2)

Parsons (1960) identified certain principal structures essential for the existence of community, among them 'home' and 'work'. Although each had a different function and location, they could only be understood in relation to each other. Home represented the more informal aspects of community - the place where people could be themselves and have the opportunity "to play certain roles which are at least not so prominent...in other places..." (1960: 253). Work locations referred to (men's) paid work. Paid work provided for the existence of the informal community. Interestingly, Parsons also noted the intersection of different kinds of work in the community.

"From this point of view, the 'local community' is, in one aspect, in a society like our own, primarily organized about the complex network of relations between places of residence and of employment of its adult population (and schooling of its children) (p. 256).

Parsons' work on family and community is reminiscent of Comte and Tonnies. From Comte, the idea that men's work in the 'public sphere' has special value and makes the intimate community characterized by the family possible; from Tonnies, the idea that true community was not only located somewhere but was also a state of mind - especially when it involved reciprocity, and that it was 'natural' to women. Wilson (1982: 42) comments on Parsons:

"...the womanly or motherly role is equated with various 'good' characteristics of family and community life, such as warmth, feeling, stability, intimacy and enduring relationships. The man, however, out in the world of commerce and industry partakes of the characteristics of the world he inhabits...these two sets of attributes come to be associated with the 'essential', 'natural' and 'biological' differences between the sexes."

Social Work

Wilson (1977: 27) argues that the ideology of the welfare state expresses itself above all in what is written about social work and social workers - "the literature of social work is the ideology of welfare capitalism". It is ironic, that early social work based on a need for social reform was to become highly individualistic (if we consider the mainstays of practice - casework or the preservation of the family). It is not within the scope of this paper to take up in detail the history of social work practice. It cannot be forgotten, however, that it had its origins in the social reform movement of the 19th century, and that that movement was fuelled by middle and upper class women (Brandwein: 1982). As Brandwein notes, the 'giants' of social work - Jane Addams, Dorothea Dix, Octavia Hill, and Mary Richmond, to name only a few - are all, women. They turned their reform efforts to public health, slum housing, child labour, women's protective legislation and so on. Social action in 'the community' was an important part of

their work (Brandwein: 1982). The notion that the poor or other special groups could be helped to become economically self-sufficient members of the community was integral to this enterprise.

In the main, social work practice has been directed toward helping people adjust within capitalism rather than challenging the unequal relations of capitalism that give rise to particular 'social problems' in the first place (Mayo: 1975). Thus social work practice tends in general to be 'conservative' although individual practitioners may not be. The trend toward grass-roots organizing or 'community work' in the sixties and seventies was seen as a radical departure from the highly individualized and psychoanalytic emphases of earlier social work practice. It was intended to facilitate local control and accountability in areas such as housing, education and health.

It has become increasingly clear, however, that while community work can be instrumental in getting people's needs met, it is unable to challenge the 'status quo' (Corrigan and Leonard: 1978). Community workers and community programs are usually state funded and, it is obvious that this work meets the needs of the state, especially over the long-term, more than it meets the needs of the members of the community. Cockburn (1977) points out that 'the state' needs 'the family'

and 'the community' as structures through which it can carry out its work. The promotion of 'community care' for various dependent groups can be seen as an example of this structuring process.

Various aspects of community care are facilitated or monitored by social workers. As well, they are usually responsible for the 'relational' work done with the dependent person's family. Their 'ideas' about family and community are important because these will generally inform what they 'do'. Bryson and Mowbray (1981: 255) were interested in accounting for the extensive use of the term 'community' to describe government social programs in Australia since the 1970's. They began their analysis with a literature review that dealt with community in general and community work practice in particular. They discovered an "amalgam of vague formulations and selective perceptions". The authors argue for a careful analysis to distinguish between the descriptive and evaluative elements of the term. They state that a recognition of this difference is crucial precisely because community "is one of those 'motherhood' words" (Bryson and Mowbray: 1981: 256). Indeed, 'motherhood' may be among its organizing concepts in some instances!

As already noted, the gross inequalities of the traditional community are lost in the textual accounts,

providing for a way of understanding it in terms of its positive attributes only. This conceptualization, taken to its logical conclusion, implies that reviving or regenerating the primary social relations of community will improve the conditions of people's lives without challenging the exploitative or oppressive organization of the society itself. Moreover, the conflation of 'family' and 'community' reinforce the belief that 'the family' is the "repository of pre-capitalist values" (Barrett and McIntosh: 1982: 27).

It is possible to see how certain forms of care in the community might become equated with care in the family and how care in the home would then be seen to be preferable to care elsewhere, especially when children are involved. This train of thought is prevalent in social work literature dealing with care of children whose special needs go beyond 'the ordinary'. The following statement appears in an influential book on home-based services for mentally and/or physically handicapped children.

"The inherent integrity of the family as the primary care system must be at the core of social policy development, and there must be built-in safeguards against harm to that system... (because) nothing takes the place in our lives of the oldest institution known to man (sic): the family" (Maybanks and Bryce: 1979: 11).

The contributors to the collection on home-based services mentioned above are a highly respected group of social workers, psychologists and educators known as the National Clearinghouse for Home-based Services to Children. The expert reputation of the Clearinghouse ensures that the book will be read by people whose work brings them into contact with disabled children as well as by special interest groups who keep abreast of trends in 'care' and even by some parents. This book is also cited in certain Ontario government documents on home-based care for children with special needs. Its circulation among these various groups is an example of how the work of one part of ruling apparatus - here as the developers of these ideas - is picked up and incorporated into other forms of ruling work such as that of provincial governments.

The intent here is not to devalue the love, concern or unconditional acceptance that characterize the family ties referred to in the work by the National Clearinghouse for Home-based Services. On the other hand, the valorization of family life apart from the larger context obscures how family life is shaped by that context - a context in which class, gender and race form a constitutive part. As I have tried to show, any analysis or understanding of the family that does not take account of the position of women in the family is not only incomplete, but inseparable from certain practices that reinforce their subordinate position there. This is precisely

the piece, however, that is dropped out or glossed over in the textual work on community and that we see perpetuated in the above statement. As Zaretsky (1982: 193) observes:

"It is a tragic paradox that the bases of love, dependence, and altruism in human life and the historical oppression of women have been found within the same matrix."

SUMMARY

I have examined selected works on 'the community' from 19th and 20th century sociology to locate the determinates of the term, and to point out how its attributes make it a powerful descriptor for care. The fact that these ideas about community are not consistent with the lived experience of it as a socially organized phenomena has special implications for women. The understanding of their work/experience as 'natural' has reinforced the idea that women's labour in the home is not 'real work'. The conflation of community and family in textual work contributes to the invisibility of women in the community.

In Chapter Five, I will provide a brief historical overview of care of retarded people, with special emphasis on the Province of Ontario. I will also show how the families of retarded people have played a part in determining government practices in recent years. It is possible to see here how an

ideological understanding of community informs government practice on care of retarded people as well as the activities of families working on behalf of their handicapped children.

V HISTORICAL BACKGROUND: RETARDED PEOPLE,
THEIR FAMILIES, 'THE STATE'

INTRODUCTION

During the middle ages, the care of poor, sick or other dependent individuals was organized on the basis of kinship, and, as mobility was limited, also on the basis of locality. The church provided piecemeal support in the form of alms or hospice, for those who had no kinship ties. There was, however, no systematic attempt on the part of the church to match material help with need (Scull: 1984).

The transition to wage relations over a period of time gave rise to an ever-growing number of people unable to provide for themselves or dependent kin. The need of labourers to seek out and follow work caused them to be separated from their 'families'. As well, the belief that payment of a wage constituted an owner's sole obligation to the labourer served to weaken the reciprocal bonds that had existed between classes and which had served to organize the relations between them in a predictable way, which included the care of those unable to care for themselves.

By the 17th century, the need to deal with the poor, a category that included the insane, criminals and so on, became an issue for 'the state' in Britain. The Elizabethan Poor Laws were an early attempt to systematize care and/or control of this group (Scull: 1984). The Poor Laws provided for the

creation of workhouses, which segregated some of the more 'troublesome' elements of the population. People worked in return for their 'care' (subsistence). Workhouses also served to distinguish between the 'deserving' and 'undeserving' poor. The latter included those it was believed could work and, therefore, should work. The workhouse and other specialized institutions for care that developed from it represented a departure from earlier 'outdoor relief' whereby dependent people, in particular, were supported wherever they lived through various allowances.

Settlers to the 'new world' brought the 'Poor Laws with them'. According to Scull (1984) the American colonies enacted Poor Law legislation very early on. At the same time, however, there is considerable evidence to indicate that the actual care of dependent people resembled older and more communal forms more closely (Zaretsky: 1982; Scull: 1984). As time went on, however, various kinds of public institutions such as jails and asylums were used to provide care, and by the late 18th century, these public institutions were overcrowded in both Canada and the United States. There was a growing demand, especially from local municipalities to higher forms of government for the provision of more facilities and to assume the costs for these. The population in public institutions continued to be a mixture of people who were unable to fend for themselves in society such as the insane or retarded (between

which very little distinction was made); the poor; and criminals. Initially, all such individuals were considered to be dangerous whether they were or not. Throughout this period in North America and Europe, there was a genuine fear that these 'dangerous elements' of the population were a threat to the existing social order, that is, that they would revolt against their miserable existence (Scull: 1984). Local municipalities, therefore, were primarily interested in containment rather than in distinguishing between the various 'presenting problems' of individuals.

The almost insatiable need for workers created by expanding markets in the 18th century, as well as a growing belief that the poor or insane could be rehabilitated by various 'treatments', gave new importance to determining which individuals were able to profit from these approaches, and which were not (Scull: 1984; Rothman: 1980). The growing importance of the notion of rehabilitation itself was due, at least in part, to the belief that the application of scientific principles in one form or another, could provide solutions to the difficulties in people's lives or the mental states they gave rise to (Zaretsky: 1982).

The asylum itself represented the model for a new kind of community, meaning here that asylum organization was increasingly modelled on 'family life' (Zaretsky: 1982).

Asylum inmates who mastered work skills were considered cured or rehabilitated and were released. Those who were unable to learn would be cared for, but in such a way that people on the outside, who were barely surviving, would not be tempted to see that care as a viable solution for their own situation (Scully 1984: 129). At this point, the care of retarded people began to be distinguished from that of the insane who were considered better candidates for the various cures and training programs that had evolved (Simmons: 1982).

CARE OF RETARDED PERSONS IN ONTARIO BEFORE WORLD WAR I

In Upper Canada, the first government activity to affect retarded persons was indirect and came in the form of legislation to deal with 'lunacy' in the late 1830's (Simmons: 1982). Lunacy laws were enacted for the express purpose of separating the poor from those who suffered some form of mental disability. The government by this time had indicated at least a minimal willingness to provide long-term care, in the form of physical accommodation, for those who were bound to become their responsibility because they had no kin willing or able to look after them. It was much less willing to finance the same arrangements for those who might be capable of paid work. The following statement made by a provincial inspector in 1865

indicates just how important it had become, to distinguish between 'curables' and 'incurables'.

"Society or the state may justify, even on the most selfish and economic grounds the expenditure of public monies in providing buildings and everything else necessary to aid in the work of restoring its insane members to reason. She is thus adding to the number of workers and diminishing the number of non-workers in the community" (Simmons: 1982: 15).

At the same time, however, a subtler distinction was being made among the 'incurables' on the basis of whether they were dangerous, and thus a threat to the general population, or whether they were merely 'helpless'. Another provincial inspector said:

"...(idiots) can as well be taken care of in the private family, as in the public institution. For the one the asylum is a necessity, for the other it is made available as a convenient means of riddance" (in Simmons: 1982: 13).

Clearly care of the 'helpless' was already understood as a problem for which the government preferred to have no responsibility. At the same time, it is also evident that the alternative to government-sponsored or public care was understood to be a family responsibility, and seems indicative of how 'family' and 'community' were understood as 'one in the same' in this instance. That is, the work of providing care was part of 'the family's' work.

During the 18th, 19th and early 20th centuries, institutions offered the most convenient means of providing basic subsistence for some dependent people. Ideas about the rehabilitative or curative aspects of asylum care, so prevalent in dealing with the insane were not as influential in care of retarded people as they were thought to be incurable.

CARE OF RETARDED PERSONS IN ONTARIO AFTER WORLD WAR I

According to Simmons (1982: 88), between 1901 and 1920 the population in Ontario increased by 34%, while between 1891 and 1921 its urban population increased by 108%. This growth in population as well as its shift to urban areas strained public resources to the limit. Jails and asylums continued to be used for the care of poor people who were disconnected from 'family' or whose families could not provide for them.

Although by the 1920's the idea of feeble-mindedness as a menace (the eugenics scare) had been recognized as 'unscientific', institutions for the retarded continued to be overcrowded. The depression forced major cutbacks in government spending on social welfare programs generally. In 1916, the total expenditures for all mental health facilities, including those for the retarded, amounted to 17% of the provincial budget. By 1930, that figure had dropped to 7%.

(Simmons: 1982: 142). All provincial hospital construction and capital improvement work was suspended by 1934 (Simmons: 1982: 143).

After the depression, the notion of home-care of retarded children in Ontario began to be discussed as a benefit to the child. One of the main proponents of the idea was B.T. McGhie, superintendent of the oldest and largest retardation facility at Orillia. In a work entitled Training and Research in a Hospital for Subnormals (1929), McGhie argued that the needs of retarded children were not dissimilar to those of other children and thus could be met within the family, especially if the specialized services the child required were made available through existing services in 'the community'. He did not advocate the closure of institutions, but saw them assuming more of a back-up role - institutional placement becoming a last, rather than first resort. To be sure, McGhie's ideas would have taken some of the pressure off superintendents like himself who were caught between the demand by families for more institutional care, and the demand of the government to reduce the costs of institutional care (Simmons: 1982). His views, however, were not merely self-serving or aimed at pleasing his superiors.

It is probable that the majority of retarded people, including children, who lived in institutions during the 19th

century and first half of the 20th century, were not that handicapped. The most severely disabled usually died in infancy or early childhood as a result of the physical disorders that often accompany severe mental handicap, and for which no medical treatment existed at that time. Although care of retarded people was not seen as amenable to medical treatment, it had come to be dominated by the 'medical model'. That is, institutional care was understood to be preferable to care in the family because it was organized and supervised by physicians or other allied professionals. Thus families were increasingly advised as a matter of course to place their retarded children in institutions, regardless of their willingness or ability to keep the children at home - especially in the early 20th century. The fact that the 'expert' care of institutions simply amounted to custodial care did not emerge until after the second world war when developments in psychology, particularly, challenged the wisdom of the custodial model.

McGhie's observations about the benefits of home care for retarded children were most likely applicable to many of the young residents at Orillia. His conflation of the terms 'family' and 'community' are apparent, however. For example, he wrote in the Canadian Public Health Journal:

"...the problem of the subnormal appears to be essentially a community problem - one which must be faced and dealt with by the community" (in Simmons: 1982: 126).

His methods for involving 'the community', actually relied on the efforts of the individual family. One of his most significant innovations was the establishment of a home-training program carried out by social workers and public health nurses who visited families on a regular basis to teach them how to care for their children. McGhie wrote in 1937 that after taking part in such training programs, families who were 'initially frantic' to have their children placed in an institution no longer felt that way when they saw how effective the programs were in helping the child become more independent. Undoubtedly the home-training program was useful to many families, however it is also possible to see how the on-going program maintenance assumed the availability of 'someone' in the home. McGhie, in describing actual cases, frequently referred to the "guidance of mothers".

McGhie's ideas about child training and the responsibility of mothers for this reflect the more general views of the time. There continued to be an emphasis in this period on developing the expertise of all mothers. The implications of mothers deferring to 'experts', however, was not an issue at this time, either in terms of its effects on the women - whose own knowledge about their children was ignored -

or how, when the experts were actually state employees, their relationship to the women and children were shaped by the state's priorities. Women were teaching themselves and being taught to recognize their experience and work in the home more and more in line with the understanding of experts. They endeavoured to raise their children, maintain their homes and so on, in accordance with that expert understanding (this was true whether their children were handicapped or not) (Wilson: 1977; Smith: 1979(b); Lewis: 1986).

This acceptance of expert advice has continued, with the education system as a major point for its dissemination as education becomes more and more the stepping stone to social and economic advancement. The understandings of appropriate child-rearing and mothering are rooted in ideological notions of community and family life and serve not only to organize women's paid and unpaid work, but their understanding of what they do as an appropriate expression of love or interest in the child (Smith: 1983(b)).

In light of this it is not surprising that the first group of parents of retarded children in Ontario, formed in 1948, was organized for the express purpose of making the Department of Education aware of the educational needs of those children not eligible for admission to auxiliary classes (established at the turn of the century). It had a core at

that time, according to Simmons (1982: 151), of "articulate professionals". Simmons is referring here to parents themselves. The persistence of old stereotypes that retardation and poverty necessarily occur together obscures the fact that mental handicap 'cuts across class'. A central point in the arguments put forth by the Parent's Council for Retarded Children, the name which the group took, was that school attendance would not only benefit the child, but would enable many families to keep their children at home rather than place them in institutions for training. Thus, the argument for increased educational opportunity was tied to the idea of home care but was put forth most vehemently at that point by families who could 'think about' and understand the child-centered theories of the period and who had the material resources to put them into practice.

The Council was successful in its efforts. The Department of Education provided funding for local associations to operate their own schools which were frequently staffed by mothers (Simmons: 1982). By the early 1950's parent's councils had sprung up across the province and amalgamated into the Ontario Association for Retarded Children (OARC) with a membership of approximately 900 members in local associations for the retarded. The rapid growth of the 'parent movement' in only a few short years and its success in getting the Ontario government to listen to its demands indicates the degree of

dissatisfaction with institution care among some families. It also attests to the skill and ability of the core membership to argue its position to the government as well as develop, at least to some extent, the understanding of government organization and practice necessary to do this. Families began to demand services from the government as a right owed to their children, rather than as an act of charity (Simmons: 1982: 158), and in so doing drew upon the ideals for greater equality of the welfare state itself. It was assumed that mothers would facilitate the children's access to the hoped-for expanded service system, or to take care of the children's on-going physical or emotional needs. Indeed, the mother-child relationship was central to the enterprise. The mother's efforts on behalf of the child were not understood as work, however, but as a natural expression of maternal love or nurturance.

The state had a number of pressures to contend with concerning care of retarded children in this post-war period. It had acceded to OARC's demands around education and while this presented a moral victory for OARC, it did not involve any great sacrifice on the part of the Department of Education. As the 1950's progressed, the provincial economy flourished and there was no lack of money - especially for educational purposes. The fact that expanded public educational services might result in a lowering of admissions to institution seems

not to have made any significant change in the thinking of government or other professionals about the appropriateness of institutional placements for children generally.

Mental retardation facilities fell within the mandate of the Ministry of Health. By 1950 there were approximately 3,476 residents in retardation facilities, and over half that number were children (0-19 years of age). There were, however, 2,500 children under the age of 16 waiting to be admitted to Orillia alone that year! (Ontario Hospital Survey Commission in Simmons: 1982) Families often enlisted the help of their MPPs to expedite admission procedures. Even the expansion of education to a greater number of children did not substantially reduce the number of potential admissions to provincial facilities.

The government responded to these pressures by increasing the number of institutional beds. Rideau Regional Centre, a 2,000 bed facility opened in 1951, and a similar size facility was planned for the Windsor area. As well, another 300 beds for children were added at Orillia in 1951 and increased by a further 300 beds in 1955. The growing demand for institutional care reflected, in part, the increase in population after the war and a proportionate increase in the number of retarded people in the population. The growing demand also indicated, however, a continuing belief by some families that

institutional care was preferable to home care as well as an indication that institutional care was still being urged on some of them by physicians, social workers and so on (Simmons: 1982).

An OARC brief to the government in 1958 suggested that new space (for approximately 800 residents) be created in London. Looking ahead, the brief noted that the facility being constructed in the Windsor area as well as another planned for Goderich (1,200 beds) would not be adequate. It suggested that another three institutions of the same size would be required by 1966 to keep up with the demand from families (Simmons: 1982: 166). Thus the government was in receipt of very divergent opinions from families about how it could best support retarded children. There seems to have been a wide tolerance within OARC itself initially as to these differences, that is, it was assumed that members had their own good reasons for favouring institution or non-institution care.

During the 1950's despite concessions to families with retarded children in areas such as education, Ontario mental hospitals and retardation facilities were overcrowded, under-funded and understaffed, a situation not unique to them (Simmons: 1982). Similar conditions existed all over North America and Europe, and governments expressed increasing

concerns about the burdens of providing long-term care to all those who were thought to require it.

Studies were underway in several countries with a view toward learning more about the socio-economic characteristics of institutional populations and about the operations of institutions themselves, for example more efficient deployment of staff (Simmons: 1982; Scull: 1984). By the end of the 1950's, the cost of maintaining institutions had increased significantly just in terms of facilities that existed. Even more worrisome was the need to add on to these systems year after year. (The OARC proposal referred to earlier is an excellent example of the predicament many governments found themselves in.)

By the time the Ontario government became involved in review processes, there had already been considerable work done on the benefits of 'community treatment' for the mentally ill in Britain and Scandinavia, thus 'the community' was coming to be seen as an option for care - presumably with somewhat different overtones - as psychiatric patients were mainly adults. The results of the reviews in Ontario created another pressure for the government - one coming from 'the inside' as it were, but also bolstered by expert texts - to look more critically at the operation of its psychiatric and retardation facilities.

With a report entitled A Proposed Revision of Mental Health Programs (1958) presented to Dr. Matthew Dymond (Minister of Health) by the Deputy Minister of Health and the Chief of the Mental Health Division, the Ontario government began to articulate new mental health (and retardation) policies. Although the report argued for the 'therapeutic community' concept (Simmons: 1982: 163) most of its proposals centered around providing services within institutions. As for mental retardation, the authors actually suggested that the government speed up its construction projects! Interestingly enough, when Dymond took the report up in the legislature, it was the 'community' aspects of it that received the heaviest emphasis.

"We want to try now to completely reverse the old order, to begin treatment where it should begin - at the home level, and direct that treatment toward keeping the patient in, or at least near, his home community (Simmons: 1984: 164).

A few years later, The Roberts Report (1963) delivered a scathing indictment of the Department of Health. The report included a special brief on care of the retarded. Although this brief, written by a special committee from the Mental Retardation Branch, agreed in substance with the main body of the Roberts Report - that large institutions should house only the severely retarded, and that even these individuals might eventually be accommodated in smaller community-based

facilities - a different emphasis was placed on the role of the provincial government as well as the role of families. The brief suggested that the government form liaisons with 'the community' in order to facilitate the establishment of facilities and services by the community. A major thrust would be the role of government in maintaining the "integrity of the family" (Simmons: 1982: 174). The new emphasis on maintaining the family on the basis that the benefits of family/community life constituted an end in itself, differed sharply from earlier beliefs which had led to the encouragement or coercion of some families into seeking institution placements for their children, even as it castigated them for failing to assume their parental responsibilities of providing for the child's subsistence.

The authors of the brief listed some of the major reasons children were placed in institutions. These were a lack of 'community' facilities, 'broken homes', and 'unaccepting families'. Thus the brief focused less on retardation than it did on the 'social' factors that militated against care in the home. The preservation of families as a first step to getting children out of institutions did not necessarily imply, however, that the government planned to do everything in its power to make home care any easier for those who would provide it. In fact, time would show that preserving the family became a metaphor for a more and more limited government role, and

greatly expanded roles for voluntary agencies like local associations for the retarded, families, and by unstated assumption, for mothers who would give day to day care. Thus, the government saw the benefits for itself of the family as a site for long-term care. It was not yet convinced, however, that full-scale 'community' care, which would include the creation of appropriate support services/programs, was the answer either.

The British psychiatrist, B.W. Richards, a visiting professor of mental retardation at the University of Toronto at that time, stated that Ontario would need an additional 3 to 4 thousand beds by 1972 to keep up with placement requests (Simmons: 1982: 170). His work also supported the findings of the Roberts Report that a substantial proportion of institutional admissions involving children came from Children's Aid Societies, and were requested primarily for 'social' reasons. Inadequate resources at the local (community) level as well as family 'instability' were the two main reasons given by Richards for this phenomena. Thus the government received two major reports that suggested that not all of the children in institutions really needed to be there.

As a result of pressure from OARC (and the members of the legislative assembly) another interdepartmental committee was formed to examine mental retardation policy in relation to the

provision of community support on a life-long basis for retarded people. The report of this committee indicated that there already was a life-long support system through institutions and that it was not possible for the government to sponsor another 'cradle-to-grave' system elsewhere. The report flatly stated that it was "not feasible for the government to institute and operate comprehensive local services" (Simmons: 1982: 170).

Simmons states that there were a number of reasons for the rejection of a 'community' approach at this time: (1) the government was unwilling to commit itself to a potentially enormous investment (the parameters of which were not clear at that point); (2) localized services implied that local governments would become responsible to some extent for funding - services had not been funded by this means for over a century - and the Conservatives counted their strongest support in those areas that would be hardest hit by such an arrangement; (3) the government was still reluctant to get involved in the provision of major social welfare programs (beyond health and education) for any part of the population.

A Federal/Provincial Conference on mental retardation held in 1964 stressed that retardation was a social rather than health problem that required specialized measures:

"the particular duty of government should be to provide, directly or indirectly, a wide variety of specialist and supportive facilities to augment individual, family and community resources. It's major role is to assist in providing the mentally retarded and other socially handicapped individuals with an environment as rich and satisfying as that enjoyed by the rest of the community to which they belong. In doing so, the government should be careful not to usurp the responsibilities of parent, families and community agencies" (in Simmons: 1982: 181, emphasis added).

When Matthew Dymond presented the Conference report in the Ontario legislature, he called it a "blueprint" for government action. His willingness to consider community care seriously may have been prompted by the Federal Government announcement that it would no longer make funding available to the provinces for hospital construction (including mental retardation facilities) (Simmons: 1982: 182).

As it was, by the end of the 1960s, all of the commissions, committees and conferences had accomplished little toward making community care a reality, although the constant emphasis on the drawbacks of institution care and the positive aspects of community care were certainly being circulated among a wide variety of specialists and professionals, as well as some parents of retarded children. A number of pieces of legislation were passed to pave the way for expanded community services: The Vocational Rehabilitation Act (1966); the Homes for Retarded Persons Act (1966); and an amendment to the Secondary School Act (1967). At the same time, however, there

were only eight community residences operating in the province
- all of them for adults.

SUMMARY

I have provided a brief historical overview of the care of retarded people, with special emphasis on the Province of Ontario. I have also shown how the families of retarded people influenced government practice in the area of education for retarded children. In both instances, it is possible to see how an ideological understanding of community informed their activities, although community care was not yet an explicit course of action.

In Chapter Six, I return to the analysis of texts and will examine government documents that describe, promote, legitimate and organize care in the community.

VI TEXTS FROM GOVERNMENT: COMMUNITY AS RULING PRACTICE

"It is the belief that the mentally disordered have, for a long time been looked upon as solely and entirely a Government responsibility and the Department of Health does not agree with that thinking. Dr. Dymond himself subscribes fully to the modern concept which looks upon mental disorder as a community responsibility in which Government participates."

Premier John Robarts

INTRODUCTION

The major shift in government policy away from large institutions toward 'community' care for retarded people occurred between 1970 and 1980 (Simmons: 1982). A number of events in the 1970's served to make de-institutionalization popular with families as well as government. In this chapter I will make an analysis of selected government documents: formal reports and papers, media releases and program guidelines, to show how these documents drew on the ideological notions of 'community' set out in Chapter Four to mediate care of severely handicapped children at home, in accordance with the Ministry's priorities. I will also continue to 'fill in' the more important background information or context that gave rise to the documents.

COMSQC -- What's in a Name?

One of the most significant events during this period was the transfer of responsibility for retarded persons from the Ministry of Health to the Ministry of Community and Social Services (COMSQC). Although the transfer did not actually take place until 1974, a few comments are in order at the outset of this Chapter about how the Ministry acquired its name.

The Department was established in 1930, as the Department of Public Welfare. Its main task during the depression years was the provision of unemployment welfare. As time went on, the Department acquired the responsibility for mother's allowances and child welfare, a rapidly expanding area of social services.

Williams (Ontario Ministry of Community and Social Services: 1984(a)) points out in his history of the Ministry that it was not known for financial generosity or a particularly kindly attitude toward the people it served in those early years. The Department acted on the basis of a 'residual' policy model - offering services only when family or private structures had broken down, and then, providing the minimum. The Department's attitudes were consistent with general beliefs about dependency that held sway until after World War II. By the end of the war, the Department of Public

Welfare included in its mandate old age pensions, mother's allowance, soldier's aid, children's aid societies, homes for the aged vocational rehabilitation and day nurseries (Ontario Ministry of Community and Social Services: 1984(a)).

It would appear that the Department's expansion and consolidation, from approximately 1950 to 1970, involved a change in its practices as well. In keeping with the development of the welfare state elsewhere, for example in Britain, its policies although not explicitly aimed at families came to be based on certain assumptions about the nature of relationships between the sexes and generations (Land: 1978: 257) in which certain 'normal' or 'natural' patterns of dependencies and responsibilities were understood to exist. In keeping with the ideological notions of 'family' and 'family life' worked up by sociologists and others and put into practice by social workers, the increased government intervention into families which resulted came to be understood as a progressive move that would benefit all family members. In 1967, the Department of Public Welfare changed its name to the Department of Social and Family Services. This change seems indicative of the Ministry's desire for a more 'progressive' and less stigmatizing image than that conveyed by the term 'public welfare'. It is questionable, however, whether the new name indicated a change in practice, as the residual attitude toward provincial welfare policy persisted.

The Ministry, as government departments came to be known, was renamed Community and Social Services in 1972. The substitution of the term 'community' for 'family' suggests more of a 'partnership arrangement' between government and individuals. Presumably the renaissance in community work and approaches during the 1960's and 70's was in some measure responsible for this, however it can also be seen as one point where the ideological organization of the state and family get more and more alike.

To continue now with a discussion of the more specific factors related to community care of the retarded, the following appear to have had special significance during the 1970's (Simmons: 1982).

SIGNIFICANT EVENTS - 1970 TO 1980

The Canada Assistance Plan

The Canada Assistance Plan (CAP) was introduced by the Federal government in 1966 to provide 50% reimbursement for provincial social assistance costs to persons "in need". The program replaced a number of separate programs such as old age assistance, disabled persons allowance, and so on. Only 'non-institutionalized' individuals were eligible. Retarded

adults living in the community who received disabled persons allowance were automatically eligible for CAP funds whereas residents in institutions were not. Each province continued to remain responsible for funding its institutions.

In the late 1960's, the province of New Brunswick set a precedent by transferring the responsibility for institutionalized retarded persons from its Ministry of Health to other ministries in order to meet Federal government criteria for access to funding (Simmons: 1982). The possibility of using Federal funds to expedite much cheaper community care was understandably attractive to provincial governments.

The Re-definition of Retardation

Both Bengt Nirje and Wolf Wolfensberger, the individuals most closely associated with the promotion of normalization (see Chapter One), worked in Ontario in the early 1970's. Nirje, the former Executive Director of the Swedish Association for Retarded Children, was hired as a consultant on mental retardation policy by the Ontario government. Wolfensberger was appointed Visiting Scholar in Mental Retardation at York University, under the auspices of the National Institute on Mental Retardation.

Wolfensberger, in particular, became well known in Canada. His position at York provided ample opportunity to acquaint students, (often people already working in the field of mental retardation) with his philosophy of normalization. As well, he spoke to parent groups and acted in an advisory capacity to the Board of Directors of OAMR. According to Simmons (1982: 196) "Wolfensberger had a profound effect on those who came in contact with him, with many people speaking of being 'converted' by his views".

While Wolfensberger found much to criticize in the traditional, government-funded services to retarded people and their families, he maintained that government could be made to conform to a new humanized and normalized perspective.

The Williston Report

Walter Williston, a well-known Toronto lawyer, undertook at the request of the Ontario government in 1971, an investigation into the arrangements for care and supervision of mentally retarded people in the province when they were not under the direct custodial care of the government. The investigation was sparked by the death of one male resident released from Rideau Regional Centre on a temporary basis and the near death of another male who had been discharged several

years before into foster care. Both incidents received considerable attention in the media and provoked a series of questions in the legislature about the follow-up procedures used by retardation facilities after residents were returned to 'the community'. Williston's report, which will be examined in more detail later, served as a catalyst for the de-institutionalization process.

The Transfer of Ministerial Responsibility

This transfer took place on April 1, 1974 with the enactment of the Developmental Services Act. At that point, the administration of provincial retardation facilities came under the COMSOC mandate. As well, all residents of psychiatric facilities with a primary diagnosis of mental retardation became known as 'residents' rather than 'patients', thereby allowing the use of CAP funding for their care. The Welch Green Paper that laid the groundwork for the transfer will be examined. These developments are not merely 'historical events', for they were shaped by 'ideas about' the benefits of 'community living' rather than the lived experience of it, which in turn became a course of government action.

I want to look at two major documents of the early 1970's - Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario, also known as the Williston Report

(1971); and Community Living for the Mentally Retarded: A New Policy Focus (1973), also known as the Welch Green Paper - in light of the criteria set out in Chapter Two.

EARLY DOCUMENTS

The Williston Report

I have already described the immediate events that prompted the report. It appears that the government was well aware of the possible impact Williston's work could have, given the circumstances for its writing. A.B.R. Lawrence, Minister of Health at the time, issued Williston with a set of instructions for proceeding.

- "While these two specific cases have pinpointed our concerns in this area, they do more than that. They indicate far more significant and very topical issues of a general nature relating to the whole area of treatment and care of the mentally retarded".
- "While I have asked Mr. Williston to look into both of these specific areas, I have emphasized to him that I want him to provide us with some clear direction as to both government and public responsibility towards such persons".
- "I have chosen an experienced lawyer to undertake this study because he has both the training and experience to analyze the factual situation of these two specific cases. But

more important as we move into this whole area of human rights we immediately get involved in fundamental legal issues, particularly those concerning the civil rights of citizens, whether or not they are retarded" (Williston: 1971: 3-4).

Williston gathered material for the report by visiting provincial retardation facilities, the few 'community' residences and training programs that existed and by listening to presentations made by the various mental retardation advocacy groups such as the Canadian Association for the Mentally Retarded, OAMR and a number of local associations. He also studied the major textual works on retardation and community care and programming, for example, the Seeborn Report (1968) and The American Monograph written by the President's Committee on Mental Retardation (1969). As well, he also examined the literature on care of the retarded in the Scandinavian countries, long considered to have the finest system of care. Williston also heard from a wide range of 'experts' - social workers, educators, physicians and so on.

The report began with the 'case histories' of the two men whose experiences had prompted it in the first place. Williston then traced the evolution of institutional care in the province and concluded that what had happened to the two young men was inevitable given the organization of that care. He stressed particularly the shortage of well-trained staff. The major portion of the report, however, was devoted to

suggestions for changing the system from one in which large institutions formed its 'backbone' to one in which they played a minor or back-up role. His thinking was not unlike that of McGhie in the 1920's and 30's, although the possibility of implementing the ideas was much more real in the 1970's given the infrastructure of social welfare services put into place in the late 1940's (see Chapter One, section on The Welfare State).

Williston made 'the family' the ideal for care, that is, as a location and as a set of relations between people. This was in keeping with his belief that any changes should begin with children and that all children ~~were~~ belonged with their families. "Every child should be with his own family until he reaches adulthood unless he imposes an undue burden on them" (Ontario Department of Health: 1971: 70). His concern for children was not simply sentimental. Most adults living in institutions at that time had been admitted as young children and sometimes even as infants. Research indicates that the effects of institutional living are most detrimental in childhood and make a return to 'normal' society later on very difficult. Thus, Williston's idea had short and long-range effects. Returning children home would immediately reduce the institutional population, but would also enhance the child's ability to live outside the institution from the very beginning.

In 1970 there were 3,323 children (0-19 years) living in institutions (Ontario Ministry of Community and Social Services: 1983: 103) out of a total institution population (adults and children) of 5,357. Medical care and treatment had resulted through the years in improved life chances for severe and/or multiply handicapped children - their very demanding and specialized care had not been much of an issue earlier. Williston was careful to note that their needs might present insurmountable difficulties for their families. While Williston placed special emphasis on the family, he also cast 'the community' in a particular role:

"True social care implies sharing in responsibility by the community in assisting parents in carrying out their part of looking after a child to the best of their ability. There is a need for acceptance of the idea that the responsibility of a community to help parents of handicapped children to bring up their children involves the providing of a totality of services" (p. 73).

It is clear that 'community' here means government services delivered at the local level, and seems at one level to be an acknowledgement on Williston's part of the fact that many families didn't have any other 'community' to rely on. His program and service recommendations, although cost-efficient in some areas, were expensive overall. Williston proposed a range of residential alternatives - specialized foster homes, and various kinds of group homes - as well as an elaborate treatment centre and support system for home care.

The report held the Ontario government responsible for the overcrowding in institutions, for a lack of imagination and initiative in improving services to retarded people and for ignoring the requests of families themselves to provide more services in the community. Williston cited the Swedish system as the ideal of life-long integrated care. Curiously enough, the relationship between the care of retarded people in Sweden and the socialist principles which informed Swedish social welfare policy seem either to have escaped Williston or been ignored by him! His assumption that the Ontario government could or would re-orient its policies after having had the 'error of its ways' pointed out was not only naive but indicative of a certain lack of critical analysis. Williston's line of reasoning did not take into account that the care of dependent people is an integral part of a society's maintenance (and mode of production) and thus not simply a matter of instituting more humanistic principles. Care in the home was certainly preferable to institution care at that time, but it can be argued that the reasons for this had more to do with the distribution of surplus product reflected in the funding and organization of institutional care in this instance rather than some magical quality inherent in family life.

The Williston Report was very well received by families and OAMR in particular, as it validated their opinions about institutions and served to make them more resolute in their

demands for change. Most of the energies of parent advocacy groups during this period focused on exposing the deficiencies of institutions with a view toward getting them closed down (Simmons: 1982).

The Ontario government was to respond to their demands a few years later, but it is clear that there was a subtle shift in the understanding of 'community'. That 'moment' occurred with the publication of 'The Green Paper'.

The Green Paper

This document provides a very sharp contrast to the Williston Report owing to its very different origin. It was prompted by the government's need to save money while, at the same time, maintaining its past level of service to retarded people. It owes its existence originally to certain recommendations made in the report of the Intergovernmental Committee on Government Productivity (1971). The Committee was formed to examine all aspects of the structure and management of the provincial government, with a view toward streamlining its operations and making it more cost-effective. Ontario government expenditures had increased from \$235 million in 1949-50 to \$5 billion in 1970-71, while the proportion of that gross provincial product comprised by government expenditure

had increased from 3.6 to 15.2% in 1961 dollars (Simmons: 1982: 201).

In order to bridge the gap between Ministries and thereby reduce costly duplication of service, the Committee suggested the appointment of Policy Ministers who would be responsible for developing broad lines of policy and shaping the priorities arising out of these. 'Social development' was one of the three umbrella areas. Retardation policy fell within social development. By 1973, there was a need to reconcile three proposals for future services for retarded people in Northeastern Ontario, where increased demands for service made some action necessary. The proposals included everything from building a brand new institution to plans for total care in the community.

While Williston's work was motivated by a genuine attempt to improve the quality of life for retarded people, The Green Paper's aim was to organize and manage that care. It made use, however, of Williston's arguments that the segregation of retarded people in institutions was unsuitable and inadequate, but used them to present the 'problems' of care as 'social' rather than 'medical' in nature (Ministry of Community and Social Services: 1973: 1). This is an important point as one of the main obstacles to whole-hearted acceptance of community care - by some families as well as certain professionals - was

the belief that medical expertise and supervision in a hospital (institution) were necessary for many retarded people. The Ministry of Health, obviously, had a vested interest in this view, and their responsibility for institutions made it difficult to effect changes that would re-orient the medical model toward a community model. In other words, proponents of institutions and community had reached an impasse which could only be resolved by a change in ministerial responsibility.

Simmons (1982: 203), states that the task force appointed by Welch to examine the situation in Northeastern Ontario had "already accepted the implications of normalization and now had to confront the fact that the Ministry of Health was directly committed to big institutions". This suggests that de-institutionalization and community care had become a priority that had to be implemented as soon as possible, rather than something that could be put off until the Ministry of Health had a change of heart about the necessity and/or benefits of community care. Presumably that pressure came from the findings of the Inter-Governmental Committee itself, which had as its main aim, the reduction of government expenditures overall.

The report (p. 5) pointed out that between 1963 and 1972, the institutional population had declined by only 10%. This was in spite of some legislative measures already taken to

provide more service in education and other areas. The high rates were attributed to a lack of co-ordination and planning between the Ministries of Health, Education and COMSOC (Ministry of Community and Social Services: 1973: 6). The Green Paper identified a number of other factors that made institutional care preferable to other arrangements: (1) lack of services in the community; (2) the costs to families or 'the community' in using/providing service. The report (p. 7) was quite specific in explaining how such a situation had come about and how, by implication it added to the Ministry of Health's 'empire'.

- The province paid 100% of the capital costs for institution programs but only 50% of those costs for community programs.
- Capital appropriations were larger for the construction of institutions than they were for the construction or acquisition or renovation of community residences.
- Children's Aid Societies incurred no costs for placing a child in an institution, but had to assume full costs for community placements.
- The Ministry of Health paid 100% of the operating costs of institutions while COMSOC paid only 80% of operating costs for community accommodation. The remaining 20% had to be made up by families, charitable agencies or in the case of adults, from their FBA shelter allowance.
- The Ministry of Education paid 100% of the education costs for children in institutions, but only an average of 58% of the costs for retarded children educated by local school boards.

The message of the Green Paper was that the current policies had created a situation in which the government paid all the costs for institutional care, but that this need not be so. By increasing its contributions to community care, thus making it a 'viable' choice for families, the government could reduce its expenditures overall. The provision of service in the community was also in keeping with the requests of parent groups. Thus, a change in policy would benefit all parties concerned, although for very different reasons.

The specific recommendations of the paper (p. 22) dealt almost exclusively with services and programs for retarded adults. It is not surprising that the needs of this group were given priority in The Green Paper. Their return to the community would not, in most instances, involve a return to their families. The practical difficulties of such arrangements are obvious - parents would be too old, deceased and so on.

That same consideration did not hold for children. Indeed, the benefits of family life for them was by this time a basic tenet in all areas of child-care and child welfare. The lack of attention paid to them in the paper is indicative of the assumption that they would, wherever possible, be sent home. The impact of releasing adults into the community was something the government could not avoid dealing with. The

same was not the case for children - here the initial impact would be absorbed by each family.

The Green Paper also put forth a number of suggestions for re-allocating Ministerial responsibility for retarded people. The most favoured one involved transfer to a Ministry committed to an understanding of retardation as a social problem. COMSOC was the logical choice given its history (already described). As well, it was already responsible for some community mental retardation services as a result of its involvement in child welfare, day care and vocational rehabilitation.

The Green Paper is particularly interesting because it makes so little attempt to downplay its basic concern with costs. For example, it raises the question of the consequences of subsidizing retarded people to live in the community - through accommodation, programs and so on - for its dealings with other special needs groups. Even more significant, it worried about having to subsidize retarded persons who had no prior claim on government support. That is, individuals who had always lived at home.

"If community services are developed to permit the transfer of institutional residents back to their communities, these services will also attract the retarded who are now living in the community but receiving no special services... It is almost

certain that the use of community services will exceed the use of services offered under the present system" (p. 11).

The Green Paper represents a turning point at which time the ideals of community care begin to provide for an intentional course of government action. Many other factors played a part however, one of the most important being the support of these measures by OAMR itself.

THE GREEN PAPER AND WILLISTON IN PRACTICE: FAMILY AND COMMUNITY

The years between 1974 and 1977 appear to have had two different themes - the internal struggles of COMSOC and the creation of various community pilot projects in the direct service area to 'test the waters'. Before the Ministry changeover, COMSOC staff numbered approximately 1,800. Afterwards, it numbered approximately 9,000. Ninety percent of the transferred staff were in direct services in the facilities themselves (Ministry of Community and Social Services: 1975). An examination of annual reports of the Ministry for several years after (1974-75 to 1980-81) indicates that the powerful institutional interests were not prepared to be swallowed up by the 'community faction'. Simmons (1982) states that a 'monumental struggle' ensued over the allocation of funds. The annual reports tend to support this, as the efforts of the

Facilities Division and Community Resources Division are reported separately. Although the Facilities Division stressed its work in preparing residents for their eventual departure into the community, it is also clear that the continued existence of institutions undermined the community approach during this period.

Many of the pilot projects were sponsored through local associations and marked a new involvement for them with the province as service providers. Associations, composed mainly of parents, considered themselves uniquely qualified to plan and provide 'community' programs and services. While this was true, and the government was quick to acknowledge it, the willingness of families also provided the critical link between local and non-local concerns understood as 'community' and government. The government's need to effect and manage more cost-effective services and the desire of families to do the best they could for their retarded dependents intersected at that point with special consequences for families.

The appointment of Keith Norton as Minister in 1977 marked another watershed, especially for the care of children. Norton made 'the family' the centrepiece of every Ministry initiative (Simmons: 1982). By this time, the recurring crises of capitalism itself had made a massive re-structuring of its social relations a necessity, yet the general understanding of

'the family' as separate, even safe, from the larger economic process gave Norton's efforts a tone of 'progressiveness' that enhanced his reputation as a 'liberal' both in the government and outside of it. His popularity, especially with OAMR, arose out of the fact that his views on family life and care in the community matched those of its membership.

Norton set out six principles on which all COMSOC policy was to be based. The principles, in one form or another, informed everything the Ministry did while he was its chief executive (Simmons: 1982). They consisted of:

"...First, strengthening and maintaining the family unit; second, promoting individual and family independence and self-reliance; third, assisting people in their own community; fourth, providing service to those in greatest need; fifth, continuing the co-operative partnership among those delivering services; and sixth, making maximum use of the resources at our disposal" (Norton: Debates, Social Development Committee, Oct. 24, 1977 in Simmons).

The principles are the quintessential expression of textual discourses on 'family' and 'community' from the 19th century on. In terms of care for retarded people, the emphasis had shifted from community care as a clearly defined family duty, which might indeed present hardships or sacrifices for family members, to one in which care in the community understood as a right, was promoted as a benefit to the entire family. Who could oppose it on that basis, especially when

COMSOC would fund programs and services that could be shown to enhance family life?

On the other hand, the idea of a partnership between the government and families made it logical for the government to put restrictions on its expenditures to local associations and require them to contribute to funding. This was presented and understood by all involved as necessary if local groups were to have a sense of ownership of services and programs.

The Results

During this period, associations that had gladly taken up the responsibility of determining the requirements for and organization of services based on local needs, found themselves hampered by insufficient funds, especially in setting up residences. The government paid only 80% of capital and operating costs, and associations were required to raise the remaining 20% themselves. This shortfall in funds meant, for example, that Associations could not pay residential counsellors salaries equivalent to those paid to them in institutions for the same work. As well, budgets did not include the costs incurred by associations of hiring the necessary administrative staff to facilitate their new relationship with the Ministry as service providers. The

typically informal work practices of associations were no longer adequate. The receipt of Ministry funds, for example, entails elaborate accounting procedures, the compilation of various statistics and reports.

'Ordinary' people who had gotten involved in developing local associations in order to ensure that their retarded dependents would have proper supports in the community, found themselves drawn increasingly into administrative/bureaucratic entanglements that made little 'sense' to them and which they were ill-prepared to deal with (see Chapter Three, discussion of the Lakewood Children's Residence). Moreover, the extra time and effort devoted to these processes resulted in little real improvement in community-based support services, especially residential accommodation for children. The need to manage programs and services in accordance with government practices tied the energies of associations to administrative work rather than the 'advocacy' or reform efforts that had characterized their earlier activities and which were more 'political'. This development not only relieved the Ministry somewhat of having to deal with the requests of associations, it also drew associations into a sphere of responsibility which they had not occupied before. 'The heat' which the government had formerly borne on its own for problems identified by associations in service delivery was now shared by the associations themselves.

By 1980 there were only 254 'community' beds available for children across the province operated by local associations (Ministry of Community and Social Services: 1983(a)). In order to offset the costs of providing this accommodation, associations were forced to charge parents/guardians a monthly fee (usually around \$200/month). These costs not only made it impossible for low-income families to use the residences, they also made the cost of their use prohibitive for many middle class families (Simmons: 1982).

The effects on families of having little or no choice but to care for their children at home were evident by the late 1970's. A 1977 study by the Toronto CAS indicated that whereas in 1970, 18.7% of the children in its care were identified as 'mentally retarded' or 'slow learners', by 1977 that figure had risen to 41% (Keys: 1977). The Ministry solution, which involved the children's group home initiative referred to in Chapter Three, did not create a significant increase in spaces and also added to the work of associations themselves.

During this period it also became clear that the costs of maintaining severely handicapped children at home were a drain on the resources of families. In keeping with Norton's aim of supporting families, legislation was introduced to provide an allowance for the child's care. It was Williston who first suggested financial support to families as a natural adjunct to

care in the home. By 1977 when the allowance went into effect, it represented much more than this. The same can be said of special needs and services funding initiatives also begun while Norton was Minister. Both initiatives served to organize the work of government and families as will now be shown.

DOCUMENTS AS WORK PROCESSES

To show how these measures which do, to some extent support families, also organize and bring families into line with the ruling interests of capitalism, I will make a brief examination of documents that set out the terms under which families may apply for such supports.

Documents that Organize Community Care

Handicapped Children's Benefits

The pamphlet that describes the allowance to prospective families states that it:

"helps the parents of severely handicapped children meet the on-going extraordinary costs arising from their child's handicap. It takes into account the family's financial circumstances and the resources such as special schools and volunteer organizations

available in the community in which the child's family lives" (Ministry of Community and Social Services: 1985: 1).

The pamphlet states its specific purpose as:

"to help severely handicapped children live as normal a life as possible - at home, in the community" (Ministry of Community and Social Services: 1985: 1).

Thus the allowance is not concerned with the difficulties of retarded children generally, but only with those whose handicaps are severe. Families must be able to demonstrate that the child is at risk of institutional placement without the allowance. The instructions state:

"As well, the (handicapping) condition must be such that the loss could be considered to constitute isolation from other factors, adequate medical grounds for admission to an active treatment or residential institution for a prolonged period of time" (Ministry of Community and Social Services: 1985: 2, emphasis added).

Moreover, even if the family has no trouble proving the above, the allowance is available only if family income is deemed inadequate to meet the child's needs. The allowance is means tested and based on family size and gross income.

Families that qualify have their eligibility reviewed yearly (at the least) as to the following (p. 5):

- admission of a child to a hospital, residence or institution
- a significant increase or decrease in family income
- change of address or marital status
- change in family size

Funding is tied to the presence of the child at home. Even short-term out-of-home placements (over 21 days) are subject to financial penalty. Also of special interest is the fact that marital status is taken into account. Both of these provisions have special effects for women.

The regulations also work against families in other ways that affect women's work as care-givers. Families above a certain income level become ineligible for assistance regardless of the costs they incur for the child, while the maximum allowance limit may be inadequate for low income families. Women have to work harder to make ends meet - translate money into goods or services. As well, supporting data on the child's disability from physicians and others must be pulled together to satisfy Ministry requirements. Women do most of this work as well as they are usually responsible for maintaining contacts with professionals. Finally, the allowance is calculated on a yearly basis, necessitating detailed long-range planning which is often difficult or

impossible to do. Unforeseen expenses cannot be provided for until the annual assessment.

Special Needs and Services Agreements

In 1981, a new funding strategy was developed for institutional and community care. Special Needs and Services, as the initiative was called, extended CAP funding to children in institutions first and, later, to children living with their families. The object of the program was to fund specialized services/programs not available in either setting. Monies are applied for on behalf of the individual child and are 'attached' to the child rather than to an institution, service or program. Families can apply for up to \$10,000 per year for special equipment, training or in-home support. Special Needs and Services was well received by families. Parents, concerned about their children's needs, whether they lived at home or in institution, saw the agreements as another opportunity for them to exercise control over services for their children.

The annual report of COMSOC for 1980-81 stated the aims of the initiative as it affected families with a child in institution:

- to encourage parents to get involved in the child's individual training and progress.
- to provide funds so additional services needed by children could be made available.
- to outline the rights and responsibilities of parents and staff in relation to the child.
- to promote the development of an individual program plan for every child living in out-of-home accommodation.

The 'catch' for parents in getting access to all of these special services - services it can be argued that should have been available all along and provided to the children by right - was the payment of a monthly fee, ranging from \$40 to \$90 per month as assessed, in order to keep them in institution. Thus families whose children were not in the community were charged for the decision to place the child - regardless of the circumstances that influenced the decision.

A year later, Frank Drea, the new Minister stressed the positive effects of the agreements.

"As a result of the special services agreements for their developmentally handicapped children, parents have become much more involved in treatment plans. This process has also helped to better the relations between parents and the staff of facilities and residences" (Hansard, May 19, 1982).

The second phase of special needs and services involved making the same funding initiative available to families caring

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for their children at home, and became available in 1982. The maximum amount per child remained \$10,000, however funding was negotiated on a six-month basis. As with Handicapped Children's Allowance, the onus is on the family to prove need. Program guidelines (Ministry of Community and Social Services: 1984(b): 2) states that eligibility is determined overall according to which of three 'target groups' the child falls into. The groups, in order of priority, are:

- "1. Those children who would likely require residential services away from home if individualized special services were not available.
2. Those children currently residing in residential programs who could likely live at home if individualized special services were available.
3. Those children who require individualized special services in order to assist in their continuing development while living in their own home, but are not at high risk of being admitted to a residential service should the special service be required."

Children in the third group are entitled to a maximum of \$3,000 only. Once again, the government's thinking is obvious. The most handicapped children are the likeliest candidates for placement and thus represent an area of concern for them. The annual cost of institutionalizing an individual is estimated to be about \$40,000 per year. It is in the government's interest to do everything possible to 'support' families in providing that care outside the institution. This has not required a

massive 'selling job' to families since many of them are anxious to have the child at home. The ideological construction of family and community make it possible to ignore the fact that a severely handicapped child's needs don't change just because she lives at home. 'Somebody' still has to tend to those needs just as they were tended to in the institution, by staff paid to do that work. That same labour in the family is tied to love and devotion which have no market value.

Special needs agreements are not meant to provide a comprehensive, one-stop service which undoubtedly would make home care easier in some respects. The guidelines point up its band-aid approach.

"The Special Needs and Services project is not intended to duplicate existing services; therefore it is expected that parents will access existing programs and services when they are available and appropriate. If a gap in service exists, then it is appropriate to apply to Special Needs funding" (Ministry of Community and Social Services: 1984(b): 3).

The following items/services are excluded from funding:

- (1) basic child care needs such as diapers, food, clothing, baby sitting, daycare, etc. If families require any of those, they must apply to Handicapped Children's Allowance; (2) basic health, dental or other professional services such as physiotherapy, etc. Families must take up these issues with the Ministry of Health; (3) assistive devices, e.g. braces and

wheelchairs, 75% of these costs will be paid by the Ministry of Health. Families unable to pay the remaining 25% are advised to apply for General Welfare Assistance; (4) home modifications. Families are expected to deal with CMHC. In very special cases, Handicapped Children's Allowance or Special Needs will pick up some portion of such costs; (5) in the case of services outside the province, COMSOC argues that it provides a full range of diagnostic, therapeutic and support services and therefore will not fund service in other provinces. These restrictions taken together make it very difficult to find something that is fundable!

After proving need, as well as pinpointing a service or program that can be funded, families must deal with the various ministries involved, each of which has its own 'bureaucratic style'. Ministry personnel often give the impression that their major concern is to determine whether or not families are entitled to receive funding from them, rather than to work in the best interests of child and family. This lack of co-operation has an especially negative effect in localities where the number and types of services are limited to begin with.

All of these stipulations affect the work of care-givers as I will show in the next Chapter. Although the Ministry has parents on its side when it supports care in the home, it takes

care to represent its practices in the most positive light. The Communications Branch of COMSOC began to release publicity about special services at home shortly after it went into effect.

A Document that Promotes Community Care

The Amell's Story

This release (see Appendix C) begins with excerpts from a letter sent to the Ministry by the mother of a 3-year old severely and multiply handicapped child, in which she thanks the Ministry for funding 48 hours of in-home parent relief per week to assist with the care of her daughter. The rest of the article points out the benefits of supporting families through this funding mechanism. The release takes for granted a particular understanding on the part of readers -- a positive idea of family life that automatically makes it superior to life lived elsewhere. This presupposes a process whereby terms such as family, community and care, are taken up, circulated through various levels of society and fed back again into the conceptual practices that give rise to them in the first place, as in the example of The National Clearinghouse on Home-based Care mentioned in Chapter Four. It is a process that "drops out", transforms, or "glosses over" certain aspects of the

actual experience of family, community or care (especially the experience of women in these).

The Ministry presents itself as a facilitator in making life in the family possible for this special group of children by indicating that it has formed a partnership with families in working toward this worthwhile goal. At the same time it is possible to see how the Ministry's interest in saving money is also met. The Ministry's interest, however, is represented as desirable for everybody because it is understood as enhancing family life. Ministry personnel suggest that families have found their own ways to 'cope' although, it is clear, the means for coping have been provided by the government funding initiative itself. The following statements are examples of the way the Ministry presents itself in the news release (Ontario Ministry of Community and Social Services: 1982):

"This is a good example of how we can keep a child at home for about \$7,000 (per year) instead of institutionalizing which is extremely costly."

"As a result (of the funding initiative) the family is functioning more easily."

"Parents are finding methods of coping with their children and keeping them at home."

In order to learn about the experience of families and its ideological construction, we would have to begin with the experience of women whose work brings care about in the family.

This news release allows us to do that because it provides a mother's description of the context in which she provides care.

This is excerpted and summarized below:

- (1) The child, Shannon, is blind, has cerebral palsy and is severely mentally handicapped. She requires constant and total care. She cries for prolonged periods. She also requires specialized programming (physiotherapy is mentioned) that involves hours of prescriptive exercises to be carried out each day. Shannon is not an only child.
- (2) Nancy, her mother, is a "former health nurse". She speaks of "tremendous pressures" and "lots of tension" in caring for Shannon. She also suggests that the demands of care have had an adverse effect on her marriage -- especially the crying that was "creating family problems".
- (3) Shannon's father is a policeman who faces considerable pressure on the job and who, it is inferred, requires peace and quiet when he gets home from work. "It doesn't help our marriage when he comes home and hears Shannon crying as much as 10 hours a day."

At the same time, however, Nancy's understanding of what she does and why is also explicit. She says: "there is no greater thrill to a parent than to have your own young child living home, even if it is with a handicap...we are all happy that Shannon is home...". The issue here is not that there is 'something wrong' with this woman for wanting to have her child at home, or that Shannon would be better off in an institution. The issue is how Nancy understands what she does in terms of her 'role' as a mother who loves her child, or wife who supports her husband. The conceptual work of sociology and

social work can be seen to be directly implicated in this understanding. The notion of 'appropriate roles' sets women's work apart and gives it a timeless quality so that it no longer appears to be connected to the 'outside world' of the market. Even though Nancy describes extraordinarily difficult work conditions that would be unacceptable in paid work - long hours and so on, they become part of the background. The concept of roles and family functioning obscures their 'real' material connection to the larger structures and interests outside that particular family.

In 1982, the same year as the news release, the Ministry announced its Five-year Plan. This was a political and fiscal policy statement to close down six institutions, phase down a seventh, return 989 residents to the community, apply the saving derived from the closures plus an additional \$9.9 million allocation to the development of community services, and allocate \$1.8 million in new capital funds to create smaller group homes on the sites of facilities. (June 30, 1982, Cabinet Document in NIMR Information Release, Sept. 12, 1984).

The plan stated that the additional \$9.9 million allocation "will be substantially offset by new federal cost-sharing revenues". It mentioned also that "a recent physical plant examination of facilities had identified \$48 million in capital requirements (1982-1987)". This allocation,

by implication would be effected by facility closures. The closures would also result in an overall reduction of 1,163 Ministry staff over the five years.

Although it is very difficult to pin down just exactly how the Ontario government has profited by its de-institutionalization and community care policies, it is useful at this point to note the following:

- (1) That de-institutionalization resulted in all of the projected plans for institutions being scrapped. By the early 1970's this amounted to approximately 6,000 beds. It can be argued that this commitment on paper implied a real financial commitment at some point in time. Becoming 'uncommitted', therefore, freed up, in theory, funds that would have to be spent in the future for construction as well as on-going maintenance and staff costs in these yet-to-be-built institutions.
- (2) The closure or phasing down of institutions set out in the Five-year Plan relieved the government of much of the on-going maintenance or improvement costs of the existing physical plant (one that is old and expensive to maintain). It is common sense that one does not invest large sums in buildings that may not be required a few years hence. At the same time, not all institutions will be closed, therefore the people who live and work in them will be subjected to a deteriorating environment.
- (3) The Five-year Plan made no secret of the fact that 1,163 institution staff would lose their jobs. These losses were to occur in direct care. Although the most recent Ministry Annual Report notes that every effort will be made to re-locate these individuals in other institutions or community-based programs, it is clear that this will be next to impossible to do. The closure of the Adult Retardation Unit at the Lakewood Psychiatric Hospital is a case in point. Accepting transfers to the nearest Provincial facilities meant re-location of workers to be closer

to those facilities or long car rides each day (the latter is not a very appealing choice for shift workers whose schedules even militate against car pools). The 'savings' from the closure did not generate new community programs or result in an expansion of those that existed. In any event, work in the community would have been at a much lower rate of pay than employees received in the institution, since community-based programs are sponsored by non-government agencies such as the local association, which receive a lower rate of funding.

- (4) The fact that former institution workers, mothers or relief providers, are scattered around doing this work as private individuals or as staff in very small groups, reduces the possibility of collective action on their part to improve their working conditions or, in the case of the mothers, to even have what they do recognized as work.

Despite the narrowing of choices for families resulting from the institution closures, and the cut-back in direct service staff, Frank Drea stated that the special services at home program was so effective in the "enhancement of family life", that additional funding would be made available to maintain it. Thus an ideological understanding of family as the backbone of care in the community, shared by government and families, provided for a very different interpretation for what was going on.

In the same year, the policy development section of COMSOC prepared a paper for Ministry staff and service providers on trends in children's services over a 30-year period, entitled Three Decades of Change (Ontario Ministry of Community and Social Services: 1983(b)). It is interesting

an 'in-house' account of de-institutionalization and community care where it refers specifically to mentally handicapped children.

A Document that Analyzes Community Care

Three Decades of Change

The paper begins by stating that although growing affluence between 1950 and 1980 made increased spending on services possible, private contributions were not adequate to meet increased demands for services and rising costs. As a result, the government became almost entirely responsible for both funding and operating costs of services that had formerly been supported by private funding (Ontario Ministry of Community and Social Services: 1983(b): 3). The Paper suggests that the government was not prepared to carry these increased costs indefinitely. Child welfare costs figured prominently in these increases. Services for retarded children outside the institution were minimal until 1980. The increased use of Children's Aid Societies as a means of care (through wardship) is noted in the paper, however, as having contributed to the problem. That is, de-institutionalization in one part of the system increased costs in another part.

The number of children (ages 0-19 years) in mental retardation facilities grew from 1,425 in 1950 to approximately 4,235 in 1965, an increase of 197% (Ontario Ministry of Community and Social Services: 1983(b): 42). By 1980, that number had been reduced to 2,004, a decline of 53% (Ibid). The COMSOC report states that "the primary residential alternative after 1965 to large institutions for children appears to have been the service provided by Children's Aid Societies (p. 43)...parents found placements difficult with the result that more retarded children were found to be 'neglected' and came into the care of societies" (Ontario Ministry of Community and Social Services: 1983(b): 16).

Although Ministry statistics show the number of children discharged from facilities, they do not provide a full picture of what actually happened between 1965 and 1980 because the figures only account for those children who were already on the posters of institutions. Another aspect of de-institutionalization policy, that of tightening up admission procedures for long-term placement, has resulted in a new group of children to be considered - those who have always lived at home and do not appear in government records. Ministry information is not inaccurate, but it is incomplete. There is no central registry system of retarded people and therefore no way to 'count heads' in the community, except through estimates

made on the incidence of retardation in the population or on community service usage.

This report tends to give the impression that de-institutionalization is a finite problem that will be 'solved' when all retarded children are living somewhere in the community. The declining institutional population becomes the measure of success, obscuring the fact that the 'problem' has not disappeared but has been shifted to 'the community' and to 'the family' in particular. The shift appears natural and is assumed to provide greater opportunity for participation by those most concerned - families, local service providers, and so on. The report not only makes the idea of care in institutions sound passeé - social policy supposedly being much more 'enlightened' in its approach to care of children generally in recent years - the focus on support to families becomes highly directive in requiring families to conform to these standards of care.

The most recent Ministry Annual Report (1982-3 and 1983-4) outlines its future course of direction for care of retarded people (p. 71). Its service delivery objectives are:

"To strengthen the capacity of the community, in partnership with the Ministry, to deliver a range of services responsive to the needs of individuals and families, in a way which supports their self-reliance in the community."

Its policy development objectives include the following:

"To develop informed policies that direct the design of Ministry services by balancing considerations from diverse publics."

Finally, its management objective is:

"to effect a responsive results-oriented management approach in support of the achievement of the Ministry's program objectives, based on clearly defined accountability and the effective utilization of resources."

The implementation of these objectives will not "balance the considerations from 'diverse publics'" but only give that appearance if we understand that 'the state' in the long term represents the interests of the dominant class. Textual work on community provided in its own way for a particular understanding of relationships between people that becomes the basis for building on what is already known. The following Ministry Document, "The Nature and Effectiveness of Family Support Measures" (Ontario Ministry of Community and Social Services: 1983(a)), illustrates how an unproblematic view of lived experience of community gives rise to efforts to augment 'community support' systems.

A Document that 'Feeds Back'

The Nature and Effectiveness of Family Support Measures

This paper purports to be a 'state-of-the-art' report on family support measures. Its purpose, as set out in the introduction written by the Assistant Deputy Minister, is to provide a comprehensive review of the literature; a definition of family support; factors (shown by research) to increase the chances of successful intervention; and the types of 'families' and 'problems' amenable to family support. The report was undertaken to assist Children's Aid Societies in particular, but it states "what has been learned will have a much broader application".

The motivation for this shift in intervention is seen as the result of accumulating evidence on the dysfunctional consequences of institutionalization. The argument stated is that people cared for in formal settings would benefit from a return to a 'natural' setting - especially with the assistance of support services. Although the report does note that there has been some concern about the new orientation, for example that it will be seen as an attack on the value of more formal, traditional services - it does not mention any other negative effects. The report states:

"Over the past decade there has been an increasing interest in alternatives to direct interventions with individuals, families, groups and communities. In particular there has been an emphasis upon work with clients that enhances their capacity for independent functioning and minimizes interventions that replace the responsibility of informal or natural systems with formal, professional or bureaucratic responsibilities" (Ontario Ministry of Community and Social Services: 1983(a): 14, emphasis added).

The informal or natural supports are identified as: (1) prevention; (2) self-help; (3) social networks; (4) home care; and (5) social supports (p. 14).

While a passing reference is made to the fact that these interventions are more cost-effective (p. 16), this fact takes a back seat as does the effects of all forms of community 'support' on the family. The remainder of the paper examines the nature of each kind of support and its usefulness in particular situations. The experience of care-givers is not a part of the data. Data is provided instead by experts. The work of the National Clearinghouse on Home-based Care, mentioned in Chapter Four, is referred to at a number of points.

SUMMARY

In this Chapter I have provided an analysis of various government documents related to community care of retarded

people and have showed how they provide for a means of thinking about community care that bring savings to the government and also organize the work practices of families in a variety of ways. The ideas about community care substitute for a material grounding of the concepts and pass over the lived experience of providing it.

In Chapter Seven, I return to the lived experience of community care with a special emphasis on those points where the work of the mothers intersects with the work of government, and allied experts. Here it is possible to see what is accomplished by the ideological construction of community care. It is received as 'natural' and 'good', passing over the mundane realities of cost-savings and the oppression of women. Widely-held and publicly declared understandings such as these underpin the imposition of oppressive work relations, women's acceptance of such views and so on.

**VII LIVED EXPERIENCE: CARE OF SEVERELY HANDICAPPED
CHILDREN AT HOME - PART 2**

INTRODUCTION

In the last Chapter I showed how government texts and documents in providing for its administrative priorities also organize family work practices. The savings realized from the phasing down or closure of the larger mental retardation facilities has not resulted in a higher level of funding at the 'community' level to improve service delivery there.

Community-based programs such as Parent Relief, aimed directly at encouraging families with severely handicapped children to keep them at home, and which contribute to the reduction in facilities expenditures, operate on very low budgets.

The restriction of relief time and the low wages paid to relief workers keep program costs to a minimum. The start-up budget for the program I set up in 1980 was \$60,000. The 1984 budget for that same program was \$65,000. This is little more than the estimated annual cost of \$40,000 to maintain one severely handicapped child in an institution. Although many factors besides the availability of Parent Relief enter into the decision to seek an out-of-home placement for a child, if Parent Relief programs contribute to the decision to keep even two or three of the children I have been talking about out of institution, the potential savings are significant, and the province-wide implications are obvious.

As the news release in the previous Chapter indicates, COMSOC makes no secret of the benefits to them of community-based programs like Parent Relief. The fact that it can publicize these views and illustrate them with a 'real-life' example like Nancy Amell's is shocking but, perhaps, to be expected given the pervasiveness of the ideological understandings of community/family which permeate government thinking as well as that of families and the general public. The understanding of 'community', 'family' and the implications of these for women who are seen to be the heart of both, provides for their 'accepting the responsibility' of providing care at home in the community for their children, but also harnesses them into emotionally and physically difficult work.

Acknowledging this does not in any way detract from the fervent wishes of some women to care for their children at home, their abilities to do so, or the benefits to the child. As I have tried to show, however, the way in which the care of the child gets organized by the government so that it conforms to its fiscal and administrative priorities, and the way in which 'ideology' brings the women's experiences into line with those government interests, shapes the conditions in which the wishes of the women get translated into a particular form of work.

No matter how much a mother loves and wants her handicapped child at home, the following can be said: she will have to learn to take care of the child with very little help from 'the community'. In fact, as I hope the women's experience will show in this Chapter, they have to make up for the existing deficiencies in the community to meet the child's needs or their own, or else 'produce' the community from scratch. Ironically, however, meeting the ~~child's~~ needs in a community setting requires them to reproduce a miniature institution in the home where they must learn and carry out the skills of a team of professionals (Bullock and Campbell: 1986). Even 'direct care' of the child is not the whole story because the mother must co-ordinate the attention the child receives from specialists of all kinds. I have been able to identify a number of common characteristics to the work of care in this situation:

1. It is private and isolated. Since it is done in conjunction with the usual work of wives and mothers it is invisible.
2. It is unpaid, even though people working outside of the home doing the same activities get paid for it.
3. It is being intensified. The women pick up extra work as the result of cut backs in other areas of support, such as education and health.
4. The work brings the women into a special relationship with the state, that is, they must learn to interact with the state on its own terms by developing proficiency in

'ruling practices' and the discourse of ruling as a condition of participating in government programs of parent support.

This Chapter will be devoted to examining these characteristics as the women described their experiences.

HANDICAPPED CHILDREN'S BENEFITS

As mentioned earlier, the allowance is means tested. Means testing works against the women's interests because a high gross family income makes their children ineligible for benefits. This approach to eligibility points up the contradictory effects of overall policy. The child's needs which are presented as the reason for the allowance are actually secondary to the family's presumed ability to provide for the child. A rigid system for classifying families by income means that the ability of a middle class family to meet the costs of care can be stretched to the utmost.

IBIS

"I find it (Children's Allowance) discriminatory. Just because we make more money than other people we don't get it. I can see how they rationalize that, of course, but my expenses are just as valid as somebody else's ... It's my money that I'm trying to get back from them and even though I make more money than other people, that still doesn't mean that I don't have expenses and maybe couldn't put aside that extra money for Patti's care later on.

That's going to save the government \$40,000 per year! I really do not think that's fair."

Even more discouraging is the demeaning treatment, reminiscent of the early days of charitable organizations and so on, which families are subjected to by COMSOC workers which deters them from pressing their cases with the Ministry.

MARY

"We were getting it (the Allowance), when we came here, but the guy gave us such a hassle, my goodness! I'm not sure if he was the head of it or what. He was horrible. He said he'd had a daughter in Smiths Falls (Rideau Regional Centre) and he'd never had help. At that point, with whatever Bob was making and with whatever extras there were (we weren't getting too much from it) we figured it just wasn't worth the hassle to bother with it."

LOUISE

"We were told we wouldn't qualify, but I think we would meet the qualifications. My husband's salary is not that high. We were turned away very briskly so we didn't pursue it."

Angie, who received benefits when she was providing for her sons on her own, was cut off when she re-married.

SPECIAL SERVICES AGREEMENTS

Parent Relief In-Home Workers

The COMSOC Special Services at Home initiative made funding available for in-home relief workers in 1982.

Out-of-home relief, as already noted, had some drawbacks with regard to the availability of relief providers. As well, moving severely handicapped children out of their own homes can disturb their routines and make it more difficult for somebody else to look after them. The possibility of having relief without having to move the child was considered a 'godsend'.

In practice, however, in-home relief leaves much to be desired.

The Special Services Regulations (1984(c)) make access to the service complicated. In some instances, the regulations can even be seen as discriminatory (as will be shown). The selection of the worker, her training and on-going supervision falls to the mother, increasing her already heavy burdens. Finally, the Ministry's control of funding can be oppressive as the women must conform to its regulations. They also don't know from one year to the next how much funding will be made available. At the time I interviewed the women, each one was funded for the maximum 10 hours per week of in-home support, and the workers were being paid \$5 or \$6 per hour, depending on whether they used their own cars to take the children places.

Access to an In-Home Relief Worker

"The most important points in the application refer to the child's present condition, the goals for improvement, and the way that the special equipment or service will help the child to develop and live more easily at home" (Ministry of Community and Social Services: 1984(c), emphasis added). The entitlement to an in-home support worker is not tied to the mother's need but to the child's. This means demonstrating in the request that the worker will be working with the child.

The application must answer the following questions: (a) why the present situation creates a problem or limits the child's potential for development or the family's ability to respond to the child's needs; (b) must outline a particular objective that will be attained by the child while the in-home worker is present, for example, teaching the child to put on a jacket; and (c) must describe as fully as possible how the worker will work with the child, as in teaching her to put on the jacket. Even in those instances where the severity of the child's disability make the need for a relief-worker clearly apparent, the mother cannot request in-home relief on the basis, for example, of exhaustion.

Mary Green is a prime example of this. Her daughter Cathy at 11 years of age is quite tall and weighs approximately

70 lbs. She cannot walk on her own, although she is, now capable of doing so if supported. Basically, Mary still has to carry Cathy everywhere even when she does her household chores.

"Even, to do the laundry when I'm alone with her - I've got to leave her sitting or I have to take her down and back up the stairs and that's a problem."

That 'problem' is not one that the Ministry recognizes. Instead, Mary's need becomes the need for Cathy to learn to wash her hands and pull her pants up and down - the two programs the in-home worker carries out with Cathy when she's there. Says Mary:

"Initially we had to write up a detailed request...you would have to write out what programs would be carried out. They have to be measured - the aide has to keep a record of what she's doing."

Obviously, many families have difficulties filling in the applications. In Union County, the Parent Relief Program staff assists parents in this process in addition to their on-going work. The local association has also seen the need to help families out with Special Service Agreements, and tries each year to get funding from sources like SEED to hire an individual whose sole responsibility is to help families with their requests. Although in-home relief is a popular request under Special Services Funding, it is not the only thing families request. Since the Ministry does not recognize the

difficulties for parents in preparing requests, it also does not recognize the administrative costs to local associations arising from any provisions they make to help families negotiate the agreements, hence the need for associations to come up with this funding themselves. If it weren't for the initiative taken by the locals to support their own families, or the good will of personnel in individual programs like Parent Relief, families (women) would be left to sink or swim in completing very complicated documents.

In-Home Relief and a Mother's Paid Work

The entitlement to an in-home relief worker rests, as Angie has discovered, on the idea that a mother who works outside the home has less entitlement when the presence of the relief worker can be construed as supporting or facilitating her work.

"Last year I had quite a problem with my Special Needs officer as to my working, and I went through a time when I really feared I was going to lose my in-home support unless I stayed home. In the Special Needs Officer's eyes, in-home support was meant for me to be able to do what I wanted but I had to stay home to do it. I could take a course, I could go shopping 15 times a week, rake my lawn, have tea with my neighbours, get my hair bleached, but I couldn't work. She began to question my in-home support hours - like why did I have someone in my home from 7 to 9 am and 3 to 6 pm. In her eyes I could work that way. I could leave for work

at 7:30 and be home at 5 and I had it wonderful because I had a paid babysitter. Meanwhile we had to farm Kyle out to the 'Y'."

In the last statement, Angie is referring to the fact that the Ministry stipulated that in order to have in-home support funding, her non-handicapped 2 year old could not be on the premises while the support worker was there with the handicapped children. The costs for Kyle's day care are, of course, borne by the family.

Angie checked out the practices around this in one of the other COMSOC area offices and was told they didn't operate the same way. It appears that the strict application of these regulations varies by area - not much of a consolation if you happen to live in the 'wrong' one! Moreover, it raises serious questions about the premises upon which special services at home are based, and the whole idea of this particular form of community care. Angie's experience indicates how Ministry regulations can affect the paid employment of at least some care-givers - whether that is an explicit motive or not. The worst possible scenario from this is one in which a woman could be forced to stay home with her child or risk losing whatever 'community' support she is entitled to even though her paid work is necessary to support the children, as it is in Angie's case. The association of women with the nurturing aspects of community in the textual discourses provides for an

understanding of women in which their only 'natural', and therefore legitimate, career is mothering.

Acquiring and Working with In-Home Workers

Good in-home relief workers are hard to find. The work is demanding and requires at a minimum excellent child care skills and, often, a great deal more in the way of specialized knowledge. Work schedules for the workers may be difficult to arrange - although the number of hours worked are the same each week, they may not always occur at the same time, depending upon the mother's needs. Furthermore, the pay is low given the intensity and responsibility of the work.

Finch (1984: 10), in discussing the creation of new low status, low pay female work categories related to 'community' care in the home, argues that notions of appropriate gender behaviour serve to assign power and to legitimate an unequal division of labour by sex inside and outside the family. This ensures that relief care-givers are likely to be middle class women who are married and presumably supported by their husbands, and whose lack of formal qualifications justify low status and pay. While this analysis seems correct, it might be taken further. The current cut-backs in social services and education (where women make up the majority of workers) now

result in the availability of highly trained women to do work such as parent relief. As Pat Armstrong (1983: 131) suggests, when unemployed, highly trained women often work in volunteer or semi-volunteer jobs because they recognize the inadequacy of (social) services, and because they cannot find paid work and want to keep up their skills and retain their sanity while unemployed.

When the women I spoke to find relief workers who meet their standards, they reported having great trouble keeping them, whether they were formally trained or not. There is a high turnover in workers, as they move on to better paying jobs when these become available. The women say others 'burn out' - an interesting commentary not only on the difficult nature of the work, but also on how care-givers who were not labouring as the child's biological mother could freely admit to the fact that the work drained them emotionally and physically. (Not once in any of the interviews did a mother say she was burnt out!) Each of the women had had a minimum of two workers in the previous year.

In-home workers are recruited and screened initially (and paid) through the Parent Relief Program. There is a pool of individuals willing and able to provide care upon which the women can draw, although they must interview these individuals

to determine their suitability both to meet their child's needs as well as fit into the family routines.

MARY

"I interviewed 12 (workers) one Saturday morning. Then I had three of them come here and my husband and I interviewed them."

Once the worker is selected she not only has to be taught how to carry out the programming and reporting that fulfill the Ministry criteria, she also has to be familiarized with a host of other details about the child's health, behaviour and so on. The mothers train the workers.

MARY

"You have to go over the way you do things. Write up routines for them."

IRIS

"(You have to) tell them what kind of things you want done. It's almost constant monitoring for a while."

LOUISE

"I feel it's really a month before you're able to say the worker can do it herself. It's hard to get someone else doing your routines the same way."

Louise described the work of maintaining a relationship with workers and the effects of having a worker in the home as follows:

"I set aside so many minutes each day to discuss what's happening. You really have to support them - let them know what they're doing is okay or, if it's not okay, you have to find nice ways or good ways to suggest something else could be done. The most difficult thing for me is really accepting someone into my home and giving them the run of the place and letting them see me as I am with no pretense or no extra things gotten ready or done...it's really an intrusion on your privacy."

Workers are supposed to be supervised by Parent Relief Program staff, but in reality, the women carry out this task because, of course, they have the closest contact with the workers. This can create confusion for the in-home workers and the women as to how the relationship should be conducted, or what its boundaries are. The mothers did not typically use this time for themselves, but to catch up on other work around the house, like getting supper started or dashing out for groceries, they were, therefore, in close proximity to the worker a lot of the time. As a result, they were uncertain as to whether they should treat the worker as 'a friend' or maintain a more formal relationship because the worker was being paid to provide a service, and because there were times when they had to act in a 'management' role (even though this is formally understood to be the responsibility of the Parent Relief Program).

ANGIE

"What I feel is that you are the employer and you shouldn't be - I'm the mother. It's a hard role to

play - employer and mother...it's not right...all their (worker's) problems come to me..."

The women take on the 'management functions' of training, supervising, evaluating job performance, and yet they must carry these out in the home, thought to be the antithesis of the work environment (even by them). It is taken for granted that the women will have the ability to act in an "executive" capacity in this instance when that ability is ignored or devalued in other aspects of care. For example, although women are generally understood to be 'natural' care-givers, they are also thought to require the help of experts in doing their work!

In light of the above, Louise and Angie's comments about worker turnover have special meaning.

LOUISE

"It's hard to find someone who fits our routine and Susan's slow rate of progress. (We're) adjusting to new people all the time. I think Susan adjusts better than I do. I find these things are shakeups...it hasn't been a picnic and in between you still have to do all the work. The last worker left in mid-February and we just haven't been able to replace her. I've interviewed and interviewed and interviewed but I just can't find anybody for love nor money" (this conversation took place in May).

ANGIE

"These workers aren't making fantastic hourly rates and no benefits - you find someone who's really

good and six months later your child has to adapt to somebody else."

The Ministry's relationship with the women, structured through its documents and/or in the person of the Special Needs Officer is fraught with 'double messages'. On the one hand, the families (women) are encouraged in every possible way to keep the child at home. On the other hand, it seems to the women that Ministry regulations, like those governing Special Needs Agreements, conspire to make care more difficult - there is always one more hoop to jump through before the Ministry actually provides funding.

IRIS

"You always have a Damoclean sword over your head - if you don't perform, you don't get it, and it makes it like a parent-child role. You have to play by their rules or you don't get their money."

In the past year, it has not simply been a question of conforming to regulations, but of whether the women can have in-home support at all.

IRIS

"As far as special needs go, it seemed like a godsend at the time. We met with the Special Needs Officer and she told us great wonderful things about this as a never-ending pool. This (funding) would go on forever and you take her at her word because you think she knows what she's talking about; but you know in the back of your mind that these sorts of things failed before and it's going to fail again. She says, 'oh no, this time you're

wrong' but, of course, she was wrong again.
(Special Services) has had its ceiling put on it."

Cut Backs in In-Home Relief

As far as funding in-home support workers goes, the news about ceilings was delivered by the Special Needs Officer in two ways: (1) that it would be less likely that families applying for the first time would receive funding; and (2) that those families already receiving it might be cut back. The cut-back, the women were told, could be made either by reducing their number of in-home support hours, or by keeping the time allotment but reducing the hourly rate paid to the workers. The clear message was that their present allotment was depleting Ministry funds and would affect the possibility of other families benefiting from in-home support.

In actual fact, the combined in-home support allocation of the five women was 'costing' the Ministry \$15,600 per year. That is, a total of 520 hours at \$6 per hour (each woman having 10 hours of relief a week), and the workers do not receive benefits other than those required by law. A residential counsellor in a provincial retardation facility earns a minimum of \$12 per hour (OPSEU: 1984), approximately \$25,000 a year, and also receives a comprehensive benefits package. Simple arithmetic tells the story.

Despite the various difficulties with in-home support, the women appreciate the efforts of their individual workers and value Special Needs generally - especially the provision of in-home support.

IRIS

"I find special needs very welcome and beneficial and I don't know if they (COMSOC) know how much that benefits us all."

The women decided to let the Ministry know how valuable in-home support was to them, and that they were not prepared to see their hours cut back or the workers' hourly rate reduced. They made a 100-mile round trip visit to the Ministry area office to state their case. The strategy was to inform the area office that they were planning to take up the issue at Queen's Park. Doreen gleefully described this meeting:

"They (COMSOC personnel) said... 'our hands are tied - we only have this budget allotment'. I said, 'yes, and that's why we're dealing with this issue and wanting to take it beyond you guys... we know you want to give us this money but you can't, and we've just got to tell Toronto that you guys need more money.' Well, they were just sitting in their seats because they don't want this going beyond their front door. They were almost begging us not to go to the politicians with it."

The area office 'came up' with the additional money necessary to keep the hourly rate at \$6, however. Doreen and the other women are aware that such expenditures of time and effort on

their part are not producing real gains. At best, such activities serve to hold the line against service reductions.

As Iris says:

"... so we ended up getting an 18% increase...it actually means we aren't paying any more than \$6, but new families can pay \$6 too rather than trying to hire at \$4. It's just a shame that you've got to fight for all these things. It's draining. You're supposed to be out there programming your kid but you're not - you're over here programming COMSOC!"

The women know that if they don't challenge the Ministry, things will get worse. They are aware that surrounding areas have lost this battle over in-home support funding because they didn't organize. Ministry personnel do not hesitate to play localities off against each other. Doreen said:

"They threatened us with 'your brother (sic) is going to hurt'. Well then our brother's got to get up and fight, and you know they did cut other areas in the region. Like I feel real bad about that but I don't feel like we're taking from them. The Regional Office is taking from them, Queen's Park is taking from them, not us."

SPECIAL SERVICES AND OTHER PROGRAMS

As shown in Chapter Six, Special Services funding can only be applied for when no other avenues exist for services. Although COMSOC has the major responsibility for mental retardation policy and programs, certain major program areas

like education do not come within its mandate. Thus, having a school-age child means negotiating with two ministries, both of which are bent on saving money.

Angie's on-going struggle with COMSUC and the Ministry of Education over who is responsible for funding communication programs for her sons is a good example of what can happen. Before turning 6, each boy was eligible for funding for speech through Special Services. Now that the boys are at school, they are no longer eligible under Special Services. COMSUC argues that communication is now an 'educational' rather than 'developmental' need, and is, therefore, the responsibility of the school board. The school board on the other hand, claims it cannot provide a communication program fitted to the boy's needs as these are 'developmental' rather than 'educational'. Angie is aware of the deficiencies in the program provided. She is also aware, however, that appropriate programming is available from school boards outside Union County. She feels really torn about the best course of action because meeting the boy's needs involves the whole family.

"We've been considering re-locating since the children became school age because COMSUC and the Ministry of Education have quite a turmoil about whose responsibility these children become... that's frustrating because we like where we are... the other option is to pull the children out of the school system they're in and send them to a private school, but to send two children privately would be

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MICROCOPY RESOLUTION TEST CHART
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a tremendous financial burden. We would not be eligible for assistance around this."

While Angie and representatives from both Ministries mount their campaigns, she says "the kids just sit".

"There is a caring and dedicated staff (at school), but just not enough resource people to address their special needs."

The School Board employs one speech pathologist for its approximately 10,000 elementary and secondary school pupils and two or three para-professionals to carry out speech programs.

"When Jimmy left special needs, he was getting speech twice a week at the hospital. He hasn't had any since he went to school."

Angie's involvement in this process is time-consuming and emotionally demanding. She usually has to take time off from work to attend meetings and must make arrangements for somebody else to take over her responsibilities at the nursing home. The meetings themselves are stressful and Angie prepares for them as if she were a lawyer preparing a court case.

"I did most of this (negotiating) myself. I spent a lot of hours going back to initial special needs contracts and seeing how much money had been paid out for program and in-home support, and then personally going back and finding out through income tax what we personally had to put out...to go in and argue that you want more money for special needs if you're at the maximum, you have to

be able to put in black and white just exactly what you want and why you want it and justify it."

The framing of the argument becomes an abstract issue, around dollars and cents, rather than a human one - Angie's desire to have the boy's learn to communicate in some way that gives them and her a measure of independence. Fortunately, she has her considerable experience as an administrator to rely on. Obviously, many women have not been in a position to acquire those skills. This suggests that community care is a 'class issue' if we assume that the higher education or specialized training more available to 'middle class' women enables them to deal more effectively in the system and thus receive more support than a woman who lacks this training. On the other hand, Angie's story also indicates that middle class women have to intensify their labour so much for so little, that the real gains are negligible. This raises questions about the effects of being a care-giver on all women, an issue I will consider in the final chapter.

Angie knows full well that COMSOC cut-backs in community programs have catapulted her into yet another position - that of case co-ordinator. This is the function she performs when, for example, she sits down with COMSOC and the Ministry of Education to discuss communication programs for her boys. Case co-ordination in this instance refers to the services normally provided by a social worker who consults with parents on the

child's needs; prepares all necessary documentation required to access service; acts as liaison between family and service providers; acts as advocate for the family when necessary and attends all meetings on behalf of and/or with the family when services are negotiated (this would not be limited to Special Service Agreements). Ministry funded case co-ordinators are paid in accordance with provincially established guidelines. Salary is based on qualifications and experience, and a master's degree in social work is usually mandatory. The minimum salary is about \$26,000 per year, the maximum about \$35,000.

Angie reminisced about the days when she had the services of a case co-ordinator.

"I had a case co-ordinator a couple of years ago, and it was just unbelievable how busy that person is. I have basically become that. I think as the years have gone on and they've overspent (COMSOC), they've had to restrain, and case co-ordination is the thing that's virtually been thrown in the garbage pail; but it's probably the thing families need the most. If you consider my ten hours of support could be used for something else if I didn't have to use them co-ordinating things for my children...it's just a tremendous burden on families...hours for case co-ordination are not a priority in their eyes."

Angie's observations about case co-ordination matched closely those of the other women, and each of them assumed that responsibility in her respective family. Visits to doctors,

meetings at school and so on complicate their already hectic schedules. The three women who worked outside the home were particularly inconvenienced and yet, as Doreen pointed out, while the child's handicaps might increase the number of such appointments, women were responsible for this work anyway.

"Don't all mothers have to do that? Don't all working mothers have to go to school interviews, have to take their children to the doctors? If there's an emergency, the mother's the one who leaves work and goes and takes care of it. Yeah, I had to do it for Judy, Peter and Steven. I guess the frustrating part is around school, special needs stuff...I've taken a fair amount of time off in the last couple of years to go to meetings and planning decisions at the school and stuff because teachers just don't do it any other time than during school hours."

Doreen is angered by the fact that her time 'doesn't count'.

Whether she is at home or at the store, the assumption is made that she can accommodate her schedule to everyone else's because she's not doing anything very important anyway! She gets caught in the classic contradiction for women in the family - personal independence balanced against the needs of the individuals they love and care most about. A contradiction men rarely, if ever, face.

DOREEN

"I mean you have to weigh it.. What are you going to do? Do I say I'm not going to take any time off either? Who gets lost in that? Judy does!"

Cut-backs in community programs are felt in other ways. Shoe-string budgets stretch worker resources in those programs to the limits, as their clientele steadily grows. Some of the women I talked to, although aware of the lack of workers, attributed part of the problem to a lack of interest on the part of program staff in working with children who are severely handicapped.

Mary spoke at some length about trying to get appropriate programming for Cathy in both speech and mobility training. She has all but given up on speech.

"There's just no help available and really, to tell you the truth, speech pathologists are not interested in working with a child like Cathy because they want to see progress too..."

Cathy's mobility training is even more problematic. Mary believes her daughter has the potential to walk. This was confirmed by a physiotherapist from the United States who did some consulting work in Canada. Mary was given the rudiments of a program to carry out with Cathy and was advised by the consultant to seek on-going follow-up. She took Cathy to a Child Development Centre in a nearby city and was told she was wasting her time. Mary continued with the program given by the consultant (a series of exercises and activities performed every day for an hour), and over a 2-year period, Cathy learned to pull herself upright and take a few steps with assistance.

Mary feels she has exhausted the possibilities of the original program because Cathy's needs have changed. She is angry because the lack of interest in Cathy's progress not only makes her work more difficult but has worked against the child's interests.

"There's no follow-up. It's really getting hard to do the program because Cathy is getting so big. It's really getting hard getting her up and down from the floor to the chesterfield because she's all arms and legs. If we had been given that stuff to do with her when she was younger, she probably would have progressed along but that time is gone and all we've got to work with is what's left to her. It sounds like an awful thing to say, but there's got to be somebody else whose sort of interested, you know? You get tired of doing it. Are you going to do it for 20 years and nobody ever says, 'now you can do this'?"

What Mary perceives as a lack of interest in Cathy's progress may also be attributed to the pressure put on workers to make their work conform to the statistical requirements of government. Clients who make very slow progress in community-based programs can detract from the overall standards of efficiency and program effectiveness on which funding is based. Thus program constraints can affect and organize Mary's work. Cathy is, perhaps, less independent than she might be had a trained worker been available for an extended period of time to provide the necessary expertise. The other side of the coin is that more active intervention in Cathy's programming could also substantially increase Mary's labour, and yet it

seems even this might be preferable if, in the long-term, her work was reduced by Cathy being able to walk on her own.

EDUCATION

The education system also organizes the women's work. While going to school is a positive experience for the child, and means that his/her care is organized outside the home for a few hours each day, the role of the women in preparing the child for school as well as their involvement in the education process itself is critical. Although as we have seen, the earliest struggles for community care for retarded children focused on their right to be educated - a struggle that produced over a 20-year period some significant gains in developing schools for retarded children and so on - the relationship of families to school boards has entered a new phase with its own form of contradictions.

Last year, Bill 82 (Ministry of Education) went into effect after a lengthy implementation period. The Bill makes school boards responsible for providing education to all pupils, within their jurisdictions according to the needs of the individual child. While Bill 82 does not state that these needs must be provided for in an integrated setting, it is becoming quite common for families to argue that placement of

the child with other students who are not disabled is an essential part of meeting the child's needs. The actual process of negotiating individual program plans for each child, (a requirement of the legislation) as well as the impact of this negotiation on schools and families merits a study in itself. I will simply point out here some of the more obvious effects of what is, essentially, a more rationalized and individualistic approach to the educational needs of severely handicapped children which mirrors the rationalized and individualistic approach of COMSOC to their developmental needs.

Although the women did not refer to integration as, 'community' schooling, it seemed clear that they thought about it as a necessary 'piece' in providing their children with a normalized environment in the community. The women feel segregated schools carry a stigma. Until recently, all of their children were in the same segregated school attended by students ranging in age from 5 to 21 years with a wide range of disabilities. Their children formed a core of the most handicapped pupils. The women were quick to point out the interest and dedication of the teachers, but felt that the teachers focused too much on the child's disabilities - one of Wolfensberger's observations about professionals generally - as well as the fact that the segregated school did not offer the children any opportunities to model normal behaviour - also a

basic tenet of normalization. By exercising their right of appeal on the individual program plan which school boards must now provide for each child, all of the women (with the exception of Angie) were successful in having their children placed in a special classroom in a 'regular' school. Mary talked about the changes in Cathy.

"I would not say she's improved a lot as far as ways we can measure it, but socially and in behaviour, she's improved so much."

On the other hand, Mary notices disturbing things like a lack of attention to Cathy's cleanliness - something that was not an issue in her old school.

"Like I'm fussy about keeping her clean, and she comes home from school filthy. Like her jacket is filthy and her hands wouldn't be washed...I don't know what it is, I really don't, when she's not looked after physically, too."

One obvious explanation, which Mary herself is aware of, is cut-backs in education. Cathy is one of nine severely handicapped children in the classroom. There is only one teacher and two aides to meet the children's needs. The children are not usually present in the classroom at the same time as each spends four periods a week integrated into regular school activities, however, an aide attends the integrated sessions with the children leaving the teacher with one aide (and a somewhat smaller class). Given the need of each child

for constant individual attention, it's hard to imagine that two people can supervise them adequately at all times.

Mary related the following incident about lunch hour:

"Cathy's fallen twice in the past couple of weeks. She's out in the yard in the playground and I think they're supervised by other children, and the wheelchair has gone off the pavement and she got a bad fall on Friday. She had a really nasty scrape on the side of her face. Her teacher felt very bad when she phoned - she was nearly in tears and I said 'don't worry those things happen'. But I don't want it to happen again, she might lose her eye. But here she came home with this cut and her hands all dirty..."

Cut-backs in education very definitely affect the child, but we can see here how they affect mothers too. If not in more work, like maintaining contact with teachers, then in making extra worry for somebody like Mary.

In this instance, one cannot help but question how normalization and general community integration as an ideal are also implicated. Although Cathy might have fallen anywhere, she would certainly not have been left in the care of other students in a segregated school where lunch periods and recesses are always supervised by staff. 'The dignity of risk', so often spoken of in community living for the retarded carries a hidden price for mothers who, better than anyone, know how vulnerable their children are. Trying to walk the

thin line between encouraging a child's potential and recognizing his/her disabilities is not easy, as Doreen stated so eloquently in an earlier Chapter. For the rest of the women this is even more critical for their children. The dignity of risk can mean real peril if the necessary material supports, such as a proper staff complement are lacking. Mary's story suggests that they are lacking in the school setting.

Although the women realize that the presence of their children in a 'regular' school affects its organization, they feel the schools (read teachers) have a responsibility to work that organization out in the best interests of the child because they are being paid to do that. In other words, the women want to see 'results'. It is easy to see how the teachers could perceive these women as threatening. They have had a very different experience raising their children than most mothers of non-handicapped children, and have acquired considerable skill in advocacy through the years. As well, they are aware of how important their input is to teachers. Louise, a teacher herself, made some observations about this:

"Last year her teacher felt really uneasy with me and I'm sure most of it was because she felt I knew more than she did...Also, I have a sharp way. Usually I don't mean anything severe, I just want a few changes and I want them now. I've never been shy about asking for those things and I don't think you can be. Susan will only have so long in school and she's got to have what I feel is the best

available. You can't wait for another year all the time..."

Louise raised another issue about the relationship of mothers and teachers.

"The other thing I try to keep in mind is that I'm her mother and for all the hours she is not in school, she's home with me. I don't get paid for being her mother. I try to do the best I can, but I feel there are times when I do have to slack off a bit or have relaxing times, but I don't feel that teachers in schools get paid for that. That is their job to do that work for that many hours. They don't have to do it for the rest of their lives; they don't have to do it on weekends or when they go home at 3:30, 4 or 5 o'clock. They don't have to think about it until the next morning if they don't want to, whereas if you're a mother it goes on and on. It doesn't quit...I think that's what we have to think about teachers. We have to be a little bit compassionate toward the other things in their lives like pupils that might cause problems or whatever, but we also have to set quite high standards for them and expect them to attain."

Louise brings into sharp focus the different value accorded the work done by mothers (within the family) and work done elsewhere. The fact that she conceptualizes this as a difference between mothers and teachers points up how cut-backs can foment differences between two groups of women whose very real difficulties are actually two sides of the same coin. Most teachers are probably involved in a double day of labour and many of them undoubtedly do carry their classroom problems home with them - at the very least in the form of preparation time for the coming school day, yet the distinction between the

teacher's paid and mother's unpaid work makes the oppressive working conditions of each difficult to see. Moreover, the ways in which their work intersect to advance the interests of various government departments is also obscured.

HEALTH CARE

Cut-backs in health care also affect the women's work. Medical problems often go hand-in-hand with severe mental disability. All of the women with the exception of Doreen have had considerable involvement at some point with hospitals, physicians and so on. At the time of the interviews, Angie was experiencing the most difficulties.

Her sons have had over 200 admissions to hospital since birth - mainly for eye surgery - in Toronto (a four-hour car drive from home). As an administrator in the health care system herself, Angie is no stranger to the admission and scheduling requirements of hospitals or to cut-backs that have resulted in more rigid admission regulations as a result of staff shortages and reduced care once the patient is admitted. The care Angie feels is acceptable for her children puts pressure on workers, for example, nurses, who are already overloaded and who have to rely on mothers being 'co-operative' or even physically present to augment the supervision of

handicapped children. Severely handicapped children, Angie discovered, are often placed in restraint devices because there is no staff available to supervise them. Ward staff complements are not predicated on the constant supervision the children require. Angie says families are not usually consulted about the use of restraints - something which is totally unacceptable to her. Since she became aware of the situation, Angie has expressly forbidden their use. Although she is determined not to settle for anything less than she thinks her sons deserve, this decision costs Angie dearly in time, emotional energy and money. Each trip to Toronto is a logistical feat which she must carefully organize so as to create the least amount of disruption to the family as a whole.

The normal hospital admitting time is 11 a.m. Angie finds it virtually impossible to meet this deadline: (a) she loses time from work; (b) there is nobody to drive with her (she cannot look after the boys and drive at the same time); and (c) she has to make extra care arrangements for her 2-year old son. The most convenient time to admit the boys, for her, is in the evening: (a) she misses a minimum of work; (b) her husband and the youngest child can go along - there is somebody else in the car, and there are no extra sitter costs for the youngest. Angie has been able to get the hospital to agree to evening admissions but, not without difficulty.

"...(these arrangements) can be very frustrating to hospitals. They think, 'here's this old nag of a mother and she's such a pain all the time...I think sometimes admitting clerks - well four hours to them is nothing, and four hours to me means a lot.'"

To save time, Angie packs a suitcase for the boys the night before they leave for Toronto. That day, she leaves work early and stops by school to pick the boys up. At home, she meets her husband who has already collected Kyle from day-care. There is a last-minute flurry of activity - to prepare food to eat on the way. Car rides are an ordeal for her sons who, because of their limited vision, are especially sensitive to changes in routine, motion and so on. Angie says they are learning to tolerate the car better, but it is not unusual for them to cry and scream throughout the trip.

Angie tries to arrange ahead of time for extra nurses or 'sitters' when she is unable to stay at the hospital, as well as a private room for each child. Not only must she negotiate these things in the face of existing hospital rules, she must assume responsibility for the costs incurred.

"That (extra staff) has not been offered to me. That's been insisted upon by myself. I have just insisted that they arrange these things prior to my coming, and I insist that each child have a private room, otherwise they'll keep everybody on the ward awake and I hear about that...often financially it's our responsibility if we want a private duty nurse to pay for that. If (the hospital) knows enough in advance, they'll try to arrange 'sitters', but I often have to pay for that as well."

ISSUES OF 'CLASS'

The effects of such cut-backs for working class mothers are only too clear - they and their children may go without the supports they need and/or may be caught up in the Child Welfare System proper if an intervention by a Children's Aid Society is deemed necessary. Although the limitations on my research prohibited me from checking very thoroughly into the situation, my impression is that many of these children do come into the care of societies, much as they did in the 1970's. An article in the Ottawa Citizen entitled "CAS Program Frees Disabled Children From Institutions" (December 27, 1984) discusses the growing number and increased needs for foster families to care for severely handicapped children. The article notes the rate for foster care is \$20 per day, and states that it is usually between \$60 and \$100 per day in an institution.

SUMMARY

I have showed in this chapter how government fiscal and financial priorities organize the women's work and how they must intensify their labour to make community care for their children fit 'the ideal' in the face of social service cut-backs. In the final chapter, I will take up the issues this raises as well as others raised by this research.

VIII DISCUSSION

I have examined a form of community care in the home which serves to organize women's work so that it complements the de-institutionalization of retarded people. Although many families of retarded people have also favoured non-institutional forms of care for their dependents, current government policies implementing de-institutionalization and community care, the latter to replace care in large institutions, favours the administrative and fiscal priorities of 'the state' - identified in this paper as a provincial government.

A shared understanding of the term community on the part of families and the government has been a crucial determinant in the widespread acceptance of 'community care'. I have been able to show, by beginning with the experience of women who care for their severely handicapped children at home, and by examining a selection of textual work on community from a variety of sources, that this shared understanding of the term is ideological. As well, it serves as an example of the experience of patriarchal relations. The experience of providing community care is at odds with the belief that community care is shared in some fashion by groups or individuals outside the immediate family where care is provided; for example, by male partners, friends, relatives, neighbours or programs expressly created to facilitate it.

The work of care, crucial to the reproduction and maintenance of any society, is usually done by women, and in capitalist societies, this includes care in the home and forms of it in the paid workplace. The socially constructed belief that the ability to care is an inborn female trait serves to obscure its importance for society as a whole as well as providing for its economic devaluation in a world where earning a wage is the basic determinant of life chances. The belief on the part of many women that care-giving is natural also serves to perpetuate the notion that care is a uniquely female activity.

The use of the term community by 'the state' at the present time to describe women's unpaid work in maintaining dependent people, is an example of how certain specialized textual work can inform its practices; in this case the 'return' of certain forms of care formerly provided through state funding to 'the family', understood to be part of the community, where it is performed by women at no cost to the state. The increasing reliance of the state on community care to solve some of its financial problems cannot be seen as wholly manipulative nor intentionally directed toward the subordination and economic dependence of women. Those who create state policy understand 'community' and women's work in the same way as academics and various experts and now families do. At the same time, however, the social relations of

capitalism itself which make a distinction between and separate the labour required to produce 'the community' or 'the family' from other forms of labour does render women dependent, especially when they are engaged in the work of caring for individuals who are unable to care for themselves.

My research indicates that community care of severely handicapped children at home by their mothers may be part of a larger re-organization of the labour force (Walker: 1986(c)) in which state practices serve to mediate between the need of capital to further accumulation and the necessity of reproducing and maintaining the work force whose labour makes that accumulation possible (Ursel: 1984). The care of severely handicapped children at home affects a relatively small number of women and thus provides only a glimpse of a possible 'larger picture'. There are, however, indications that the work of a growing number of women is being organized on the basis of them providing care to a growing number of people defined as dependent. Care of the elderly is the most obvious example but is not unique.

Guberman's (1985) analysis of recent social and fiscal policy in Quebec shows clearly how the maintenance of various dependent groups is a matter of increasing concern to the provincial government, and how 'the family' and 'community' are coming to the fore - in the name of everything most positively

associated with both - as the ideal solution to these state concerns. Guberman notes for example how the category of youth, which has one of the highest unemployment rates, is being redefined to include those between the ages of 18 and 30. The Quebec government plans to offer tax incentives to families who continue to care for their 'youthful' dependents.

The notion of dependents who are 'forever young' and, by implication, 'forever dependent' on the services of a care-giver, does not seem like a motherhood issue in the literal sense (if we consider that the 'bottom line' on motherhood for the vast majority of women has been in the past the reproduction of a new generation of workers). Motherwork now appears to be shifting its focus from one of raising future workers toward one of maintaining people who are unable to work because of age or disability, or who are able-bodied but cannot find work.

The organization of women's work as care-givers does not appear to affect all women in the same way, although it would be difficult to say that any group of women actually benefit from the current arrangements - if care of severely handicapped children at home serves as any indication. My work shows how middle class women must intensify their labour to reproduce the ideals of community in the face of diminishing resources - both in terms of what is required to care for the handicapped child,

as well as what is required to maintain the standard of living for the family as a whole. Working class women, on the other hand, may be subjected to the more intrusive and coercive intervention of Children's Aid Societies when they are unable to conform to a standard of community care that is derived from 'middle class' ideas about the family as well as 'middle class' access to the resources necessary to produce it. As well, community care of dependent people is creating new low-paid or volunteer work for women. In some instances, cut-backs in state services such as health and education contribute to their availability for this work; the availability of other women is the result of a lack of 'formal' work experience or relevant training that would give them access to work outside the 'female job ghetto'.

It is clear that men do not share equally in the work of caring for dependent people. They retain some choices about the circumstances in which they provide care as well as what aspects of it they wish to be involved in - options available to few women whether they are middle class or not. The unequal arrangements for care of the disabled children in this study make clear how male privilege and power work against the interests of women and may actually limit their freedom. On the other hand, it is clear that male privilege and power in this instance is inextricably connected to capitalism itself and the forms of work it gives rise to.

Requiring men to devote a greater share of their time to providing care can be of short-term benefit: (a) in providing women with immediate support; and (b) in serving to educate men in how to provide care. At the same time, this action alone is not sufficient to produce substantive changes in who bears the major responsibility for long-term care. As things now stand, this 'reversal of roles' represents a poor economic bargain for the majority of families. Men generally earn more money than women. Community care in the home, although cheaper in some respects for the government, is very expensive for families who must provide it. The needs of dependent people can require costly special services or even personal items that the government subsidizes in a very limited way or not at all. It is not in the interests of families who find themselves in this position to alter the present division of work when this could impair their financial ability to provide care. There is, of course, much less likelihood that women, relieved of their care-taking responsibilities, will find work equivalent to that of their male partners. This is especially true for working class families where women may be further disadvantaged in the job market by lack of training and are compelled to take the lowest paid work.

Long-term changes in the responsibility of caring for dependent people would not only require a greater understanding and appreciation of the work of care, but of how it fits into

and is a part of the organization of work as a whole. This is especially important when work itself is in a constant state of change, as it is in capitalist formations, and where, also, that work gives rise to and is constitutive of the dependence and economic subordination of women as well as the various forms of oppression they experience. In other words, there is a need to develop a politics of care which takes these facts into account. Such a 'politics' would require concessions from men and women. For men, it means giving up their dominant position in the economic order and the privileges that accrue to them from this position. For women, it means giving up one of the attributes by which we measure ourselves as feminine or womanly, that is, our 'predisposition to care'. For both, it implies challenging the structure of society that gives rise to class, gender and racial inequality.

The state organization of women's work as care-givers at the present time, militates against developing a politics of care as it tends to reinforce and deepen the forms of inequality mentioned above - particularly those arising out of gender. Not only are women bearing the brunt of the state's requirement to divest itself of expensive long-term care responsibilities, many of them are rendered more dependent on a male wage as a result. That economic dependence can be more 'silencing' even than the 'invisibility' of care in the home.

The gains made by women in recent years have been predicated on them speaking out about their oppression. Women who care for dependent individuals are in a vulnerable position, especially if care limits the possibility of their being able to take paid work. They may be compelled to 'put up' with more from individual men and/or take the extra responsibility of negotiating their living arrangements to the benefit of their (male) partners. In many instances, this may be preferable to jeopardizing a relationship upon which they rely for the necessary material resources to provide long-term care.

There is nothing 'wrong' with wanting to provide long-term care at home for a family member - what is at issue is the way these activities have been shaped to reflect and serve interests that lie outside those personal ones. For example, the lack of other residential accommodation in the community, or current standards of institution care that are unacceptable to the dependent person's family. It is often difficult, however, to draw the line between the two; especially when the personal experience and the extra-local understanding of that experience are mediated by textual work that takes the inequalities of capitalist society as a 'given'. The same holds true for the social relations we call 'community' and offers a means of understanding why the experience of 'community' is an oppressive one for women.

"There is a difference between a society organized around kin and community and the survival of kin and community in a society organized around wage labour" (Zaretsky: 1982: 194).

The ideals of 'the community' and 'the family' are actually the antithesis of each other. Community implies an equalitarian social organization that benefits all of its members. The family implies a privatized, hierarchical and gendered work organization that oppresses women but that also foments differences between families. This appears to be the basic contradiction which provided for the ideological construction of community to begin with, and which has been compounded in particular ways and in particular social periods ever since. Implementing the ideals of community would require a corresponding weakening of family ties (Barrett and McIntosh: 1982). The family, as presently organized, does not work in the interest of all of its members, and lessens the chance of receiving support from anywhere else. The organization of women's work in the home is especially insidious because home, family and now community are believed to be safe from state intrusion.

Things can and do change, however, as a result of human effort. The changing notions of what constitute appropriate care of ~~re~~perarded people is a case in point. It is an indication that the state is a viable although difficult area

in which to make changes when its practices are at issue. This is of special importance to women since so much of our paid and unpaid work is shaped implicitly or explicitly by state practice, and because we appear to be losing ground at the present time.

The bleak outlook at the moment does contain some 'rays of hope', but only if we struggle to break down the distinctions between men/women; paid and unpaid work and so on. The work of mounting and organizing collective struggles is difficult. Social workers involved in various aspects of community care have an important role to play in this, however, as we are in a position to 'connect' a number of individuals or groups who, along with care-givers, have an interest in care: in the case of community care of severely handicapped children these might include unions who have lost workers as part of de-institutionalization, teachers or nurses who are hampered in their efforts to provide the specialized services the children need, as well as associations for the ~~mentally~~ retarded or other advocacy groups. We can also support care-givers by recognizing that care is work, and that the assumption that it is 'natural' can serve to oppress women. The degree to which we are open to these possibilities and effective in using them for change, rather than conforming to certain ideological constructs, depends upon a critical analysis of the meaning of

organizing terms and concepts as well as a recognition of how those meanings can provide for 'ruling'.

My research raises a number of questions. We need for example, to know more about the 'connections' between the subjective understanding of care-givers, which is the sum total of their lived experience, and the social organization of care. We also need to make more detailed analyses of the 'understanding' men have of care. It is also important to show empirically how the present organization of care is implicated in the organization of class.

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APPENDIX A

INTERVIEW SCHEDULE**I GENERAL**

1. Mother: Age; General Health; Education; Paid/Unpaid Work.
2. Partner: Age; General Health; Occupation.
3. Children: Age; General Health; School Level.
4. Home: Own, or Rent.
5. Access to Car: Yes; No.

II PLACEMENT CHOICES AND 'COMMUNITY'

1. Has _____ always lived with you?
2. Was there ever a time when you considered other options?
If Yes: What were these? Why were they rejected?
If No : What led to that decision?
3. What's different about caring for _____ at home as opposed to somewhere else?
4. Why is care in the 'community' important for mentally handicapped people?

III HOME CARE OF THE CHILD

1. What sort of help would _____ need with:
Mobility; Feeding; Dressing; Bathing; Toileting?
2. Do any of these present special difficulties for you?
Describe.
3. How is _____'s health?

Any special medical problems.
Medication or special treatment required.
4. Can you tell me about other special aspects of care?
Behaviour; Communication; Sleep Routines, etc.

III HOME CARE OF THE CHILD (cont'd)

5. Are there any special satisfactions/pleasures in caring for _____?

If Yes: Describe.

If No: What's standing in the way of this?

6. Are there times when it's especially difficult to cope? Describe.

IV CARE OF THE CHILD - MOTHERS AND 'EXPERTS', GOVERNMENT PERSONNEL, ETC.

1. Is _____ involved in any special programming? Describe.

What is your role in this? Taking child to appointments; carrying out programs at home; recordkeeping, etc.

How do you fit these responsibilities in with paid/unpaid work?

How much time is involved? Costs? Who helps?

2. Medical/professional consultations and team meetings.

Who is involved and where do these contacts take place?

What is your role in this?

How do you fit these responsibilities in with paid/unpaid work?

How much time is involved? Costs? Who helps?

3. School.

Do you have much involvement with the school?

What is your role with regard to the school?

How do you fit these responsibilities in with paid/unpaid work?

How much time is involved? Costs? Who helps?

What effects (if any) has Bill 82 had on _____'s education? Describe.

IV CARE OF THE CHILD - MOTHERS AND 'EXPERTS'.
GOVERNMENT PERSONNEL, ETC. (cont'd)

4. COMSOC.

Are you receiving handicapped children's benefits?

Describe process whether yes or no.

Is _____ receiving Special Services Funding?

How did you negotiate the Special Services Agreement?

Did you have help (from program personnel) to do this?

Did you have help from anybody else? —

What is _____ being funded for?

Emphasis here on in-home relief workers.

How much time does negotiating the agreements take?

How much time does supervising and organizing in-home relief take?

Are you satisfied with Special Needs?

Are COMSOC personnel helpful (or not)? Describe.

How could the Special Needs process be better?

What would you do if you were in charge of COMSOC for a day?

5. Child's social activities.

Does _____ take part in swimming, bowling, etc.? Describe.

What is your role, e.g. driving, supervising, etc.

Does it take a lot of effort to get _____ ready for these activities? Describe.

Do these activities create scheduling problems for you? Describe.

V PAID WORK

1. Do you work outside the home?

If Yes:

Is this a full or part-time job?

Do you have a job title?

What do you do in your job?

How many hours do you work each day?

Do you work overtime?

Do you work evenings or weekends?

How long does it take you to get to work?

Do you expect to keep on working?

If No:

Did you ever have a paid job?

What did you do?

Why did you stop working?

Would you like to go back to work?

Do you see any possibility of going back to work?

VI PAID WORK AND DAILY LIFE WITH THE CHILD

1. Is your employer aware of _____'s special needs?
2. Do you ever need to take time off for appointments, etc.?
3. Is this a problem for you and/or your employer?
4. Does having _____ at home make it more difficult for you in any way at work? Describe.
5. Do you shop or do household chores before work, on your way there, at lunch hour or on the way home?

If Yes:

What kind of things?

Is this a problem (or not)? Describe.

VII HOUSEHOLD CHORES

1. Is it difficult to find time to do housework? I'm thinking here of laundry; cooking; cleaning; shopping; dishes.

If Yes.

Which ones and why.

2. Is there a difference between the way you do this work during the week and on weekends? Describe.

VIII WHO HELPS?

1. Immediate Family

(a) Do you have help with housework from other family members?

If Yes.

Who?

What do they do?

How often do they help and how does this get arranged?

If No:

What stands in the way of this?

(b) Do other family members help with _____'s care?

If Yes.

Who?

What do they do?

How often do they help and how does this get arranged?

If No.

What stands in the way of this?

VIII WHO HELPS? (cont'd)

2. Extended Family

- (a) Do you or your partner have relatives nearby?
- (b) Do you see much of them?
- (c) Do relatives take care of _____?

If Yes:

Who?

What do they do?

How often do they help and how does this get arranged?

If No:

What stands in the way of this?

- (d) Are relatives at ease with _____?

3. Friends, Neighbours and Acquaintances

- (a) How would you describe your neighbours (re helping out)?
- (b) Do you have friends nearby?
- (c) Does anybody else help? How did you come in contact with them?
- (d) What do any of above people do?
- (e) How often? How does help get arranged?
- (f) If they don't help, what stands in the way of this?
- (g) Are they at ease with _____?

4. Parent Relief Program (out-of-home)

- (a) How often do you use the Program?
- (b) Under what circumstances do you use it?
- (c) What's involved for you in getting relief?

VIII WHO HELPS? (cont'd)

(d) Is the program a help to you?

If Yes. Describe

If No : What stands in the way of this?

5. General

(a) Is it difficult for you to get (ask for) help/support?

(b) When you have it, is it as much as you would like?

(c) What sort of help/support is most useful to you?

(d) Special considerations, e.g. cost? Availability? Skill in caring for the child?

IX LEISURE

1. Do you have any special interests or hobbies?

2. Do you have a chance to pursue these?

3. Do you get out on your own as much as you would like?

4. Are you active in clubs, church, etc. (other than activities related to mental handicap).

5. Has having _____ at home made a difference in your social life?

6. Who looks after _____ when you go out?

7. How do you feel about leaving _____ with other people?

8. Have you had a holiday recently? When was the last time?

X LOCAL ASSOCIATION AND/OR OTHER ADVOCACY WORK AROUND MENTAL HANDICAP

1. Are you a member of the local association or any other group?

2. Describe your involvement and/or responsibilities.

X LOCAL ASSOCIATION AND/OR OTHER ADVOCACY
WORK AROUND MENTAL HANDICAP (cont'd)

3. How much time does this take?
4. How do you feel about these involvements? e.g. benefits to the child; furthering care in the community generally?

XI TELL ME ABOUT YESTERDAY

(from getting up to going to bed)

APPENDIX B

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LOG

TIME ACTIVITY

WHERE
WERE
YOU?

WHO WAS
WITH
YOU?

WERE YOU DOING
SOMETHING ELSE
THE SAME TIME?

WHAT WAS
DOING?

News

APPENDIX C

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FOR USE ANY TIME

COMMUNICATIONS BRANCH
965-7252

"...We realize how very fortunate we are that you have approved this program of (parent) relief and help for our family. You have not just helped another handicapped child, you've saved a marriage and a good little family..."

Péter and Nancy Amell

(from a letter sent to the Minister
of Community and Social Services)

The Amells, from Cornwall, became the first family in Ontario to receive assistance from a \$2 million provincial government program introduced by the Ministry of Community and Social Services.

Through the "Special Services at Home" program, set up to assist parents whose developmentally handicapped children live at home, \$4,200 was made available for a six-month period to hire a trained parent relief worker.

The specialist will help with the home care of their youngest daughter, Shannon, who at the age of three is blind, has cerebral palsy and is severely handicapped. Constant care is required daily. She even needs someone to feed her. The money will allow the worker to provide help six hours a day, four days a week and be available for a complete 24-hour period, one day a week.

"Shannon is part of us and there is no greater thrill to a parent than to have your own young child living home, even if it is with a handicap," said Nancy Amell, a former health nurse. "It has been tough. There are tremendous pressures and lots of tension that goes along with caring for someone who is not normal. We are all happy that Shannon is home, but the stress has led to some rough times."

She explained.

"My husband is a policeman and has considerable daily pressures while on the job. It doesn't help our marriage when he comes home and hears Shannon crying as much as 10 hours a day."

According to Mrs. Amell, the crying is due to a number of factors including a constant need for rest or a change in clothing. She says that prolonged crying usually means there is something wrong. Usually, it is difficult to determine the problem in a short period of time. In the past, the crying has been due to allergies to food, stomach indigestion and toothaches.

"The crying builds on a person's mind and, in our case, it was creating family problems. Our marriage was in jeopardy. We wanted Shannon at home but needed a way to cope with the responsibilities of caring for her.

"The government program came at just the right time. With the money to get someone to help us, it has saved our marriage, kept our family together and provided a very important helping hand for Shannon."

In the Amell household, a typical day starts at 5:00 a.m., when Shannon awakes, and ends some 15 hours later. Throughout that period, she is bathed, fed a carefully selected diet and put through a series of physiotherapy sessions involving selected exercises to various parts of her body.

The Amells' story is just an example of the way the Special Services at Home program can help. The limited-funding program is intended to provide needed services that have not previously been available to children like Shannon, and especially those up to the age of 18.

"This is a good example of how we can keep a child at home for about \$7,000 instead of institutionalization which is extremely costly," said Frank Brideau, Special Agreements Officer with the ministry's Ottawa area office.

It's also the second phase of a Special Needs and Special Service project implemented last year in which \$3.7 million was made available to children living in residential facilities and community residences.

The new program has created a strong partnership between the Community and Social Services Ministry and parents of developmentally handicapped children.

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"There is no question about it," said Valerie Elliott, Co-ordinator of the Special Services at Home Program for the ministry. "People have waited for this program a long time. It is serving their needs and, most important, helping them keep their child at home."

John Haddad, Executive Director of the Ontario Association for the Mentally Retarded (OAMR), agrees.

"It's an excellent program and also a much more humane and desirable course of action than the very costly institutions," he said.

The Special Services program was developed by the Ministry with the support of the OAMR. The Provincial association played a key role in consulting with the private sector as well as various community groups.

In short, the new program will allow these children to receive selected services and equipment, such as a bath lift and hearing aids. Services could include the purchasing of a person trained in behavior management or hiring someone to help in teaching daily living activities. The latter is what the Amells chose.

As a result, the family is functioning more easily. There's also a better opportunity for ongoing assessment of the child's condition.

"We expect the parents of children who have a developmental handicap to meet the basic care of those children," said Agnes Samier, manager of the ministry's mental retardation services unit. "Sometimes, however, the child's special needs can be overwhelming and could lead to placement of the child in an institution. With a relatively small investment of funds through this program families are finding methods of coping with their children and keeping them at home."

"Families who have received assistance have indicated that it is not the funds alone which are important, but also the feeling that their problem is now known and shared with others and that there is a commitment to help."

Children with a documented developmental handicap -- the diagnosis must be made by a registered physician or psychologist -- may be eligible to receive assistance.

The program requires that the child's parents or guardians make the application for funds to the local area office of the Ministry of Community and Social Services.

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October 1982

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