

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of  
Ethnic and “Racial” Minority Women**

by

**Shari Brotman**

**A thesis submitted in conformity with the requirements  
for the degree of Doctor of Philosophy  
Graduate Department of Social Work  
University of Toronto**

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**AN INSTITUTIONAL ETHNOGRAPHY OF ELDER CARE: UNDERSTANDING ACCESS  
FROM THE STANDPOINT OF ETHNIC AND "RACIAL" MINORITY WOMEN**

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**Doctor of Philosophy, June 2000**

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**ABSTRACT**

The current study addresses the problematic of access for ethnic and "racial" minority elderly women through an examination of the working processes of a publicly-funded organization which provides elder care services in Ontario, from the standpoint of these women. Using Institutional Ethnography methodology, the study explicates how state ideologies become infused into the operating policies and guidelines of elder care organizations, shaping the actual way access is both conceptualized and operationalized and the subsequent interactions between workers and their elderly clients. Interviews conducted with 43 participants (elderly women, agency staff, community agency and institutional staff) explicate how actors both reproduce relations of oppression and counter or resist those relations.

Several problematic constructions have been identified which highlight the disjunctures between older women's expressed desires regarding access and the way access to services are operationalized in elder care agencies. These include: family involvement in care; prolonged engagement as a means of facilitating access; the influence of acute health care models on eligibility for and delivery of care; and, a focus on cultural competence and language in the delivery of ethno-specific services. Program and practice implications are highlighted in order to shift the dominance of state-orchestrated ideologies which operate to shape the experience of women who are multiply situated on the margins and who have been and continue to be oppressed within elder care institutions.

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**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic and "Racial" Minority Women**

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Over the past several years, health professionals and policy makers in Canada and

the United States have focused greater attention on improving access to health care, particularly among historically disenfranchised populations such as those from ethno-

“racial” communities, poor persons and women. Among those concerned about health care access are feminist and ethnic and “racial” minority community activists and

researchers who have, for over a decade, brought our attention to the fact that both

women and ethno-“racial” communities have faced and continue to face barriers to

receiving health care. They have repeatedly demonstrated that poor persons and ethnic and

“racial” minorities of all ages suffer from higher rates of mortality, and among the poor,

ethnic and “racial” minorities and women, morbidity is high (Blakemore & Bonham,

1994; Bolaria & Bolaria, 1994; Damron-Rodriguez, 1991; De-La-Rosa, 1989; Markides,

1990; Muszynski, 1994; Ruiz, 1993; Schoenbaum & Waidmann, 1997; Shea, Miles &

Hayward, 1996; Zong & Li, 1994).

In the field of aging specifically, the impetus for highlighting access as a major

problem in recent years has largely been one defined by professionals working with the

“frail” elderly in long term care. As a result, the current discourse on access and aging in

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“The term “race”/“racial” is purposefully set off in quotation marks in order to emphasize the fact that it is a socially constructed concept or category associated with colonialism and oppression in which skin colour and other visible, socially selected traits are used to classify groups hierarchically (Christensen, 1996). These terms are consciously separated from the terms “ethnic” and “ethnicity” which refer to people who choose to associate for the purpose of maintaining common bonds, such as those of language, ancestry or attachment to geographic location (Christensen, 1996). Thus, the terms ethno-“racial” community and ethnic and “racial” minority woman are used throughout the paper as a means of identifying and separating out these two categories. The terms “white ethnic” and “visible minority” were used when it was necessary to distinguish white women of ethnic ancestry from women of colour in order to advance analyses. A more detailed discussion of the problematizing of categories of “race” and ethnicity are made in Chapter 2.

both the United States and Canada has been largely framed by professional ideology. This professionally-guided movement to improve access has been influenced by “alarmist” rhetoric popular in both countries (Adams & Dominick, 1995; Barer, Evans & Hertzman, 1995; Binstock, 1994a; Denton & Spencer, 1988; Katz, 1992). The rate of population aging has been a serious concern for health care professionals and policy makers over the past decade. Much has been written about the potential impact of aging on the ability of the health and social service system to respond adequately to the increased demand placed upon it by the rapidly growing population of older people (Chappell, Strain & Blandford, 1986; Rittner & Kirk, 1995). Increasingly, however, the focus of discussion has begun to shift from questions of how best to provide older persons with universally accessible programs to questions of whether or not governments actually have the capacity or the responsibility to provide these services to older people. The introduction of state policies designed to reduce the deficit have led to the embrace of corporate “streamlining” and “downsizing” strategies by the public sector. Although ostensibly designed to bring about “increased efficacy” and reduce “service duplication”, these strategies do not necessarily mean improved access to health care for elders in Canada or the United States.

Recently, gerontologists have highlighted that the task of streamlining services to elderly people has been made easier in this environment, by a new emphasis on describing older persons as a relatively advantaged cohort (Myles & Street, 1995). Declining poverty rates among all seniors generally, a focus on assets rather than income and outlining the benefits seniors have received from universal programs have all been used to highlight seniors’ wealth in recent years. In a model which places seniors in competition with younger persons in a climate of shrinking public dollars, governments have tended to

blame seniors for being the largest threat to the public purse (Government of Canada, 1996:3-4). In the United States, Minkler and Robertson (1991a; 1991b) have coined the phrase "age/race wars" to describe rhetoric which places the affluent white elderly and their choice universal health care programs against the poorest children of colour. This "alarmist" definition of population aging has, in principle, led to the acceptance of government reduction of services to elderly people in Canada and the United States (Barer et al., 1995).

It is in this environment that governmental efforts to improve access to care are occurring. Within this discourse of scarcity of resources, access may simply be used as a tool for reducing health care costs. One example of this has been a movement among gerontology researchers and policy makers away from promoting service models based on universal criteria toward ones based on servicing only the medically-needy, that is "elders at risk", "dependent elders" or the "sick old" (Binstock, 1994a; Binstock, 1994b; Cutler, 1991; Kutza, 1995; MacAdam, Greenberg, Greenlick, Gruenberg & Malone, 1991; Zweibel, Cassel & Karrison, 1993). In addition to criteria based on physical functioning or illness status, some have also chosen to incorporate social determinants of health, such as socio-economic status and ethno-"racial" origin into their targeting practices (Kamikawa, 1991). What this means is that elder care programs are increasingly aiming their gaze solely at those who "fit" these categories of "need" and "risk", namely the disabled, sick, poor and ethnic and "racial" minority seniors - most of whom are women. Only those elders deemed "needy" or "at risk", such as those who are too poor to purchase services such as home care, assisted housing, or meal programs, will receive them from the public sector. Others will have to obtain services through the private sector, if and when they are

available. But who is “needy enough” or who is “at risk enough” and who is not remains unclear (Aronson, 1992; Neysmith, 1987).

What becomes evident here is that the “everyday practice” of access to elder care is fundamentally targeted, largely shaped by state and professional ideologies such as those of scarcity and medicalization. These ideologies are not simply conceptual notions, rather, they represent the organization of specialized practices of access which are made manifest through particular relations between the state, elder care institutions and elderly clients and which have a central impact upon how elderly clients are themselves constructed and which serve to exclude and dominate them (Smith, 1987). Defining ideology as the organization of specialized practices has major implications for the way access, as it is currently made manifest, is understood. Ideology, defined through practice, *as* practice, situates and roots it in the real world and in the actual practices of persons, organizations and institutions. As such, the state ideologies or “meta-narratives” of scarcity and medicalization, paramount in the field of aging, become infused into the operating policies and guidelines of elder care organizations and institutions, shaping the actual way access is both conceptualized and operationalized and the subsequent interactions between workers and their elderly clients. The process by which practices become shaped and clients dominated and excluded has been identified as “ruling relations” (Smith, 1987a: 3). Smith asserts that these processes of ruling reflect the,

intersection of the institutions organizing and regulating society... [it] is a concept that grasps power, organization, direction and regulation as more pervasively structured than can be expressed in traditional concepts provided by the discourse of power and includes that familiar complex of management, government administration, professions and intelligentsia, as well as the textually mediated discourses that coordinate and interpenetrate it. (Smith, 1987a: 108)

Smith asserts that relations of ruling are textually-mediated, that is, documents (such as policies, forms, directives, memos) “enter into, organize, shape, determine, coordinate, concert and accomplish social relations and organization” (Smith, 1987b:16). This is particularly true in late capitalist welfare state societies where texts have played an increasingly fundamental role in arranging relations between “professionals” and “clients” and in controlling and defining specialized categories of people, such as women or the old. This is viewed as a contemporary practice of domination which is experienced in every institutional setting to varying degrees.

This concept of ruling relations helps us understand how worlds are organized by social relations that are both immanent and extend beyond them (Smith, 1987a:106). By emphasizing the point that ruling relations *extend beyond* the organization of social relationships, Smith calls our attention to the fact that the individuals implicated within relations of ruling, who are themselves confined by these relations, are not, indeed can not be, fully aware of how their experiences are constructed by processes of ruling. In elder care, the processes by which interactions are shaped remain largely invisible to those at whom these processes are aimed, namely elderly female ethnic and “racial” minority clients. Experienced solely in the brief moment of everyday interactions or interfaces with their agency worker, clients who are constructed and defined by state processes, rarely are cognisant of the impact of state and professional ideologies on their experience of care. In explicating relations of ruling as they are made manifest in elderly ethnic and “racial” minority women’s lives, it therefore becomes necessary to go beyond the account these women have of their own everyday experiences to explore broader social relations not

necessarily visible in their lives. The inquiry from this perspective is focused on the problematic of the everyday, as Smith suggests,

looking at social relationships as “actual practices” which are not wholly located within women’s own experience. Thus inquiry begins not in women’s experiences but in the juncture between how women experience and know their everyday worlds and how this same world is known or constituted socially. In other words, beginning with the rupture is to start at a place in and between official knowledge (as mediated through texts and official counts of reality) and women’s own experience of that reality. The task then becomes locating this juncture within “the organization of social relations that has accomplished women’s oppression and exclusion. (Smith, 1987a: 78)

The invisibility of ruling relations (Smith, 1987a: 3) in the everyday experiences of elderly clients is particularly problematic for ethnic and “racial” minority elderly women since the gaps between the language, ideology and culture of professionals from “mainstream institutions” and those of ethnic and “racial” minority elderly female clients are exceptionally wide, resulting in little common ground from which to explicitly identify the processes by which access is constructed and maintained. Ethnic and “racial” minority elderly women are themselves socially and politically situated on the very margins vis-a-vis state and institutional discourse and this intersectional location of oppression is particularly evident in health care. As women of colour, ethnic minorities and/or immigrants, these women are located far from the andro-centric and white supremacist sites of power and authority in health care. This experience of multiple oppression renders older ethnic and “racial” minority women’s voices singularly mute. Ironically, these women may be the ones most profoundly affected by current emphases on adapting access in elder care. It is after all, older ethnic and “racial” minority women who are the potential targets of this new stress on streamlining and improving access. Often identified as the most

vulnerable to access barriers, the hardest to serve and representing an increasing proportion of client caseload, older ethnic and “racial” minority women may end up, inadvertently, being the focus of new efforts even when their voices are the ones that are the least heard by professionals in the field. Their particular experience is totally invisible and is rendered more so by the increasing proliferation of professional discourse in and control of elder care institutions. Older ethnic and “racial” minority women may be least likely to articulate their experience in a way familiar to the professional language of everyday practice in elder care thus having even less influence on the shape of care than Anglo-Canadian elderly women. This is exacerbated by the lack of activist and research allies who can contribute a critique of current discourses and practices in elder care from the standpoint of ethnic and “racial” minority elderly women. Feminist and anti-racist activists and researchers, who have claimed space for women and ethno-“racial” communities in health care generally and who have enabled their voices to be heard, at least to some extent, in larger debates on health care access, are still largely silent in the field of aging. So, the potential allies of ethnic and “racial” minority elderly women continue to be absent. In this context, ethnic and “racial” minority elderly women’s voices are even further marginalized.

Since older ethnic and “racial” minority women with disabilities and illnesses are the ones most profoundly affected by the current emphasis on access and since they have the most to gain or lose by these new efforts to streamline long term care, it is essential that gerontologists undertake research projects which seek to gain a better understanding of the process of access and the way in which this process is experienced by older ethnic and “racial” minority women. Undertaking research on the process and practices of elder

care institutions from the standpoint of ethnic and “racial” minority elderly women’s everyday experience of access is essential to the project of unmasking the way state and professional discourses such as those of scarcity and medicalization influence the everyday practices of elder care, and through these everyday practices, the interactions between these institutions, workers and ethnic and “racial” minority elderly female clients. This inquiry can serve to illuminate institutional processes which also have an impact upon those differentially (and often less problematically) marginalized but who are, nonetheless, still subject to ruling relations in elder care, such as elderly Anglo-Canadian women and elderly ethnic and “racial” minority men.

The current study seeks to address the problematic of access for ethnic and “racial” minority elderly women through an examination of the working processes of a publicly-funded organization which provides elder care services in Ontario, from the standpoint of these women. Two pivotal features of the present inquiry are: (1) the centrality of women’s voice and women’s experience, and (2) the explication of social processes of access as articulated in the everyday workings of organizations. These social processes refer not only to the interaction between workers and clients, but include as fundamental, the relationships between clients and their families, front-line workers, managers, community members and state apparatuses through organizational texts (such as agency guidelines, forms and client files). In other words, this study is anchored in understanding how things happen the way they do for older ethnic and “racial” minority women. The research questions are: How do we understand older ethnic and “racially” diverse women’s experiences of access to health care? and, What is the relationship between this experience and the work processes of the elder care organization?

**This study attempts to create a deeper, richer understanding of access, one which is based on broader definitions than those currently used by gerontologists in both Canada and the United States and which is more reflective of older ethnic and “racial” minority women’s experience. It explicates the processes by which access is currently being defined and how actors both reproduce relations of oppression and counter or resist those relations. In particular, the study sets out to explore the actual social relations of accessing health care as they arise in the agency setting. It seeks to uncover what organizes the problematic experience of access and what maintains it. What is meant by social relations is the complex of actions, interactions and relationships which define and shape access to health care; those actions which are articulated through the practices and processes of the agency being studied. These practices and processes include assessment and referral practices, case management models and approaches, and policies and procedures which govern the treatment of gender, ethnicity and “race” and which are made manifest between clients, front-line workers, managers, ethno-specific communities and state apparatuses (through the articulation of policy and other documents). This enables an exploration of how macro structures impact upon the micro level, from the standpoint of older ethnic and “racial” minority women.**

**The methodology of this study is informed by the Institutional Ethnography approach (Smith, 1987a, 1990a, 1990b). The actual practice of doing Institutional Ethnography is premised on Smith’s theory of the “social organization of knowledge” (Smith, 1987a, 1990a, 1990b) which posits that: (1) what has historically counted as “truth” in society has been shaped and defined by male authority; (2) ideology is not only a viewpoint (images and symbols) but an organization of *specialized practices* made**

manifest through *relations of ruling*; and, (3) the specialized practices of ruling apparatuses, such as those of exclusion and marginalization, have “provided modes of thought and knowledge that constrain women and force them to treat themselves as objects, to deny their own subjectivity and experience” (Smith, 1987a:36). To counter the discourses and constructions that have removed women from positions as knowers, research must shift these paradigms and “take up the standpoint of women as an experience of being, of society, of social and personal process that must be given form and expression in the culture, whether as knowledge, as art, or as literature or political action” (Smith, 1987a: 36). Smith’s sociology for women insists both that research begins from women’s experience and that it go beyond it to understand how this experience has come under the influence of specific ruling practices. In the current study, the central inquiry informed by an Institutional Ethnography approach focuses on the explication or examination of the organization of the specialized practices of ideology in elder care and the impact of this organization on the real lives of elderly ethnic and “racial” minority women. It seeks to explore the problematic within the working processes of the elder care institution, namely those focused on “managing the relationship between institutions and ethnic and “racial” minority elderly female clients...and within which varying perspectives arise and are embedded” (Smith, 1987b: 28). This problematic actually refers to the points of disjuncture between older ethnic and “racial” minority women’s experience of access and that of the institution which provides elder care to them (through an examination of workers’ practices and institutional texts). As such, the current study sets its gaze on the macro structure from the micro level, from the standpoint of sites in the everyday world of ethnic and “racial” minority women (Smith, 1987b: 5). Sites of interrogation focus on how

professional and state discourses of scarcity and medicalization are made manifest in the everyday practices of access in the elder care institution, how these practices shape and confine interactions between elderly ethnic and “racial” minority women and their workers, and in specific, how these practices and relations are both gendered and racialized. This requires an examination, not only of ethnic and “racial” minority elderly women’s standpoint as clients but also that of ethnic and “racial” minority women’s standpoint as workers. Exploring the experiences of these ethnic and “racial” minority women who are differentially located but who continue to be fundamentally marginalized from sites of power in elder care institutions specifically, and oppressed in Canadian society generally, will serve to further expose how relations of ruling shape, confine and construct ethnic and “racial” minority women.

The practice of doing Institutional Ethnography research is fundamentally political and transformative. Rendering older ethnic and “racial” minority women’s voices, and the processes by which their voices are made invisible, visible, is part of a project intent on critiquing, exposing and shifting the dominance of state orchestrated ideologies which operate to shape both how service is provided and how ethnic and “racial” minority elderly women are themselves constructed by the system. This project is critical to the process of altering status quo relations of ruling in elder care. This is particularly relevant in the field of gerontology, in which professional and state ideologies of scarcity and medicalization are firmly entrenched and in which the voices of elders, particularly those of ethnic and “racial” minority women, are fundamentally marginal. Gerontologists are rarely engaged in debates over whether or not health care services are appropriate, how needs are defined and by whom (Dill, 1993; Fraser, 1989). Changes that are currently undertaken within the

system often serve only to tinker with it, rather than make fundamental changes in health care ideology or culture. In this context, access as a paradigm from which to focus service adaptation will continue to be embedded in ruling relations which oppress those to whom both governments and institutions claim to be most intent on improving services, that is, ethnic and “racial” minority elderly women. It is hoped that this project will contribute to the shifting of this paradigm.

The study report begins with a detailed review of the current gerontological research on access in Chapter 2. Chapter 2 also reviews how both elderly women and elderly ethno- “racial” communities are constructed in this body of research. This review provides justification for the need to redress the paradigm of access within the field of gerontology. Chapter 3 examines the social and historical construction of access to health care among ethnic and “racial” minority elderly women by drawing from several theoretical perspectives, most notably, theories on the historical development of medical hegemonies including critical theories of aging, feminist bio-ethics theories of power and agency, disability theories on bodily control, and critical race theories on essentialism, intersectionality and multiculturalism. Justification is made for infusing current research in the area of elder care access with these theoretical perspectives. Chapter 4 provides a review of the study’s methodology and design. Chapters 5-9 detail the quantitative and qualitative findings of the study. Chapter 5 reviews the socio-demographic data on ethno- “racial” elders in the city in which the organization studied is located, Chapter 6 examines the role of families in elder care, Chapter 7 discusses the notions of relationship-building in elder care services from the standpoint of ethnic and “racial” minority women, Chapter 8 examines more directly the relations of ruling in elder care and the prominence of the

medical model in the provision of services. Finally, Chapter 9 examines current models of multicultural service delivery in elder care and the impact these models have on ethnic and “racial” minority women. This includes a discussion on the primacy of language services in elder care and an exploration of the articulation of “race” and racism from the standpoints of ethnic and “racial” minority female workers and clients. Chapter 10 provides a discussion of the main findings (of each of the preceding Chapters 5 through 9) and attempts to link these to the larger theme of “ruling relations” in elder care from the standpoint of ethnic and “racial” minority elderly women. Central to this Discussion Chapter is the development of an analysis which is fundamentally rooted in the disjuncture between older women’s standpoint and the practices of state ideology in elder care institutions and the development of a conceptual map of how these relations operate to confine and exclude older ethnic and “racial” minority women. Finally, implications of the study’s findings for theory, public policy, programs and practice in gerontology are outlined.

## **Chapter 2: Review of the Research Literature**

To date, our understanding about how access is created and experienced has been limited by the ways in which the field of gerontology has conceptualized and carried out research on access to health care, particularly in relation to older ethnic and “racial” minority women. Several problems exist in the large body of research in gerontology generally and within ethno-gerontology specifically. These are: (1) a failure to define the nature and parameters of access; (2) a focus on reductionist, individual and relational barriers to care with a corresponding lack of focus on structural or ideological issues; (3) little recognition of older women’s differential experience of access; (4) the use of essentialist categories of ethnicity and “race” and the lack of definition of these concepts; (5) the hierarchical nature of studies on ethnic and/or “racial” minority elderly women; and (6) a focus on monocultural or add-on models of ethno-geriatric service delivery. Finally, cutting across most of the gerontological literature is (7) the creation of a monolithic interpretation of “need” based on physical or mental criteria which determines accessibility. The combined effects of these problematic areas in the gerontological research have a dramatic influence on the way access is defined and operationalized and the way in which elders, particularly ethnic and “racial” minority elderly women are both constructed and acted upon by professionals. Each of these is described turn.

### **Methodology**

A comprehensive review of the gerontological literature was undertaken in order to examine the ways in which health care access is currently being constructed in the field generally and to review the extent to which both gender and ethnicity and/or “race” have been considered in this body of literature. Emphasis was placed on ascertaining where and

how access was conceptualized within the literature regardless of research method used or epistemological stance of the author(s). The review consisted primarily of an 8 year (1990-1997) audit of 10 gerontology journals (Canadian Journal on Aging, Journal of Gerontological Social Work, The Gerontologist, International Journal of Aging and Human Development, Journal of Aging Studies, Journal of Applied Gerontology, Journal of Women and Aging, Ageing and Society, Journal of Cross-Cultural Gerontology and Generations) and a broad search of medical and social service journals for relevant work. See Table 1 for a list of these journals. The review generated 255 articles addressing issues of access to health care, women and aging and ethnic and “racial” minority elders’ health. These articles are referenced in Table 2.

### **Review Findings**

#### **Access: Often Discussed- Rarely Defined**

Despite the current emphasis on issues of access in the realm of aging policy, gerontological research literature rarely names “access” as a central focus of inquiry. When these issues are addressed, the literature often fails to define the nature and parameters of access. More often than not, issues of access have been subsumed in the literature as either integral or minimal components of studies on service utilization, service delivery, provider-elder patient relations or resource allocations. Of the 204 articles reviewed which dealt in some manner with issues of “access”, 18 focused on provider-elder patient relations (8.8%), 40 on service delivery (19.6%), 57 on resource allocation (27.9%) and 71 on utilization of health care services (34.8%). Only 18 (8.8%) articles centred explicitly on access. See Table 3.

Exploring the issue of access within health care utilization and/or service delivery research has had an impact on the way access has been conceptualized. In the past two decades, health care utilization literature in both Canada and the United States has been largely preoccupied with developing models to predict use. The most prominent model which has emerged is the Andersen & Newman (1973) model which classifies determinants into predisposing (e.g. gender, age, "race", education), enabling (e.g. income, transportation, availability) and needs (e.g. health status, functional impairment) variables. Much of the utilization literature has focused on testing the efficacy and reliability of this model or components of it (Mitchell, 1995; Slivinske, Fitch & Mosca, 1994; Spence & Atherton, 1991) often adding additional variables such as service need and awareness (Calsyn & Roades, 1993), attitudes (Wister, 1992) or social support (Coward, Duncan & Freudenberger, 1994; Nelson, 1993) to the equation to increase its predictive value. Some authors have focused on women (Ishii-Kuntz, 1990) or ethnic and/or "racial" minority groups (Mui & Burnette, 1994; Spence & Atherton, 1991; Starrett, Rogers & Decker, 1992; Tran & Dhooper, 1996; Yeatts, Crow & Folts, 1992) in attempts to test the model's usefulness with diverse populations of elders. In addition, some researchers have suggested expanding utilization research beyond the Andersen Newman model in order to test other statistical tools (Beland, 1989; Roy, Dietz & John, 1996), research designs ( Baker & Pallet-Hehn, 1995; Mutschler & Callahan, 1990) or to broaden our understanding of the experience of using services (Chappell, 1994). Within the research on service delivery, emphasis continues to be placed on utilization, however the focus of inquiry is not predicting use but developing programs and services to deal with under or inappropriate utilization (Biegel, Petchers, Snyder & Beisgen, 1989; Black

**& Mindell, 1996; Chadiha, Proctor, Morrow-Howell, Darkwa & Dore, 1995; Hughes and Guihan, 1990; Morrow-Howell, Proctor & Berg-Weger, 1993; Spector & Kemper, 1994).**

**In several studies, researchers have attempted to identify “access” more explicitly in order to operationalize and test the significance of service barriers. Most commonly identified is the triad of availability (does the service exist?), accessibility (can the client get to it?) and acceptability (is the service acceptable to the client or group of clients?) (Wallace, 1990). Within this framework which describes accessibility as being able to “get to” a service, access has been defined as one or several of the following elements; transportation, knowledge/service awareness and/or affordability (Coward et al., 1994; Damron-Rodriguez, 1991; Diwan & Moriarty, 1995; Gerritsen, Wolffensperger & Van Den Heuvel, 1990; Minear & Crose, 1996; Mitchell, 1995; Vinales-Cunningham, 1991; Wan & Ferraro, 1991), quality (Woodruff & Applebaum, 1996) social support (Ganzer & England, 1994; Minear & Crose, 1996; Mitchell, 1995; Tennstedt, McKinlay & Kasten, 1994) and location or isolation (Cohen-Mansfield, Besansky, Watson & Jones Bernhard, 1994; Coward et al., 1994; Crowell, Rockwood, Stolee, Buehler, James, Kozma & Gray, 1996; Gerritsen et al., 1990; McCabe, 1995; Vinales-Cunningham, 1991). Others have added lack of service coordination and client and/or worker attitudes (Biegel, Shore & Silverman, 1989), language or communication difficulties (Black & Mindell, 1996; Camp, Burant & Graham, 1996; Saldov, 1991; Saldov & Chow, 1994) waiting periods (Health Care Services Utilization and Research Commission, 1997), and cultural relevance (Vinales Cunningham, 1991) as additional access criteria.**

**In recent years, increased attention has been placed on the issue of service duplication and efficiency within gerontological research and policy. This focus emerged**

from a concern that seniors were experiencing unequal access as a result of the large and increasingly 'fragmented' array of services available in the community. These issues have largely been framed within a case management approach (Chambers, Tugwell, Goldsmith, Caulfiend, Haight, Pickard & Gibbon, 1990; Havens & Bray, 1996; Hugman, 1994; Parker, 1990). According to Aronson (1990); "One of the common features underlying emerging policies...is an emphasis on the value of a single gatekeeper to services and efficient case management as ways of facilitating access, assessment, planning and monitoring" (Aronson, 1990: 76). Several authors have questioned the usefulness of a case management approach in reducing access barriers (Aronson, 1990; Hughes & Guihan, 1990; Lloyd, 1991; Mutschler & Callahan, 1990; Sofaer, 1994). Within the case management model, access has also been conceptualized as "can the client get to a service?", thereby focusing on organizational and relational issues, such as professional-client continuity, service co-ordination and knowledge of community services.

Among the 18 provider-elder patient relations articles reviewed, access barriers were never explicitly identified. However, as the health care provider remains the most common gatekeeper of health care resources and often the elderly person's first link with the formal service sector, it is essential to consider the provider-elder patient relationship in a definition of access. In this body of literature, communication patterns among health care providers, elderly patients and their families (Greene, Edelman, Freedman & Charon, 1994; Kaufman, 1995; Morrow, 1997; Risteen Hasselkus, 1992; Risteen Hasselkus, 1994; Waitzkin, Britt & Williams, 1994), health care providers' behavioural attitudes towards elders and health care (Adelman, Greene & Charon, 1991; Applegate & Morse, 1994; Fineman, 1994; Haug, 1994; Wasson & Jette, 1993) and elders' behavioural attitudes

towards health care providers and their own health care ( Ascione, 1994; Rantucci, 1989) were often the focus of inquiry. For the most part, methods for resolving communication and attitudinal problems were discussed in order to reduce barriers to appropriate care and improve compliance with medical treatment (Ascione, 1994; Fineman, 1991). These factors were also often considered in ethnogeriatric literature which focused on provider-elder patient relationships (Camp et al., 1996; Fung, 1994; Gamel & Yeo, 1993; Sakadakis & MacLean, 1993; Saldov, 1991; Saldov & Chow, 1994).

What is evident throughout this entire body of literature is that there are no commonly accepted definitions of access. Indeed, despite the abundance of research on barriers to care in the utilization, service delivery and provider-elder patient relations literature, there lacks broad consensus on the central components of access. This lack of consensus has resulted in reduced clarity and consistency with regard to parameters for study. Without a clear understanding of what constitutes an access barrier, access cannot be thoroughly tested as a construct within the gerontological literature. This has reduced the explanatory power of access criteria.

Overall, however, there has been a general emphasis, within the research, on framing access within individual and relational rather than systemic parameters. That is, access barriers are defined as originating in the beliefs, attitudes or health status of the elder person, in family relationships or lack thereof, or in unsuccessful communication patterns between health care provider and elder patient. Highlighting only individual or relational issues can result in the marginalization of structural barriers, including those of sexism and racism. Problems that should or could be addressed at the organizational or institutional level as policy initiatives get filtered down to be dealt with by professionals

and their patients/clients on a case by case basis. Examples of this are abundant. In a study which examined elder patient adjustment to illness and utilization of health care services, it was found that elders who were not well-adjusted to their illness tended to over-use services. The study concluded that helping individuals adjust and cope will result in less demand on health care resources (Browne, Arpin, Corey, Fitch & Gafni, 1990). By framing utilization in individualistic terms, the article assumes blame for inappropriate utilization patterns should be placed on the patients themselves, that is, if only patients were better adjusted to their illness, they would stop making so many demands on services or misusing services (Browne et al., 1990). In another example, Fineman (1991) attempts to reconceptualize compliance as predominantly a provider-constructed category. The author suggests that “efforts to eliminate noncompliance should focus as much upon changing providers expectations as upon changing patients’ behaviours” (Fineman, 1991: 222). Unlike Browne, Fineman does attempt to address the role of the health care provider in shaping patient outcomes although compliance is never seen as an issue resulting from larger institutional or systemic barriers to care. In both of these examples, blame might be better placed on inappropriate or inadequate services rather than on individuals themselves. While individual and relational barriers to care are important components of health care access, they must not be explored in a vacuum. Rather, they must be examined within the larger context of health care policy, ideology and practice. Situating access as the sole responsibility of the provider or patient/client without also considering broader social forces may result in blaming elders for causing their own utilization problems (Cooper, 1994; Rantucci, 1989) or in promoting the simplistic belief that once knowledge

about elders' needs are understood, programs and policies will be automatically developed to respond (MacLean, Siew, Fowler & Graham, 1987).

Funding and cost emerged as the most often tested "systemic" barrier to care in the utilization and service delivery research as well as being the central focus of inquiry in the resource allocation literature. In the past decade, aging policy research in both Canada and the United States has become increasingly preoccupied with the combined problems of rising health care costs and the impact of aging on the health care system. Much of aging policy centres on debates regarding appropriate allocation of scarce resources given demographic change (Adams & Dominick, 1995; Barer et al., 1995; Binstock, 1994a; Cox, 1993; Crystal, 1990; Deber & Williams, 1995; Denton & Spencer, 1995; Dreiger & Chappell, 1987; Evans, Barer & Stoddart, 1995; Havens, 1995; Havens, 1996; Katz & Karuza, 1992; Kingson, 1994; Kutza, 1995; Minkler & Robertson, 1991; Moon, 1990). In the United States, the emphasis on cost has largely been focused on insurance coverage (Brill, Perkel & Chen, 1991; Butler, Brame, Kahn & McConnell, 1992; Estes & Swan, 1994; Newhouse, 1989; Ross, 1992; Ruiz, 1993; Simmons, 1996; Taira & Taira, 1991; White-Means & Hammond, 1993; Wray, 1991). Given current inequities in health care coverage in the United States, it is not surprising to find this issue given so much attention. By doing so, however, much of the resource allocations literature coming out of the United States provides little fodder for Canadian gerontologists. Indeed, comparisons between Canada and the United States written by American gerontologists tend to focus on Canada's great accomplishments in the area of universal health care coverage while ignoring many of the common problems faced by both countries in the area of access

(Clark, 1991a; Clark, 1991b; Mizrahi, Fasano & Doona, 1993) such as differential treatment experienced by women and ethnic and/or “racial” minority elders.

Utilization and service delivery research does not address the larger structural issues of funding and cost in a detailed or comprehensive manner. Variables such as income and private insurance have not shown a consistent relationship with service utilization in this literature (Calsyn & Roades, 1993; Rabiner, 1992), and as a result, these important policy issues are often only superficially addressed (Chappell, 1994). In empirical studies, large structural or policy changes are often dismissed as being too difficult to implement and therefore irrelevant to practitioners. Minear & Crose (1996) state,

When such barriers as transportation, location and rising costs may be difficult to address in the present economic climate, other barriers such as communication problems, emotional issues and lack of knowledge require a change in attitude and approach which is possible to achieve with little money and with volunteer resources. (Minear & Crose, 1996: 62)

Again, in an article by Biegel, Shore & Silverman (1989), strategies and solutions were developed to overcome barriers to serving aging/mental health clients. However, these solutions incorporated two criteria (the possibility of providing meaningful and positive change and feasibility of implementation) which by design, eliminated discussion of larger policy initiatives. Of the 10 strategies developed, none looked at advocating for changes to broader health care policy. By relying on feasibility as a criteria, structural policy changes were ignored. Finally, Yeatts et al. (1992) developed a conceptual framework for assessing minority elders’ barriers to access which are focused on “what can be addressed by organizations”. By so doing the authors fail to explore systemic forms

of racism. Attempting to deal with only those issues that are seen as “changeable” or “fixable” within the current climate, results in a broad literature which rarely challenges the health care and social service systems.

### **The Inclusion of Gender, Ethnicity & “Race”**

The effects of gender, “race”, ethnicity and/or class are increasingly being used as criteria to assess utilization of or barriers to health care services (Johnson & Wolinsky, 1994). However, the extent to which these issues or categories of analysis are considered in the literature, either separately or interactively, varies greatly. As a result the treatment of gender, ethnicity, “race” and class within the gerontological literature is often inconsistent and problematic. These issues will be explored in the following four sections.

### **The Treatment of Women**

In order to review the extent to which the experiences and realities of female elders are included in the gerontological research on access, a framework was developed based on Eichler’s (1987) article entitled “The Relationship Between Sexist, Non-sexist, Woman-centred and Feminist Research in the Social Sciences”. In it, she outlines four models of social science research and the implications the use of these models have on our understanding of the lives of women. Concentrating on the aspects of overall perspective, Eichler describes sexist scholarship as that in which the “social universe is constructed around males...irrespective of its subject matter” (Eichler, 1987: 40-41) so that even when research focuses on, or includes an analysis of women it does so from a male-centred perspective. Studies which explore causes and symptoms of heart disease in the general population by using only samples of males is one example of this type of research model. In these studies, women’s experience and world view are seen only as incidental or

marginal. Women-centred models, on the other hand, construct social reality focusing on women themselves. This is often done to “expose the androcentric biases” so common in social science research (Eichler, 1987: 42). Studies which explore women’s experience of caregiving is one such example. Non-sexist research models conceptualize the social universe as constructed around both men and women, “but since the position of men and women are unequal”, research in this area develops two separate but equal focal points or lines of inquiry (Eichler, 1987: 42), this way encompassing the real lived experience of both women and men. This is evident in research which explores, for example, the differences in income status among elderly women and men and uses separate criteria to explain the incidence of poverty by gender. According to Eichler, it is within the non-sexist model that feminist models can emerge. All non-sexist models, however, are not necessarily feminist. In order to make the transition from non-sexist to feminist research, models must incorporate the principle of social justice. Eichler states,

**Feminist research can be defined as research that is informed by a commitment to social justice for women and/or research that exposes prevailing sexist biases and/or creates unbiased alternatives and/or constructs reality from a female perspective. Although this is an extremely broad definition, it nevertheless does make a statement about the content of feminist research: although feminist research may deal with any subject matter-relocation of the aged, uranium mining, solar energy, urban planning, leisure activities, the micro-chip, etc.-unless we can establish some connection between the topic and the achievement of social justice for women, either in concrete terms, or in abstract terms through the manner in which knowledge is generated, it does not qualify as feminist research. (Eichler, 1987: 47)**

By using this framework to analyze the location of women’s interests and experience in the gerontological research literature on access, we can begin to understand the extent to which older women are considered. Of the total 255 gerontological articles

reviewed, 69.4% (177) could be classified as sexist, either by ignoring gender issues completely (38.8%) or exploring gender only minimally (4.3%). 9.8% of the articles were woman-centred, 9.4% were non-sexist and 11.4% were feminist. Overall, 23.9% of all articles reviewed treated the issue of gender in an integral fashion, while 32.9% used gender as a variable only. See Tables 4 and 5.

The burgeoning literature on older women attests to the fact that aging has emerged as a feminist issue (Gould, 1989; Neugebauer-Visano, 1995). Gerontological research in the field of gender and health has tended to be focused on three main thematic areas: a) health indicators (many older women have higher incidences of chronic illness, use medications more frequently and in greater combinations, have lower mortality rates and fewer acute illnesses and perceive their health differently than older men or subgroups of older women) (Canetto, Kaminski & Felicio, 1995; DePoy & Butler, 1996; Gale, 1994; Hammond, 1995; Leigh & Fries, 1994; Loomis & Thomas, 1991; Markides, 1990; Ozawa, 1993; Penning & Strain, 1994; Saxon, 1993; Trypuc, 1994; Wilson-Ford, 1992); b) caregiving (developmental issues of caregiving and the impact of caregiving on service utilization) (Aronson, 1990; Eckert & Shulman, 1996; Kaden & McDaniel, 1990; Palo Stoller, 1993; Shenk, 1991; Tarman, 1994; Trippet, 1991); and, c) the feminization of poverty thesis (health-wealth connection) (Barer, 1994; Davis, Grant & Rowland, 1990; Gonyea, 1994; Hardy & Hazelrigg, 1993; Hardy & Hazelrigg, 1995; Harrington Meyer, 1990; Harrington-Meyer, 1994; Hartman, 1990; Jecker, 1991; Kirk & Rittner, 1993; McDonald, 1997; McLaughlin & Holden, 1993; Minkler & Stone, 1985; Moon, 1990; Perkins, 1993; Rosenthal & Morith, 1993; Russell Hatch, 1990; White-Means & Hammond, 1993; Wilson-Ford, 1991).

While these thematic areas relate in some way to the issue of access to health care, it is rare to find any thorough discussion on access, particularly within empirical studies. As with general studies on health care utilization, those that focus on older women's use of health services or health behaviours tend to disregard structural problems of access in favour of those which are individual, familial or relational in cause (Depoy & Butler, 1996; Gale, 1994; Ishii-Kuntz, 1990; Sanders-Phillips, 1994; Saxon, 1993).

There are two important exceptions to this trend. The first deals with the feminist literature on informal care. In recent years, much of caregiving literature has been influenced by feminist analysis and, as a result, has begun to explore the structural influences on women's role as caregiver and the implications of this role on women's lives. Feminist caregiving literature has highlighted and explored the social role of women within the private sphere of the family and the problematic effect this has had on women's economic security and labour force activity. This literature, has, to some extent, attempted to refute the popular assumption that there are distinctions between the private and public spheres and therefore has the capacity of helping gerontologists re-think access in relation to connections between family care, community care and institutional care. However, given that the majority of studies continue to focus on 'woman as caregiver', the voice of 'woman as care-receiver' remains largely absent and thus renders this body of literature far less useful to those interested in examining older women's experience of access to care (Aronson, 1990; Groger, 1994; Neysmith, 1987).

The second area in which structural issues are often addressed relates to the feminization of poverty thesis. The emphasis here has been on the cumulative disadvantage model (Gonyea, 1994) which hypothesizes that disadvantage in old age is reflective of life

long economic inequities including employment and pension discriminations. Within this broad body of literature, connections are sometimes made to inequities and barriers in health care, especially those related to older women's reliance on Medicaid in the United States ( Davis et al., 1990; Harrington-Meyer, 1990; Jecker, 1991; White-Means & Hammond, 1993). Health indicators studies have, at times, also connected poorer health and lower access to health care to the issue of income disparities throughout women's lives (Hammond, 1995; Leigh & Fries, 1994; Ozawa, 1993) and emphasized the relationship of "race" and class to health inequities (Perry & Johnson, 1994).

The focus on the feminization of poverty thesis presents some challenges in relation to an expanded definition of health care access. While it is extremely important to explore the impact of poverty on older women's ability to access health care services, looking solely at poverty can offset addressing problems of discrimination not related to insurance coverage and income, most notably those related to sexist health care ideology and practice (Jorgensen, 1993; Liska Belgrave, 1993). This subject is taken up with greater breadth and sensitivity in the general women's health literature ( Meltzer Olson, 1994; Milmo McCarrick, 1995; Puentes-Markides, 1992; Rodin & Ickovics, 1990; Self & Olivarez, 1993; Zambrana, 1987). For example, Puentes-Markides does an overview of the concepts which should be included in a discussion of health care access. In this article she names issues such as the structure and culture of health services, behaviour of providers and economic policies as factors which should be included in an exploration of access (Puentes-Markides, 1992:619). Still problematic is the fact that the majority of this feminist literature continues to be unrelated to the elderly (Rosenthal, 1990) or to ethnic and "racial" minority women. In a recent review of social work journals, Millner &

Wideman found only 3 of 36 articles on women's health dealt with aging (Millner & Wideman, 1994). The gap in geronto-feminist theory and research, particularly in relation to health care access and ethnicity and/or "race" continues to pose problems in the way older women are conceptualized in the literature and in the way structural issues, including those of ageism, racism, classism and sexism, are addressed (Calasanti, 1993; Ward-Griffen & Ploeg, 1997).

### **The Treatment of Ethnicity and/or "Race"**

There is a vast ethno-gerontological literature. Of the 255 articles reviewed 46.3% dealt with ethnicity and/or "race" in an integral fashion while another 6.3% treated ethnicity and/or "race" as a variable only. If we look across studies, we find that the treatment of ethnicity and/or "race" was not consistent. Whereas, 95.9% of articles catalogued as focusing on ethnicity and/or "race" considered these components as integral and discussed social justice issues, only 27.4% of articles focusing on women, 11.1% of physician-patient relations studies, 3.8% of utilization studies, 13.8% of resource allocation studies and 4.3% of service delivery studies examined ethnicity and/or "race" at all, either treating ethnicity and/or "race" as integral to the subject, as a variable under study or in introductory or concluding remarks. See Table 6.

Ethno-geriatric studies have been predominantly focused on the following five areas: a) ethnicity and/or "race" and health with an emphasis on the wealth connection (this includes a testing of the age as leveler hypothesis, whereby ethnic and "racial" differences in disease epidemiology and income/insurance coverage diminish with age) (Bazargan & Hamm-Baugh, 1995; Blandford & Chappell, 1990; Calasanti, 1993; Chipperfield, 1992; Gibson & Burns, 1991; Hamm, Bazargan & Barbe, 1993; Johnson,

1994; Johnson & Wolinsky, 1994; Kramer, 1991; Krause & Wray, 1991; Masi & Disman, 1994; Mercer, 1994; Schoenbaum & Waidmann, 1997; Schoenberg, Coward, Gilbert & Mullens, 1997; Shea et al., 1996); b) ethnic subculture (accept or dispute the theory that ethnic and “racial” minority groups take care of their own, citing both cultural and socioeconomic reasons for caregiving practices) (Burton, Kasper, Shore, Cagney, LaVeist, Cubbin & German, 1995; Cantor, Brennan & Sainz, 1994; Cox & Monk, 1996; Groger & Kunkel, 1995; Hagan Hennesy & John, 1996; Morrison, 1991; Penning & Chappell, 1987; Perry & Johnson, 1994; Shoemaker, 1990; Sokolovsky, 1985; Sook Lee, Crittenden & Yu, 1996; Walls, 1992; White-Means, 1993); c) ethnic and “racial” minority health beliefs, perceptions and practices (self care, health service utilization) (Congress & Lyons, 1992; Cowart, Sutherland & Harris, 1995; Cox & Dooley, 1996; Galanos, Strauss & Pieper, 1994; Groger, 1994; Johnson, 1995; Lew, 1991; Lozano Applewhite, 1995; Wylke & Haug, 1993; Young Chung Pang, 1996); d) barriers to service utilization and in service delivery (Capitman, Hernandez-Gallegos & Yee, 1991; Falcone & Broyles, 1994; Fung, 1994; Gamel & Yeo, 1993; Hart, Gallagher-Thompson, Davies, DiMinno & Lessin, 1996; Jones Morrison, 1995; Krassen Maxwell & Maxwell, 1992; Liska Belgrave, 1993; MacLean & Sakadakis, 1989; MacLean et al., 1987; Mokuau & Fong, 1994; Mui & Burnette, 1994; Roy, et al., 1996; Saldov & Chow, 1994; Spence & Atherton, 1991; Stanford & Gwynne Schmidt, 1995; Tran, 1990; Tran & Dhooper, 1996; Yeatts et al., 1992); and, e) ethnogeriatric policy and education (Burton, Dilworth-Anderson & Bengston, 1991; Calasanti, 1993; Calasanti, 1996; Damron-Rodriguez, 1991; Dreiger & Chappell, 1987; Filinson, 1992; Giordano, 1992; Hyde & Torres-Gil, 1991; Kramer &

Barker, 1991; Rivas & Torres-Gil, 1991; Stanford & Yee, 1991; Wray, 1991; Yee & Weaver, 1994; Yeo, 1991; Yeo, 1996).

The ethnic subculture thesis attempts to explain ethnic and “racial” minority elders’ use of health care and often expands the definition of family to include fictive kin and community ties to churches and other organizations (Cox & Monk, 1996; Johnson & Barer, 1990; Shoemaker, 1990; Walls, 1992). Research findings in this area are not always consistent with regard to the impact of the availability of kin on utilization of services (Burton et al., 1995). Critics of ethnic subculture theories point to the fact that these theories often have the effect of romanticizing the social network of people of colour while minimizing both cultural explanations (value of support) and socio-economic explanations (historic systemic exclusion from access to resources) which may explain differential care patterns (Groger & Kunkle, 1995; White-Means, 1993). Critics have also suggested that the predominance of the ethnic subculture thesis in ethnogerontology has resulted in a lack of recognition of the need for formal services for minority elderly and a tendency to distract policy makers from addressing institutional and systemic problems of access including those rooted in racism and/or ethnocentrism (Morrison, 1991; Sokolovsky, 1985).

The research on health beliefs and practices also suffers from this problem of myopia. The focus on “alternative” or “traditional” medicines to explain why elders do not use “Western” medicine draws conclusions away from explanations based on elders’ inability to access this type of health care (Congress & Lyons, 1992; Galanos et al., 1994; Groger, 1994a; Lew, 1991; Sanders-Phillips, 1994; Wykle & Haug, 1993; Young Chung Pang, 1996). In this way, self-care is simply seen as a preference rather than as a strategy

for overcoming inequities in health. Some researchers have pointed to this fact and demonstrated that higher self-care among ethnic elders is correlated with institutional neglect and low access to health care (Coward et al., 1995) or is used in response to unsatisfactory medical care (Lozano Applewhite, 1995).

The literature on health indicators and the wealth connection, service utilization, service delivery and ethnogeriatric policy and education have considered the issues of structural access barriers to varying degrees. Much of the literature, however, continues to focus on individual, relational or institutional approaches to change, for example highlighting provider's attitudes and how these attitudes can be changed through education and/or ways in which organizations can best attend to language or cultural tensions without noting the need for advocacy to address systemic barriers (Camp et al., 1996; Capitman et al., 1991; Fung, 1994; Gamel & Yeo, 1993; Giordano, 1992; Hamm et al., 1993; Hart et al., 1996; Kramer, 1991; Krause & Wray, 1991; MacLean & Sakadakis, 1989; Mercer, 1994; Sakadakis & MacLean, 1993; Saldov & Chow, 1994; Schoenberg et al., 1997; Stanford & Gwynne Schmidt, 1996; Tran, Fitzpatrick, Berg & Wright, 1996; Yee & Weaver, 1994). Examples of attempts to make relational or institutional change include ethnic matching strategies, outreach and language competence (Vinales-Cunningham, 1991) and/or changes to mission, governance and administration, caregiving, targeting and marketing strategies (Capitman et al., 1991).

Still, there is an abundant literature which places these individual and institutional issues alongside those of "racial" and/or economic inequality in health care (Blandford & Chappell, 1990; Calasanti, 1993; Chadiha et al., 1995; Dreiger & Chappell, 1987; Gibson & Burns, 1991; Hyde & Torres-Gil, 1991; Johnson, 1994; MacLean et al., 1987;

Morrison, 1991; Perkins, 1993; Schoenbaum & Waidmann, 1997; Shea et al., 1996; Stanford & Yee, 1991; Whetstone & Cruise, 1995; Wray, 1991) and a smaller literature which addresses the relationship between cultural ideology in health care systems and discriminatory practices (Falcone & Broyles, 1994; Yeo, 1997). In the few studies undertaken on Aboriginal health care, colonialism has also been identified, alongside poverty, racism and sexism as a central feature shaping both aging services and health care systems generally (Kramer, 1991; Krassen Maxwell & Maxwell, 1992; Waldram, 1994; Wotherspoon, 1994). Policy makers and researchers have been urged, by these authors, to more seriously address colonialism in order to rectify disadvantages in health faced by Aboriginal persons. In specific, Lowe, Kerridge & Mitchell (1995) have identified several factors which have led to higher rates of morbidity and mortality among Aboriginal persons. They are “destruction of Aboriginal culture, limited education about health and nutrition, high levels of unemployment and low status jobs, and alienation from their land” (Lowe, Kerridge & Mitchell, 1995: 357). These factors are clearly related to systemic forms of discrimination against Aboriginal persons. The authors suggest that discrimination in the form of “dispossession of land, informal ‘ethnic cleansing’ and government policies which oscillated between forced assimilation and extermination” (Lowe, Kerridge & Mitchell, 1995: 357) have dramatically altered not only the health of Aboriginal persons, but the way these persons choose to interact with the health care system. In fact, the authors explain that the lack of compliance with medical directives as well as the under-use or misuse of health care services, often reported in health research is likely rooted in Aboriginal persons’ view that health care services form part of white

man's "colonization policy" (Lowe, Kerridge & Mitchell, 1995: 359) and are thereby avoided at all costs.

### **Essentializing, Defining and Ordering Oppressions**

Ethnogeriatric research and theory is largely essentialist in nature. The majority of work in this area has tended to homogenize categories of "race" and ethnicity by grouping what are often very diverse ethnic and/or "racial" groups into simplistic categories. Of the 133 articles which dealt, in some way, with ethnicity and/or "race", 64.7% used essentialized categories. See Table 7. This has been a more common practice in the United States where gerontologists and health care providers have focused research and policy on four "special needs" minority groups; (1) Black (or African American), (2) Hispanic, (3) Native American/Native Alaskan, and (4) Asian/Pacific Islander (Kramer & Barker, 1991: 128).

Critics have stated that the essentialization of ethnic and "racial" groups in gerontological research results in the failure to address the diversity within groups (Tanjasi, Wallace & Shibata, 1995; Vinales-Cunningham, 1991; Yeo, 1996) and results in oversimplification and the minimization of social, historical, demographic and socio-economic conditions within groups (Mui, 1996). Much of the data available to researchers from federal or state databases only contains information on these four ethnic groups making information relatively useless to local ethnic populations. This is also true in Canada (Torczyner, 1997). In addition, where only one group is studied comparisons are often made between that group and Whites or that group and members not in that group (i.e., Blacks and non-Blacks). This model creates a false-dichotomy within which results become highly oversimplified. Gelfand and Yee (1991) have stated that research

which compares essentialized dichotomous groups like Black and White or Hispanic and non-Hispanic represents the largely hierarchical focus of ethno-geriatric research and that it “results in assumptions that “ethnics” simply need to catch up to Whites on a variety of health indicators including health status and service utilization” (Gelfand & Yee, 1991). Finally, by labeling all persons not from these four visible minority populations as “White”, White ethnic groups (i.e., Jewish, Greek, Italian, Ukrainian) are rendered invisible.

Very little effort is placed on theorizing or explaining concepts of “ethnicity” or “race” in the ethno-geriatric literature. This leads to broad assumptions that ethnicity and “race” are static rather than fluid concepts and have little to do with other factors such as cohort, time of immigration, class and gender. Only a few articles address trends in immigration period or mobility and have commented on the need to look more closely at “racial” categories by immigration criteria (Damron-Rodriguez, 1991; Gelfand & Yee, 1991; Sanders-Phillips, 1994; Stanford & Yee, 1991; Tran, 1990). Finally, Canadian ethnic populations are substantially different from American ethnic populations (for example, White ethnic and visible minority seniors are a smaller proportion of the total population in Canada and have arrived more recently than in the United States), thus making international comparisons difficult (Dreiger and Chappell, 1987). Clearly, gerontologists must begin to address “race” and ethnicity more sensitively.

As was previously identified, much of the gerontological research on access to health care has ignored the experience of women. It is even rarer to find studies on older ethnic and/or “racial” minority women. Of the 255 gerontological articles reviewed, only 19.2% (49) explored the issues of older minority women. Of the 37 that were classified as primarily being research or theory on women, only 35.1% (13) minimally referred to

“race” issues in introductory or concluding remarks. Another 18.9% (7) treated “race” as a variable only. Therefore, less than half of these studies (45.9%) treated gender and “race” as integral components of the studies. Of the 97 articles originally classified as being focused on ethnicity and/or “race” only 12.4% (12) considered gender. Within this group only 2.1% (2) were considered feminist.

Where gender and “race” experiences were highlighted, analyses were often undertaken within a hierarchical framework, that is by relating gender, “race”, ethnicity and class as though they were ordered levels of oppression which could be separated out from each other, a practice traditionally associated with “double jeopardy” models. In fact, some research has gone so far as to attempt to predict which “oppression” explains inequalities (Hardy & Hazelrigg, 1995). This model assumes that the experience of being a woman, an elder and a minority are additive. Of all 49 articles addressing gender, age, ethnicity and/or “race”, 63.3% (31) made explicit reference to the double jeopardy hypothesis (Bazargan & Hamm-Baugh, 1995; Black & Mindell, 1996; Blandford & Chappell, 1990; Bonar, 1994; Burton et al., 1991; Chipperfield, 1992; Davis et al., 1990; DeCroix Bane, 1991; Dreiger & Chappell, 1987; Gee & Kimball, 1987; Giordano, 1992; Hagan-Hennessey & John, 1996; Harrington-Meyer, 1990; Johnson, 1997; Jorgensen, 1993; Kaden & McDaniel, 1990; McLaughlin & Holden, 1993; Millner & Widerman, 1994; Minkler & Stone, 1985; Muszynski, 1994; Palo Stoller, 1993; Perkins, 1993; Quinn & Keys Walsh, 1995; Rivas & Torres-Gil, 1991; Rodeheaver & Datan, 1988; Rodin & Ickovics, 1990; Saldov, 1991; Saldow & Chow, 1994; Schoenberg et al., 1997; Sook Lee et al., 1996; Wilson-Ford, 1991) including one study which rejected the double jeopardy

theory based on the assertion that ethnic identity protects elders from negative associations with age and discrimination (Simic, 1993).

### **Institutional and Organizational Models of Service Delivery**

Ethnogeriatric service delivery research and theory has been quite limited with regard to models of health care delivery. This is partially attributable to essentialist ideologies regarding “race” and ethnicity, but is also a reflection of current thinking about multicultural health care delivery and culturally competent practice predominant in health and gerontology. In order to review the application of ethnogeriatric models of service delivery in the literature on aging, Tator’s work on anti-racism in the human service delivery system will be used as a framework (1996). Tator outlines the key assumptions and practices of four ‘multicultural models’ of service which can be applied to gerontological health care organizations and institutions. These are; (1) the monocultural/assimilationist approach; (2) the add-on multicultural approach; (3) the integrated multicultural/anti-racism approach; and (4) the ethno-cultural community-based approach. The first approach, is the prevailing model of human service organizations in which a monocultural or Anglo-Canadian perspective is dominant. In these organizations, “racial” and cultural diversity is viewed as irrelevant to the shape and nature of service delivery, rather, all persons are treated “equally” regardless of “race” or ethnic status. Within this model, ethnic and “racial” barriers to care, such as language and culture remain largely invisible, resulting in lack of access to services by ethnic and “racial” minority communities (Tator, 1996: 154-155). The add-on multicultural approach incorporates organizations somewhat willing to address diversity and improve access to services but who do so mostly through organizational and individual approaches such as translation

and/or ethnic matching of staff or volunteers. Rather than being pro-active, issues are often dealt with on an ad-hoc basis. "Organizational structures are left intact and barriers are often left to be dealt with by front line workers who may work in non-supportive environments" (Tator, 1996: 156). The multicultural/anti-racism integrated approach involves "racial" and cultural groups in all areas of the organization including staff, volunteers and board members. Systems of accountability and responsibility are established to ensure a multicultural/anti-racist approach, including ongoing training and advocacy (Tator, 1996: 156-157). Finally, the ethnocultural community-based approach has emerged to respond to the needs of specific ethnocultural communities who have often been lost in the gaps currently existing in mainstream institutions through the development of alternative organizations and advocacy strategies which ensure that the needs of ethnic and "racial" communities are or will be met by larger institutions and systems (Tator, 1996: 157). Using these models as a basis of review it was found that of the 75 articles which dealt in some manner with service delivery and/or ethnicity and/or "race", most (36.0%) used a monocultural approach to service delivery . Another 29.3% used an add-on approach, 16.0% were multicultural/antiracist in focus and another 18.7% used or suggested an ethno-specific model of care. It is important to note that of the original 23 articles classified as service delivery research, only 1 (4.3%) used an add-on approach (Black & Mindell, 1996) while the remainder (93.7%) were monocultural in focus. See Table 8. Clearly, the field of gerontology mirrors that of other human service fields in their lack of consideration of anti-racist or critical multicultural institutional and organizational models.

## **The Predominance of Need as a Determinant of Access to Health Care**

Gerontological research and theory in the field of access to health care is largely preoccupied with determining “need”. This is true of both policy and empirical studies. Much of the recent emphasis on “need” has emerged as a consequence of state efforts to ration services. Within this scarcity model, gerontological researchers and policy analysts have concentrated their efforts on determining under what conditions limited services can best be delivered and to whom. In other words, the focus has been on attempting to ensure that those who need service will get it. The major debates in policy studies have revolved around the competing criteria of age and need (Cutler, 1991; Dreiger & Chappell, 1987; Katz & Karuza, 1992). Some authors have attempted to critique the impact of age-based rationing on older women (Jecker, 1991) and/or older ethnic and “racial” minority groups (Hyde & Torres-Gil, 1991; Wray, 1991). In recent years there has been an attempt to develop arguments which reject rationing based on age (Adams & Dominick, 1995; Binstock, 1994; Gonyea, 1995; Lanoie Blanchette, 1997; Minkler & Robertson, 1991; Zweibel et al., 1993) in favour of rationing based on need (Kutza, 1995; Moon, 1995). Empirical research in this area is largely preoccupied with determining what level of “need” predicts use and why.

This focus on “need” represents a dramatic shift from earlier efforts to universalize aging services to efforts based on directing care to the “most needy” (Myles, 1995; Spector & Kemper, 1994). Mitchell (1995) states,

**Service targeting is becoming more important, given the shift in national and local policy away from entitlements towards needs-based services in an attempt to control the rising cost of institutional care, and given the shift in the care of the elderly and chronically ill patients from hospital care to ambulatory and community-based care. (Mitchell, 1995:196)**

As this discourse will fundamentally influence the shape and nature of access, it becomes increasingly important to explore the ways in which “need” is constructed in the gerontological research.

In general, there is little debate about what constitutes “need” in the literature. In fact, “need” has been one of the most uniformly constructed variables in utilization, service delivery and resource allocation research. It is most often defined and operationalized as health status and/or functional impairment (Ahroni, 1990; Beland, 1989; Beland & Arweiler, 1996; Calsyn & Rodes, 1993). Much of the utilization literature concludes that “need” in the form of health status and functional impairment is one of the most important predictors of use of health services including institutionalization (Calsyn & Rodes, 1993; Chambers et al., 1990; Cohen-Mansfield et al., 1994; Coyne, 1991; Gerritsen et al., 1990; Gonyea & Silverstein, 1991; Mitchel, 95; Mutschler & Callahan, 1990; Schneider, Kavanagh, Knapp, Beecham & Netten, 1993; Shapiro & Roos, 1989; Slivinske et al., 1994; Steinbach, 1992; Wolinsky, Callahan, Fitzgerald & Johnson, 1992) and this is consistent regardless of country, sample or measurement tool used (Chappell, 1994). Health status has been operationalized as diagnosed chronic conditions, number of prescription medications and/or self perceived health status (Calsyn & Rodes, 1993; Coward et al., 1994; Mitchell, 1995; Wister, 1992) while the most common measure of functional impairment has been that of limitations in Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (Cohen-Mansfield et al., 1994, Coward et al., 1994; Crowell et al., 1996; Nelson, 1993; Rabiner, 1992; Slivinske et al., 1994; Spector & Kempler, 1994). ADL eligibility has gained prominence in the health and

social service sector over the past decade. Originally viewed as a more socially oriented model because it considered a person's ability rather than just their medical diagnosis, it was hoped that using ADL criteria for service eligibility would lead to more consistent application of "needs-based" accessibility criteria across agencies and regions (Robert and Norgard, 1996). As a result of this emphasis, current legislative proposals in long term care often refer to ADL criteria (Spector & Kemper, 1994) and there has been general acceptance of a model in which three or more impairments in functional or cognitive ability serve as a basis for admittance to long term care services ( Ganzer & England, 1994; Spector & Kemper, 1994).

Social support is also often tied conceptually and empirically to "need". Functional impairment and a lack of social support are increasingly used as criteria for access to services (Diwan & Moriarty, 1995; Tennstedt et al., 1994). In addition, functional impairment and caregiver burden are often tested together in equations to predict or explain variations in service use (Ahroni, 1990; Bass & Noekler, 1987; Lieberman & Kramer, 1991; Nelson, 1993; Wister, 1992). Finally social support has been linked in the provider-elder patient literature to compliance (Ascione, 1994; Belgrave & Moorman-Lewis, 1994; Leirer, Morrow, Decker Tanke & Pariente, 1991).

The consistency of findings in regards to functional health and service use does lend important credibility and validity to the research. However, it also embeds notions of "need" in physical criteria which can have a negative impact on the way we think about elders and, consequently, the way we think about access (Ganzer & England, 1994). A focus on physical functioning tends to "embody" the elderly, defining them solely within terms of illness and disease, within their aging bodies. Within this totalizing construction it

is only those we define as chronically sick, impaired, and disabled elderly that have a right to access services and on whom the literature focuses to improve and coordinate services. Broadly referred to as the “frail” elderly (Becker, 1994; Black & Mindell, 1996; Chadiha et al., 1995; Coward, et al., 1994; Davies, 1993; Hughes & Guihan, 1990; Katz & Karuza, 1992; Mui, 1993), it is this group that is most often targeted in the access literature. To need services is to be frail; thus “need” and “frailty” are, in the end, synonymous.

Given this focus on “frailty”, gerontologists tend to lose sight of the elder person as agent. “Frail” persons are instead, acted upon, by professionals and researchers in the field. Thus, elders are often classified as dependent (Ellis, 1996; Gibbs & Bradshaw, 1988; Schneider et al., 1993), are rarely asked about their own experience of need (rare exceptions are Aronson, 1990; Bonar, 1994; MacLean, Houlahan & Barskey, 1994; Woodruff & Applebaum, 1996), and aging health services are viewed as protective rather than rehabilitative or curative in function (Kane & Kane, 1990; Kapp, 1990). Examples of the professional classifications of elders are abundant in the literature. According to Slivinske et al. (1994), “professional social service staff were better able to identify need factors associated with above-average service usage than were the users themselves. Perhaps predicting the need for social service is more in line with the training, duties and responsibilities of such professionals” (Slivinske et al., 1994:136-137). Once again, according to Ahroni (1989), “there is a fine line between giving elderly persons a sense of support and fostering dependency” (Ahroni, 1989:86). This professional discourse (Abramson, 1990) is also evident in health care ethics research and theory. This body of literature is almost exclusively focused on increasing patient control over daily decision-making and advocates within this field are charged with the task of increasing autonomy

through professional intervention (Hofland, 1990; Hofland & David, 1990; Markson & Steel, 1990; Teaster, 1995; Walker & Blechner, 1995). This reality has further entrenched the professional nature of “frailty” and “need” and has reduced and homogenized access to fit narrow criteria. In light of this, social forces may be seen as tools to improve the lives of seniors but are never examined as causes of “frailty” or the roots of older people’s oppressed status.

### **Conclusion**

Through a comprehensive review of current gerontological research in the area of health care access, several limitations have been made apparent. They include: (1) a failure to define the nature and parameters of access; (2) a focus on reductionist, individual and relational barriers to care with a corresponding lack of focus on structural or ideological issues; (3) little recognition of older women’s differential experience of access; (4) the use of essentialist categories of ethnicity and “race” and the lack of definition of these concepts; (5) the hierarchical nature of studies on ethnic and/or “racial” minority elderly women; and (6) a focus on monocultural or add-on models of ethnogeriatric service delivery. Finally, cutting across most of the gerontological literature is the creation of a monolithic interpretation of “need” based on physical or mental criteria which determines accessibility. The combined effects of these problematic areas in the gerontological research will have a dramatic influence on the way access is defined and operationalized and the way in which elders, particularly ethnic and “racial” minority elderly women are both constructed and acted upon by professionals. It therefore becomes necessary to broaden the debate and draw on critical bodies of literature not necessarily associated with aging which can help us more fully understand the social and historical roots of these

**problematic constructions and to theorize how they may be challenged and ultimately changed.**

### **Chapter 3: Analysis of Theoretical Frameworks**

In order to fully examine the social and historical construction of access to health care among ethnic and “racial” minority elderly women it is important to draw from several theoretical perspectives, most notably, theories on the historical development of medical hegemonies including critical theories of aging, feminist bio-ethics theories of power and agency, disability theories on bodily control, and critical race theories on essentialism, intersectionality and multiculturalism. By doing so I hope to a) re-conceptualize the discourse of “frailty” and “dependence” which so permeates the gerontological literature; b) re-examine the concept of power inherent in discussions of access but which are not, at present, explored consistently in the literature, and; c) address the impact of health structures on older women in general and ethnic and “racial” minority older women in specific. Finally, I will attempt to bring these theories together to create a holistic definition of access which will be more sensitive to the issues facing ethnic and “racial” minority elderly women.

#### **The Bio-Medicalization of Aging**

An exploration of the historical roots of Western thought on illness and disease can contribute greatly to our understanding of current gerontological discourse. Michel Foucault’s work on the rise of ‘noso-politics’ (disease politics) in 18<sup>th</sup> and 19<sup>th</sup> century France (Foucault, 1973; Foucault, 1980) as well as Ivan Illich’s (1976) thesis of iatrogenesis (doctor induced disease) are integral components in an examination of the rise of medicine as a mechanism of state control in Western societies and the subsequent association of aging with illness (Chappell, 1988; Davis, 1995; Katz, 1992; Kirk, 1992).

**Foucault (1973) examines the transformations in medicine throughout the 18<sup>th</sup> and 19<sup>th</sup> centuries, focusing particular attention on the professionalization and technologization of medicine and the process of social marginalization experienced by the infirm, poor, disabled and elderly through the course of modern history (Davis, 1995; Dill, 1993; Estes & Binney, 1989; Findlay & Miller, 1994; Fraser, 1997; Katz, 1992). Prior to these transformations, the occupation of medicine was not highly ranked by the populace.**

**According to Findlay & Miller (1994):**

**The great prestige doctors presently enjoy is a relatively recent phenomenon. Until the mid 19<sup>th</sup> century, surgeons occupied the same low rung on the ladder as barbers-the low status of both owing to the manual nature of their work and to the undesirable association with blood. (Findlay & Miller, 1994:117)**

**In the mid-nineteenth century, Foucault claims, Western medicine's foray into population health and its growing connection with "science" changed the status of medicine enormously. Physicians, increasingly preoccupied with the urban problems of hygiene, epidemics and inadequate housing, aligned themselves with the state in order to expand their role in the maintenance of population health. The emergence of state controls over population health and physical well-being became a central objective of political power (Foucault, 1980: 170) and had the effect of rendering the field of medicine largely as an arena of government (Osborne, 1993). Through this medical-state alliance, medicine became involved with administration, a move which raised its status and enabled it to develop closely controlled uniform standards of professionalization (Chappell, 1988). Medical administrative apparatuses concentrated on the diagnoses of social diseases and the monitoring of population health, creating a "medicine of social spaces" (Foucault,**

1973) whose chief task was to define and categorize the population in terms consistent with the interests of the state. "Government and medicine became components of each other within a medico-administrative regime that ruled the population by distributing it into categories of healthy/unhealthy, normal/pathological, productive/idle and living/dying" (Katz, 1992: 139). Foucault termed this alliance 'noso politics' (Foucault, 1973; Foucault, 1980) or 'disease politics' which referred to the politicization of illness as a means of governing.

The new noso-politics inscribes the specific question of the sickness of the poor within the general problem of the health of populations, and makes the shift from the narrow context of charitable aid to the more general form of a 'medical police', imposing its constraints and dispensing its services (Foucault, 1980: 171)...and which was characterized by the medicalization of the family and privilege of hygiene and the function of medicine as an instance of social control. (Foucault, 1980: 175)

The modern state increasingly associated demographic health and population differentiation with economic productivity and political stability (Foucault, 1980). Thus, population health was directly tied to economic production; anyone outside of the narrow definition of economically productive (i.e., the elderly, disabled and infirm) was labeled a threat to political and social life. The notion of citizenship became equated with the category "worker" and thus industrialization redefined the body into one based on being productive in the labour market (Davis, 1995; Findlay & Miller, 1994). Medicine was integral to the entrenchment of the state ideology of citizenship as represented through productive bodies. The larger the role of disease-focused politics in the division of the population according to categories of normal versus pathological, the more the medico-administrative apparatuses acquired the authority to intervene (Katz, 1992). In no time,

the clinical gaze of medicine problematized all facets of life as being under its jurisdiction (Estes & Binney, 1989; Kaufman, 1994). Government orchestrated social surveys, which became common practice at this time period, were integral tools of medical surveillance and thus enhanced state and medical control over populations. The social survey also lent “scientific” legitimacy to the process of defining individuals as “normal-productive” or “deviant-unproductive”. According to Davis (1995), “bourgeois hegemony brought scientific justification for moderation and middle-class ideology. The average man, the body of the man in the middle, became the exemplar of the middle way of life” (Davis, 1995:26). The scientific classification of the “average man” set a standard of “normalcy” for the entire population (Findlay & Miller, 1994: 124). “In a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants” (Davis, 1995: 29) and can ultimately be classified as dangerous to the long term prosperity of the state.

Illich (1976) described this process of medical appropriation of health in his theories of iatrogenesis (physician induced disease). According to Illich, three forms of iatrogenesis resulted from the growing hegemony of medicine in social and political life. Clinical iatrogenesis, refers to the “damage that doctors inflict with the intent of curing, prolonging life or exploiting the patient” (Illich, 1976: 32-33). Illich claims that the medical profession has been responsible for the creation of much illness and injury due to the combined effects of unwanted side effects of medicines, technological efforts to prolong life, unnecessary surgeries and the hospital as a site of “sickening agents”. Social iatrogenesis is the societal manifestation of clinical iatrogenesis. According to Illich, medical practice has “sponsored sickness by reinforcing a morbid society that encourages

people to become consumers of curative, preventive, industrial and environmental medicine and social over-medicalization” (Illich, 1976: 33). Through the act of diagnosing, physicians effectively re-create individuals as “diseases”, and by so doing, remove them both from social life and from sites of political struggle, sites which have often been responsible for creating disease in the first place (i.e., work place injuries, environmental disease and poverty are all social causes of disease). Finally social iatrogenesis expropriates health as being under the jurisdiction of the professional (Illich, 1976: 32-33), thus rendering people’s subjective knowledge of their bodies inferior to that of the physician’s objective clinical knowledge. The result of these processes is referred to as cultural iatrogenesis. According to Illich (1976):

Cultural iatrogenesis is the ultimate backlash of hygienic progress and consists in the paralysis of healthy responses to suffering, impairment and death. It occurs when people accept health management designed on the engineering model, when they conspire in an attempt to produce, as if it were a commodity, something called “better health”. As a result of cultural iatrogenesis, people experience their bodies as commodities outside of themselves, give up control over their bodies to the “higher authority” of medicine and inevitable lose the ability to know and understand the relationship to their bodies and their experience of disease and death as potentially empowering. (Illich, 1976:34)

Disease and death are ultimately experienced as failures to obtain health, thereby framing what was once considered part of normal life experience as “deviance”. The result of these iatrogenic processes are medical, state and social oppression and marginalization of sick, old and disabled persons (Illich, 1976). Lyman (1989) examines this process in the specific case of dementia. According to Lyman, the problem of dementia is an example of the “medicalization of deviance” (Lyman, 1989: 598). Dementia as a category of illness and thus in need of medical intervention supported the expansion of medical turf in the

early 20<sup>th</sup> century (Lyman, 1989: 598). Viewing dementia as a biomedical condition helped bring order to dementia care but it also entrenched behaviours within an individualistic, pathological framework. Wandering and many other behavioral problems associated with dementia which were once tolerated as 'misbehaviour' were now diagnosed as pathological dysfunction (Lyman, 1989: 600).

Political and social ideology which categorizes so-called non-productive persons (i.e., elders, disabled persons) as deviants have both grown out of and result in practices of "custodial marginalization" (Katz, 1992: 220) such as those tied to the history of the poorhouse in Britain and the Elizabethan Poor Laws of the 17<sup>th</sup> and 18<sup>th</sup> centuries. Several authors have attempted to trace the history of medical and social services and their impact on the treatment of elders and other marginalized groups such as the poor, in England, the United States (Katz, 1992; Fraser, 1997) and Canada (Chappell, 1988; Havens, 1995). The English Poor Laws, developed in England between the 17<sup>th</sup> and 19<sup>th</sup> centuries, were designed to counter the problems of vagrancy which increased as a result of urbanization and population mobility. The Poor Laws generated tax revenues for 3 categories of the indigent: children, able-bodied and the infirm. "The Poor Law, by outlawing begging, politicized relief as a means to ensure social order...the poor were made responsible for their improvidence and victimized for their marginality...the common root of these state reforms were the creation of the deserving and undeserving" (Katz, 1992: 213). In an attempt at further control over the indigent and to narrow access criteria to welfare aid, support was eventually directly tied to institutionalization. Those who were classified as able were put to work, all others who wanted aid, were housed in poorhouses. "Sickness was only one, among a range of factors, including infirmity, old age, inability to find work

and destitution, which composed the figure of 'necessitous pauper' who deserves hospitalization" (Foucault, 1980: 168-169). Thus, the English Poor Law Reform, which intricately tied aging to the status of poor and indigent, denied relief unless those who wanted to receive it, entered the poorhouse. Increasingly, only the infirm and the old resided in state institutions and by the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, elderly persons made up the majority of residents. Eventually poorhouses became old age homes.

In return, the institutions made visible the social presence of the elderly as a poor, dependent, infirm, incapacitated, unproductive, unperformable and differentiated population. The public got to 'know' the elderly through a custodial gaze that uncharitably framed them as a subjected population who had been 'means tested' and classified as 'deserving' by state's welfare laws. (Katz, 1992: 213)

Similar ideological processes of custodial marginalization and distinctions between deserving and undeserving populations were at work in the development of public welfare and health care in Canada. In the 19<sup>th</sup> century, public welfare medicine was primarily concerned with serving categories of the indigent who did not have homes or families who would provide care, including elderly persons and the infirm (Chappell, 1988: 143). Long-term care at this time was essentially provided within the private sphere of the family, occasionally being supplemented by the voluntary sector, primarily the church. "By the early 1900s, long-term care became almost exclusively institutional and continued largely outside the health care system" (Havens and Bray, 1996: 32) as it was narrowly defined. Therefore, public support was largely institutional and relegated the elderly, infirm and indigent to the category of unproductive and incapacitated. According to Foucault (1980) and others, "the most enduring legacy of the policing model was not its establishment of healthy urban environments but its equating poverty and unproductivity with deviance and

marginality" (Foucault, 1980: 214). Minkler quotes the 19<sup>th</sup> century historian Thomas Cole as saying,

The primary virtues of Victorian morality- independence, health, success - required constant control over one's body and physical energies. The decay of the body in old age, a constant reminder of the limits of self control, came to signify precisely what bourgeois culture hoped to avoid: dependence, disease, failure and sin. (Cole in Minkler, 1990: 256)

The present day social construction of the elderly can be traced to the ways in which they have been invented over the past two centuries as a population marked by poverty, illness and dependence. These views are still prominent in the decline and loss paradigms and "failure models" (Cohen, 1990: 14) of gerontological theory. Attitudes that elders are unproductive or deviant continue to contribute to the devaluation of the old, a view of aging as synonymous with disease, disability and decline and to ambiguous status in old age (Becker, 1994: 60; Minkler, 1990: 247). This paradigm of aging as disease results in the social control of the elderly through medical definition, management and treatment (Estes & Binney, 1989; Kaufman, 1994; Kirk, 1992; Warnes, 1993), reduces elders to the "patient role" (Kaufman, 1994: 49) and denies systemic structures of domination and oppression at work in gerontological practice (Estes & Binney, 1989: 590). Bio-medical practices in aging have resulted in the entrenchment of illness criteria for access to care (Kane & Kane, 1990) and in the development of a focus on objective technological tools to measure these criteria (Dill, 1993).

As is evidenced in current gerontological research and theory, elders at "risk" or in "need" become the objects of concern in the professional literature. The words "risk" and "need" are used in a variety of ways to "provide justification for the reductionist recommendations of caregivers and professionals" (Silberfeld, 1992:124-125; Kaufman,

1994; 55-57) and is often used in the “language of long term care regulations, eligibility requirements, requests for proposals..and too often it is the language of ombudsmen and advocates” (Cohen, 1990:14-15). Service delivery has become heavily dependent on medical definitions of “need”. “Institutions by the way they are financed, organized and conceptualized influence the dependence of older people” (Baldwin, Harris & Kelly, 1993). Risk and need are based on functional tests of ability and are closely tied to notions of harm and protection.

For who would want another to come to grief? It becomes altogether natural-perhaps even obligatory- to interfere in the life of that person for their own good. Starting from assuredly good intentions, risk becomes part of an unconscious rhetoric for controlling elderly people...In all these attempts to invoke risk there is a view of normalcy which is silently being advocated. People should die in bed and not as a result of an accident. “People should” statements are the driving forces for the conclusions about risk. (Silberfeld, 1992: 134)

Fraser has examined the ways in which the construction of need has been used as a political instrument in welfare state societies (Fraser, 1989: 161). Fraser’s theory of “expert needs discourse” is closely linked to needs preoccupations in gerontological theory and practice. According to Fraser, expert discourses are “best understood in the context of “social problem solving”; institution building and professional class formation” (Fraser, 1989: 171) and emerged as a state strategy of control. In defining public problems, expert needs discourses tend to act administratively, shaping issues to increase state control and maintain the status quo, thereby making problems manageable in ways non-threatening to current hegemonic practices. According to Fraser, “people whose needs are re-defined by expert discourses are often rendered ‘individual cases’ rather than members of political movements and thus expert discourses tend to be de-politicizing, or

**'normalizing'" (Fraser, 1989: 172), once again rendering those outside this "norm" to the status of pathological.**

**This "experting" of needs is common in current aging service and policy. Social services have developed "reliance on bureaucratic technology and the ascendance of professional hegemonies" (Dill, 1993: 455) to determine risk and need. However, within this techno-medical framework, the fact that aging services are "founded on only one interpretation of needs is obscured" (Aronson, 1992: 74). Within the field of gerontology, expert definitions of needs are paramount and have sustained systemic legitimacy marked by a high degree of control over access and treatment. This issue is particularly relevant given the growing interest in case management and single-point-entry access models (Aronson, 1992; Kaufman, 1994). According to Aronson (1992):**

**As single-access gatekeepers, they (case managers) effectively hold a monopoly over publicly provided services, so that old people voicing needs outside the dominant discourse would have little choice but to accept their limitations. Theoretically, old people could exercise some choice in the private market, but having such a choice presupposes both economic privilege and sufficient physical and mental energy. It seems, then, that, rather than being flexible or responsive practices, case management and single access to service are likely to lock us into a limited service repertoire and close our ears to interpretations of need that diverge from the dominant discourse...from this perspective, anyone expressing needs that do not fit into the available possibilities - that cannot be "squeezed" into a form that can be satisfied within the present service repertoire - is likely to be construed as problematic and difficult...while the broader conditions that generate individual needs go unremarked and are obscured. (Aronson, 1992: 82-83)**

**The emphasis on compliance in Aronson's statement is important. Within the bio-medical paradigm, elders who speak or act from a position outside dominant discourse are often viewed as non-compliant or in need of 'fixing'. According to Conrad (1987), "from**

a medical perspective, patients who do not comply with the doctor's orders are usually seen as deviant, and deviance requires correction" (Conrad, 1987: 15). Gerontologists have suggested that responses to non-compliance are best handled within the therapeutic alliance of health care provider and patient, asserting that improved communication will ultimately improve compliance. While this may be true, without re-examining the ways in which non-compliance may be used as an elder's only means of resistance to medical domination, the therapeutic alliance may simply be used as a tool to increase professional control over elderly patients. From this "medical perspective", the therapeutic alliance, most commonly associated with nursing and social work, becomes entrenched in a model of social control (Conrad, 1987).

This point is emphasized in recent critical gerontological research which has documented the dominance of professional definitions of need and the impact this professional discourse has on elders' views of their own problems. According to researchers, elders are likely to define their needs and wants within the professional framework in which they find themselves or are more likely to be submissive to what they view as professional authority (Kaufman, 1994). Aronson states,

It seemed that women who were already receiving services of some kind, whether at home or in an institutional setting, spoke most clearly from within the terms of the official discourse. They expressed their wishes in terms of service options available to them rather than in terms of the underlying needs those options addressed; their responses were very much locked into the images of community and institution that characterize the dominant discourse. (Aronson, 1992: 81)

This notion of speaking within the official discourse is closely related to Foucault's conception of social regulation:

**In general, the monitoring of health and bodyweight which originated outside the individual, in the state and the medical profession, also has been internalized by those individuals themselves, bearing out arguments for a shift in the form of social regulation from policing-by-others, to self-policing in 20<sup>th</sup> century Western society. (Foucault, 1979 in Findlay & Miller, 1994: 126)**

**This subservient position of elders reinforced through social regulation and medical control has influenced the shape of access to health care. Access continues to be tied to notions of deservedness which are themselves tied to illness and dependence. This will continue to have an impact on the way elders see themselves and the way they do or do not make claims over service entitlement. Since “frail” elders have not historically asserted claims over service delivery, it has been assumed by professionals that they either accept the nature of health care services delivered to them or waive their rights to demand change. According to Cohen, “those unwilling to assert claims are assumed either to have waived them or to be unworthy. Given the necessity to assert claims in order to secure autonomy rights, those who are disadvantaged and worse yet, those who perceive themselves to have no future - do not assert claims” (Cohen, 1990: 1<sup>6</sup>). Clearly, professional needs discourses will continue to entrench aging services within a paradigm of charity and decrease elderly persons’ ability to act as agents in their own lives.**

### **Disability Theory on the Construction of ‘Normalcy’**

**In recent years, there has been considerable interest in building bridges between the independent living movement made up of younger disabled persons and the field of gerontology (Ansello, 1992; Ansello & Eustis, 1992; Binstock, 1992; Eustis & Rose Fischer, 1992; Minkler, 1990; Racino & Heuman, 1992). While there are many reasons to**

be suspect of such a merger, particularly when initiatives originate with governments whose attempts may not be to alter arrangements but simply save money, there is reason to believe that the theoretical work of the disability rights movement has a lot to teach those in the field of gerontology, particularly with respect to access and service delivery. Disability theory has, in recent years, been developed by persons with disabilities, lending not only a unique credibility to the work but also covering a degree of breadth and complexity not seen previously in the field of disability studies. In gerontological studies, there has been little theorizing done by elders themselves. The field is still largely controlled by pre-retirement academics and health professionals and thus remains distinctly socio-medical in focus.

Disability theorists have been central in critiquing forms of medical and social domination, particularly those rooted in 18<sup>th</sup> and 19<sup>th</sup> century historical and social constructions of normalcy and the general project of control and regulation of the body (outlined previously in the section on the bio-medicalization of aging). They have also undertaken the task of documenting the impact of these constructions on the lives of persons with disabilities. One of the most important efforts of disability theorists is that of tracing the 'socio-political processes' at work in relation to the body which have pushed persons with disabilities to the periphery of social and communal life (Davis, 1995; Dejong, Batavia & Bouscaren McKnew, 1992; Fine & Asch, 1988; Luborsky, 1994; Mechanic, 1991; Wendell, 1996). Davis (1995) and Wendell (1996), in particular, have critiqued individualistic and reductionist constructions of disability prominent within the medical paradigm and challenged the discursive practice of dichotomous thinking in relation to the body. According to Davis (1995):

**What does not occur to many people is that disability is not a minor issue that relates to a relatively small number of unfortunate people; it is part of a historically constructed discourse, an ideology of thinking about the body under certain historical circumstances. Disability is not an object-a woman with a cane- but a social process that intimately involves everyone who has a body and lives in the world of the senses. Just as the conceptualization of race, class and gender shapes the lives of those who are not black, poor and female, so the concept of disability regulates the bodies of those that are 'normal'. In fact, the very concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability, or rather, the concept of disability is a function of a concept of normalcy. Normalcy and disability are part of the same system. (Davis, 1995: 2)**

**By linking the normal with the disabled and connecting it to the same system of social processes, Davis attempts to challenge the invisibility of the 'hegemony of normalcy', uniting non-disabled and disabled people within the same totalizing construction. He goes as far as to call able-bodied persons the "temporarily-abled" to further emphasize his claim (Davis, 1995: 1). He also draws our attention to the politics of naming. Having the power to categorize and to cause that categorization to have social and material consequences is key to the critique of medical authority according to disability theorists. Disabled people have historically been named by "able-bodied others" in ways meant to separate, disempower and oppress. This "binarism and polarity of naming" that Davis describes (you are either able or disabled, young or old) is central to an "ideology of containment" which is rooted in fear of the other (Davis, 1995: 1). Thus, those who are able-bodied separate themselves from those who are not so that they will not be seen to be like them and in the process of this act of disabling, "ableist society creates the absolute category of disability" (Davis, 1995: 7). The disabled, like the old, are**

successfully walled off by assigning them to the private sphere of the family. According to Wendell (1996):

When public and private worlds are split, women (and children) have often been relegated to the private, and so have the disabled, the sick and the old. The public world is the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults. Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected. Coming into the public world with illness, pain, or a devalued body, people encounter resistance to mixing the two worlds, the split is vividly revealed. Much of the experience of disability and illness go underground...(Wendell, 1996: 40)

Ideological "otherness" is reinforced through this practice of separation and marginalization which, although state orchestrated, has ramifications on individuals' beliefs about and responses to persons with disabilities. Fear and disgust of the disabled person, although an individual response is learned through the acting out of societal norms such as incarceration, institutionalization, segregation, discrimination and marginalization. "Thus, the 'normal', 'natural' response to a person with disabilities is in reality a socially conditioned, politically generated one" (Davis, 1995: 13). Because disability is so often defined by able-bodied persons as "visible", that is disability is defined through both function and appearance, controlling and patrolling the disabled person is made manifest through "the power of the gaze" at the individual, familial, communal and societal level (Davis, 1995: 11-12). In other words, where disability is made visible and absolute, it is possible for the disabled person to be continually "policed". The disabled person can always be identified, classified and thus shunted from participation in public life, a process Wendell has called the "cultural banishment of the rejected body" (Wendell, 1996: 91).

The status of the body switches from being a silent integral background for personhood and the self to become a foreground external feature of

constant awareness. The basis of one's social identity switches from achievements, roles and identities to the fact of physical inability so the impairments become a master identity subordinating all abilities. (Luborsky, 1994: 248)

According to disability theorists, failure to control the body is one of the most powerful symbolic meanings of disability in Western society (Wendell, 1996). Much work has been done in theorizing the body as a site of medical authority and control.

According to Wendell (1996):

In the societies where Western science and medicine are powerful culturally, and where their promise to control nature is still widely believed, people with disabilities are constant reminders of the failures of that promise, and of the inability of science and medicine to protect everyone from illness, disability and death. (Wendell, 1996: 63)

Idealizing the body as being under the full control of its owner is problematic in shaping the lives of those whose bodies are sites of chronic illness, disability or pain. Wendell gives an example of how idealizing the body impacts on the lives of people with disabilities:

...when the pace of life increases, stamina becomes more important to participation in every aspect of society, and what was once regarded as an ideal level of energy gradually comes to be regarded as normal. Everyone who cannot keep up is urged to take steps (or medications) to increase their energy and bodies that were once considered normal are pathologized. (Wendell, 1996: 90)

Disability theorists have examined the ways in which medicine has reinforced the myth of control through the belief that illness is temporary and that "normal" persons are returned to the optimum state of health through curative medical intervention. It has also implied that health is the sole responsibility of the individual, that all one needs do is take

care of oneself properly to avoid illness and disability (Ward-Griffen & Ploeg, 1997; Wendell, 1996). Persons whose bodies are 'out of control', that is disabled, ill or aging, face guilt and stigma, after all, to be ill is to have brought it upon oneself. "The context of any attempt at healing in my society is a culture that considers controlling one's body a criterion of full humanity and of social acceptability" (Wendell, 1996: 98). Those who cannot maintain control over bodily processes are relegated to the status of a non-person.

Wendell describes the impact of medical authority over the body. She states that the combined effects of idealization and the myth of control result in, a) alienation from one's body and bodily experiences and limited cognitive or social authority over one's own body, b) the justification of medical management of bodily processes; c) epistemic invalidation, that is one's own beliefs in oneself as knower is undermined; d) social abandonment, that is many people who are very ill and disabled are abandoned out of reach of any social safety net, friends or family, and; e) a vocabulary of illness which is third-party- scientific in focus rather than based on subjective personal experience (Wendell, 1996: 120). Wendell states that, "not only does modern medicine take little interest in treating suffering that it cannot eliminate, but its conceptual schemes deprive suffering of meaning and context in a patient's life, when meaning and context are often essential to living with chronic pain" (Wendell, 1996: 137). As Illich described in his theory of social and cultural iatrogenesis, medical authority serves to deny the possibility that "illness and disability could be sources of knowledge or valuable ways of being" (Wendell, 1996: 68).

Finally, disability theorists have critiqued the virtual silence of critical theorists on the issue of disability. Despite the fact that "disability can be seen rightly to belong with

the more heavily lobbied categories of race, class, gender and sexual orientation” (Davis, 1995: xx), there has been little emphasis placed by critical or feminist theorists on expanding these categories to include disability. Davis describes this silence as:

especially strange since much of left criticism has devoted itself to the issue of the body, of the social construction of sexuality and gender. Alternative bodies people this discourse: gay, lesbian, hermaphrodite, criminal, medical and so on. But lurking behind these images of transgression and deviance is a much more transgressive and deviant figure: the disabled body. (Davis, 1995: 5)

Within leftist critique, the body has been seen as a ground of pleasure and not one of pain or disfigurement (Davis, 1995), leading to ostracism of those bodies that are not under the control of their owners. “Until feminists criticize our own body ideals and confront the weak, suffering and uncontrollable body in our theorizing and practice, women with disabilities and illnesses are likely to feel that we are embarrassments to feminism” (Wendell, 1996: 93). According to Davis, “in the realm of the body, ableist culture still reigns supreme” (Davis, 1995: 6). The result is that disabled persons are rendered invisible within the broader field of critical studies, a fact which has further entrenched their social and political marginalization. Since it is within critical and feminist studies that the process of deconstruction takes place, the absence of considerations of disability is highly problematic.

Disability activists working from within a deconstructivist perspective have completely re-thought and re-formed medical and social services for persons with disabilities. They have worked to debunk the individualist and reductionist control paradigm and have focused on reframing disability as at least partially resulting from decisions made in the political and social spheres. Disability activists have fought the

dichotomous division of private and public and demanded recognition by and in the social world. They have claimed that the private sphere of the family is a potential site of oppression, not only for disabled persons but for caregivers as well and should not, as a result, be the primary arena of health care delivery. Disability activists have been and continue to be concerned with promoting agency and have seized on the term 'disability' in an attempt to control its usage and in order to occupy a social location of their own design, to name themselves. Over the last fifteen years, activists have developed an independent living movement focused on increasing control of health care services. During the 1980s, the concept of non-facility-based services began to replace the concept of a service continuum among disability activists.

As the basis for service design, the continuum concept is considered flawed because it 1) legitimates the use of restrictive environments such as institutions, 2) erroneously assumes a necessary link between segregation or integration and a particular level of service, 3) supports the primacy of decision-making by professionals, 4) sanctions infringements on people's rights and 5) directs attention to physical settings instead of the supports people need to be integrated into the community. (Racino & Heumann, 1992: 44)

According to Cohen (1992), "the attendant care consumer model proceeds on the assumption that people with disabilities who are well versed in their own healthcare needs have the necessary ability and skill to direct and monitor their own personal care" (Cohen, 1992: 51). One cannot underestimate the power of this ideological shift. Moving from a model of benevolent care to that of the rights to service fundamentally changed the nature of care to persons with disabilities from that of protection to that of participation.

For many reasons, disability theory has much to offer the field of gerontology. It is not difficult to find many parallels between the social-political processes at work in

relation to disabling the body and those at work in relationship to aging the body. Embodiment, control, marginalization and medical authority all have an impact upon the so-called "frail" elderly in ways similar to the impact they have upon persons with disabilities. "Frail" elders are, after all, elders with disabilities. This has not been altogether apparent in the gerontological literature. The rise of "frailty" discourse in gerontology is reflective both of the dominance of the medical model in aging and professional attempts to hold on to medical control over their elderly patients; a control they have lost in relation to persons with disabilities. Social processes of "normalcy" also ostracize the elderly, reduce and homogenize them, place them within the private sphere of the family and thus render them invisible. The category of "frail" is as totalizing a medical definition as disability theorists have claimed that the medical definition of "disabled" has been to persons with disabilities. "Frail", like "disabled", is defined as "seen" and as "functional" thereby making it manifest through the power of the gaze. In addition, the reductionist approach to impairment in old age has distorted the experience of old age, "a problem that is magnified as biomedical perspectives increasingly dominate gerontology and impaired elders are more and more frequently scrutinized and subjected to objective measures of physical and cognitive ability in order to determine their capacity for autonomy" (Gadow, 1996: 72). Elders are thereby, socially controlled, the boundaries surrounding definitions of "frailty" largely policed by medical and social service professionals, communities and families. Elderly persons can also make a claim that they are included within Wendell's concept of the 'cultural banishment of the rejected body' which contributes to societal fear and disgust with aging and a relationship of aging with death. This focus shears away

elders' identity and replaces it with a new existence concentrated on bodily care (Tulloch, 1990: 85).

The concepts of embodiment and the myth of control are important concepts for aging theorists. Despite this, gerontologists have not applied these concepts to those that are old and "little work in gerontology has addressed the body" (Gadow, 1996: 62). Elders with disabilities are stigmatized as a result of having bodies which are "out of control". They suffer from medical management, epistemic invalidation and medical authority. They also have little reinforcement which helps relate their lived experience of illness as a source of strength. One example of this latter point is the hegemonic discourse of speech within medical encounters. Davis (1995) has examined the ways in which medicine has prioritized speech as the most effective mode of communication in medical settings. By doing so, medicine has marginalized other more bodily forms of communication including sign language and touch. Shifting from this hierarchical model to a horizontal model in which different modes of communication are honoured, would no doubt, produce dramatic effects on the ways in which gerontologists interact with understand and know elders, particularly those who are cognitively impaired. A language of touch can open up new channels of communication between health care providers and elderly patients and help to provide alternative models of strength and capacity wholly ignored within the present bio-medical paradigm.

Gerontologists must also more seriously consider an independent living services model for older people in order to challenge the totalizing medical construction of aging services and the paradigm of protection and custodial marginalization common in service delivery (Binstock, 1992; Racino & Heuman, 1992). To date, aging and disabled services

have not been conceptualized in tandem. According to Eustis & Fischer (1992); “beyond a shared preference for staying out of nursing homes, however, the independent living movement of younger adults with disabilities, on the one hand, and people in the field of aging, on the other, have conceptualized and implemented the idea of living in the community very differently.” (Eustis & Fischer, 1992: 17). As Cohen (1992) states,

In contrast to the field of aging, the independent living movement views services less as compensating for physical and psychological deficits than as enhancing or limiting independence. Services are examined with an eye to whether they are controlled and directed by the consumer or by the agency. The purposes of services are measured against a standard that accepts risk-taking and uncertainty rather than a standard that concentrates on assured safety, quality, and protection. And finally, services are directed at goals that (1) include involvement and engagement, which give life meaning and (2) go beyond survival and the limited aim of staying out of an institution. (Cohen, 1992: 49)

Several reasons exist to explain the marked differences in approaches between disabled and aging services. First and most important is that the “professionally-constructed” character of disability health care services has been challenged and reconstructed by disabled activists. Disability activists have been largely responsible for reshaping services for disabled persons in a way which more strongly reflects their own definitions of need (Fraser, 1989). This has resulted in the transformation not only of the services themselves but of the name of the movement from one focused on “disability” to one which centralizes on the goals of the movement, namely “independent living”. This self-defined focus of current disability activism is largely absent in services to “frail” elders. In fact, “young people have defined and theorized a movement while in aging it is professionals that define elders” (Eustis & Fischer, 1992: 18). Elder services have been resistant to change largely because:

provider groups tend to have a direct economic interest in issues of long term care, and this interest is not well served by a participant-directed model of service delivery...Thus, the homecare industry attacks the independent living approach by challenging the accountability of personal assistants and the quality of services received by persons with disabilities. (Dejong et al., 1992: 91)

Academics, policy makers and at times, elders themselves have also claimed that the independent living movement is not a useful model for aging services. Some researchers have stated that elders often express anxiety about taking on the role of managing their own care, are not interested or concerned about this role or would prefer simply to rely on family or professionals to manage their care (Eustis & Fischer, 1992). While these are valid concerns and must be addressed, one wonders whether or not they are rooted in a distrust of current medical hegemonic practices. That is, elders may not feel capable of managing formal care in a situation where they are constructed and, as a result, construct themselves as passive and dependent on professional intervention. Gerontological policy makers and planners must, at minimum, consider how notions of protection and dependence have shaped models of service delivery. This may include a re-examination of the single entry point, case management approach. Independent living movement activists have not been preoccupied with service duplication and efficiency as have been those in the field of gerontology. In fact, independent living movement activists have praised a multiplicity of services which may be duplicated in different neighbourhoods or for different populations in order that individuals can meet their own particular needs. What has been labeled duplication in aging services has often been called diversity in disability services. Issues of diversity may be more easily ignored or marginalized within a single entry system which tends to essentialize and homogenize

persons according to functional impairment. While cases may be more efficiently managed within the case management approach, elderly persons may lose even more control and choice than what had previously been available to them.

Moving from a construction of frailty to a construction of disability can make radical changes to the way agency and aging is conceptualized. It can help gerontologists shift from myopic analyses of individual responsibility for health to a contextual analysis of institutional and systemic responsibility for entrenching disability as deviance and can ultimately challenge the way we view care and service. The one question that remains is whether or not aging activists should align themselves politically with disability activists in a single independent living movement. At the present time, a merger of the two fields does not seem to be a good strategy. Such a political merger may simply diffuse the efforts of disabled activists and bend the disability rights agenda to the desires of a professional class of gerontologists. Given the professional hegemony of aging services, it is no surprise that younger disabled persons view a merger of younger persons with disabilities and frail elders with trepidation and concern. At the present time, efforts would be better placed on infusing gerontological studies with the voices and concerns of disabled elders themselves and exploring the ways disability theory and activism can influence thinking in the field of gerontology without developing a joint movement. Collaboration can only be successful if and when the field of gerontology is shaped by elderly activists. Only then can disabled activists in both communities define common agendas from common ground.

In concluding this discussion, it is important to draw attention to the fact that disability theory can help us radically re-think health care access. Wendell (1996), for example, has re-framed the concept of independence/dependence which has been so

central to aging studies into the notion of accessibility. Wendell states that focusing on accessibility rather than independence, sets the gaze upon the adaptation of systems and institutions, not of people. She explains that a focus on independence has forced disabled people to “expend tremendous energy being ‘independent’ in ways that might be considered trivial in a culture less insistent on certain forms of self-reliance” (Wendell, 1996: 148). Like Davis, Wendell asserts that all persons are disabled in some way but are unaccustomed to seeing the obstacles in their environment and the technological devices they rely on as helping to diminish disabilities. According to Wendell (1996):

While most non-disabled people in industrialized societies believe that being able to perform the so-called activities of daily living by and for oneself is a necessary condition of independence, and therefore regard people with disabilities as dependent if they cannot perform them, they do not recognize their own dependence on services, such as the provision of water that comes out of a tap, as obstacles to their own independence. (Wendell, 1996: 145)

Emphasizing this reality will force “non-disabled” people to reconsider accessibility as a normal feature of their environment, thus improving their understanding of the fluid and changing nature of ability and disability. Improved access will likely lead to a broader acceptance of persons with disabilities. As Wendell states,

When I imagine a society without disabilities, I do not imagine a society in which every physical and mental ‘defect’ or ‘abnormality’ can be cured. On the contrary, I believe the fantasy that someday everything will be ‘curable’ is a significant obstacle to the social deconstruction of disability. Instead, I imagine a fully accessible society, the most fundamental characteristic of which is universal recognition that all structures have to be built and all activities have to be organized for the widest practical range of human abilities. (Wendell, 1996: 55)

This goal must also inform the work of aging activists and gerontologists concerned with developing social, medical and political accessibility for disabled seniors.

## **Feminist Bio-ethics Theories on the Marginalization of Women's Health Care**

Gerontological research and theory has been remarkably silent on the 'woman question'. Unfortunately, this silence is also manifest in critical literature on the historical and social construction of medicine. There is little, if any, attempt to incorporate an analysis of gender in explorations of the social control function of medicine (Ward-Griffin & Ploeg, 1997). To date, little emphasis has been placed on developing theory which merges feminist studies and bio-ethics theory with gerontological research and practice.

Feminist thought, clinical ethics and gerontology are tandem disciplines in many healthcare settings. They flourish side by side, but rarely converge. At most, two of the three combine. Gerontologists have explored a feminist approach to aging, but without a focus on health concerns. Healthcare ethics has begun to focus on elderly patients, but without a feminist perspective. Feminist ethics addresses women's health during reproductive years, but without equal interest in women beyond that age. (Gadow, 1996: 35)

This is a significant weakness in current aging health care policy and practice. It is difficult to create new forms of thinking in health care access without incorporating these three fields. Gerontology is limited by a narrow prescriptive model entrenched in the biomedical paradigm and has little or no understanding regarding the structure of medicine and its role in a patriarchal society (Sherwin, 1996). More needs to be done to adequately address aging and health through the feminist model, particularly in relation to the themes of power and agency (Ward-Griffin & Ploeg, 1997).

In order to explore the political role of medicine within a patriarchal context and patterns of gender dominance in health care generally, it is necessary to turn to the growing body of literature on feminist bio-ethics and women's health. Feminist bio-ethics and women's health theories have emerged over the past fifteen years to address the

concerns of women's health and their experiences in the health care system (Sherwin, 1992). The literature grew largely in response to traditional medical ethics and health theories, within which current gerontological theory is based. Feminist theories outline the ways in which "sexism limits women's opportunities and subjects them to an array of situations including marginalization, powerlessness and exploitation" (Ward-Griffin & Ploeg, 1997: 280). Both medical and feminist bio-ethics are interested in developing frameworks for dealing with real life problems and have come to reject the abstraction, generality and objectivity associated with traditional ethics (Gadow, 1996; Purdy, 1996; Sherwin, 1992; Tong, 1993; Warren, 1989). They both also attempt to discuss power dynamics and differentials within relationships, such as those between provider and patient (Bishop, 1992; Borges & Waitzkin, 1995; Foster, 1989; Wuest, 1993). According to Sherwin (1992), however, that is where feminist and medical ethics part ways. Medical ethics suffers from a lack of analysis of power. Feminist ethics derives from the explicitly political perspective of feminism, wherein the oppression of women is seen to be morally and politically unacceptable. While feminist bio-ethicists point to current medical practices which constitute a powerful social institution contributing to the oppression of women and address the notion of personal agency within oppressive regimes, medical ethicists have continually failed to comment on the political role of medicine. Gerontologists interested in expanding their understanding of health care access will find an abundant literature on the political role of medicine and the place of woman within the bio-medical paradigm which can inform their understanding of older women's health generally and the marginalization of older women's needs in the long term and health care delivery systems.

Feminist forays into women's health have explored the emergence of modern medical knowledge, the rise of medical authority and have considered why and how women's lives have become territory for medical intervention (Findlay & Miller, 1994: 115). Particularly important to this analysis is the fact that women, and especially mothers are assigned cultural responsibility for the health of the family and, as a result, watch over and regulate the bodily practices of the family (Sherwin, 1992). In order to gain access to the entire population it became necessary for the medical profession to set their clinical gaze upon women who then acted as the crucial bridge between the medical establishment and the rest of the family. (Findlay & Miller, 1994:127). State interests in controlling and maintaining women within the private sphere of the family were reinforced through the definition of the family as the primary site of medical intervention and surveillance. Thus medical and state apparatuses acted together to oppress and confine women. Feminist bio-ethics theory is largely preoccupied with unmasking the extent of medical control over women's bodies, particularly as they relate to regressive interpretations of women's role within the family and have focused a great deal of attention on reproduction and childbirth. Given the important focus placed on unmasking state ideology and the entrenchment of women within the private sphere of the family, it is not surprising to find that one of the only aging issues undertaken by feminist bio-ethicists is that of caregiving (Gadow, 1996).

The analysis of the distribution of power between the genders, and the ways in which health care systems, structures and practices contribute to women's "depowerment" is one of the central features of feminist bio-ethical theory (Gadow, 1996; Tong, 1993; Tong, 1996a; Tong, 1996b; Tong, 1997). Feminist bio-ethical theory claims to be

implicitly political and emancipatory. Tong has coined the phrase “feminist ethics of power” to highlight the relationship of feminist ethics to structural analyses of domination and subordination. Patriarchal structures in health care systems have shaped the context of both provider-patient relations (Donchin, 1995; Farrell Smith, 1996) and physician-nurse relations (Lindemann Nelson & Lindemann Nelson, 1996), have determined research and treatment, rationalized authoritarian structures as being good for achieving health, and have been used to entrench social attitudes towards women, particularly women of colour (Roberts, 1996) . According to Lindemann-Nelson (1996b):

Just as privileged men have occupied the positions of dominance in their epistemic communities, so too have physicians. These observations are of course, interrelated; many physicians are privileged men and they have lent the profession epistemic sheen. What dominant men-and physicians of either gender-have wanted to investigate has been socially supported as worth investigating; what they have not regarded to be worth knowing has frequently been passed down the epistemic hierarchy, to be known by those of lesser status. (Lindemann Nelson, 1996b: 25)

According to Sherwin, “the standpoint of medical privilege, like the standpoint of male privilege, is precisely the one from which important features of the lives of those below are not visible. And as it is the lives of those below with which the physician is professionally concerned, the inability to see clearly here is particularly unsatisfactory” (Sherwin, 1992: 25). Conflicts between the perspectives of physician and patient arise also in the context of physicians’ gatekeeping role, determining which patients are suitable candidates for their services.” (Donchin, 1995: 47). Directly tied to these structures is the medical ideology of autonomy and its role in stigmatizing women. The medical model of acute care has placed most of its attention on the “ideal” patient as a normally healthy, autonomous person, who makes decisions independent of outside influence, including that

of family or community. When relationships are taken into account in dominant discourse, there is an assumption of voluntarism which remains intact.

**They view individuals as bound to each other, both to their communities and their physicians, principally through contractual relationships that are to be respected insofar as individuals freely choose them. This contractual picture of human relations has dominated North American bioethical theory and continues to function as a paradigm for relations between providers and patients. (Donchin, 1995: 47)**

However, feminist bio-ethicists have pointed to the fact that most women's relationships do not fit into this model of voluntarism (Sherwin, 1992: 140). Women often choose to define themselves from within a relational or interdependent position, particularly in consideration of children with whom women do not have a mutually-voluntary contractual bond. In addition, feminists have pointed to the fact that structural factors, including those which reify women's position within the private sphere of the family and render them economically and politically dependent on partners, dramatically shape the nature of women's "autonomy". Ignoring these elements seriously disadvantages women within the health care system and as a result, women may find themselves alienated from health care systems and providers (Sherwin, 1992).

**Feminists have argued that liberalism fosters a misleading ideal of the autonomous individual that intensifies the already disadvantaged position of women within healthcare systems...Physicians for instance, assuming women's reasoning capacities are compromised or that they lack the knowledge appropriate to proper decision-making, tend to judge women incompetent to make their own healthcare decisions with far more frequency than men. On the basis of this presumption, they are also more inclined to attribute women's symptoms to emotional rather than physical causes. (Donchin, 1995: 45)**

Finally, the issue of agency has been taken up in greater depth from within feminist frameworks and analyses. Sherwin posits that an even more distressing tendency than that of “ignoring women’s agency altogether and/or viewing her as a passive participant in the medically controlled events is the growing practice of viewing women as a genuine threat to their own or others’ well-being” (Sherwin, 1992: 107). This point is illustrated in current health promotion strategies which, by emphasizing individual responsibility and autonomy, have a tendency to blame the patient’s illness on her own negative self-care practices or in those practices performed in her role as caregiver. However, feminists point to the fact that “How we understand what it means to be autonomous influences our judgements about what counts as voluntary action. How we characterize relations between individuals and the societies that give context to their lives affects our perception of the range of choices available for voluntary action” (Donchin, 1995: 45). Instead of being myopically focused on individual autonomy devoid of notions of power, “the primary question to ask is usually whether agents are making their own decisions freely or as a result of some combination of external and internal coercive focus” (Tong, 1996c: 150). Therefore, part of the task of feminist analysis of autonomy in the context of power is the empowerment of women so that their ability to act as agents is enhanced.

Strategies should be devised to expand women’s capacities to claim their own agency as concrete others, to articulate their preferences in light of their own understandings, even if this requires challenging authoritative constructions of them by medical professionals”. Women are not passive victims of medical institutions. They have been controlled by mainstream professional medicine but have also influenced it on occasion. In the end, the encounter between women and the medical profession is much like women’s encounter with other institutions of social control—neither victory, nor defeat, but an ongoing struggle. (Findlay & Miller, 1994: 136)

Although feminist bio-ethicists have not taken up the issue of health care access and older women to any great extent, their work in the areas of power, autonomy and agency can greatly influence the field of gerontology in many ways. Gerontologists must begin to more fully address the fact that women constitute an oppressed group which is clearly disadvantaged within the health care system. Women, particularly older women, are the primary consumers of health care, but the care they receive does not always serve their overall health interests. Both American and Canadian health care systems, despite their obvious differences “reflect the existence of differential patterns of health and illness associated with gender, race and income level” (Sherwin, 1992: 226). Gerontologists and other health care policy analysts and researchers must begin to acknowledge that access issues are shaped by power. Too often access issues have been described as existing in the neutral environment of the physician’s office or long term care institution with little regard for power differentials between persons, most often white males and females, in positions of authority over elderly females and powerful structures which promote male supremacy to the detriment of women.

Another task of gerontologists interested in infusing feminist bio-ethical theories into aging studies is that of re-thinking autonomy in aging. “Feminist criticism has shown the coerciveness of an ideal that posits women’s autonomy as a means of concealing constraints on their freedom” (Gadow, 1996: 39). Agency, as it is examined in the field of gerontology, is limited by the traditional ethical model of autonomous health care decision-making in the absence of any analyses regarding the ways in which power influences older women’s experience of care and the means available to them to modify the care they receive from formal or informal care providers (Bennett, 1988; Boyajian,

1988; Capitman & Sciegaj, 1995; Checkland & Silberfeld, 1993; Collopy, 1990; Davitt & Kaye, 1996; Foster, Sharp, Scesny, McLennan & Cotman, 1993; Iris, 1990; Jecker, 1990; Michel, 1994; Neveloff Dubler, 1990; Roy, 1988; Schafer, 1988; Zuckerman, 1994).

According to Donchin (1995), "...a critical appraisal of the ways gender differences have structured medical care would not only dispel unjustified negative appraisals of women's behaviour, but also help to expose the partiality of perspective reflected in the governing norm" (Donchin, 1995: 51) and lead to the recognition that change must occur in the way health care is delivered to older women. Gerontologists can turn to the women's self-help movement in order to find models which can democratize and demedicalize health care (Dressel, 1997; Lindemann Nelson, 1996a; Lindemann Nelson & Lindemann Nelson, 1996 ) in the interests of older women.

This exploration involves searching for a way of empowering those who are now subordinate through the creation of different relationships and new, non-oppressive social structures. Without such analysis, women would be left with the morally unsatisfactory prospect of insisting on equal access to the existing positions of power and dominance. An ethics built on a rejection of oppressive structures cannot settle for reformist measures...but must offer new perspectives on social and political possibilities. (Sherwin, 1992: 56)

Perhaps it is time for feminist gerontologists to consider the shape and nature of a feminist long term care system (Neysmith, 1997). What would it look like? How would it be administered and funded? Who would have access? How would access be defined? Clearly these questions are complex and do not lend themselves to simple answers. But the questions themselves are rarely asked and so feminist gerontologists and other feminist activists concerned with health care across the life cycle have had neither much opportunity nor an appropriate forum to engage in debate regarding a vision for a feminist

long term care system. This fact must be challenged in order to improve the treatment of older women, particularly older women of colour, by the health and long term care systems.

### **Critical Race and Anti-racist Theories on Essentialism, Intersectionality and Multiculturalism**

Critical race theory has emerged over the past fifteen years in an attempt to expose and examine “the historical centrality and complicity of law in upholding white supremacy (and concomitant hierarchies of gender, class and sexual orientation)” (West, 1995: xi) in the United States legal system. Formed for the most part, by legal theorists of colour, critical race theory addresses American law’s treatment of indigenous peoples and people of colour and the role the law has played in shaping and maintaining social domination and subordination (West, 1995: xi). This critique has developed from within a radical framework, focusing on the liberatory struggles and resistance strategies of persons of colour as well as state and legal mechanisms of oppression. Critical race theorists have paid a great deal of attention to contemporary manifestations of these historic processes, commenting on the role of both neo-liberal and postmodern discourses in law, the state and society. The liberatory project of critical race theory is ultimately useful to many other theoretical and practice disciplines, particularly those considering contemporary problems in health care and aging. Social gerontologists, health care theorists and social service practitioners will find critical race theory fundamental to a re-thinking of the role of health care in the maintenance of white supremacy and in the subordination and oppression of racialized groups in both the United States and Canada. Particularly useful in the present context are critical race and anti-racist theories on essentialism, intersectionality (critique

of double jeopardy theories) and multiculturalism. As has been demonstrated in the review section, these three issues have not been well addressed by researchers, theorists and policy makers in health and aging in recent years.

### **Essentialism**

Critical race and anti-racist theories have exposed the role of essentialism in subordinating ethnic and racial minority groups. As previously discussed, the practice of essentialism is rampant in gerontological literature dealing with issues of access. Most predominant is the practice of grouping ethnic and racial minorities within four so-called “special needs populations” according to the United States Older Americans Act, an act which legislates that attention be placed upon Blacks (African Americans), Hispanics, Asians/Pacific Islanders and Aboriginals/Alaskan Natives. Gerontologists in health tend to treat a diversity of ethnic and racial groups from within these four totalizing and homogenous categories, partly out of necessity and partly out of convenience as national data sets include information on only these four major groupings. Researchers and theorists, however, rarely point to these limitations or define their ethnic and racial categories used. Others use the terms of “race” and ethnicity interchangeably as though they meant the same thing (Blakemore & Boneham, 1994). These practices are unacceptable from within a critical race and anti-racist framework and need to be more fully challenged. In fact, one of the first tasks of critical race theorists is to render visible the complex nature of ethnicity and “race” and the necessity of paying attention to these terms, of constantly defining and re-defining them (Haney Lopez, 1995). According to Christensen (1996):

**Race is a European folk concept associated with colonial expansion and oppression in which skin colour and other visible, socially selected, traits are used to arbitrarily classify populations of the world into hierarchical order in terms of human qualities. Ethnic groups are often confused with races, but they actually comprise people who associate with each other to maintain common bonds of language, ancestry or attachment to geographic location. (Christensen, 1996: 141-142)**

**“Race” typologies which derive from this ‘scientific’ or ‘biological’ definition have been completely discredited (Anthias & Yuval-Davis, 1992; Davis, 1996) and, according to Davis (1996), many carefully set “race” off in quotation marks to indicate “that we do not take seriously the notion of “race” as biologically grounded, neither are we able to think about racist power structures and marginalization processes without invoking the socially constructed concept of “race”” (Davis, 1996: 43). “Race”, therefore, cannot be understood outside of the ideology of racism with which it shares a common historical evolution (Davis, 1996). Racism refers to “modes of exclusion, inferiorization, subordination and exploitation that present specific and different challenges in different social and historical contexts” (Anthias & Yuval-Davis, 1992: 2-3).**

**In contemporary liberal society:**

**racism is not often articulated in explicit ideologies..., but as different forms of exclusion, on the basis of a group not belonging to the culture of origin of the dominant ethnic group within the state apparatus. The notion of cultural difference has largely displaced the notion of biological difference, as a basis for excluding or inferiorizing, both in discourse and practice. (Anthias & Yuval-Davis, 1992: 14)**

**Three forms of racist discourse have been identified which impact upon practice and are useful in highlighting the way racism manifests itself within institutions and structures in contemporary society. It is important to note that these forms of racism are**

easily definable in theory but often act simultaneously in practice. The three forms of racism include: subjective racism, that is, prejudice and differential treatment by key individuals who can block or alter access to systems, institutions and organizations (ie. nurses, social workers, doctors, teachers); institutional racism, that is, practices or policies which operate at the institutional or organizational level which reduces or alters access to resources (ie. unilingual signs on public buildings in neighbourhoods which service allophone populations); and, systemic racism, that is policies which operate within large systems such as governments which limit people's opportunities and access to resources (ie. immigration policies, the workings of the labour market) (Ginsburg,1992). These distinctions, although important in naming and confronting racism in practice, are wholly ignored within current gerontological thought.

A second problem examined in critical race theory is the practice of assuming that "race" and ethnicity are "somehow fixed, immutable, given and unchanging." (Muszynski, 1994: 6-7). Exposing this practice is central to the development of anti-essentialist forms of research and theory. Ethnicity and "race" are not static concepts. They are, in fact, fluid, flexible and shifting according to situation and context and are shaped by many factors including communal and individual age, cultural background, language, immigration and/or refugee status, degree of assimilation, and socioeconomic status (Nowrojee & Silliman,1997; Li, 1994). They also have higher or lower salience in relation to other identities depending on context and situation. So for example, an older Black woman might prioritize her Black identity if she lived in an Anglo-society which attempted to ignore or oppress her because of this identity. In another context, such as that of church or family, she might prioritize her identity as woman or mother. But ethnic and racial

identities are not always self-defined or self-managed. In fact, critical race theorists critique liberal analyses which claim that all identity is determined at the level of the individual or group. "Racial" and ethnic identity is not necessarily symmetrically shared by insiders and outsiders, who often have different criteria or signifiers for membership in the collectivity (Yuval-Davis, 1994: 410) and this identity is often "constructed outside the group by the material conditions of the group and/or its representation by other groups or the state" (Yuval-Davis, 1994: 412).

According to Yuval-Davis (1994):

Although the boundaries of ethnicity and race are ideological, they involve material (biological, legal, social) practices and therefore have material origins and effects. They involve struggles, negotiations, the use of ethnic resources (such as language, culture, religion, material assets and state political powers) in their power relations with other collectivities. Ethnic practices can be used for countering disadvantages or for perpetuating advantages stemming out of the inclusionary/exclusionary boundaries and the relations of power, of dominance/subordination which are aspects of this. (Yuval-Davis, 1994: 411)

Hegemonic ethnicities, that is, those ethnic groups with material and political power "often have the power to "naturalize" their *weltanschauung*, usually using their privileged access to the state apparatus. Thus, they can construct any different ethnicity as deviant in some other way" (Yuval-Davis, 1994: 411). For example, Kaufert & Putsch (1997) have identified how health care systems often problematize "culture" as a barrier to appropriate and equal treatment by health care providers (Kaufert & Pusch, 1997: 73). By doing so, theorists and practitioners successfully entrench Anglo culture as "natural" and minority culture as 'deviant". In this way, it is only minority relations which must be altered, leaving the ideology and culture of health care institutions invisible and therefore,

intact. In fact, "this privilege to ignore their race gives whites a societal advantage distinct from any received from the existence of discriminatory racism" (Grillo & Wildman, 1995: 565). Much of the gerontological literature which addresses minority culture and health care fits this essentialist model, suggesting individual or relational alterations in clinician training, communication "style" or the improvement of clinician understanding of the cultural inventory of the patient, the patient's family and his or her community as the most appropriate means of dealing with cultural barriers to care.

According to Li (1994), "scholarly inquiries of "race" and ethnicity must begin to more accurately unravel these unequal relationships which constitute the process of constructing race and ethnicity" (Li, 1994: 1). To concentrate only on "race" or only on ethnicity, or to use the term ethnicity synonymously with "race", neglects the specific impact of both factors on the identity of ethnic and "racial" communities. "In using both race and ethnicity as explanatory terms, therefore, it is important to consider the balance of power between the dominant and subordinate groups. A minority's "racial" and ethnic identity does not emerge in isolation, but from interaction which takes place between minority and majority" (Blakemore & Boneham, 8). To date, the fields of gerontology generally and ethnogerontology specifically are plagued by such essentialist analyses. Problems of "ethnicity" and "race" are only approached through the model of cultural interaction. As Anthias & Yuval-Davis (1992) explain,

**Race and racism are seen as complicating variables within the central focus on questions of cultural adaptation, maintenance, integration or assimilation of ethnic minorities. In these discussions, ethnicity is often treated as a voluntaristic normative identification process, or as a form of culture. ..This means that the role of racism in structuring the position of 'Black' groups is ignored. Such an approach also tends to treat Blacks as**

belonging to the same ethnic group, ignoring the diversity within the category. (Anthias & Yuval-Davis, 1992: 6)

Clearly these practices, so common in gerontological health care literature serve to minimize their applicability and effectiveness in relation to the experiences of ethnic and “racial” minority elderly communities in both Canadian and American health care systems and must be reconsidered.

### **Intersectionality**

Critical race and anti-racist theories, and particularly feminist thought within them have provided good reason to reject the double jeopardy approach so common in research and writing on “race”, gender and class in aging. What double jeopardy theory does is create a hierarchy of domination and oppression, and draws conclusions as to which source of domination is the essential variable in creating barriers to access (is it really gender, age, class or “race”?). This kind of theorizing so rampant in aging research is detrimental to the health of older ethnic and “racial” minority women. Intersectionality, based on the premise that intersections of racism and sexism cannot be captured wholly by looking separately at the race or gender dimensions of women’s experiences (Anthias & Yuval-Davis, 1992; Caldwell, 1995; Davis, 1996; Grillo & Wildmann, 1995; Harris, 1995; Mama, 1992; Muszynski, 1994; Williams Crenshaw, 1995) may provide a new avenue for addressing the combined experiences of old ethnic and “racial” minority women.

“Double jeopardy” theory is attributed to the National Urban League (1964) who suggested that a twofold handicap of age and race discrimination was experienced by older blacks, particularly in the combined disadvantages of income and ill health (Blakemore & Boneham, 1994: 38). Early attempts to consider combined disadvantage

with regard to women's experience posited that older women endured a double burden with respect to their age and gender and "in the case of Black or ethnic minority women a notion of a triple burden was used" (Anthias & Yuval-Davis, 1992: 100).

Double jeopardy theory has often been labeled "unsatisfactory because it treats forms of subordination and oppression through race, sex, and class as cumulative rather than as articulating or intersecting together to produce specific effects" (Anthias & Yuval-Davis, 1992: 100). Most often, class effects were prioritized with one or another of the constructs of gender, ethnicity or race. Different social divisions including class, "race", gender and age were conceptualized as "internally homogenous" (Anthias & Yuval-Davis, 1992: 97), thereby rarely addressing heterogeneity within categories (Blakemore & Boneham, 1994). Finally, "with regard to women there was a tendency within mainstream sociology to talk of the 'position of women' as though women were undifferentiated in terms of class, culture and ethnicity" (Anthias & Yuval-Davis, 1992: 97). According to Harris (1995):

The result of essentialism is to reduce the lives of people who experience multiple forms of oppression to additional problems: "racism + sexism = straight black women's experience", or "racism + sexism + homophobia=black lesbian experience". Thus, in an essentialist world, black women's experience will always be forcibly fragmented before being subjected to analysis, as those who are "only interested in race" and those who are "only interested in gender" take their separate slices of our lives. (Harris, 1995: 255)

Feminist (including feminist bio-ethics) and anti-racist theory can be critiqued from an intersectionality perspective for ignoring the intersection of race and gender (Caldwell, 1995; Williams Crenshaw, 1995). According to critics, racism and sexism seldom intersect in feminist and antiracist practices, thus, "relegating the identity of women of colour to a

location that resists telling” (Williams Crenshaw, 1995: 357) or “reinforce stereotypes regarding black womanhood which are indispensable to the maintenance of an interlocking system of oppression based on race and gender that operates to the detriment of all women and all blacks” (Caldwell, 1995: 272). According to Williams Crenshaw (1995):

**The failure of feminism to interrogate race means that feminism’s resistance strategies will often replicate and reinforce the subordination of people of colour; likewise, the failure of anti-racism to interrogate patriarchy means that anti-racism will frequently reproduce the subordination of women. (Williams Crenshaw, 1995: 360)**

Intersectionality, a newly emerging theoretical framework developing within critical race theory posits the examination of race, sex, and class and how they interact in a system of oppression. (Delgado, 1995: 241). Essential to this theoretical framework is the notion that oppression and subordination as they exist in the real lives and experiences of women cannot be separated and analyzed individually. Sexism is not experienced in the same way by both Black and White women as racism compounds the experience of sexism in the lives of Black women. To attempt to explain experiences of oppression one component at a time in order to build commonalities between White and Black women or to use White women’s experiences of sexism as indicative of all women’s experience regardless of colour, is not only futile but harmful to Black women’s sense of identity and their ability to act politically.

Williams Crenshaw (1995) describes three forms of intersectionality theory. The first, structural intersectionality, refers to the burdens faced by Black women, largely the consequence of gender and class oppression, which are compounded by structural racially discriminatory practices often faced by women of colour (Williams Crenshaw, 1995:

358), including housing, employment, health care and immigration. Williams Crenshaw points to the fact that, intersectional subordination does not necessarily result from the intentional practices of systems and institutions but “is frequently the consequence of the imposition of one burden interacting with predisposing vulnerabilities to create yet another dimension of disempowerment” (Williams Crenshaw, 1995: 359).

Another mode of intersectionality outlined by Williams Crenshaw is that of political intersectionality. This mode highlights the reality that women of colour are situated in at least two subordinated groups that frequently pursue conflicting political agendas. “The need to split one’s political energies between two-sometimes opposing groups is a dimension of intersectional disempowerment which men of colour and white women seldom confront” (Williams Crenshaw, 1995: 360). As a result of this political subordination and splitting, black women’s identity and sense of agency are often submerged, ignored or marked by controversy within political and social communities (Evans, 1995; Caldwell, 1995). For example, Western feminist agendas have focused attention on women’s subordinate role within the private sphere of the family and have theorized the family as a site of women’s oppression. This has masked the political and supportive role of the family within black communities as “a source of resistance to racism” (Anthias & Yuval-Davis, 1992: 124). In addition, “in the case where women are forcefully separated from their families because of racist immigration controls women may staunchly support the nuclear family” (Anthias & Yuval-Davis, 1992: 124). In both of these examples, ethnocentrism on the part of Western feminists have marginalized the emancipatory experiences of family for Black women and have thus, rendered invisible the voices of women of colour.

The process of self definition and self creation for women whose identities are doubly bound is fraught with conflict and challenge. This complex issue is referred to as intersectionality and identity. Often labouring to reconcile both identities, that of ethnicity or “race” and that of “woman”, black women can become caught between two worlds, forever defined as “other” by both their ethnic/”racial” and gender communities. In attempting to define and maintain loyalties to many often politically, morally or philosophically opposed communities, these women may become hybridized subjects (Bhabha, 1994). As Khan (1995) states,

These dynamic and contradictory forms of agency draw upon Bhabha’s notion of hybridized states, where dialectic polarities demand the subject’s allegiance at the same moment. Hybridized individuals, caught in the discontinuous time of translation and negotiation, erasing any claims for inherent cultural purity, inhabit the rim of an ‘in-between reality’ marked by shifting psychic, cultural and territorial boundaries. (Khan, 1995:3)

The concept of intersectionality is an important one for the field of gerontology, particularly for those persons interested in re-thinking both the concepts of gender and “race”/ethnicity and the experiences of ethnic and “racial” minority older women. Gerontological research and theory have been remiss in the way they have historically de-contextualized women’s lives and their use of double jeopardy theories has often been “a convenient label for the facts, and has rarely been used as a means of developing a more sensitive recognition of heterogeneity” (Blakemore & Boneham, 1994: 38). Clearly gerontologists cannot continue to separate out and prioritize components of women’s experience of oppression. The shifting territory of older ethnic and “racialized” women is not easily captured through homogenous totalizing definitions of woman so prominent in both dominant feminist gerontological discourse and ethnogeriatric discourse. These

totalizing constructions are not only inadequate but serve to further repress and render women of colour invisible. As Harris (1995) states,

In my view, however, as long as feminists, like theorists in the dominant culture continue to search for gender and racial essences, black women will never be anything more than a crossroads between two kinds of domination, or at the bottom of a hierarchy of oppressions; we will always be required to choose pieces of ourselves to present as wholeness. (Harris, 1995: 256)

## **Multiculturalism**

Multiculturalism is both an ideology and a practice. Clearly these two definitions are intertwined, as ideological constructs of multiculturalism are embedded in state policies designed to address the needs and priorities of multicultural communities and practices have served to reify particular ideological processes. Within current multicultural strategies, there exist wide gaps between the concept of multiculturalism as a progressive ideology which seeks to advance understandings of “race”, power and identity within social institutions (Newfield & Gordon, 1996) and state policy initiatives in multiculturalism. Multiculturalism has, over the last twenty years, been the most common policy promoted by both liberals and those on the Left, as a response to earlier policies of immigrant absorption and assimilation and in order to establish a way for minority cultures to be represented in school curricula and other cultural institutions in pluralist societies. (Yuval-Davis, 1994: 418). Multiculturalist policies have tended to “graft customs, celebrations and other symbolic signifiers of the cultures of communities onto the hegemonic culture” (Yuval-Davis, 1994: 418). In Canada, however, the state has adopted multiculturalism as a major social policy tool, and as a result special services geared to fulfill the special needs (linguistic, religious and so on) of cultural communities have been

funded by central government (Yuval-Davis, 1994: 418) to a much larger extent than those earmarked for cultural events and celebrations (Puttagunta, 1997). Still, in both the United States and Canada, multiculturalism has taken the form, in both the public and private sectors of a kind of “diversity” management approach, whereby the needs and interests of a plethora of cultural communities are managed, contained and thus more readily understood.

Several problems with multiculturalism as a policy have been outlined by critical race and critical multicultural theorists who claim that multiculturalism policy is an ineffective anti-racist policy. “First, they pointed out that concentrating on cultural difference, rather than on issues of discrimination and disadvantage, would not enable any major shift in class and power relations between the black minority and white majority” (Yuval-Davis, 1994: 418-419). According to Mama (1992), “the culturalization or ethnicization of race as a state-orchestrated process which, by focusing on the language, food, habits and clothing of black (African Asian or Caribbean) people, masks and denies the fact of discrimination. Systemic and institutionalized racism is thereby reduced to cultural misunderstanding and is so depoliticized” (Mama, 1992: 80). Critics point to multicultural policy as an ideology enacted by the state in order to “shift attention from racialization and in so doing, treat racialized groups as one of many diverse cultures which in turn makes racism invisible” (Newfield & Gordon, 1996). Aboriginal theorists have noted that multiculturalism policy has neglected to address state orchestrated processes of colonization as forms of racism, thereby rendering Aboriginal persons invisible in multiculturalism programs (Guerrero, 1996). In addition, these policies have obscured the role class connections play in the racialization of groups (Hamilton, 1996). In fact, “many

of the current strategies that propose to make marginal cultures visible and accessible tend to reproduce ideologies of racism, as well as male dominance and middle-class privilege” (Davis, 1996: 40).

Multiculturalism policy has also reified essentialist, ahistoric, static, victim notions of culture which are markedly silent on gender and sexuality (Newfield & Gordon, 1996) and which are seen to be, “in their “essence”, mutually exclusive from other cultures, especially that of the host society (Yuval-Davis, 1992: 418). This essentialism is reinforced by funding strategies which:

have also played a major role in the categorization or naming of groups, and the criteria for designing groups in terms of race, colour, oppression, deprived, not only are imposed from the outside, but are both opportunistic and contradictory. A grouping would have to emphasize its members deprivation and marginality in order to claim funding. This then leads to ghettoization of ‘needs groups’. It is in this way that minorities indirectly become defined and constructed by the state and their ‘empowerment’ can be of a very limited and specific nature. (Anthias & Yuval-Davis, 182)

State and institutional bureaucratic practices have also attempted to silence opposition through the co-optation and incorporation of minority leadership into planning networks (Yuval-Davis, 418-419). Minority representation or ethnic matching strategies are often envisioned as ends in themselves, ensuring that systemic and institutional structures which serve to dominate and oppress cultural communities remain intact. Institutions and bureaucracies tend to view persons of colour as representative of their particular “racial” or ethnic group, thus oppressing individuals and ignoring heterogeneity. Finally, multiculturalism in practice continues to be embedded in the Anglo-centric ideology of autonomy and individual responsibility resulting in the tacit acceptance of the idea that an individual’s failure to ‘make it’ in society is due to his/her inability to

successfully become bicultural, rather than being due to racist political and social structures (James, 1996).

Several authors have attempted to outline how both the ideology and practice of state multiculturalism policies have shaped health and social service organizations (Christensen, 1996; Dominelli, 1992; James, 1996; Tator, 1996). According to James (1996), the premises of multiculturalism include: society is democratic and egalitarian, therefore citizens have freedom of choice - freedom to access and participate in whatever services they wish; racism is the result of ignorance; and, culture is a set of information and observable practices that can be easily communicated. Organizations that practice from within this framework tend to believe that everyone must get equal treatment and that majority group norms are seen as 'neutral' and 'value-free'. There is a reliance on making contact as a way of heightening awareness and thus eliminating biases and prejudices (James, 1996: 4-6). Dominelli (1992) describes common practices of multiculturalism within social work as including, denial strategies (no such thing as cultural and institutional racism - only personal prejudice); colour-blind strategies (all people are the same); patronizing approaches (false acceptance of equality but in the final analysis white persons lifestyles always come out superior); dumping strategies (place responsibility for eliminating racism on shoulders of black people); omission (racism can be safely ignored in most situations); decontextualization (acknowledge the existence of racism in general terms but fail to do so in specific instances); and, avoidance (racism exists but denying particular responsibility) (Dominelli, 1992: 167).

Some critical multicultural theorists have drawn attention to the fact that it is essential to separate out these common practices of state multiculturalism from the

**progressive ideology of multiculturalism. Historically, multiculturalism was viewed by anti-racist activists as a means of ensuring plurality and representation of cultural groups in school curriculum and other institutions. To this end, multiculturalism has produced some good. It has succeeded in undermining “white norming”. Multiculturalism:**

**addresses the need to avoid even benevolent white oversight over the process by which various groups reconstruct democracy and social justice. Multiculturalism’s tradition does specifically challenge the most lethal cultural aspect of white rule-assimilation-which allows the mere presence of white people to be a form of control...a strong multiculturalism can at least extract cultural equity out of the pluralism such a multitude of Americans claim to favor. (Newfield & Gordon, 1996: 80)**

**According to Puttagunta (1997), critics of multiculturalism must be careful to situate their critiques of multiculturalism within an analysis of state policy while at the same time maintaining support for multiculturalism as an ideology. Confusing ideology and practice simply adds fuel to those arguments made by the political right in both Canada and the United States, that multiculturalism is a dead ideology, serves the interests only of “specialty groups” and satisfies no-one regardless of political affiliation, and should therefore, be eliminated. In critiquing multiculturalism policy without standing up for multiculturalism ideology, critics may be viewed as attacking minority groups themselves, particularly those who have benefited both from multicultural funding and the ideology of multiculturalism. Several authors have suggested the necessity of a more complex analysis which focuses on determining “what kind of multicultural approaches can potentially take on the political task of challenging the gender, class and race hierarchies that continue to shape institutions?” (Davis, 1996: 42) rather than throwing out the term altogether. Most consistently, theorists have stated that the promotion of an anti-racist or critical**

**multiculturalist approaches are necessary to this political task (Dominelli, 1992; James, 1996; Newfield & Gordon, 1996; Tator, 1996). According to James (1996), an anti-racist perspective is premised on a belief that: access to power and opportunities are influenced by “race”, ethnicity, class, gender, sexual orientation, disability and other corresponding factors; racism is seen as an ideology that is rooted in the socio-economic and political histories of colonialism and oppression; culture is not static, it is dynamic and its expression is related to the distribution of power; the experiences of oppressed groups are critical to the analysis of how inequality and racism produce differential social situations; and, society's institutions must reflect the diverse needs and aspirations of “racial” and ethnic minority groups in their missions, policies, practices and services (James, 1996: 6-7). As Erickson stated; “The primary criterion for a strong version of multiculturalism is that it not be reducible to a pluralism structured in dominance” (Peter Erickson in Newfield & Gordon, 1996: 102).**

**This theoretical claim is very important to gerontological theory and practice. Current research on health care access is heavily focused on a weak multicultural, ethnic studies model which highlights the individualistic and relational issues of cultural competence and sensitivity in the absence of theorization regarding “race” and “racism”. In research on both health and aging, the multicultural model has flourished in recent years as a way of ‘dealing with’ the diversity of the Canadian and American populations. Critical race theorists are quick to point out the liberal ideological roots of multiculturalism, which, in its current form, tend to mask domination and oppression and render these forces politically neutral. Within multiculturalism, racism may be potentially erased from**

our professional vocabulary, thereby eliminating its eradication as a primary goal. This must be more comprehensively challenged by critical gerontologists.

### **Discussion and Conclusion**

To date, our understanding about how access is created and experienced has been limited by the ways in which the field of gerontology has conceptualized and carried out research on access to health care, particularly in relation to ethnic and “racial” minority older women. Several problematics have been identified in this proposal, namely that gerontological research and theory: (1) fails to define the nature and parameters of access; (2) focuses on reductionist, individual and relational barriers to care with a corresponding lack of focus on structural or ideological issues; (3) provides little recognition of older women’s differential experience of access; (4) prioritizes essentialist categories of ethnicity and “race” and rarely defines these concepts; (5) posits the experience of gender, ethnicity, “race” and class as hierarchically ordered; (6) focuses on monocultural or add-on models of ethno-geriatric service delivery; and, (7) defines “need” based on physical or mental criteria.

A new understanding of health care access can be theorized by merging several oppositional discourses, namely feminist bio-ethics theories, critical gerontology theories, disability theories, and critical race and anti-racist theories, with an historical deconstruction of the influence of medical hegemonies in Western societies. The integration of theories on power, bodily control, agency, essentialism and intersectionality provides gerontologists with evidence for the need to expand upon and challenge current constructions of access in order to more appropriately and adequately address older ethnic and “racial” minority women’s daily lived experience of accessing care as well as restore

them as social and political agents in their own lives. To date, gerontological policy makers and researchers in Canada and the United States, interested in access issues, have failed to consider how these theories might influence their work.

Feminist bio-ethics, critical race and disability theorists can help gerontologists re-think service delivery and aging policy. These theories have each emphasized the oppressive practices of traditional medical paradigms, exposed the ways in which power has historically worked invisibly to the detriment of women, persons of colour and disabled persons and have attempted to re-insert the voices of previously invisible actors into debates regarding appropriate service and treatment. They have also attempted to outline how ideologies such as sexism and racism operate in practice and impact upon the everyday experiences of women, persons with disabilities and ethnic and “racial” minority groups as well as to theorize the influence of intersectional sites of oppression on the experience of access. By challenging hegemonic constructions of gender, “race”, disability and class, the nature and substance of what constitutes access can be reconsidered as both a potential category of oppression in health care and as a site of political struggle.

A new understanding of access to health care must consider several levels of analysis and be rooted in an understanding of how the everyday practices and processes of organizations impact upon older ethnic and “racial” minority women’s experience of access. According to Puentes-Markides (1993), access occurs as the interaction of the structure of the health system, health professionals and populations or individuals seeking care. These elements are in turn influenced in varying degrees by other macro factors including government orientation, macroeconomic policies, health policies and culture and the status assigned to particular groups including women, minorities and disabled persons

**(Peuntes-Markides, 1993: 621). Mapping the terrain of access as it is experienced by older ethnic and “racial” minority women would require gerontologists to both begin from women’s authentic position as expert knowers and explicate the processes by which individual, relational, institutional and structural practices are made manifest. This focus necessitates an exploration of the ways in which power operates in relationships, how it operates to create and maintain unequal relationships. For while it is important to recognize that access is experienced at the level of the individual, that is between elderly person and health care provider, it is also essential to consider that individuals do not enter into this relationship as equals. Power is a central dynamic operating in the interaction between health care provider, health care institution, governmental policy and elder patient. Gerontologists must continually reflect on the ways in which the health care system has historically been a site of social control of ethnic and “racial” minority older women.**

**Gerontological researchers and practitioners interested in reconstructing access must pay constant attention to the intersectional nature of oppression faced by older ethnic and/or “racial” minority female elders and to the ways older women have resisted medicalization. To date, the voices of older disabled ethnic and/or “racial” minority women in gerontological research, policy and practice are largely absent. This fact undermines attempts to re-examine and challenge current conceptions of access. For without the voices of those who are most greatly affected by current health care practice, the professional status-quo of aging services can remain intact and unaltered. Those of us interested in challenging this reality have the responsibility to become involved in iterative research and practice processes which can enable “users of services” to take on a larger**

role in shaping research, defining priorities and evaluating programs. A liberatory health care system must therefore have a conception of knowledge based not on individualism, but instead on community, that addresses diversity, challenges objectivity (Scheman, 1995) and focuses attention on the self as knower. Finally, there must be greater recognition by gerontologists that what has historically counted as knowledge in the field has contributed to the subordination and marginalization of older ethnic and “racial” minority women. Acknowledging this relationship between knowledge and power will irrevocably connect theory and research to politics.

The project of infusing gerontological discourse on access with alternative theories that serve to advance a position of emancipation and critique, is ongoing. Theoretical perspectives introduced in the current study are meant to be seen as fluid and flexible, not as static and fixed. In fact, it is hoped that the theoretical analyses undertaken presently will contribute to debates about access in elder care research and theory and will serve to highlight the necessity of continually challenging assumptions regarding the integration of theory and practice, so that models developed are not simply and uncritically accepted as “truth”. By engaging in debate, a process of critical reflection which highlights and explores the dilemmas, contradictions and problematics inherent in the engagement of theory with practice, is ensured. There is clearly no single meta-narrative which can be applied to the discourse of access. While it is suggested that the alternative theories described in the current chapter can further advance the development of a critical perspective in gerontological theory on access, they must remain open to critique and transformation. Engaging in this exploration as a reflexive and fluid process, ensures the

**emergence of responsive and innovative visions of access which can change over time to meet the needs of diverse populations of elders.**

## **Chapter 4: Methodology**

### **Research Question**

This study addresses several problematic constructions of access found within gerontological research and theory as laid out in the previous section. Specific attention is placed on examining the impact of these constructions on our understanding of older ethnic and “racial” minority women’s experience of accessing health care. This research is informed by oppositional theories which have much to contribute to the re-conceptualization of older ethnic and “racial” minority women’s experience of access, but which have not been adequately examined by gerontologists in the field of health care to date. Table 1 (on page 404) identifies these problematic constructions of access and the implications redressing these problems have on the development of my research questions and methodology.

Two pivotal features of the present inquiry are: (1) the centrality of women’s voice and women’s experience, and (2) the explication of social processes of access as articulated in the everyday workings of organizations. These social processes refer not only to the interaction between workers and clients, but include as fundamental, the relationships between clients and their families, front-line workers, managers, community members and, state apparatuses. In other words, this study is anchored in understanding how things happen the way they do for older ethnic and “racial” minority women. My research questions are:

1. How do we understand older ethnic and “racially” diverse women’s experiences of access to health care?

2. What is the relationship between this experience and the work processes of health care organizations?

This study attempts to create a deeper, richer understanding of access, one which is based on broader definitions than those currently used by gerontologists in both Canada and the United States and which is more reflective of older ethnic and “racial” minority women’s experience. It explicates the processes by which access is currently being defined and how actors both reproduce relations of oppression and counter or resist those relations. I am primarily interested in the processes by which health care access for older ethnic and “racial” minority women gets constituted. The goal of this study is to create a “power dynamic map” of the process of “accessing health care” from the standpoint of ethnic and “racial” minority women. I hope to explicate women’s everyday lived experience of accessing care and situate these experiences within the working processes and organization of a publicly funded home and community care agency in Ontario, hereafter known as *Eldercare*. In particular, I want to explore the actual social relations of accessing health care as they arise in the *Eldercare* setting. I seek to uncover what organizes the problematic experience of access and what maintains it. What I mean by social relations is the complex of actions, interactions and relationships which define and shape access to health care; those actions which are articulated through the practices and processes of *Eldercare*. These practices and processes include assessment and referral practices, case management models and approaches, and policies and procedures which govern the treatment of gender, ethnicity and “race” and which are made manifest between clients, front-line workers, managers, ethno-specific communities and state apparatuses (through the articulation of policy and other documents). My research includes questions

regarding how documents (i.e. assessment forms, policy) organize and shape these relationships within the *Eldercare* organization. This enables me to consider how macro structures impact upon the micro level, from the standpoint of older ethnic and “racial” minority women.

It is important to emphasize that this work goes beyond a focus on how work processes reproduce relations of oppression in order to address how persons within these systems also work against oppression, specifically older women and front-line staff. In an attempt to explicate oppressive practices and processes, research can downplay the importance of agency. To this end, moments or sites of resistance are utterly lost to the larger goal of explicating how oppression is made manifest in the everyday. I want to theorize more explicitly how workers and clients both reproduce oppressive relations and work against them.

*Eldercare* is a compelling site from which to do this work. *Eldercare* is one of many publicly funded organizations which have recently (within the past year and a half) opened across Ontario mandated to facilitate access to community care services and act as single-entry access points to community care. These organizations emerged out of two Ontario community care programs, namely home care and placement coordination. The organization currently provides case management and referral services for persons living independently in the community (non-institutionalized persons) and placement coordination services for people requiring placement in a long-term-care residential setting, such as nursing homes and chronic care facilities. *Eldercare* does not provide personal support services, homemaking and professional services such as nursing, directly to clients. Instead, case managers assess clients and develop care plans and then contract

out the direct service provision to service provider agencies (both for-profit and not-for-profit) in the community. In its early development, *Eldercare* did provide some professional services such as social work and physiotherapy, but these services are currently being phased out in favour of the contracting-out process. As a result, *Eldercare* functions primarily as a case management and placement organization. The majority of *Eldercare*'s clients are older persons and persons living with disabilities. Thus, *Eldercare* agencies are well placed as sites of interrogation into the way access operates and is experienced by older women.

I have chosen to do my research at an *Eldercare* which is situated in the Toronto census metropolitan area, in a community with a large representation of ethnic and "racial" minority groups, hereafter known as Area P. According to 1996 Census data, 51.9% of the Area P population was made up of four visible minority populations. These populations included 55,195 Black persons (representing 20.1% of the total Black population in the Toronto Census Metropolitan area (CMA)), 75,390 South Asian persons (representing 22.9% of the total South Asian population in the Toronto CMA), 92,225 Chinese persons (representing 27.5% of the total Chinese population in the Toronto CMA) and 22,005 Filipino persons (representing 22.2% of the total Filipino population in the Toronto CMA). In addition, 5,400 Aboriginal persons lived in Area P in 1996 (representing 13.5% of the total Aboriginal population in the Toronto CMA). White ethnic groups were also represented in Area P. For example, there were 18,035 Greek persons (representing 22.5% of the total Greek population in the Toronto CMA), 9,275 Portuguese persons (representing 5.7% of the total Portugese population in the Toronto CMA), 25,040 Italian persons (representing 6.0% of the total Italian population in the

Toronto CMA) and 6,910 Ukrainian persons (representing 7.2% of the total Ukrainian population in the Toronto CMA) living in Area P in 1996. Given the number of diverse ethnic and “racial” groups living in Area P, the issue of access must be considered of paramount importance.

Each *Eldercare* organization in the Toronto Census Metropolitan area has its own internal structure, although the general function of the organizations and their relationship to the Ministry of Health (the government Ministry that funds and oversees these public institutions) are relatively uniform. At the time of the research project, the particular *Eldercare* organization studied was somewhat “flat” hierarchically, with only one level of management between the Executive Director and front-line staff (case managers and placement coordinators), although this was in the process of being re-thought. These managers supervise front-line workers, administrative support workers and clerical staff, as well as engage in the management of operations and external relations. In the months following the data collection phase of the research, the organization engaged in a process of hiring a new tier of managers as front-line supervisors in order to re-balance workload.

Clients “enter” the system in a variety of ways; through self-referral, community (i.e. family physician, family member, community organization) referral and hospital referral. *Eldercare* organizations have case managers who work directly in the hospital, the goal of which is to smooth out the process of discharge planning. These case managers communicate daily with the main agency through the fax machine, transferring the necessary forms between the hospital and the organization’s main office. *Eldercare* also has one “off-site” location in a local multicultural service provider agency and was negotiating for a second such location at the time of the study. Initial connection with the

organization is via the telephone. A central telephone line is used and general information taken on the client by the person who answers the central telephone line. The organization currently has a centralized intake, but this was also under review at the time of the study. Once it is deemed that the client is eligible for services, their case is transferred from intake to a specific case manager based on the geographic location of the client. Case management workers are generally divided up into teams, based on geographic boundaries. Each team has a series of “quads”, that is, groups of four who work closely together and share responsibilities. Each “quad” has an administrative support worker with whom they work. This support worker is responsible for managing the engagement of service provider agencies and other administrative tasks. One team includes all of the placement coordination workers as a distinct and separate group, although this was being reviewed at the time of the study. In total, there are about 150 employees at the agency. Case managers’ case load size varies somewhat, but on average hover at about 130 clients.

Service providers play a central role in the delivery of community care services, however, they are not directly employed by *Eldercare* organizations in the new system in Ontario. Instead, as stated above, *Eldercare* contracts out to provider agencies in the community. This is done through a process called Request For Proposals (RFP) in which service provider agencies vie for contracts with *Eldercare* to provide services. Depending on the total amount of service provision needed, *Eldercare* can and does contract with many provider agencies who provide the same services. These include nursing, home making, occupational therapy, physiotherapy, social work, testing services (such as blood tests) and medical equipment. The process of contracting out is complex and decisions

based on a mix of “highest quality-lowest price” criteria, which are articulated vaguely by the Ministry of Health and subject to interpretation by individual Eldercare organizations (Williams, Barnsley, Leggat, Deber & Baranek, 1999). The Eldercare organization studied was in the process of beginning to operationalize RFP criteria for homemaking and professional services. As a result, the impact of contracting out has yet to be fully articulated. Clearly, the organization is in a process of formation and transformation. During the process of data collection, the organization celebrated its first year of operation. As such, *Eldercare*, as a site for the study on the processes and experiences of access, is both rich and dynamic.

## **Design**

### **Institutional Ethnography**

The methodology of this study is informed by the Institutional Ethnography approach (Smith, 1987a, 1990a, 1990b). Institutional Ethnography is a complex research paradigm first introduced by Dorothy Smith in her ground-breaking text *The Everyday World as Problematic* (1987). Although first articulated as a means of redressing sexism in social science and reinserting women’s experience into knowledge generation, the Institutional Ethnography approach has since been adapted by others who also seek to expose and critique the impact of state or ruling apparatuses on the everyday experiences of oppressed or marginalized people (G. Smith, 1990:631). The actual practice of doing Institutional Ethnography is premised on Smith’s theory of the “social organization of knowledge” (Smith, 1987a, 1990a, 1990b). This theory posits that: (1) what has historically counted as “truth” in society has been shaped and defined by male authority; (2) ideology is not only a viewpoint (images and symbols) but an organization of

*specialized practices* made manifest through *relations of ruling*; and, (3) the specialized practices of ruling apparatuses, such as those of exclusion and marginalization, have “provided modes of thought and knowledge that constrain women and force them to treat themselves as objects, to deny their own subjectivity and experience” (Smith, 1987a:36).

Defining ideology as the organization of specialized practices has major implications for the way oppression is understood and ultimately challenged (G. Smith, 1990). According to Smith, “it directs us to examine who produces what for whom, where the social forms of consciousness come from” (Smith, 1987a: 54). That is, ideology as practice goes beyond an interpretation of ideology in terms of abstract principles, but rather, situates and roots it in the real world and in the actual practices of persons, organizations and institutions. Thus our central inquiry becomes an explication or examination of the organization of these specialized practices of ideology and the impact of this organization on the real lives of women. Smith defines this complex of practices and processes within the term *relations of ruling* (Smith, 1987a, 1990a, 1990b). Elsewhere it has been described as the *ruling regime*, a term which brings together political and bureaucratic forms of ruling (G. Smith, 1990). Relations of ruling refer to the “intersection of the institutions organizing and regulating society... [it] is a concept that grasps power, organization, direction and regulation as more pervasively structured than can be expressed in traditional concepts provided by the discourse of power” (Smith, 1987a: 3). Relations of ruling include “that familiar complex of management, government administration, professions and intelligentsia, as well as the textually mediated discourses that coordinate and interpenetrate it” (Smith, 1987a: 108). According to Smith, relations of ruling organize real spaces into “abstract and generalized modes [which are] vested in

categorical systems, rules, laws and conceptual practices” (Smith, 1987a: 108). These modes both transcend local experiences and are located within them. This concept of ruling relations helps us understand how worlds are organized by social relations that are both immanent and extend beyond them (Smith, 1987a:106). Smith asserts that relations of ruling are textually-mediated, that is, documents (such as policies, forms, directives, memos) “enter into, organize, shape, determine, coordinate, concert and accomplish social relations and organization” (Smith, 1987b:16). This is particularly true in late capitalist welfare state societies where texts have played an increasingly fundamental role in arranging relations between “professionals” and “clients” and in controlling and defining specialized categories of people, such as women or the old. Textually-mediated relations have resulted in the removal of the situated knower in favour of objectified forms of knowledge which are more readily administrable (Smith, 1987b: 10). This is viewed as a contemporary practice of domination which is experienced in every institutional setting to varying degrees.

To counter the discourses and constructions that have removed women from positions as knowers, Smith states that knowledge re-creation must go beyond simply adding in women’s voices to the current project of male thought and paradigms. Smith also rejects feminist research models which simply seek to develop women’s experience as part of the knowledge-building in research, to “incorporate the female voice” (Davis, 1986:40-43) or “reclaim the feminine” in social science research (Code, 1991:12). Research must, instead, shift these paradigms and “take up the standpoint of women as an experience of being, of society, of social and personal process that must be given form and expression in the culture, whether as knowledge, as art, or as literature or political action”

(Smith, 1987a: 36). Smith's sociology for women insists both that research begin from women's experience and that it go beyond it to understand how this experience has come under the influence of specific ruling practices. Women's standpoint must not be equated with perspectives or world view as it avoids universalizing women's experience. In fact, Smith has emphasized that because women are differentially located, they will experience and make meaning of their experience very differently. Instead, women's standpoint must be viewed as "a method that at the outset of an inquiry, creates the space for an absent subject, and an absent experience that is to be filled in with the presence and spoken experience of actual women speaking of and in the actualities of their everyday worlds" (Smith, 1987a:107). Women's standpoint is a place to begin which is embedded in people's lived experience, outside standardized forms of knowing (Campbell & Manicom, 1995: 7-8) Since the goal of inquiry is to explicate relations of ruling as they are made manifest in women's lives, it becomes necessary to go beyond the account women have of their own everyday experiences to explore broader social relations not necessarily visible in women's lives. According to Smith (1987a):

social organization is only partially discoverable within its scope and the scope of individuals' daily activities. Its local organization is determined by the social relations of an immensely complex division of labour knitting local lives and local settings to national and international social, economic and political processes. (Smith, 1987a:154)

It is essential that the everyday world be seen as organized by social relations not observable within it. Thus, "an inquiry confining itself to the everyday world of direct experience is not adequate to explicate its social organization" (Smith, 1987a: 89). Here is where the notion of the problematic enters. The concept of the problematic, as outlined

by Smith is characterized as an abstraction of organization from the everyday world to externally structured relations (Smith, 1987a:94). Focusing inquiry on the problematic of the everyday “suggests looking at social relationships as “actual practices” which are not wholly located within women’s own experience. Talking about the problematic of the everyday world means needing to look extra-locally (outside of every day practice) to explicate relations of ruling” (Smith, 1987a:161). Thus inquiry begins not in women’s experiences but in the juncture between how women experience and know their everyday worlds and how this same world is known or constituted socially. In other words, beginning with the rupture is to start at a place in and between official knowledge (as mediated through texts and official counts of reality) and women’s own experience of that reality. The task then becomes locating this juncture within “the organization of social relations that has accomplished women’s oppression and exclusion” (Smith, 1987a: 78).

Since, Smith asserts, we can only understand and know about the system and how it works through our experience of it, Institutional Ethnography seeks to examine the problematic within the working processes of an actual institution. As a methodology, Institutional Ethnography “is concerned with exploring a particular ‘zone’ of the relations of ruling, namely those focused on managing the relationship between institutions and clients...and within which varying perspectives arise and are embedded” (Smith, 1987b: 28). Institutional Ethnography sets its gaze on the macro structure from the micro level, from the standpoint of sites in the everyday world (Smith, 1987b: 5).

Working from an Institutional Ethnography approach has important consequences for research design. These include: (1) The researcher must begin in the same world that she is attempting to explore. In the course of doing research the intent is to discover more

about the setting than what one would otherwise be aware of, to come to a deeper understanding of women's experience. The researcher must begin with women's own experience and look up to the organization through these experiences (bottom-up approach); (2) Since women are seen as expert knowers of their own lives, they are not defined as research subjects as in the traditional social science method, but as active participants in shaping their worlds and in guiding the research; (3) Research must focus on women's actual activities and the way they bring about those activities. This is so because, according to Institutional Ethnography, the world happens through and in one's activities. Experiences are, after all, socially organized. Less concern is placed on the individual or individual meaning. Instead one is looking for how women are bringing their activities into a coordinated site in relation to themselves and others; (4) The central focus of the research is on explicating ruling processes. Since social relations of the everyday are seen as extending beyond the boundaries of the everyday experience, so must the inquiry. The precise interest is in finding out how objectified and standardized forms of knowing are put together and how they work in particular settings (often in ways not immediately visible to people in the settings, a key feature of objectified forms of knowing)(Campbell, 1998). In addition, since one's experience is organized by things beyond the experience of the here and now it becomes necessary to look at important interactions that happen both in the agency and outside it in order to determine what is going on. Ruling relations are carried out in our lives in interactive practices such as health care service provision and other forms of administration, management, professional practices, government, etc. Textual documents carry the priorities of organizations into the interaction that coordinates what is happening. Therefore, data collection consists of observation,

interviews and analysis of documents; (5) The research process is iterative in design. Experience is the point of departure for the analysis, but analysis must also return to experience, having explicated how the experience came to happen as it did, in order to more fully understand the impact of these ruling relations on women; (6) The research focuses on processes, not on categories. According to Smith, Institutional Ethnography is against categorizing because “categorizing removes women from her own interpretation of the everyday...the answer is to look not at categories but at processes” (Smith, 1987a: 132-134); (7) The goals of Institutional Ethnography are emancipatory as they are meant to challenge exclusionary and oppressive constructions and “open up possibilities for people who live these experiences to have more room to move and act on the basis of more knowledge about them” (Campbell, 1998: 1).

### **Reflexivity**

Institutional ethnography research is, at its root, reflexive. Reflexivity refers to the capacity to locate one's research activity in the same social world as the phenomenon being studied. According to Eakin and colleagues (1994),

researchers who take a reflexive stance do not see themselves as occupying a privileged position outside of the world they study. The research they engage in is not a neutral procedure for discovering an “objective” reality that exists independent of human perception and interpretation. The aspects of the environment which are noticed and singled out for inquiry and the procedures used to describe and explain phenomena are ‘ideological’ in the sense that they are socially constructed in a particular time and place and in conformity with prevailing ‘rules’ for knowing and reaching conclusions about what is ‘real’. (Eakin et al., 1996:162)

Because theories or perspectives often contain hidden or unacknowledged assumptions of how society functions, reflexivity leads us to make these assumptions

explicit and search out alternative views of reality. The concept of reflexivity has been taken up and expanded upon by feminist researchers. According to Cook and Fonow (1991), reflexivity is an analytic stance in which feminists have reflected upon, examined and explored analytically the nature of the research process in order to gain insight into the assumptions about gender relations underlying the research process (Cook & Fonow, 1991: 2). Feminist researchers are committed to developing and enhancing reflexive research practices which incorporate elements of consciousness raising, collaboration and rendering apparent the heretofore unexamined stages of the research process. Women's research has purposely made explicit the risk of subjective involvement in order to obtain new knowledge (Callaway, 1981:470) and, as such, has enduring value for feminist researchers. Reflexive research practices help bridge women's individual experience with political-structural analysis, make apparent the ways in which researcher and research process influence the nature and subjects of inquiry, and are instrumental in mobilizing women as active participants in their own emancipatory struggles.

As is consistent with feminist reflexivity, Smith asserts that as a researcher, one must begin in the same world as those being studied. That is, to fully understand the depth and richness of women's experience of access I must begin with women. "Thus, a neutral or disengaged position, from which the professional sociologist has traditionally launched his/her investigations, no longer exists. Smith's (1987a) inquiry into the problematic of the everyday world is best understood as an effort to extend her knowledge as a member of this world to its extra-local forms of social organization" (G.Smith, 1995: 19). This is done to increase our understanding of how experience is reflexively and inextricably bound to regimes of ruling (Campbell & Manicom, 1995: 9). This statement is very important for

**Institutional Ethnography. The world is experienced reflexively, therefore we cannot theorize people's experience as though it is somehow removed from the everyday practices and processes of being in the world, of living it, shaping it, making meaning of it and experiencing it on an everyday basis. This is equally true of research participants as it is of the researcher. Each of us is situated locally within our particular social location and this fundamentally shapes how we experience and make meaning of the world. Researchers are not immune to this reality; we should not and cannot strive to be neutral observers of women's experience, situated outside the practices and processes of both the research and the institution which has provided the local site of interrogation. Instead, researchers and participants both shape and are shaped by relations of ruling as they are made manifest within that institution. For the researcher this means explicitly reflecting on one's positions as "expert" within that institution and one's privileged relationship to the university as a site of "expert knowledge". As university researchers we have access to "expert knowledge" which is often couched in technical language and procedures intent on mystifying the research practice.**

**Because of the specialization of knowledge and research "technique", ordinary persons are rarely considered knowledgeable. They are, by definition, excluded from the specialized research industry because they are barred by the necessity of specialized knowledge or scientific rigour. In most research, oppressed persons are subject to research processes which treat them as objects. Hence, traditional research processes have been alienating and dehumanizing (Maguire, 1987: 45).**

**Feminists have rejected the notion of the "expert". At the very least, the concept of distance between the researcher as "knower" and the subject of research as "known" is**

actively challenged. A feminist perspective begins with the premise that the people with the problems are best-placed to reflect on and analyse their oppressive circumstances and to find solutions to their problems. Women themselves are seen as the "experts". The research process, then, remains open to those who are being researched in an attempt to break down the distinction between researchers and the researched, the subjects and objects of knowledge production, by the participation of women-for-themselves in the process of gaining and creating knowledge (Gaventa, 1993:34). This project is not always easy to carry out. For, even as we attempt to reduce the barriers of privilege that exist between researchers and participants (including in this case, clients, front-line workers and administrative staff, most of whom are women) by engaging in feminist reflexive research practices, our privileged position is reinstated by the institution. This is particularly true within the rigid hierarchies of health care institutions where professional status and education are used to manage and coordinate relations of power. Despite this, we must strive to engage as equals with participants and render explicit those aspects of the research process in which our own positions as researchers influence our work with women who are differentially situated, particularly in relation to age, class, "race", ethnicity and ability. This is best achieved through reflexive practices and processes.

This discussion requires a brief description of how my own social location has influenced both topic choice and methodology. I worked for several years as a gerontological social worker at an ethno-specific (Jewish) homecare agency and have served on committees dealing with elder care within the organized Jewish community of Montreal. This experience has led me to an overall interest in the ways in which older ethnic women experience health care, both in the public sector and the private non-profit

ethno-specific community sector. I have seen many times older women's frustrations regarding their experience of care, the difficulties they had understanding and maneuvering through the service network, the rejection they faced and feared facing in relation to children's ability to help, the frustration of not being given adequate help by their primary care physician, their lack of awareness of services, their experiences of anti-semitism among homecare staff, their insistence that in order to get adequate service they, or others around them, had to fight very hard as advocates, their worries about getting lost in the system. I have also experienced first hand, the way in which our existence as a "Jewish agency" served the public sector in that they did not have to adapt their services to the needs of Jewish clients "as long as we were around to pick up the slack". I have witnessed the impact of budget cuts on seniors themselves, their ability to stay out of an institution or to rely on family members to complement formal services. These issues are, of course, central to the problematic of access.

In addition, and more personally, as a person with a chronic disease, whose life has been framed and managed by the health care system, I have experienced, in a very personal way, some of the problems and frustrations associated with attempting not only to access health care but also to engage with it, make it appropriate to my needs, my cultural and gender identity. Although I am much differently located than those whose experiences I wish to study (older ethnic and "racial" minority women), I am linked, through my experience as an ethnic minority woman who is intimately and constantly dependent on the health care system, to other women similarly situated. I can share in an understanding of how our lives get shaped by the totalizing construction of us as "diseased" and in need of medical control. These experiences have fundamentally shaped

my work and my commitment to understanding the processes of access from the standpoint of ethnic and “racial” minority women.

### **Grounded Theory Influences on Methodology**

Institutional Ethnography is a powerful political and emancipatory methodology which gives salience to both women’s particular experience and the macro structures which shape that experience. As a methodology it articulates an epistemic, ideological and philosophical position which is both sensitive to voice and explicative of larger macro discourses. Given its breadth and scope as a critical tool for social science research, authors have tended, to date, to favour publishing information on Institutional Ethnography research which examines ideology and epistemology over explanations of strategies for data collection and analyses. As a result, new researchers interested in undertaking Institutional Ethnography research are often left to fend for themselves in designing these studies, particularly in relation to methods of and strategies for data collection and analyses. It is for this reason that I have attempted here to describe and articulate how I went about doing the research in a more concrete and step-by step fashion. It is hoped that, through this articulation of research design, alongside explorations of epistemic stance, the present study, and by extension Institutional Ethnography as a methodology, will be enhanced. In order to achieve this end, I have borrowed some Grounded Theory strategies for data collection and analysis. It was felt that, while ideologically dissimilar, Institutional Ethnography and Grounded Theory share some compatibilities in research design, thus lending credibility to merging components of these two methods.

Grounded Theory is a research methodology which was developed in the late 1960s by Glaser and Strauss (1967) as a model for “theory generating” research. Grounded Theory argues for “grounding theory in social research itself-for generating it from the data” (Glaser & Strauss, 1967: viii). According to Strauss and Corbin (1990), “a grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis” (Strauss & Corbin, 1990:23). While grounded theory emerges from the data it is also conceptually transcendent. That is, doing grounded theory research ensures that analysis is both grounded in the data and stretches it to create understandings useful to other situations and settings. While not a common approach, grounded theory can also be used to test pre-conceived theories. This is referred to as “emergent fit”, a strategy in which grounded theory processes are designed to ensure theoretical models which have been previously tested on other data also register as authentic to new data sources (Glaser, 1998).

Grounded theory attempts to understand the process of some phenomenon in order to explain it. Central concepts in this method include: the necessity of studying phenomena from within; the centrality of developing theory which is grounded in reality; an understanding that persons are actively involved in shaping their worlds and their experience in the world is constantly evolving; an emphasis on process and change; and the assumption that conditions, meaning and actions are inherently interrelated (Strauss & Corbin, 1990: 25). Four criteria are necessary for judging the applicability of a theory to a phenomenon. These are: fit (theory is faithful to the everyday realities of those under study), understanding (theory should make sense to persons studied), generality (theory

should be applicable to broader contexts related to the study area), and control (theory should describe process from theory to action) (Strauss & Corbin, 1990: 23). The Grounded Theory approach was originally designed as a complete research package, that is, it offered a systematic set of procedures for developing and carrying out qualitative research but remained open enough so that these procedures could be adapted for a variety of uses. This method is based on the notion that data collection, analysis and theory are reciprocal and that the process of analysis is inductive. "One begins with an area of study and what is relevant to that area is allowed to emerge" (Strauss & Corbin 1990: 23). Collection, coding and analysis of data are undertaken simultaneously and there is a constant shifting back and forth within these three operations throughout the research process. According to Glaser and Strauss, "The generation of theory, coupled with the notion of theory as process, requires that all three operations be done together as much as possible. They should blur and intertwine continually, from the beginning of an investigation to its end" (Glaser & Strauss, 1967: 43). By merging these three functions, the researcher is able to check and recheck assumptions and ideas which emerge from the data by constantly comparing it to other data sources to both confirm and disconfirm emerging, working hypotheses and by adapting sampling and interviewing strategies as she moves through the stages of the research process.

Upon critical review, it is not immediately evident how Institutional Ethnography and Grounded Theory approaches can be combined to produce a fluid and consistently articulated methodology. Institutional Ethnography is inherently positioned and located both socially and politically. It is a methodology which is fundamentally aligned with those persons under study. Institutional Ethnography is based on women's standpoint theory

which makes it concerned with, not only explaining, but re-creating, critiquing and exposing relations which undermine, marginalize and oppress women. Grounded Theory makes no such claim to political or social standpoint and as such, is very differently situated as a methodology. Grounded Theory is based on being grounded in the data itself, and, as such, would not as part of its epistemic position, move beyond what women say in order to explore or expose invisible relationships behind and beyond the direct immediate data. Although conceptual transcendence is a component of Grounded Theory, it is not well articulated or widely seen as a central component of the method. In addition, while Grounded Theory does, at times, explore the influences of structural conditions on behaviour (Wuest, 1995: 127), it is not necessarily done from a position of critique, rather it seeks simply to explain the relationship between social conditions and behaviour or experience. This stance of relative neutrality is rejected from an Institutional Ethnography perspective. When Grounded Theory and Institutional Ethnography meet epistemically it is only as a result of the choice of the Grounded Theory researcher to engage more critically or politically with the subject matter and not as a matter of design. In comparison, Institutional Ethnography researchers must engage politically with the material as a fundamental and primary activity of the methodology, by design. At its root, Institutional Ethnography is grounded in the everyday experience of participants, as is Grounded Theory. What separates them is that Institutional Ethnography attempts to move beyond this everyday experience to explicate relations and processes of ruling, while Grounded Theory simply seeks to explain, conceptualize and theorize about that experience itself.

Despite their fundamental epistemic differences, Institutional Ethnography and Grounded Theory do approach the practice of data collection and analysis somewhat similarly, enough so that it becomes possible to borrow strategies of Grounded Theory to help articulate the “doing Institutional Ethnography research” more concretely. Both use multiple methods and purposive and theoretical sampling strategies in order to achieve saturation of ideas and experiences. Both take an iterative stance, moving between data collection and analysis simultaneously in order to verify assumptions and expand upon theories which emerge from participants’ stories. Institutional Ethnography is a more critical approach which attempts to retain the complexity of women’s stories in the analysis while Grounded Theory often begins more broadly but continually narrows or restricts the voice as theory is developed so that while Institutional Ethnography continually analyzes all of women’s transcripts, Grounded Theory sets out to confirm or disprove theories and thus may compartmentalize and select out pieces of women’s voices for analysis. Both Institutional Ethnography and Grounded Theory set out to “map” findings, although Grounded Theory’s matrix map is not inherently politically defined. Institutional Ethnography sets out to trace relationships of ruling through identifying everyday experience and its relationship to state practices and ideologies, while Grounded Theory only sets out to map “patterns of interactions”.

While philosophically and epistemologically quite different and opposed approaches, Grounded Theory methods for collecting and analyzing data can help strengthen Institutional Ethnography, whose design components such as data collection and analysis, to date, have only been weakly articulated. By infusing Institutional Ethnography with Grounded Theory strategies in order to strengthen sampling, data

collection and analysis the processes by which research takes shape can be more clearly articulated. Grounded Theory's strength is found in its articulation as a complete method with easily defined steps needed to do the tasks associated with developing theory in a more complete way. Grounded Theory's three stage analysis method are interesting strategies and well documented. The step-by-step description of data analysis provides a useful guide which can be easily incorporated in to the Institutional Ethnography approach without disturbing its epistemic, philosophical or ideological basis. Table 2 (on page x) compares the two approaches along epistemic and methodological lines.

### **Implications of "Race" and Ethnicity on Method**

Just as women have been excluded as a group from dominant forms of knowledge in social science generally, so ethnic and "racial" minorities have been excluded from both dominant and feminist forms of knowing. These exclusionary practices have resulted in research which has little use for ethnic and "racial" minority women. This is particularly true for elderly ethnic and "racial" minority women "whose lives have perhaps been the most distorted by social scientific research" (Andersen, 1993: 46). It has "...produced a cumulative impact on the empirical generalizations that constitute the elements of feminist theory. As a result, the prevailing literature, which seems to identify particular "social realities" merely represents White and middle-class experiences. The social realities of other groups, such as minorities and the working classes, become relegated to side issues in the field" (Weber Cannon, Higginbotham & Leung, 1991:116). Qualitative research, although potentially less essentializing than empirical positivist research models, has also contributed to the marginalization of ethnic and "racial" minority groups within knowledge generation in the social sciences. Often qualitative researchers have used homogenous

groups of participants to simplify what could otherwise be very complex analyses or have simply ignored ethnic and “racial” differences completely. This is also the case with the Institutional Ethnography methodology. In her large body of work, Smith has rarely attempted to identify how interlocking positions of women of colour might further problematize her approach. This weakness serves to render invisible how “race” influences the paradigm and/or the method of Institutional Ethnography. “Correcting this imbalance in feminist scholarship requires theoretical conceptualizations that include all dimensions of inequality, more complex research designs, and strategies that confront the obstacles to the incorporation of diverse groups of women” (Weber Cannon, Higginbotham & Leung, 1991: 107). Researchers must begin by questioning how the project of correcting these imbalances within feminist research can be undertaken and achieved. This question is especially important for White researchers to consider so that our research does not reproduce White supremacist models in the social sciences but challenges and redresses them.

Stanfield (1993b) suggests our first task as researchers is to locate our research within the frame of human rights. He states,

Both the dominant (researcher) and the subordinate (subject) have human rights that can be recognized totally, selectively or not at all. Usually what happens is that the researcher recognizes and exercises his or her human rights, usually defined in academic freedom and professional credential terms, whereas the human rights of subjects are at best defined in the bureaucratic guidelines of academic institutions and funding sources. Human subjects and/or the populations they represent have rarely been consulted or, better yet, included in the decision-making processes that produce guidelines for research on human subjects. This tendency for researchers and their institutional sponsors to define the human rights of subjects is indicative of the hegemonic power relationships that undergird research processes. (Stanfield II, 1993b: 32)

**This concept relates closely to the feminist project of reflexivity. In this sense, “the study of method must begin with questions concerning the life histories of researchers and the embedded norms values and beliefs of the institutions communities and movements they build, stabilize and transform” (Stanfield II, 1993b: 33). White scholars doing ethnicity and “race” research “must examine self-consciously the influence of institutional racism and the way it shapes the formulation and development of their research, rather than assume a colour-blind stance” (Andersen, 1993: 43). Finally, in doing analysis, “dominant group researchers must examine their own “racial” identities and actively challenge the societal system of “racial” stratification in which what they observe is situated” (Andersen, 1993: 43). This reaffirms the project of connecting micro practices with macro structures with an emphasis on considering the role of white supremacy in the project of ruling relations. In addition to this practice of looking inward at oneself as researcher and looking outward to the racist practices of ruling relations, anti-racist research projects must endeavor to engage with participants in ways not necessarily considered appropriate in traditional social science research projects. This means taking a reflexive stance with those we are studying. Historically,**

**the scientific framework of social science research actually obstruct[ed] the formation of relationships essential to understanding women’s lives...sociologists are routinely instructed to interview research subjects by manipulating them as objects of study...researchers are admonished not to get too emotionally involved with subjects. Such a method assumes the passivity of respondents and forces them to adapt to the situation as defined by the interviewer. Moreover researchers are told never to inform interviewees of their own beliefs and values. (Andersen, 1993: 46-47)**

**This is particularly problematic when interviewing women of colour. By assuming passivity of respondents we as researchers may be enforcing modes of relating closely**

aligned with the dual oppressions of sexism and racism. According to Andersen, “this conventional methodological approach is counter to that required for white scholars to produce more inclusive and less partial and distorted accounts of race, class and gender relations” (Andersen, 1993: 47). She goes on to state that the women of colour interviewed in her study were “savvy to the potentially exploitative character of academic research” (Andersen, 1993: 48) and as such, adapted their positions to challenge these oppressive constructions of them such as refusing to be formally interviewed but agreeing to talk with her for hours or refusing to be tape recorded. Thus, we must allow that field research and interviews may blur as research methods (Andersen, 1993:47). It is essential to stay open to adapting research methods to suit participants’ needs, engage in participants’ worlds and be open about oneself when doing anti-racist research. According to Weber Cannon, Higginbotham & Leung (1991):

we will need to adapt more labour-intensive strategies for recruitment because of ethnic and racial minority women’s obstacles to participation, including such things as skepticism about the purpose of the research, worries about protection of anonymity, and structural obstacles such as a lack of free time. (Weber Cannon, Higginbotham & Leung, 1991:113)

As researchers, we must acknowledge that “dominant group women have less reason than minority-group women to suspect that they or members of their group will be exploited in research” (Weber Cannon et al., 1991:113) and maintain sensitivity to women’s experience as subjects in research and skepticism regarding working with institutional structures which have historically served to dominate and oppress them and their communities such as the university or the health care system.

Another important issue in the development of research designs sensitive to ethnicity and “race” concerns the use of folklore to explain phenomena. According to Stanfield, “much of our thinking about race and ethnicity is convoluted and otherwise blurred by ideological intrusions encouraging the use of folklore in collecting and interpreting data. The use of homogenous and reified terms such as Black and White buy into and indeed reproduces traditional “racial” stereotypes more than it facilitates adequate data collection and interpretation” (Stanfield II, 1993b: 34). This means both expanding our categories of ethnicity and “race”, defining them and moving beyond using specific ethnic or “racial” group behaviour or coping strategies to explain phenomena. “Evolutionary cognitive styles have inhibited the asking of interesting and important questions regarding the historical and contemporaneous influences people of colour have had in shaping dominant US culture and society as well as their own indigenous life worlds” (Stanfield II, 1993b: 34). This requires, once again, focusing on processes of social oppression which influence experience. “Relativistic and pluralistic meanings of cultural difference, rather than evolutionary meanings, would encourage more complex research into how populations in their various stratified positions come to create, maintain and change a society through reciprocal processes of interaction and separation” (Stanfield II, 1993b: 35).

Finally, as Andersen states,

In doing ethnic and racially sensitive research, investigators must acknowledge and take as central the class, race, and gender relations in which researchers and research subjects are situated... White scholars must work in ways that acknowledge and challenge white privilege and question how such privilege may shape research experiences. Developing analyses that are inclusive of race, class and gender also requires that discussions of

race class and gender be thoroughly integrated into debates about research process and the analysis of data. (Andersen, 1993:51)

### **Sample<sup>2</sup> Sampling Procedures**

In conducting the study, I have undertaken both purposive and theoretical sampling procedures. This was done to ensure that sampling decisions emerged from an exploration of women's standpoint but were not limited to women's own interpretation of their experience. So that even when, for example, women themselves did not indicate the influence of state funding or policy in their accounts, I was able to draw on the macro data to explain their experiences. This is a consistent and implied technique of an Institutional Ethnography approach, thus using purposive sampling techniques which are not wholly based on women's accounts but which emerged from prior theoretical readings of the literature was a central strategy in sampling. Theoretical sampling techniques were used in order to confirm and disprove emerging concepts in previously collected data. Theoretical sampling strategies included: open sampling (staying open to guide sampling choice as derived through data); relational and variational sampling (maximizing the findings of differences); and, discriminate sampling (maximizing opportunities to verify the story line and relationships between categories, filling in poorly developed categories) (Strauss & Corbin, 1990: 176).

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<sup>2</sup>As part of my effort to provide explicit and track-able records of my thoughts and decisions regarding sampling and analysis, I have created a detailed audit trail entitled *Journal of Process and Decisions*. This audit trail provides evidence of sampling and analysis strategies to ensure trustworthiness, validity and authenticity. Please refer to Appendix 1 for a detailed account of the research process.

## **Description of Sample**

The data sources included: individual and group interviews with a variety of cohorts including older ethnic and “racial” minority women and their families, front-line workers and managers at *Eldercare*, and workers from ethno-specific and multicultural agencies and hospitals; textual data; and participant observations. These represent a complex triangulation of data sources in order to enhance research credibility. Front-line service providers working in service provider agencies, although central to the delivery of elder care services, were not interviewed in the current study. Instead, the perspectives of service provider agencies were included through interviews with multicultural agencies in the community who provide direct service provision to elderly clients. This was so, because the central focus of the study was on an explication of the institutional process of the *Eldercare* organization specifically and on experiences of access among older ethnic and “racial” minority women. As such, the explication of the relationship between *Eldercare* and service provider agencies was undertaken from the localized site of the *Eldercare* organization, rather than from the perspective of individual service providers. To this end, interviews with older women which highlighted their relationships to and with service providers as well as with case managers at *Eldercare* and in service provide agencies which describe the relationship between *Eldercare* and these agencies, were prioritized.

Thirty separate interviews and three focus groups were completed for this study with a total of 43 participants. Participants included 10 older ethnic and “racial” minority women and 3 family members, 16 staff of the organization *Eldercare*, where the study was undertaken, and 14 people who worked in the community. In recruiting participants, the

following strategies were used: approaching local ethno-specific and multicultural agencies to advertize the research project and speaking with key informants in these areas (this was particularly necessary for recruitment of older women not already identified as clients of *Eldercare* as well as professionals working in these agencies); approaching front-line workers and intake workers to identify older women who may be appropriate for inclusion in the study (this included both older women accepted as clients and those who had not received or were currently not receiving services); and, approaching front-line workers and managers in *Eldercare* individually to ask about potential involvement both as interviewees and for participant observation. The following section briefly describes some of the characteristics of these participants.

#### **Older Ethnic and “Racial” Minority Women**

In interviewing older women themselves, my intent was to diversify rather than homogenize the sample by ethnic and “racial” groups. Therefore, I did not interview women of one or two specific groups but instead strove for heterogeneity. This was done to avoid conclusions which may have otherwise been seen as being based on folkloric concepts, such as descriptions of how Chinese women or Black women, for example, cope with access. Rather, my intent was to explicate the broader issues of the impact of ethnicity and “race” on older women’s experience of access. In selecting people to interview, I was guided broadly by the 1996 Census data on ethnic origin and visible minorities. That is, I attempted to interview members of those ethno- “racial” communities which are highly represented in Area P. These included Black, Chinese, South Asian, Italian and Greek persons.

Ten older women were interviewed for the study, two individuals from each of the following ethno- "racial" groups: Chinese, Italian, Black, and Greek; one individual of South Asian origin and one individual of Iranian origin. In three of these interviews, (with a South Asian, a Greek and a Chinese elderly woman) family members also participated. A South Asian and Chinese daughter participated in interviews with their mothers and a husband participated at the end of an interview with his Greek wife. This type of participation was not discouraged in an effort to allow women to define, for themselves, how they would participate.

Several interviewers were hired in order that older ethnic and "racial" minority women participants who did not speak English could be interviewed in their mother tongue. Indigenous interviewers were of Greek, Chinese, South Asian and Italian origin. These people were recruited from a variety of sources including the Faculty of Social Work at the University of Toronto where two were currently either employed or attending university; a women's organization where one of the interviewers was employed, and; through a case manager at *Eldercare*. Interviewers all had experience working either with seniors or in the field of social work and several had previously participated in research studies. Interviewers all participated in a three-hour training which familiarized them with the methodology, the purpose of the study and the particulars of the questionnaire. This training was very important particularly as the interview guide itself was meant to be used as a flexible tool, adapted to allow women to share their stories in a fluid and holistic manner. Subsequent meetings were held with these interviewers when adaptations were made to the guide. All interviews were transcribed directly into English so that the researcher could analyze the transcripts. In two cases, older women did not want to tape-

record their discussions and so interviewers took notes during the interview which were later translated and typed out for the researcher. All interviewers were asked to write notes about their own feelings and thoughts regarding the content and experience of the interview and these were also counted as data. Data which resulted from these interviews were rich, despite the fact that transcripts had to be translated into English in order to be analyzed. Still, it was felt that the data which emerged from these interviews were closer to the voices of elderly female participants because women had the opportunity to participate in an interview in their mother tongue. This resulted in a more fluid and deeper interview which established trust between interviewer and participant. Indeed for two participants, this was the first time in their experience of care that someone from their own community came to speak with them. Three interviews with English speaking elderly women were conducted by the principle investigator. This gave me the opportunity to test out the interview guide and ensure that the questions included captured the detail and experiences needed for the Institutional Ethnography. This proved a valuable exercise which enabled me to appropriately train and guide the interviewers. At one of these three interviews, the older woman participant expressed disappointment at not being interviewed by someone of her own ethno- "racial" background, demonstrating once again the importance of undertaking ethnic and language matching in this type of research.

The older women interviewed were between 67 and 83 years of age. The average age of elderly female participants was 75.6 years. Four of the ten women lived alone with the remainder living with spouses, children, other family members or non-related persons (in one case, a woman was living with her home maker). Five of the ten women had immigrated to Canada in the 1950s-1960s. The remainder arrived relatively recently,

within the last ten to fifteen years. Seven out of ten of the participants spoke neither English nor French. All the women interviewed described their health as poor, and one participant was bed-ridden due to advanced arthritis. Table 3 outlines these data.

Six of the ten women interviewed were referred to the study by their case managers, indicating that these women had been or were currently on the caseload of the home care agency at the time of the study. Two women were referred by a local community agency but were also receiving services from the home care agency. The remaining two women were referred through other sources (word of mouth) and were not receiving any community services.

### **Agency Employees**

In total 12 staff from the agency under study participated in individual interviews and 4 participated in a series of focus group discussions revolving around the sharing of preliminary findings. Of these 16 staff members, four were managers, two worked in placement coordination, one was a service provider and the remaining 9 were care coordinators including those with off-site and intake responsibilities. Of the total 16 participants, 3 were of white ethnic origins and 6 were visible minority workers.

### **Community Workers**

In total, 14 people from the community participated in individual or group interviews. One of these participants was a member of a political watch dog organization, 11 were from community organizations, 5 of whom were from 3 ethno-specific organizations (3 persons interviewed in a group were all from the same organization) and 6 of whom were from 3 multicultural service delivery organizations (4 persons interviewed were all from the same agency). The remaining 2 participants were hospital social

workers. Nine of these workers were themselves visible minority persons and 2 were of white ethnic origins.

### **Textual Data**

Collection of data for document analysis consisted of gathering and “asking questions of” several types of documents. The inclusion of documents as data is a central component of both Institutional Ethnography and Grounded Theory not only as a means of data triangulation but also through the assertion that social relations are, in fact, fundamentally organized by and through texts (Ng, 1986; Smith, 1987a). The use of documents, thereby helped describe relations, stimulate questions, direct sampling and validate information obtained through analysis (Strauss & Corbin, 1990: 52). In order to direct this interrogation into documents, I was also guided by a set of pre-conceived questions consisting of both how these documents are organized and what meanings are embedded within them (McCallum Swift, 1990: 42). See Appendix 6 for the Document Analysis Protocol. Textual data, such as work guidelines, minutes of meetings and assessment forms used in the everyday work of case workers with their clients at *Eldercare* were collected. In addition, as part of the analysis of textual data, several client files were briefly reviewed to verify usage of ethno- “racial” identifiers in client files.

### **Participant Observations**

Participant observation is a strategy for bringing the researcher into the social world of informants (Gilgun, 1994: 118). Through participant observation, the researcher literally observes people in interaction in ordinary settings in order to “discern pervasive patterns such as cultural themes” (Creswell, 1998: 59). Culture consists of “looking for what people do (behaviours), what they say (language), and some tension between what

they really do and what they ought to do as well as what they make and use (artifacts [in this case filling out a variety of forms or making decisions about care])” (Creswell, 1998: 59). Participant observation consists of the note taking of field observations either during or after key incidences including meetings, interviews and discussions in order to capture data and understand the working processes of the field under study (Dennis, 1993; Gilgun, 1994). These notes are specific and directed by a guide of questions for consideration including “portraits of the informants, the physical setting, particular activities and [my] own reactions” (Creswell, 1998: 125). See Appendix 5 for the Participant Observation Protocol. Approximately 25 participant observations were undertaken, including such activities as professional-client meetings, home visits, assessments, committee meetings and informal conversations. These observations were documented and were valuable data sources.

## **Data Collection Methods**

### **Phase 1**

I began the research by first interviewing the Executive Director. My intent here was to get a firm grasp of the macro and mezzo issues in the development and operationalization of the *Eldercare* agency. I developed a series of questions focusing on organizational development, government and “agency” relations, inter-organizational relations and the impact of diversity on these items. This initial interview helped to broaden my understanding of the development of the agency (including government procedures and processes through which the agency and service provider agencies related and the history of Board development), *Eldercare*’s relationship to the community and to

ethno-“racial” community agencies. This interview served as the preparation stage for my beginning inquiry of older women’s experience.

All interviews, including the initial interview with the Executive Director used consent procedures. In cases where older ethnic and “racial” minority women did not speak English, these consent forms were translated either in written form (as was the case for the Chinese interviews) or in verbal form, so that interviewers read out the consent form to older women and then older women signed. In several cases, older women who could not write, gave verbal consent and this was recorded by the interviewer on the consent form itself or in their interview notes. In each case, information letters and copies of the consent form were left with the participant. The name and phone number of both the interviewer and the researcher were left with these women in case they wanted to follow up with either person. These adapted procedures for obtaining written consent were necessary components of the study in order to guarantee that the widest possible criteria for participation were used. Adapting procedures for consent ensured that the voices of older ethnic and “racial” minority women often left out of research, that is those that do not communicate, either written or verbally, in English, were included. All staff, including those that worked at *Eldercare* and those that worked in community agencies or hospitals were subject to rules of consent and signed consent forms before proceeding with interviews. Appendix 3 includes the information letter and consent forms used in interviewing older women, community workers and agency staff. It also contains the information package used to gain access to the agency as research site.

In the first phase of the research, my focus was specifically placed on exploring older ethnic and “racial” minority women’s experience of access to health care as a guide

for developing concepts which influenced the way in which I began my exploration of *Eldercare*. This meant beginning in older women's everyday experience. My entry point was that of interviews with older ethnic and "racial" minority women.

Participant recruitment took a long time and a great deal of effort to achieve. Prolonged engagement, through spending time at the "agency" in order to familiarize myself with the environment and to spend time explaining the project to staff in order to earn trust enabled this participant recruitment phase. Approximately one month of intense prolonged engagement was necessary to familiarize potential referral sources about my research and to establish trust. This phase of the research was particularly important in establishing trust with persons and communities of colour, particularly since I am myself a white woman. This pattern of trust-building was consistent with other research referred to earlier in this Chapter, which has theorized that ethno-"racial" communities and individuals may have more to lose in their interactions with mainstream university-based researchers and therefore are more hesitant to become involved in research endeavors. Experiences of racism, disenfranchisement and disempowerment often accompany "being researched", particularly when research does not get undertaken from a participatory or emancipatory perspective. This leaves participants as frustrated outsiders in the research process and powerless to shape either how questions are asked or how results are used. Rarely does participation in research endeavors benefit people of colour who participate. This experience of being "researched upon" has left many ethno- "racial" communities, particularly women, resistant to participating in studies. In the present study, a visible minority worker running a local senior's group refused to participate, citing three recent occasions where university researchers had been given permission to interview elderly

members of the group, promising to return with the results, and had not been heard from since.

Initially I relied heavily on a couple of staff to get names of appropriate women to interview. Once I received several names of potential elderly ethnic and “racial” minority women participants, their workers called either the older woman or her family to ask if her name could be released to the researcher so that I or one of the indigenous interviewers could call the older woman to explain the study and ask about participation. Often, I had to go through their children before speaking with older women directly. Sometimes children did not want their mother disturbed by the research. This common occurrence of going through the child was partly the result of the nature of operations at *Eldercare* where children often served as the point of contact for the case coordinators. Given the length of time it took to recruit older women, I spent much time at *Eldercare* “hanging out”, presenting to teams at staff and team meetings, and training interviewers. This time proved an important period to develop an understanding of the culture of the agency, establish trust and build contacts with workers, both mainstream and visible minority workers, who then later served important roles of participant recruitment and member checking.

Four purposively selected interviewees were chosen (two older visible minority women and two older white ethnic women) and the interviews were conducted and data analyzed to develop working hypotheses which informed the next phase of the research. One of the interviews with a visible minority woman included her daughter as well, thus introducing the voice of family members into the study. For the fourth interview, relational and variational sampling was used. Since the first three interviews were with women who

were seen as “not knowledgeable about services” by those who referred them, I sought out a client whom workers saw as “knowledgeable” as a point of comparison.

In developing the interview guide for older women participants I recognized the need to pay attention to feminist and anti-racist interviewing principles of reflexivity. This invariably meant leaving room for “talk” in the interviewing process and engaging with participants through the incorporation of personal involvement (DeVault, 1990; Reinharz, 1983; Stanley and Wise, 1993). This proved highly important in subsequent analyses. For example, women often “went off” direct questions and gave responses that, on the surface, had little to do with the question asked. For example, they spoke more readily about their experiences of immigration and employment than about their health status, at times directly replying to a question about their health with a story about their past. This led to rich analyses regarding the central place stories of struggle and survival have in older ethnic and “racial” minority women’s conception of self and of their health, a finding which would have been totally missed by focusing them back to the topic or question at hand. (See Appendix 4 for Interview Guide 1 for the first phase of interviews).

At this early stage, I also retrieved some demographic information from the 1996 Canadian Census. This demographic information included ethnic and “racial” categories (based on highest number or largest representation of ethnic and “racial” groups in the area), level of poverty, gender, living arrangement and immigration status. The information garnered from this source was used to provide a context for understanding the lived realities of elderly ethnic and “racial” minority women in Area P through an analysis of the socio-demographic characteristics of ethno- “racial” communities. (See Appendix 2

for the table descriptions of these data). Phase 1 ran for approximately 8 weeks (May-mid July 1998).

## **Phase 2**

Phase 2 began my analysis of the *Eldercare* agency. Multiple data sources and methods for data collection were used and as a result, this phase took several months to complete (mid-July-December 1998). The focus here was on broadening and going beyond women's everyday experience to understand more deeply the relationship between the work processes of *Eldercare* and the experience of access. My attempt was to understand the role of the agency in determining older women's actual lived experience of access. My research questions included: How do the work practices and processes of *Eldercare* impact upon older women's experience of access, frame it, shape it and construct it?; How do *Eldercare* workers talk about access, particularly as it relates to ethnic and "racial" minority women?; How do the work processes or activities actually play out this definitions?; and, What are the junctures, gaps and coherences between older women's experience and work processes of the agency (including the ideology driving work processes as mediated by texts)? Data sources included interviews with front-line workers and managers, participant observation, and document analysis. It also included six further interviews with older women to compare, contrast and triangulate with these other data sources. Interviews with ethno-specific and multicultural community agencies were also warranted to highlight the relationship of *Eldercare* with local ethno- "racial" communities and multicultural agencies.

Recruitment of staff at the agency predominantly occurred through the process of trust-building. Initially, I asked for volunteers for participation. At this stage only a few

individuals came forward to volunteer to participate. After having completed these interviews, I developed a purposeful sampling strategy technique in order to ensure that the sample was inclusive of persons occupying different positions at the agency, such as case manager, both off-site (as in those working from hospital or community agency) and on-site (as in those working at the main office) employees, managers, service providers and placement coordinators as well as representative of White ethnic, visible minority and Anglo-Canadian employees. One of the workers, who is herself a visible minority women, with whom I established an ongoing and trusted relationship helped to identify and recruit other visible minority workers for participation. Her efforts proved invaluable to helping me gain trust with these women. As is consistent within the health care field generally all agency workers interviewed for the study, except one, were women. I chose ethno-specific agencies to approach based first on those ethno- "racial" communities which, according to the 1996 were highly represented in Area P. I located workers and/or ethno-specific agencies which serviced South Asian, Black, Greek and Chinese communities in Area P. Once located, I called these agencies and asked to speak either to workers who worked with seniors or those that did front-line human service provision. All of those interviewed had some level of experience working with senior women from their respective communities. Initially I had not planned to interview people from multicultural, mainstream agencies or organizations. However, after having attended a meeting of an umbrella group of agencies servicing seniors in Area P, it became evident that workers in these agencies felt that their experiences of working with and views on access for multicultural seniors was unique so that some of these agencies needed to be included in the sample in order to achieve theoretical saturation. I therefore approached two of these

such agencies for interview. Finally, near the end of the study it became clear that *Eldercare* focused much of its attention and received the majority of its referrals from hospital sources warranting an interview with hospital workers who dealt directly with *Eldercare* but who were not employees of that agency. All interviews were undertaken by the principal research. This completed the data collection phase of the research. (See Appendix 4: Interview Guides 2-4, Appendix 5: Participant Observation Protocol, and Appendix 6: Document Analysis Protocol). Data collection and analysis were undertaken in a simultaneous and constant comparative process with concepts derived from one interaction informing and guiding the next. At this stage, adaptations were regularly made to each interview guide for the purpose of testing, proving, disproving, and expanding concepts and ideas and to achieve saturation. Therefore the guides were used as tools which were open and fluid to allow for this iterative process of progression to take place.

## **Analysis**

### **Quantitative Data**

Quantitative data analysis was based on simple cross-tabulations of demographic data as the emphasis here is not on testing explanatory models but on describing the population under study in Area P for use as a reference point in examining the qualitative findings.

### **Qualitative Data**

Although I have separated the discussion of analysis from data collection, it is important to note that, as is consistent with both Grounded Theory and Institutional Ethnography, qualitative analysis of data is conducted on an ongoing basis as the research proceeds, alongside data collection. In fact, analysis informs data collection in an iterative

process. Analysis in the current study, consisted of content analysis of all data in the form of coding (Gilgun, 1994: 119). Most interviews (except for two with older ethnic and “racial” minority women who refused to be taped but allowed the interviewer to take notes) were tape recorded and then transcribed by a trained interviewer or translator. In phase 1, the transcribed interviews with older women were analyzed in order to come up with working concepts and hypotheses which informed future phases of the work. At this stage, broad concepts focused on what older ethnic and “racial” minority women said about how they go through the system, who provides their care, the problems they encounter, the strategies they use and the processes by which they may be constrained and empowered. This latter theme was quite vague at this stage because I had not yet begun to interview workers themselves and was still quite unclear about the processes and culture of the agency. Concepts reflected such broad themes as women’s perceptions about their health status, their needs and their care.

Analysis or coding in Grounded Theory uses three styles or types of coding (open, axial and selective), which although are related somewhat hierarchically (open and axial coding often take place early in the analysis) do not necessarily take place in stages. Rather these three coding types are often used simultaneously as the researcher moves from one phase or stage to another (Strauss & Corbin, 1990: 58). Coding or analysis in Grounded Theory uses the constant comparative method, that is, analysis depends on making comparisons both within data sources and between data sources and asking questions of the data in order to search for both similarities and differences in the data.

Unlike quantitative methodologies which seek to identify the most often stated themes, Institutional Ethnography and Grounded Theory pay closer attention to unique

ways of speaking or marginal themes which emerge in the data. This includes what feminist researcher DeVault (1990) considers “listening around and beyond words” (DeVault, 1990: 101). By this she means paying attention to recovering unarticulated experience which is outside or counter to androcentric language and definition. Women, she states, are often confined or restricted to using androcentric language not wholly reflective of their own experience (DeVault, 1990). Researchers, therefore, must learn strategies for listening beyond traditional definitions to get at the meaning of women’s talk in which and for which there is no adequate language. For example, the word “independence” as it is commonly used and referred to in health care settings is reliant on a conceptual model linked directly to white male definitions of physical, mental and financial capability. But when women use the word “independence” to describe their lives and their agency, we may lose their truth, if we do not seek out women’s particular meanings. In traditional research models, this differential use of a word like “independence” may go unnoticed, its everyday use no longer is questioned. It is the task of the feminist researcher to look behind and around words like “independence” to the ways in which women are using and making meaning in them, “to the various ways that women manage to deal with the incongruence of language in their everyday speech” (DeVault, 1990: 102). DeVault states that women often use words that are “familiar and close enough to experience for most purposes, relying on [other] women to understand” (DeVault, 1990:102). In fact, in the current study, it was found that women do not often themselves refer to notions of independence, rather concepts and categories of ‘relationships’ surfaced more frequently, thus enabling a shift of current discourse from one of ‘control over myself’ to ‘shared or reciprocal control’. Paying attention to these “points of translation” analytically, requires

listening to particular phrases that seem to demand investigation and “to analyze the disjunctures that give rise to them” (DeVault, 1990: 102). This technique of listening to the everyday speech of women turned out to be extremely important in the current study as disjunctures between what older ethnic and “racial” minority women said and what workers said about the same subject matter, became a rich and central point of analysis.

In the first pass through the data (this included all sources: transcripts of interviews, document analysis and participant observation material), I identified conceptual themes, ideas or assumptions located in the data such as discourses of “family”, “access” or “relationships”. Once this was achieved, I attempted to categorize the data broadly based on the way themes or labels related to each other, such as how both older women and workers talked about these themes. Thus the process was an inter-relational one. Here and throughout the process of coding and analyzing, I used “in vivo” codes, that is the identification and labeling of themes based on what women actually said, using words or phrases that were commonly understood by them. This reduced acts of smoothing over women’s talk and removing their voices from the text. An example of this related to how women spoke about access, never actually using the term, but spoke about relationships they required in order to access care such as those with ‘people they trusted, liked or who were from their own ethno- “racial” community’. So ‘trusted people’ became a category instead of ‘access’. In addition, women rarely directly spoke about experiences of racism but used terms such as ‘rude’ to describe acts of racism against them. So, ‘experiences of rudeness’ became a category or point of analysis. Initially, I undertook a line by line analysis on order to stay true to voice and generate the largest number of themes or ideas. In subsequent interviews, I undertook sentence or paragraph coding to look for major

ideas brought out in these passages, and entire document coding to look for broader conceptualizations including the questions of “what is going on here” and “how is this document the same or different than the previous one I analyzed?” Code notes were written first in the margins of the data texts and then collected, typed out and filed separately as coding notes. This was largely achieved through the use of NUD-IST software.

In the second pass through the data, I engaged in axial coding as well as open coding. Just as open coding fractures data to allow for the development of conceptualizations and categorization, axial coding is meant to put those data back together in order to make connections between these categories. This is an important step, particularly for an Institutional Ethnography, as the analysis of process, of how things operate, takes precedence over simple categorization in this methodology. “In axial coding, our focus is on specifying a category (phenomenon) in terms of the conditions that give rise to it; the context (its specific set of properties) in which it is embedded; the action/interactional strategies by which it is handled, managed, carried out; and the consequences of those strategies” (Strauss & Corbin, 1990: 97). This focuses on linking categories to a set of relationships and in linking individual experiences to the larger functions and structures of the ruling apparatus. Through this coding process a paradigm model or map is created which relates data in a very complex way. This is both an inductive and deductive process. During this analytic process I moved to Phase 2 and began data collection and analysis within the institutional frame. The data I collected (written policies and program material and participant observation notes) were analyzed using the same strategies as those of transcribed interviews. Here a focus began to develop

more concretely on the disjunctures between what women said and what workers said. It is within this disjuncture that the state processes that shape access became visible. Therefore, this stage of analysis focused more steadily on integrating an analysis of how work processes shaped the voices and experiences both of elderly ethnic and “racial” minority women and workers.

Finally, I did selective coding which is a strategy that enabled me to fill in the map integrating categories and concepts at a higher and more abstract level of analysis which incorporated a model based on the core category or idea of ruling relations. Central to selective coding is the rounding out or filling in of data analysis. At this stage, uncovering patterns, validating relationships and solidifying connections were my central tasks. This included validating theories of ‘relations of ruling’ against the data to complete its grounding (Strauss & Corbin, 1990: 133). This involved tracing backwards for cases that did not fit (negative case analysis), for cases that elaborated on or validated what had been said in order to make the analysis richer, more complex and to enhance credibility. To complete this process, effort was placed on creating a power map of the terrain of access to track the phenomenon of access from older ethnic and “racial” minority women’s standpoint with particular attention to the context of relations of ruling. This formed the basis of my final analysis and appears in the discussion section of the study.

As stated at the beginning of this section, throughout the research process, I created both an audit trail and reflexive journal. The audit trail recorded the process of the research including any alterations to the research design and interview/analysis guides that occurred. Notes included: memos which contained notes on coding; theoretical notes (products of my thinking on issues, potentially relevant information on mapping); and,

operational notes which were directions to myself regarding sampling, questions, and thoughts that arose during the research process. This note taking served very important functions. First it provided an audit trail which helped in establishing transferability, dependability and confirmability of both research results and process. Since all aspects of the research process were openly recorded, they can be scrutinized for authenticity and grounding. Second, it served to guide and enhance the process of the research. In particular, the reflexive journal helped me find clues to the social organization of knowledge by accounting for my own thoughts and feelings on the subject on an ongoing basis (DeVault, 1990: 105).

### **Establishing Research Validity**

According to feminist researchers Ristock and Pennel (1996), there are many ways of conceptualizing validity in social science research. The most traditional and empirical means are often linked to notions of generalizability, that is providing evidence that the results of research are generalizable, or mean something beyond the sample used in the study. This notion of generalizability is relatively useless to feminist and other critical researchers who undertake research which seeks to critique the notions of homogeneity and universalizability inherent in notions of generalizability. Ristock and Pennel (1996) state,

For feminist researchers, however, the concept of validity reflects a different understanding of the nature of research findings and a different understanding of 'reality'...Instead of asking whether the project design permits the researcher to uncover the truth, we ask how can we ensure that the research has integrity. Our concern is not to bias the results in favour of a particular community, but to ensure that the information we gather will 'ring true'-that it will resonate with the experience of participants- and that we are accountable both to them and to the broader communities that may be affected by our research. (Ristock & Pennell, 1996: 50)

Validity, therefore, in feminist and critical research, takes on new meaning more aligned with that of naturalistic inquiry and which is related more closely to the concepts of integrity, trustworthiness and authenticity than to standardized notions of generalizability. In the present study, several techniques have been adopted to ensure that the research process and the findings are indeed trustworthy and authentic. These techniques emerge from Patti Lather's (1991) three constructs of validity and Lincoln and Guba's (1985) five constructs for establishing trustworthiness. Each of these will be discussed in turn.

Patti Lather (1991) has identified three essential constructs of validity for feminist social science research. These are: 1) construct validity, that is, the development of flexibility in research design so that researchers and research both recognize and challenge the theoretical traditions within which research traditionally operates; 2) face validity, which focuses on establishing strategies such as member checking to ensure that research processes and results makes sense to others and truly reflect the participants' experiences and, 3) catalytic validity, which results when participants and/or the broader community feel energized or re-oriented in some way by the project through the development of new understandings or the altering of ways of thinking about or responding to social issues (Ristock & Pennell, 1996: 50).

Lather's constructs of validity are highly political and participatory in nature, themselves challenging the 'objective stance' of traditional inquiry. Catalytic validity, in and of itself, ensures that research results are used beyond simply building knowledge, rather, it suggests that knowledge itself must be transformative. While Lincoln and Guba

(1985) do not make such a claim in the development of constructs of trustworthiness, they do provide further detail for ensuring data are “valid” both to participants and those who may be effected by the results. As such, they contribute to the development of rigor in qualitative research.

According to Lincoln and Guba (1985), establishing trustworthiness is an ongoing process which takes place both in data collection and analysis. They list these techniques of developing trustworthiness as “credibility”, “transferability”, “dependability” and “confirmability”. Each are directly related to activities in the field which promote and ensure these criteria are met. These are:

1) activities in the field which increase the probability that credible findings and interpretations will be produced- prolonged engagement, persistent observation, and triangulation; 2) an activity that provides an external check on the inquiry process- as peer debriefing; 3) an activity aimed at refining working hypotheses- negative case analysis; 4) an activity that makes possible checking preliminary findings and interpretations against archived raw data- referential adequacy; and 5) an activity providing for the direct test of findings and interpretations with the human sources from which they come- member checking” (McPhee, 1997).

Each of these techniques is discussed in detail with their application to the present study.

**Credibility: Activities that increase the probability that credible findings and interpretations will be produced**

#### **1) Prolonged Engagement**

Prolonged engagement is a strategy of “staying in the field” long enough to build trusting relationships and to ensure understanding of context from which participants’ stories originate (Lincoln & Guba, 1985: 301). This is a particularly important strategy for research on ethnic and “racial” minority women who may have negative historic

experience as subjects of research which served to further marginalize and oppress them (Reinharz, 1992: 64). Prolonged engagement is a reflexive process in which researchers must be constantly sensitive to “gendered behaviour, racism, cultural misogyny and coping behaviors” (Reinharz, 1992: 64). My own previous experience as a professional working in the homecare field provides me with a history of prolonged engagement which originated eight years ago. Having worked in elder care services gives me a deep and rich understanding of the field not available to those without this prior experience. In addition, prolonged engagement in this particular setting was established through intensive and ongoing involvement at *Eldercare* for a period of 7 months. Relationships of trust were built during this time, which was evidenced through the increasing level of openness and trust awarded me as researcher and colleague.

## **2) Persistent Observation**

Persistent observation refers to the researcher’s task of remaining open to multiple dimensions and focusing on relevant information in detail, providing depth to analysis (Lincoln and Guba, 1985: 301). To satisfy the criteria of depth, I conducted in-depth interviews with older ethnic and “racial” minority women, ethnically and “racially” diverse staff and community workers, the majority of whom were women and thoroughly explored the agency’s policies and procedures as well as maintained an office in the setting for seven months. I provide in the section on analysis and in the audit trail attached as Appendix 1, evidence of how I stayed with the data, analyzing it consistently and through a variety of layers of specificity in order to ensure adequate attention to both detail and themes within these data. This process of analysis was consistently applied to transcripts, textual data and participant observations. Flexibility was another essential component of

my data collection and analyses so that I remained open to multiple and complex voices. Thus, as is consistent with the constant comparative method of Grounded Theory, I adapted analyses and sampling in keeping with the emergent themes of the research process thus remaining flexible and responsive to the data. Finally, I used participant observation and on one occasion interviewed the same person more than once in order to ensure complete information was gathered, contributing to persistent observation.

### **3) Triangulation**

Triangulation refers to utilizing different data sources and types to gather data about the same topic (McPhee, 1997: 50). This strategy was embedded throughout the research study as part of its design. Triangulation was achieved through incorporating individual and group interviews with older ethnic and “racial” minority women and their families, agency workers (case managers, service providers, intake workers, placement coordination workers, and managers), ethno-specific and multicultural community and hospital workers, textual data, and participant observation.

### **4) Peer Debriefing**

Peer debriefing requires “exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purposes of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (Lincoln and Guba, 1985: 308). It provides a basis for probing information, exploring, expanding, defending or reconsidering positions, and testing ground for evaluating method and design (McPhee, 1997).

Peer debriefing was continuous in the current study. I had bi-monthly meetings with my supervisor as well as regular meetings with colleagues (a feminist-gerontologist to

discuss components of gerontology and health care, including health care restructuring issues and the views of the *Eldercare* by hospital social workers, as well as colleagues who specialize in the area of anti-racist practice in order to discuss components of anti-racist practice and institutional change). In the last few weeks before I went to Montreal I did peer debriefing by presenting to a group of social workers at the “agency”. As well, I did ongoing peer de-briefing with a woman of colour who worked at the “agency”. Finally, I presented preliminary findings to an umbrella organization of agencies in Area P that provide services to seniors. Feedback from this session proved to confirm the relevance of my findings to date. I also presented to two committees of *Eldercare* about data collected as I went along to provide feedback to and receive feedback from the agency and encourage a continued collective process. These were a meeting of the Board of Directors (Nov. 19) and the Team Managers (Nov. 26).

#### 5) Negative Case Analysis

Negative case analysis refers to the refining of information as more becomes available. In particular, the researcher searches for opposites in order to strengthen and challenge results obtained to date (McPhee, 1997: 51). Negative case analysis is central to the Grounded Theory approach and thus was incorporated into every stage of analysis and data collection. Negative case analysis is also central to the larger goals of Institutional Ethnography for it is not necessarily what people say in common that is important, but the gaps between what people say and do that render visible the operating and ruling practices of agencies. Therefore, in seeking out negative case analyses, the researcher becomes more adept at locating the points of disjuncture which lay underneath the “common” and therefore the potentially “institutionally practiced” responses. As described on page 136,

**this process was integral to theoretical sampling and the development of working concepts and hypotheses.**

#### **6) Referential Adequacy**

**In order to achieve referential adequacy, researchers must keep a portion of raw data for future reference, recall and comparison. In keeping records of all data, including tapes, transcripts and notes and in writing both the audit trail and reflexive journal, referential adequacy was achieved.**

#### **7) Member Checking**

**Member checking, as outlined by both Lather (1991) and Lincoln and Guba (1985) is a strategy for ensuring that participants have adequate opportunity to review both the research process and findings to see if they 'ring true' for them. This was achieved in the current study in a variety of ways. The research advisory group, made up of visible minority and white workers at the agency, reviewed the research critical path, consent forms and other material before the research proceeded. This group also acted as a focus group which met three times to review preliminary findings. The constant comparative method of analysis ensures that findings were continually brought back and talked about with participants as the research proceeded so that all findings were ultimately reviewed. Participants were all given an option to receive and review their own transcript, thereby giving them the opportunity to add, delete or reflect on their responses. Finally several participants have agreed to read the document draft to ensure its resonance.**

#### **Transferability**

**Transferability refers to the use of thick description to enable the reader to reach his/her own conclusion about whether or not transferability is possible with respect to the**

analyses and interpretations provided. In the current context, detailed and adequate quotes are provided to back up analyses in the text. In addition, both purposeful sampling and the inclusion of a wide range of information in selecting data sources and participants also ensure transferability.

### **Dependability**

Dependability is the process of the research, of coding and analyzing of data, which is sufficiently well documented so that this study can be recognized as having been conducted in a consistent manner. Here, using Grounded Theory strategies for analysis made the issue of dependability more easy to articulate for there is a distinct set up processes by which qualitative analysis is undertaken. Both the section on analysis and the audit trail included in this text provide evidence of dependability.

### **Confirmability**

To confirm the relevance and appropriateness of findings, the reader must be able to examine the research product itself. The findings, interpretations and recommendations must themselves be supported by data and show that there is internal coherence, rendering the overall conclusions of the inquiry acceptable. Here the adequate and appropriate use of quotes from a variety of participants, the audit trail, and references to other textual data and participant observations provide evidence of confirmability.

### **Construct Validity**

Construct validity is the development of flexibility in research design so that researchers and “researched” both recognize and challenge the theoretical underpinnings within which research traditionally operates. Once again, triangulation of data and the use of the constant comparative method ensure flexibility in design of the current study. This

study is undertaken from a fundamentally iterative stance, that research itself must both emerge from the voices of those who experience the problem in the everyday and move beyond those individual voices to capture the relationships that rule this everyday experience which are largely invisible to those individuals. In order to achieve this analysis, it become essential to be flexible in research design and process, to move where analyses take you, to listen with ears that extend beyond the everyday utterances but to take care to listen to and document the voices of women as they speak their own truths. This iterative process is fundamentally challenging to the status quo of traditional research and to the status quo of institutional operations and procedures.

### **Face Validity**

Face validity focuses on establishing strategies to ensure that research processes and results make sense to others. Once again, member checking and peer debriefing took place on a regular basis and were embedded in the process of analysis known as the constant comparative method so that face validity was adequately achieved. Providing thick description of the research participants and many quotations also enhance face validity.

### **Catalytic Validity**

According to Lather (1991), catalytic validity or catalytic authenticity results “when participants and/or the broader community feel energized or re-oriented in some way by the project, either through the development of new understandings embedded with strategic implications or the disruption of current ways of thinking about or responding to social problems” (Ristock & Pennell, 1996: 50). While it is impossible to state for certain if catalytic validity will be achieved at the point of writing, as I have yet to return to the

agency to present the final document, several activities occurred during the data collection and analysis phases of this research that are worthy of note and point to emerging steps in catalytic validity being achieved. First, it is important to recognize the important contribution and level of trust that the agency and its workers put into the research study itself. This is especially significant given that the project was not generated by and through the agency. Instead, I, as the student, approached the agency and asked if I could undertake my research there because of the relevance of the setting and the larger community to my subject matter. By agreeing to be the site of this research and participating fully in its development, the agency and its workers really put themselves out and opened themselves up. This was achieved through their acceptance of me into the culture of the agency and trusting me with some very delicate and sometimes troubling information. Given the critical nature of this study, this level of trust was truly extraordinary. Clearly, despite institutional and governmental processes which make institutions “stuck” in power dynamics and in old ways of practicing, the workers in this agency exhibited immense good will and a desire to critically look at themselves and improve services by allowing me in. The research process was as inclusive as possible and I did set out to develop many opportunities for sharing of information throughout the study. Rather than withhold findings until the study was fully completed, I engaged in a process of informing and presenting my emerging ideas throughout the data collection phase. This meant presenting preliminary findings not only to the Research Advisory Group, but I also presented at Team Management meetings, board meetings and informally to the Executive Director and other managers throughout the study. What this meant was that a process of discovery and critique regarding agency processes was

ongoing. For example, the lack of representation of persons of colour in management and the lack of training on issues of interpretation and ethnic-matching were quite regularly brought up as issues for the agency to tackle. In addition, the continual problem of high case load was also discussed. Once again, while I cannot claim that the research is the cause of change at the agency, it is clear that it did have a part to play in the moving forward of certain actions at the agency which are seen as positive. For example, when the Executive Director told me that they had developed a new layer of management to try to deal with time constraints and hired visible minority workers for five out of the six positions, she told me that my work helped to reinforce the need for this change. In addition, a visible minority worker has taken on the role of education around issues of diversity at the agency and there has begun to be a consensus that these efforts are vital to the growth of the agency. Finally, and perhaps most importantly, it is hoped that this study will contribute to the larger project of Institutional Ethnography; a project which seeks to explore the social organization of knowledge (Smith, 1987a). Therefore, the results of this study can be compared to other such projects already undertaken. Common and divergent observations, concepts, patterns and themes can be examined in order to increase the dependability of the research, improve the methodology and enrich our understanding of how ruling relations shape the experience of marginalized people.

### **Educative Authenticity**

Although this research was not undertaken as a participatory action project, it seeks to expand our understanding of the way social processes impact on the construction of access from the standpoint of ethnic and “racial” minority elderly women. In engaging with the workers at *Eldercare*, through gaining their trust to allow me access to them and

**their worklife and clients, they began to become more informed of the issues I was exploring. This process of consciousness raising and exploring new ideas is part of the goals of Institutional Ethnography. It is also one of Erlandson, Harris, Skipper and Allen's (1993) criteria for achieving educational authenticity in research.**

## **Chapter 5: Setting the Context: Socio-Demographic Characteristics of Ethno-“Racial” Minority Elders in Area P**

The present chapter highlights selected socio-demographic information on five ethno- “racial” groups living in the community in which the institution under study is located, hereafter referred to as Area P. The purpose of highlighting these socio-demographic data is to provide a context from which to understand and interpret the qualitative findings which follow.

### **Data Source**

The quantitative data used in this study were retrieved from the 1996 Canadian Census which provides a 20% randomized sample of the entire Canadian population with regard to questions of ethnicity and visible minority status. From this comprehensive data set, a specialized data set was requested from Statistics Canada which compiled socio-demographic characteristics of five of the largest ethno- “racial” community groups in the neighbourhood in which the organization studied is situated (Statistics Canada-Census Division, 1996). The socio-demographic data included in this data set are: age, sex, living arrangement (persons are either unattached: living alone or with non-family persons (this latter category represents about 1% of the population overall) or living with family members), immigration status, knowledge of English or French and poverty status (living below the low-income cut-off line). The data set focuses on socio-demographic characteristics which have been shown, in previous studies, to have a particularly detrimental impact on access to care (See Chapter 2 for a discussion of these indicators) and which are retrievable through the Census. It is not intended to be exhaustive but to

provide a “picture” of some of the conditions under which elders from five of the major ethnic and “racial” minority groups in Area P live.

### **The Definition of Ethnicity and Visible Minority**

The question of defining ethnicity in Canada is a difficult one. In the current context, definitions are limited to the concept of ethnicity and visible minority as defined by Statistics Canada (Statistics Canada, 1993). According to the Canadian Census, ethnicity is defined through ethnic and cultural group ancestry. The Census question asked, “To Which Ethnic or Cultural Group(s) Did Your Ancestors Belong?”. Included in the notion of ethnic ancestry is the concept of homeland. Country of origin (homeland) is the most common option for respondents on the Census (ie. my ancestral ethnic or cultural group is African or British or Italian). Respondents to the Census were able to choose up to four ethnic affiliations thus allowing for multiple conceptions of ethnic ancestry. These multiple ethnic responses, however, were not reported in order of priority so it is impossible to determine which is the strongest ethnic identifier for any one respondent. The current database sought to develop a hierarchical data set which maximized responses while at the same time, avoided double counts of the population. Thus, for the present sample, no persons were counted in more than one ethnic group. Ethno- “racial” groups counted through the ethnic origin variable are Greek and Italian. For the purposes of the present study, anyone who stated they were both Greek and Italian were included as Greek. This was done because the absolute number of Italian persons was large enough so that any reduction in number of Greek-Italians identified through their incorporation as Greek did not significantly alter the analyses.

In 1996, Statistics Canada included a second variable entitled Visible Minority in the Census which was meant to incorporate components of “race” identity into the Census. Previous to 1996, persons of colour were able to identify only through the question on ethnic origin/ethnic ancestry in the Census, which, based on a single component of identity, proved to be a more restrictive approach. This new question on Visible Minority introduced in 1996, was meant to be a more expansive, inclusive grouping. Based on the work of the Royal Commission on Equality in Employment, it had previously been determined that ethno-racial communities were being dramatically undercounted through the ethnic origin variable alone. Many were not reporting themselves on the ethnic origin variable. For example, in 1991, only 224,000 persons reported their ethnic ancestry as Black in the Census. By using a larger construct, adopted by the Royal Commission on Equality in Employment, Statistics Canada was able to incorporate those people who had not reported their identity as Black on the ethnic origin question but were “likely to be Black” based on responses to other variables such as place of birth, language and religion (i.e. a person who was born in Haiti and whose mother tongue was Creole would “likely” be Black and thus was included in the count), the count of Black persons in Canada more than doubled through the Census to over 504,000 in 1991. Clearly, the implications of using this approach in identifying the Black population are profound in terms of understanding communities, as well as in terms of these communities’ claims to public resources and opportunities. Because of the success of this approach in counting Blacks and other visible minority groups, an effort was made to include a visible minority variable in the 1996 Census which would more accurately count, and therefore reflect, visible minority populations in Canada. The question simply

identified several ethno- "racial" categories and asked respondents to tick off which category applied to them (i.e. Black, White, Asian, South Asian). The responses to the visible minority variable closely reflect the earlier composite variable approach undertaken by the Employment Equity Commission thus verifying its validity. In the current study, counts of South Asian, Black and Chinese persons were collected through the Visible Minority variable.

Undercounting ethno- "racial" persons has historically been a major problem of the Canadian Census. For many ethnic communities, identifying oneself as a minority on the Census is potentially threatening. Often, the historical relationship of minority groups with governments has been one of persecution and identifying oneself to government (especially on official documents or through research projects) has resulted in discrimination. The Canadian government, for example, has historically used Census counts of Aboriginal populations to settle issues, such as income transfers, against the interests of Aboriginal peoples. For this reason, Canadian Aboriginal persons may choose not to identify on the Census. Black persons, also having experienced state discrimination, may choose not to identify on the Census. Finally, immigrants who have arrived in Canada from countries controlled by totalitarian regimes may not wish to identify themselves on the Census for fear of reprisals.

Despite these limitations, the data available on ethnic origin and visible minority provide a unique opportunity for analysis. Five ethnic groups were chosen for the present study to reflect the ethnic diversity of the Canadian population and more specifically that of the area studied. Both White ethnic and visible minority populations were included in the sample. These are the Chinese, South Asian, Black, Greek and Italian communities.

Sensitively addressed, analyses of these populations can reveal valuable information about the status of ethno- "racial" groups in Canada.

#### **A Note About the Limitations Regarding Gender Analyses of the Current Data Set**

Although data on sex (male-female) were collected in the current Census data base, these data, particularly those which look specifically at age-sex breakdowns for seniors (65+), cannot be analyzed at the present time because of small sample size. When ethno- "racial" variables and sex-age variables are combined with variables on socio-demographic characteristics, the data are too small to ensure reliability of findings. It is for this reason that the data presented here consider age crossed by the five ethno- "racial" variables only. The picture presented therefore, will provide a more general context from which to understand some of the socio-economic realities facing all ethno- "racial" seniors studied, and by extension elderly ethnic and "racial" minority women.

#### **Low Income Cut Offs**

The poverty rates presented here are based on the 1996 Statistics Canada Low Income Cut-Offs (Statistics Canada, 1996). These low income cut offs are derived using a subsistence conception of poverty which states that an individual or family that spends more than a certain designated percentage of gross income on the necessities of life (ie. food, shelter and clothing) is considered poor. Each Cut Off point represents a dollar value which fluctuates by the size of geographic area in which the family resides and the size of the family unit. Family size ranges from a family of '1 person' to a family of '7 or more persons'. The geographic areas range from rural areas to cities with 500,000 or more residents. For example, a family of four living in a city with 500,000 or more residents would have been poor in 1996 if their family income fell at or below \$35,494.

See Appendix 7 for more details regarding the Statistics Canada Low Income Cut-offs used in the 1996 Census.

### **Results:**

#### **Ethno-“racial” Communities as a Proportion of the Total Population of the Neighbourhood CSD (Area P)**

The institution studied is in one of the most ethnically and racially diverse areas, not only in Ontario but in Canada as a whole. This makes it particularly important as a location for the current study. For each of the five ethno- “racial” communities studied, their proportion of the total population was higher in this area than in Canada as a whole in 1996. So for example, while 2.0% of the Canadian population as a whole was made up of Black persons, in Area P, almost 10% of the total population was made up of Black persons. This was 3.5 percentage points higher than in the Toronto Census Metropolitan Area (CMA). The same was true for each of the other ethno- “racial” communities studied. For example, while 3.0% of the Canadian population was Chinese in 1996, 8% of the Toronto CMA and 16.7% of Area P was Chinese. (See Table 1).

Excluding persons of Italian origin (who were highly represented numerically but not statistically, with over 24,000 living in Area P), each of the ethno- “racial” groups studied were over-represented in Area P. That is, as shown in Table 2, in total, 13% of all residents of the Toronto CMA lived in Area P in 1996, however, over 20% of each of the Black, South Asian, Chinese and Greek communities living in the Toronto CMA, lived in Area P. Amongst Chinese persons, over 27% living in the Toronto CMA, lived in Area P.

What these data suggest is that Area P is an ethno- “racial”ly dense and diverse community. This reality drives home the importance and legitimacy of examining the issue

of ethnic and “racial” minority access to health care within this area. All together, the five ethno- “racial” groups under study made up over 48% of Area P’s total population in 1996.

### **The Proportion of Elderly**

In 1996, 11.5% of the Canadian population as a whole was made up of persons 65 years of age or older. This figure was similar to that of Area P with 11.3% of Area P residents being 65 years of age or over. The proportion of aged among ethno- “racial” communities studied both in Canada and in Area P varied considerably from the general national and Area P averages, although for the most part, were similar to each other. In Area P, only the Chinese (10.4%) and Italian (11.2%) communities had a similar proportion of elderly to the general population (11.3%). For all other ethnic groups studied, the proportion of elderly was considerably lower than the overall rate with Black (4.3%) and South Asian (4.6%) communities having the lowest. These trends were similar when comparing Area P with the Toronto CMA as a whole. Finally, both the Chinese and Italian communities of Area P had a proportion of seniors more than 1 percentage point higher than the national rate for these ethno- “racial” groups. Table 3 describes these relationships.

### **Gender**

It is well understood that the proportion of elderly in the Canadian population is not uniform, in fact the population of elderly people is increasingly made up of women. There is a distinct imbalance overall in the sex ratio among older people and women are now expected to live an average of seven years longer than men (Baker and Dryden, 1993:288). In Canada in 1996, the proportion of older women was almost four percentage

points higher than that of men. Fifty-six-point seven percent of all elderly people in Canada were female and 43.3% were male in 1996.

This imbalance in the gender ratio of older persons in Canada is reflected among ethnic communities as well. There was a larger proportion of females than males in elderly ethnic populations in 1996, although the gap was generally smaller amongst ethnic communities than among Canadian seniors generally. Within Greek and Italian communities nationally, the gap between elderly males and females was virtually non-existent. In Area P these trends were similar, although among Greek and Italian elders, the proportion of males was higher than females. Only amongst Blacks was the gap between males and females 65 years of age and older greater than in the general population. Sixty-four-point-six percent of Black persons 65 years of age or older were female and 35.4% were male in Canada in 1996. In Area P, these figures were ever more substantial with 66.2% of Black elders being female and 33.8% being male. (See Table 4).

This unique feature is consistent with previous studies undertaken among ethnic elderly communities in Canada (Brotman, 1998). In the Brotman study it was found that differential findings among Black seniors in Canada were partially explained by Canadian immigration patterns experienced by Black communities during the 1950's. Popularly known as the Canadian domestic scheme, immigration policy at that time, dictated that only single Black women, mostly from the Caribbean, could immigrate to Canada to take up domestic employment. By allowing only Black women to immigrate and limiting the entry of their families and Black men, the domestic scheme of the 1950's profoundly shaped the gender makeup of Black communities in Canada in a way which still reverberates today (Cohen, 1994; Elliot & Fleras, 1990; Ng, 1992) (See Table 4).

## **Living Arrangement**

Elderly people live alone at a much higher rate than the total population in Area P. For example, in 1996, while 8.8% of all persons regardless of age lived alone, 22.2% of elderly people lived alone. Similarly, in all ethnic communities studied, the percentage of elderly people who lived alone was higher than the rate for all persons in the same ethnic group. For example, while 3.6% of all Greek persons lived alone in 1996, 10.2% of Greek elders lived alone (See Table 5).

When comparing the rates of seniors who lived alone amongst ethnic communities with the general Area P population, it was found that, as described in Table 5, the Black community was the only ethnic group which had a higher percentage of seniors who lived alone than within the general population (25.4% in the Black senior population lived alone compared to 22.2% of the general population). For all other ethnic communities studied, the rate of persons who lived alone was lower than 22.2%.

## **Recent Immigration**

Previous studies have indicated that it takes approximately 20 years for immigrants to achieve comparable levels of economic security as the Canadian-born population (Torczyner and Brotman, 1995). In this study, it was theorized that economic insecurity has a negative impact upon access. This suggests that considerable attention should be placed on the needs and potential barriers that recent immigrants might face in accessing and receiving care. In Area P, 26% of all residents 65 years of age and over, regardless of ethnicity, arrived in the twenty year period between 1976 and 1996. The proportion of Black, South Asian and Chinese seniors who were recent arrivals was substantially higher than this average with over 80% of both South Asian and Chinese seniors having arrived

during this same period (See Table 6). On the other hand, Italian seniors have lived in Area P for a longer period of time with only 2.9% having arrived in the past twenty years. Clearly this points to potential vulnerabilities within visible minority immigrant populations in Area P.

### **Knowledge of English or French**

Currently government policies mandate service delivery in the official languages of Canada, that is English and French. It therefore becomes important to know what proportion of seniors speak either of these languages. Lack of knowledge of either English or French may prove to be a significant access barrier. In 1996, as shown in Table 7, 16.9% of seniors overall, living in Area P, spoke neither English nor French. Excluding Black elders, who for the most part speak one of Canada's official languages (only 1.5% spoke neither English nor French), a higher proportion of seniors in each of the ethnic communities studied did not speak either official language. Chinese seniors (68.4%) were the most likely not to speak either English or French.

### **Poverty Levels**

Despite improvements in the income status of elderly people in Canada over the last fifteen years which have seen poverty rates for both senior men and women drop in every province (NCW, 1996:84) poverty amongst elderly people in Canada continues to be a common experience. In Area P, in 1996, 25.8% of seniors lived below the poverty line. This represents one in four persons 65 years of age or over.

When comparing the poverty rates among ethno- "racial" seniors (see Table 8), it was found that all ethno- "racial" groups studied had rates of poverty higher than the average. This is true for all communities except for Italian seniors which exhibited a

similar poverty rate to the general rate for all seniors. The poorest seniors were those from Black communities which exhibited a rate of poverty of 43.6%. Among seniors who lived alone in 1996, more than half lived below the poverty line (58.2%). Still this rate was lower than among all ethno- "racial" community groups studied. Again, Black seniors who lived alone were the most likely to be poor with almost 85% living below the poverty line in 1996.

## **Conclusion**

These data provide a context from which to understand the analyses that follow. In general, Area P is a distinct community which is one of the most diverse in Canada. Almost half of its population is made up of persons from five ethno- "racial" communities, namely Black, South Asian, Chinese, Greek and Italian communities. This means that the issues surrounding ethno- "racial" access to service are particularly relevant to institutions which provide elder care services in this area. Although seniors represent a smaller proportion of ethnic communities than they do in the general population, seniors do represent a sizeable and growing proportion of ethno- "racial" minority communities in this area. This is particularly true for Chinese and Italian communities which have larger proportions of seniors, almost reaching that of the general population. Within the Black communities of Area P, issues facing elderly women are particularly crucial to consider, given that the large majority of Black seniors, far larger than other ethnic populations or the general population, are women. Ethnic and racial minority seniors generally face a number of realities which make them vulnerable to access barriers. Although gerontological research defines access in a myriad of ways, several are of particular importance here. These are language, isolation, recent immigration and poverty

**(Brotman, 1998). On each of these indicators, seniors from ethnic and “racial” minority communities are particularly vulnerable. In Area P, many ethnic and “racial” minority seniors have exhibited significant lack of knowledge of English or French, higher proportions of recent immigration and higher rates of poverty. Different communities are differentially vulnerable. While Black seniors have substantial knowledge of English or French, they have the highest rates of poverty and are the most likely to live alone. Chinese elders are the least likely to speak English or French, have recently arrived in Area P and are also likely to live alone. Almost one-third of South Asian seniors cannot speak either official language and almost three quarters lived below the poverty line in 1996. These are just some examples of the complex nature of the lived realities of ethno- “racial” seniors living in Area P. Although it was impossible to undertake a complete gender analysis of these variables, previous studies have indicated that, particularly with reference to poverty and living arrangements, older ethnic and “racial” minority women are substantially more vulnerable than their male counterparts (Brotman, 1998). This makes understanding their experience of access crucial to the development and adaptation of services to meet their needs. With this broad overview completed, we now turn to an examination of the experiences of ethnic and “racial” minority elderly women in accessing care.**

## **Chapter 6: The Primacy of Family in Elder Care Discourse**

The role of family members emerges as a central theme in interviews with all three participant cohorts, namely case managers, community representatives and older women themselves. The issues surrounding family roles and responsibilities in the access to and experience of elder care are quite problematic. There is a fundamental gap between what older ethnic and “racial” minority women themselves express in terms of their experience of family in helping gain access to and in providing care and the ways in which the system constructs and interprets family involvement.

### **Older Women’s Experiences**

Older women interviewed for the study spoke frequently about their families when referring to health care access. This “talk” emphasized the central role that families, particularly children, have in helping elders negotiate the system. While daughters provided most of the hands-on service provision, sons were also often actively involved in instrumental activities such as those of interpretation and system-linking. This is consistent with research which has theorized a gendered division of labour within families in which sons often serve as mediator between public and private spheres by acting as the “public voice” with institutions providing elder care (Coward & Dwyer, 1990; Dwyer & Coward, 1991; Finley, 1989; Horowitz, 1985; Horowitz, 1992; Lee, 1992). This serves to reinforce women’s social location within the private sphere of the family and thus entrenches direct, hands-on care as the responsibility of female kin. The multiple roles of children were articulated by ethnic and “racial” minority women in the current study as including hands-on care, maintaining links with health care providers and case managers, transportation

**and accompaniment and general advocacy. In response to a question about whether or not the doctor sends service providers to her house, Mrs. T. stated,**

**“No, my son calls him and reminds him and then he sends them...it’s up to us...see how they do it? My son even phones Penny to remind her. She used to come here before but now he has to call her...” (Mrs. T., lines 53-55, 61).**

**In relation to accessing services, Mrs. L. described organizing her appointments around her children’s schedules:**

**“All my relatives were busy and they had to go to work. They could not drive my husband and I to see my old doctor. If we need to have chest X-ray or blood tests, my children would drive me to those places after they finished work” (Mrs. L., line 22).**

**Referring to the involvement of her daughter in helping her gain access to care, Mrs. C. described “needing”:**

**“...a strong person who can fight for you” (Mrs. C., line 29).**

**The central role of families is even more apparent among women who do not speak English. In these cases, children often took on the role of interpreter between their mothers and formal care providers. Mrs. K.’s daughter described this experience:**

**“When my mother goes to see her doctor, I need to find her an interpreter. I cannot go to the doctor with her all the time. I have to take time off work. Yesterday I took her to the doctor to have her eyes checked. The hospital only has one Chinese interpreter. When they have lots of patients who need Chinese interpreters, I cannot get one. I have to go...The home care program has been providing us with good service. I can call them. My mother cannot call them. I have to call them and arrange for everything” (Daughter re: Mrs. K., lines 47-51, 185).**

**At the same time as women expressed relying on their children to arrange services and maintain ongoing communication with their case managers, they also struggled with**

**this role their children played. Older women expressed feelings of great unease about these arrangements. Women simultaneously spoke of their desire to have their children interact with the system for them as well as their discomfort with the burdens this placed on their children.**

**The following comment by Mrs. F. exemplifies this struggle:**

**“You know this is my child and I would do the same for her but uh, the fact that knowing that she was so busy and had responsibilities of her own and to take time off to come to me, I felt guilty...I do ask them to get things done sometimes, but I also realize that they are very busy so it’s not possible. By the time they leave their work to come home it’s too much.” (Mrs. F., lines 78 & 100).**

**Women coped with this dilemma by attempting to “take care of themselves” whenever possible, to relieve some of the burden on their children. This was achieved in a variety of ways, including more actively engaging in doing things on their own:**

**“I told them ...they have to work...I could go myself. Because one is a nurse and she knows that the service would give me a taxi. I told them that I would be alright” (Mrs. H., line 108).**

**Relying on children in emergency or crisis situations only;**

**“Well I’m such an independent woman, that’s the thing. I tried to help myself, I have kids but I know they have their own lives and I cannot get a hold of them so quickly and unless something is really a big problem, I’ll get on the phone and get in touch with them” (Mrs. R., line 15).**

**Creating other avenues for support;**

**“ Kay asked me if my children could help with money but my daughter was laid off her job. She has her own family to worry about and take care of. They’re (the daughter and son-in-law) afraid that he may get laid off from his job. I didn’t want to burden them. That is why I married this man so that they wouldn’t have to worry about me and I wouldn’t be a burden. My daughter has enough problems...she has a heart condition and she lost her son...just nineteen (19) years old” (Mrs. Q., line 53).**

Or concealing information about their situations from their children;

“It is not easy for them to go to work and face their bosses... It must be hard for them. If at all possible I would not tell them anything” (Mrs. L., line 233).

These data are consistent with the literature on burden which describes the significant expression of strain that family caregivers, most of whom are women, experience as a result of the caring role (Brotman & Yaffe, 1993; Cicerelli, 1988; Globerman, 1994; Skaff & Pearlin, 1992). The quotes included here suggest that older women themselves are highly cognizant of the burden that their families, particularly their daughters, face in providing care and as such, develop strategies aimed at helping to reduce the burden their children feel. Aronson (1991) has identified that this strategic practice of mothers to manage when and how care was requested from daughters, is an attempt to lessen their sense of dependence and indebtedness to their daughters and to protect their daughters from undue strain. In this way, older women are trying to manage tensions in the caring relationship. This constant struggle to manage when and how support was requested does not come without a cost, however, as older women and their children continue to feel guilt, strain and internal conflict between the desire for self-enhancement and the need to self-sacrifice in order to balance and maintain good relationships with their kin (Aronson, 1991: 157-158). This is clearly evident amongst the older ethnic and “racial” minority women who participated in the current study.

In the end, however, individual strategies do little to reduce the burden on elderly ethnic and “racial” minority women’s children, especially their daughters. Feminist gerontologists have highlighted and exposed the gendered nature of elder care policy in

which services are defined and organized with little attention paid to the impact of such policies on female kin (Neysmith, 1997). Therefore, scarcity models of care which put pressure on families, particularly female kin, to provide care, are rarely contested. Given women's marginalization from decision-making processes in the public domain, older women's strategies to reduce the pressures on female kin do nothing to alter arrangements between public elder care services and those services provided by female kin. This gendered nature of care made manifest in negotiations between public and private spheres is also fundamentally racialized. Older ethnic and "racial" minority women require their children's help, not only to provide hands-on care which is unavailable to them in the public sector but also to help their mothers successfully negotiate the public sector. Older ethnic and "racial" minority women may require their children's involvement to a greater extent than Anglo-Canadian women because of institutional demands for cultural and language interpretation and because of conflicts between white western practices and indigenous values and understandings of the system. In addition, older ethnic and "racial" minority women's desire to free their children from burden may be more intense than Anglo-Canadian elderly women, as this desire is directly tied to their own experience of hardship as a result of immigration and, more importantly, to their reasons for choosing to immigrate in the first place. It appears that a central component of ethnic and "racial" minority elderly women's identity as immigrants is bound up with the desire to improve the life chances of their children and to provide opportunities to their children which were unavailable to them. Thus, central to elderly ethnic women's sense of self and purpose is the notion of sacrifice for the sake of their children. According to Mrs. F.,

**"I came for my boys, to make a better life for them. I came with my boys and my daughter was married at that time so she came later..." (Mrs. F., line 47)**

**Older women shared their realities of economic hardship and spoke about the difficulties that face ethnic and "racial" minority persons in their efforts to "make it" in Anglo-Canadian society. As a result, older women have expressed that children may have less time available to engage in support of elderly family members and may face greater barriers to economic security which would require them to forego family care for paid employment. As these two older women stated,**

**"But coming here most of the ethnic people are busy working, trying to be able to make...maybe double income families so it's very difficult for them even to give too much time to each other" (Mrs. F., line 106).**

**"My children had a few children of their own and they lived very far away. I did not want to complain to them. They worked very hard. They got up at five o'clock in the morning to go to work and they did not return home until after five in the evening. How could they help me?" (Mrs. L., line 52).**

**These data point to an essential experience of conflict in the lives of older ethnic and "racial" minority women requiring elder care. There are institutional pressures put on older women's families, particularly daughters, to provide care or advocate for access because of a scarcity of resources. But while women may need their families to provide care or help them negotiate the system, they struggle with not wanting to burden their children. This results in older women experiencing a double bind. This struggle is rarely articulated in gerontological research on burden. Rather, burden is typically defined and viewed solely from the point of view of primary family caregivers (Horowitz, Silverstone and Reinhardt, 1991; Quayhagen and Quayhagen, 1989). Thus, older women's sympathy**

with the pressures families face and their attempts to actively relieve their families of responsibilities largely go unnoticed. What becomes clear is that not only families feel stress when providing care and negotiating access for their elderly female relatives, older women suffer as well, attempting to juggle their need to have family advocate for them and provide care and their desire to relieve them of this burden.

### **Case Managers' Constructions**

Women's expressed discomfort with burdening their children is in direct conflict with the experience of case managers interviewed for the study. Case managers stated that often, older ethnic women complained to them that their children did not help out enough and that they wished their children were more available to provide support. As these workers stated,

"My experience is that they want their children around more. And they won't feel... they feel they should be there, they are the mother and they feel that the kids should be there" (Doreen, line 57)

"...there are cases when the senior feels it is their due to be looked after by the child, but the child says I'm holding down a job or two jobs and I'll do it in the evening or I'll do it on the weekend but I need to have someone come in and do it another time" (Olive, line 85).

This disjuncture between what workers say and what women say is an important area for analysis. What accounts for the differences between the experiences women shared with the interviewers and those case managers reported hearing?

In order to answer this question, it is essential to examine the ways in which the system constructs access to health care and subsequently constructs elderly women themselves. This construction will fundamentally shape the interactions between elderly ethnic and "racial" minority women, their families and service providers. It will also

**influence both older women's experience of care and the way in which they present themselves to workers in order to communicate their needs effectively or to be understood within the system.**

**Although there is a written eligibility guideline at *Eldercare* which states that "service is not denied if family is not required or available to assist in the treatment program", workers spoke repeatedly about the "unstated expectations" regarding family in the operation of elder care services. They explained that, while the lack of children or other family members living nearby is not a condition to gaining access to elder care services or to increasing levels of service, in reality those who have family members around to provide care do receive less attention, such as reduced frequency of home visits from workers. One worker explained how those elders with family members do not get visited as often:**

**"so the ones I feel most comfortable leaving are not the ones that live alone, they're the ones who live with family members" (Greta, line 103).**

**Another worker stated,**

**"so it seems to me they were writing that person off because there seemed to be supportive family..." (Olive, line 11).**

**According to a hospital worker,**

**"...because people can have large support systems and that is on the chart and people look through the chart. So we don't need to put in as much [service]. I think it's an unspoken expectation that if a person has family, the family should put in their fare share...for some of the care. And again that's fine and good" (Marge, lines 53-54).**

Agency documents also reinforce this perception. Listed as a reason for non-admission on the agency's assessment form is "family participation not available". This criterion is specifically applied only when 24 hour palliative care is required. According to one worker,

**"Family participation not available" – this is for 24 hour care needed and the agency cannot put in 24 hour care and therefore with no family involvement the person needs to be placed. 24 hour care for palliative care is only available for a short period, for a total of three months. The doctor has to say three months to initiate palliative care and rarely does it go over this amount of time" (PO 12).**

Clearly this quote points to the way textual documents translate government and institutional priorities to the workplace. The term "family participation not available" is a strong indicator of the requirements of family involvement to provide more intensive home health care services, even when these services will only be required for a limited time.

Workers also spoke about the expectation that children become involved in some capacity, either through providing supplementary care or in mediating relations between elders and the formal service system. It is only when these children are not available that other more formal arrangements will "kick in":

**"Do we say you have to do it daughter? No, we can't really. We have to individually assess what the relationship is between the daughter and the client. Is there care needed that can be provided first of all with that person? Are they willing? Are they able? Do they have other things going on like small children? Do they have long working hours or those kinds of things? Do they have a back injury from lifting mom to the tub before? So usually there's a lot of discussion about basic things. And often compromise and suggestions made. Perhaps if we get some equipment it would be manageable by you or perhaps we can teach you some of the dressings or the wound care and we'll have the nurse come in twice a day at the beginning and then we'll have you do it some times and then we'll have the nurse twice a week. Usually there's some bartering back and forth" (Olive, line 83).**

The notion of bartering here is quite telling of the ongoing dilemmas in negotiating care arrangements between workers and clients. One might ask oneself who barter best, professionals with a knowledge of and experience with the system and how it operates or elderly female clients and their families, most of whom are female kin, who have little, if any, power to shape how and when care is provided? Clearly in situations where bartering becomes necessary, elders and their families are likely to lose out. This is particularly true for families in which the elderly client speaks no English or French.

“...that will create some inconvenience if they cannot have the homemaker who speaks the same language or the service provider who speaks the same language. In that case, I will try to uh... to ask the family to write out some roles for the homemaker. At least the family can give the instruction to the homemaker on what can be done. Or in case of a need for uh... interpretation then we call the family. I will try to suggest that. Yes. I think there is the ATT. I haven't used that yet. It's not really a major problem so far. Yah, I've been able to like call the family and ask them to meet with the client when I need somebody to help me, interpret for me. [A client without family] is in real trouble. Yah, that's true. I will find they are sometimes... is at risk. Sometimes...” (Kathy, lines 189-195).

In other words, there is often silent pressure placed on available ethnic and “racial” minority children to take on the role of “link” or “mediator”, particularly when linguistic or cultural barriers to care are more likely to occur. Workers stated that this pressure has become more prominent in the current climate of health care cutbacks and as a result of growing populations of elderly people requiring community based health care services. The combined effects of the rise of the proportion of elderly people in the population, restructuring in hospitals resulting in shorter bed stays and cutbacks in community health and social services which have occurred over the past several years in Ontario, have

resulted in a situation in which more elderly persons are needing fewer public elder care services. As a result, there are fewer available hours for such services as homemaking and nursing to individual clients, although the total number of clients has increased dramatically. In effect, more people are getting fewer services. Previous research has shown that, in this type of climate, services end up being downloaded on to the backs of families, mainly women as mothers and their daughters, and it is these women who end up filling in the resulting formal care gaps (Aronson, 1991; Chappell, 1993; Neysmith, 1997).

As one community worker stated,

“We approached [*Eldercare*] already but they can only provide that service... once or twice a week... it’s no use, because you know you have to take medicine maybe three times a day, right? But we cannot help them, that’s why now... only we can involve the children... we invite them. They have to come every day, my goodness... every evening” (Maya, line 30).

This reality, too, is racialized. For ethnic and “racial” minority children must not only provide more direct service to their elderly parents, as do mainstream children, but they must also serve more concretely as the link between the formal sector and the parent.

As one service provider stated,

“It’s probably got to do with time constraints, like we have x number of visits we have to do daily. They’ve (other service providers) got even more they’re supposed to do a day. So it’s probably got something to do with they don’t have time to go look around for interpreters. They tend to use families a lot to do interpreting which probably, in the course of their work, most of the time probably is appropriate” (Pamela, line 172).

Arranging services, making telephone calls, being available to provide interpretation not only to case managers but to service providers, are all central roles of ethnic and “racial” minority children, which may not be necessary for mainstream children. Although it is unclear as to whether the provision of formal interpretation was ever a

priority in elder care services, paying for services such as linguistic or cultural interpretation is presently strongly discouraged in institutions:

**“Well I think what I would say is... because of the uncertainty in the last few years, pennies had to be watched very very carefully. And although we had a translation service we were not really all that encouraged to use it. I think that’s not the case here. But you would first try and find an individual, a family member. That isn’t always the best scenario. Second, if you couldn’t find someone within the family, you would try and find someone within your own office, whatever, uh... or some provider that speaks the language to help you. And thirdly, last resort you would go to the telephone translation service. But as I say, when it was introduced it was suggested that it was very expensive and uh.. It wasn’t to be used with extravagance and I think having come through that I still don’t think of that, I’ll go to one or two and if I can’t find anyone within the one or the two, meaning here or with a provider situation, I may struggle along with a family member” (Greta, lines 35-37).**

Not only do elder care agencies have less money available to pay for these services, but ethno-specific agencies in the community which used to be funded to provide advocacy and interpretation services for members of their communities in their interactions with public institutions, are losing these components of their budgets, rendering formal interpretation a thing of the past. According to one community organizer,

**“And even people ask here sometimes whether we would be able to provide an interpreter but the outreach is prohibited. There is no funding for us to do outreach work. If we have any volunteers then of course we help them...[but] in many of the cases we never provide it because we don’t have such large numbers of volunteers with us. And we see people at appointments, you may have seen in the waiting room and we can’t go and sometimes it takes about five or six hours for us to go while people are waiting here in large numbers, so we can’t go and wait for six seven hours with one person. Then mostly they [governmental funding body] count the number of clients we serve so actually we can’t give our service to those who need outreach service” (Joe, line 7).**

**A case manager also expressed this problem:**

**“Certainly my experience has been with some of the ethno-specific agencies, the way that they receive their funding is so lacking that they are very, very stretched and you know sometimes we try to negotiate, you know, collaborating on servicing the client together and they just, a lot of them there's just no way they can come into it, their doing a lot of you know basic stuff where clients access them in their office, not home-bound clients which are the ones we serve. So it's difficult to really take advantage of some of the ethno-specific agencies” (Pamela, line 48).**

**As a result of these systemic gaps, workers in the system face the added pressure of finding informal sources for interpretation between themselves and their clients. Increasingly, children are called upon to bridge the language and cultural gap between clients and service providers. It is only if and when these children are not available that alternative resources are put in place, whether informally through connecting to agency staff who speak other languages or by using such services as telephone translation. Rarely do these professional services include face-to-face contact. More often than not, these interpreters work over the phone. This means that the child is frequently the only on-site interpreter between their mother and case manager or service provider.**

**Compounding these problems is that, in an increasingly financially and resource strapped public social service sector, workers are called upon to do “more with less”. Larger and more complex caseloads have further problematized the development of relationships and opportunities for communication between workers and clients. In the case of work with ethnic and “racial” minority women, the reality of “less time” puts added pressure on families to get involved as the central “link” between their mothers and case managers. After all, it takes more time to communicate with an elderly woman who speaks little English and for whom the formal sector and the way it operates is foreign. Children and other family members are seen as the most capable of interpreting the culture**

and language of their mothers to the case manager in a way that is understandable by the standards of Western health care practices. They are also the most capable of interpreting these health care practices, expectations and rules to their families and ensuring compliance. As the following workers stated,

**“It’s usually family who will better able to express and articulate exactly what it is...you know she is very supported by her family who would speak on her behalf when accessing care or help” (Olive, line 20, 126)**

**“Uh...the client though, didn't speak English and would not have been able themselves to explain what they needed. It was only because there was a younger...a niece actually...to explain the whole story and had... if I didn't have the niece, if I needed a translator, I think it might have been fairly difficult to get one. (Greta, line 13)**

**“If there are some strong advocate family members they may be keeping an eye on them, trying to make sure the home also looking after...or trying to communicate with the home. Cause the family could play a very helpful part in verbalizing what the client usually needs, what her daily routine prefers to be, what’s her habits or that kind of thing... the family will have to play a more important role, supporting the seniors in the home, So in these kind of situation it helps if the family is supportive” (Liane, line 21-22)**

**“that has not been a major major problem regarding the language barrier because usually a family member would be able to speak” (Kathy, line 261).**

**This invariably smooths out and speeds up the process for case managers, not being required to attempt to bridge these gaps themselves, although it may limit the capacity of the client to determine her own needs, make decisions about and modify care plans. In the end, case managers and service providers find themselves in positions of requiring family’s involvements to help them “keep up with” their caseloads.**

Finally, workers are increasingly expected to juggle the competing demands of clients and those of the system which are focused on efficiency and the managing of scarce resources. So workers are forced to focus on how resources can be saved for those who truly need them. In this environment, workers are put in a bind, struggling to balance the needs of both the institution and the client. The scapegoat for this struggle is often the family, particularly the daughter. If families are perceived as being available to provide care, then workers are often expected or themselves expect that families “should” do “their part” to reduce burdens on the system. Workers, in fact, have expressed frustration when dealing with families who are “around” but who are not perceived as “helping enough”. This was expressed by a number of workers:

“When we do our assessment though, we zero in on who’s there in the daytime. If they are there in the evening and on weekends, we often say “well, I’m sure they’ll probably help you, will they not?” And sometimes we almost phrase it like that “would they not help you? Would they not supervise?” Surely if you just needed a little help, they would help you?” I’m thinking, “they will, won’t they?” I know that’s a bad way of putting it.” (Olive, line 140).

“Of course you’ll find a lot of daughters that are calling for service for their parents that really, in my opinion, could do it for them, but because the service is there... they’re calling for it, you know” (Elaine, line 45).

“... this one particular person that I remember, can speak the language can really get around and manoeuvre through the system and she actually told me stuff that I wasn’t aware of and she told me... cause I said to her “How about asking your daughter?” and she says “No I don’t want to involve any of my children. They’re all busy, they all have busy lives, they have young children and you will do just fine”. And I had to deal with some resentment there, myself at the personal level because I felt, you know... this is not fair cause she was just leaning a lot on the service that were available, you know just using them... in a way I was proud of her for doing that but at the same time I felt “Gee, you know the kids have some responsibility”. She was a new immigrant so there was that issue of the sponsorship to it. I

had to go talk to my supervisor. I said “you know I don’t think that this is fair” and she said “well, that’s not something that I need to get involved in”. That was a tough one” (Ann, line 58).

“and again, those sponsored immigrants, the children are responsible for ten years, right? If we look at it realistically, does the other taxpayer have to put their part for a person who is coming for example a few years? I mean, part I see money is for essential use, not lavishness because our population is getting older and their demands are going to be more. So for me essential needs, there should be money, not lavishness because someone said they’ll do for ten years, if they said they’ll do it for ten years, they should do it for ten years. Our taxpayers shouldn’t be expected. But there are exceptions to the rule, we shouldn’t punish them for not...” (Carol, line 59)

The paradox is that workers expect families to function as interpreters, care providers and negotiators, yet have strong opinions and positions on the “shoulds” and “oughts” of families. Families are “barterers” without currency or leverage because of both personal and institutional expectations held by workers, who also hold the purse strings.

This discourse gets reinforced and racialized through the mythology of the extended kin network. Several authors have spoken about the myth of the extended kin network. As described in the literature review section, there is a large body of ethno-gerontological research which theorizes that ethnic persons take care of their elders to a much greater extent than Anglo-Americans or Anglo-Canadians and research in this area tends to look at this phenomenon as a given within ethnic families. As discussed in detail in Chapter 2, this research, labeled “folk research” by some more critical of the generalizations embedded in this research, has led to conclusions that, within ethnic families, children and other extended family members maintain a value of family care which in turn, results in increased commitment to and hours of care provision by ethnic family members. This trend has been popularized by the term “ethnics take care of their

own". Although there is a growing body of literature which contests the assumptions inherent in "ethnics take care of their own" ideology by pointing to changes taking place within immigrant ethnic families through assimilation and the taking up of western values and practices by second generation kin, perceptions regarding the involvement of kin networks in the care of older ethnic people are still omnipresent among health care professionals.

"I think there are perceptions like how the Chinese population might look after the old lady, or any other group similarly" (Olive, line 8).

"I just recently had an incident here where someone was referred but they were referred by the family. The family had brought up the need for services at home to the resource nurse and he came to me "Oh by the way the family of so and so want home care. I don't know what they want homecare for really. There's a very supportive family. I don't know what they want" (Greta, line 10).

"...often with diverse people culturally there is a lot of family involvement that really participate more than we realize in their care. So I consider that really important" (Melanie, line 11).

As a result, sometimes ethnic families who do not provide care are perceived even more strongly as being non-compliant, uncaring or abusers of the system.

"I would phrase it in the way, I would try to get the person to tell me about what is going on in their life instead of making a judgement "if this person is living with you why isn't this person doing so and so, so and so, so and so?" Uh... I would say you live here with how many people and what do they do? And not ask any questions at all about why this person can't because usually you just get because they're busy. Or they have their own life or this crap... Uh... but if you can sort of try and figure out from what they're trying to tell you, where everybody fits into the picture then you could usually figure out why it's so important to this individual, that extra hour of homemaking or that extra hour of nursing visit... and really if it's really over ... over done... uh you know, you do have to make the hard call

and you do have to say “well, I’m really sorry but I just can’t offer you this service” and try and help them find some alternatives”(Greta, line 29).

The use of the terms “this crap” and “over done” in the above quote exemplifies the level of frustration which is sometimes apparent in workers’ “talk” about family involvement and the demands families make on the system. There is a clear expression here that the request for additional support by client and family is unwarranted, despite the worker’s statement that she will probe to identify what other burdens the relatives of the client face which might have an impact upon the care they provide to their elderly relative. What is apparent is that what is stated practice and what is felt about ethnic families’ lack of involvement are not always aligned.

Ethnic and “racial” minority workers in the system also fall prey to this ideology and would sometimes chastise ethnic family members, particularly daughters, for not taking their responsibilities seriously and for abandoning values which may have been held in home countries:

“I don’t relate it to the fact that they’re coming but sometimes I myself think you know, there’s so much there’s so much that is offered here in this society and uh... but they quickly getting uh...acculturated where they’re asking and asking and nobody wants to do anymore at home. And the ethnic non-White are fast falling onto the same thinking. I had one lady call me this morning and she was from the Philippines and she works evenings and she was telling me her mother is at home and in the morning she wants to sleep in but she has to get up to help her mother. So I said like what’s wrong with that? You know? And I said look I can hear... I said to her I can hear that you’re from another country and I recognize it as Philippines and I’m from [...] and in our country if our mothers needed help we gave it. You know. There was no problem with giving it. Now what’s so difficult? Why do you think now you have to have somebody to come do it? You know? I said it’s just the society we’re in, so what’s wrong with helping your mother in the morning and then going back to bed.. Cause your mother goes out to day care four days per week. So that is enough of a relief that she’s getting from 9 o’clock in the morning till 3:30. I said it’s

just like having children. You get up, you get your children ready for school, and you go back to bed if you're working your evening shift. So you can look at your mother like a child. You help her, she goes off to day care and then you go back to bed. But this society has her into thinking you gotta have help" (Elaine, line 37).

In this climate and as a result of these systemic pressures on families in general, and ethnic families in particular, to provide care, it is likely that only those clients who express a lack of available social support who will be able to get a little more service from the public sector, thereby providing their already overburdened children with a much needed break from caregiving. As women learn this "unstated policy", they may realize that "playing up" their lack of support will increase their chances of receiving more homemaking services. The result is that the system itself may be forcing women to take on the voice of "complaint" or "pathology" in order to get their needs met. Despite the "formal" statement that institutions do not require families to be involved in care, the subtle informal expectation is that they will provide some care and manage the negotiations of care. Reliance on families, particularly female kin, is made more evident among ethnic and "racial" minority elderly women, especially those that do not speak English. So, in the end, elderly women, who are attempting to get more service and relieve the burden on their children might have to re-create themselves in the eyes of the system as people with little support and family intervention.

Older women in this study have to both rely on their children to negotiate care, access care and manage care while downplaying and complaining about their children's involvement. They not only experience guilt at asking their children for help, they also had to recreate themselves as passive users to get more formal care from the system. This

dilemma may be quite acute among ethnic and “racial” minority elderly women for whom the struggles of their children are more intense, for whom the desire to help their children make it is more central to their life experience and for whom there are few alternative allies and avenues in the formal elder care network.

Workers have added another dimension to this discussion regarding the re-creation of oneself as “passive” or “dependent” in order to get more care. Workers themselves perceived that older ethnic and “racial” minority women re-create themselves as “passive” or “dependent” in attempts to get more support, not from the public home care system, but from their families. The goal, according to these workers, is the same, receiving more care, but it is directed primarily at kin rather than at the system. According to the following workers:

“There is something else though, depending on the person of course but I think some [people]... where they could look after themselves, they could take care of their business going out getting groceries, taking care of what needs to be done, but they are so afraid that if they show that they are independent, the children will take the Western ways and not have any... the children will take off so they’ll lose out on whatever connection they have with the children so you make yourself helpless, which is a terrible scenario, but that’s part of what’s happening with some people. Because with the one on one talking with some women, they know how to look after themselves. Whatever it takes, if they’re on their own they can fend for themselves but they make themselves helpless when there’s family around so that the family will do for them what they will not do for themselves” (Ann, line 28)

“My grandmother had all the resources and everything but like she got into this dependency state and when I spoke to her one day it was her way of ensuring that her kids would always be around. If she couldn’t do something, then they would have to visit her and help her with it” (Barbara, line 33).

So why don’t ethnic and “racial” minority women simply complain more often to workers about the lack of available care, rather than focus on the lack of availability of

their children? For these women, the issue of complaint may be quite sensitive. Women interviewed for the study repeatedly stated that they did not want to cause any trouble in the system or to ask for more help than that which is currently being provided. Women interviewed for the study expressed that they accept what the system provides, regardless of whether or not the service completely meets their needs. Older ethnic and “racial” minority women do not often fight for increased service by themselves. This reality partially reflects their lowered expectations about what is available in the system given the current health care climate. More importantly though, older women’s hesitancy to complain may be a manifestation of their multiple locations as outsiders within society generally and within health care specifically. Health care is itself gendered and racialized. As has been highlighted by feminist bio-ethicists (Lindemann Nelson, 1996b; Sherwin, 1996; Tong, 1996a; Tong, 1996b) and anti-racist writers and activists in the field of health (Bolaria & Bolaria, 1994; Markides, 1990; Zong & Li, 1994), health care in both Canada and the United States is mired in andro-centric and white supremacist ideology, making access highly problematic for both women and ethno-“racial” minority communities. The historic experience of multiple oppression and exclusion that older ethnic and “racial” minority women face in these settings, as women, as persons from white ethnic and visible minority backgrounds and as immigrants, may have contributed to their perception that explicit complaint is dangerous and potentially threatening to their relationship with mainstream institutions. Thus, the act of outright complaint is rarely undertaken. Doing so engenders fears regarding potential backlashes that may result from speaking up. In this study the older women’s talk often expressed a sense of fatalism or resignation regarding

service provision which was related to this sense of powerlessness. The following quotes reflect this notion of fatalism and resignation:

**“Well we spoke about it a while back but I’ve been trying to reach her and the number on the card she gave me must be wrong, because every time I call they say no one by that name works there. Oh I don’t know about all that, when they tell me she doesn’t work there I just hang up” (Mrs. Q, lines 21-23).**

**“But I’ve learned...don’t expect too much from people. You know...these women (home care workers) they have a lot of work to do in very little time...what can you expect...they don’t have a chance to do too much...No I wouldn’t ask...I get enough help already...I can’t expect too much from them. Because...you know ...they have cut back so much...they don’t give money for these things so much anymore. Like I said before, they have so much to do in so little time” (Mrs. T., line 93-100).**

**“I think they suggest to me that they’ll come and put in a bathroom rail and the bath tub and all that. They didn’t come. Someone called me and asked how I am appreciating it. And I said, “I never get it”. And she said “Oh, sorry, I thought you got it”. So now I manage to get in and out of the tub myself” (Mrs. H., line 94).**

**“Sonia is often not in the office, she should come more often. But what can you do?” (Mrs. T., line 59).**

**“I do not want to trouble Mrs. Lo. I feel embarrassed” (Mrs. L., line 76).**

One woman expressed this sense of resignation in relation to her experience of immigration. In this example, there was evident an element of self-blame regarding not being able to get care in her own language because she had chosen to immigrate in the first place:

**“It would be nice if we spoke the same language...but that’s what happens when you leave your country...your homeland... we’ve been dealing with this our whole life now...what do you expect when you leave your homeland” (Mrs. T., line 109).**

One woman discussed the notion of ageism in relation to this issue:

**“Sometimes people give the impression that the old people are burden on society and it reflects when they are dealing with old people and this makes them not to ask for available services” (interviewer about Mrs. C., line 25).**

**The issue of backlash was explicitly mentioned by these two participants:**

**“Sometimes they have complaints and they don’t know who to talk to about it and also they are scared that they will be treated badly next time they go” (Interviewer about Mrs. C, line 21).**

**“Twice I’ve had to complain and I do complain. Because I feel I lived here long enough, I paid my dues, you know, when I was working and I need this help and I must get it. And it’s good for other people too if they know about it so they be careful. I think it’s my nature and sometimes people don’t know that they can do that. And they feel that if you complain you might get a backlash” (Mrs. F., line 116-118).**

**Given this fear of raising complaints about service with the formal service sector, women who want to get more services appear to have found a more acceptable and “passive” way of making demands on the system by indicating a lack of family support. This means of complaint is largely unthreatening to status quo practices and ideologies in elder care and will therefore more likely be “heard” by professionals in a way which will not undermine relationships between themselves and ethnic and “racial” minority elderly clients. In these instances, older women may be more likely to receive the additional help they are seeking.**

**On the other hand, workers mentioned that it is the children who often complain on behalf of their elderly parents. Workers talked about the children being “the pushy ones”. Given that children are called upon to interpret, negotiate and manage care by the workers it appears that children often advocate hard for their parents because they understand that the system is difficult to access for ethnic and “racial” minority elders, particularly when issues of language and culture are prominent. Considering that older**

women do not want to make demands on the system, often, children must take on this role of advocate for their mothers yet paradoxically, this is a sensitive issue for workers and not always perceived as welcome. According to one worker:

**“It’s not so much the women themselves but the families, a lot of times too. They know they can get things. Not all of them I mean some of them are really ... they don’t ask for much but some of them are very very aggressive” (Doreen, line 80).**

Despite these issues, it is important to state that some women do feel a sense of disappointment regarding the lack of involvement of their children in their ongoing care and this does get expressed, in real terms, to case managers. This issue is greatly related to the concept of extended kin networks. According to some of the women interviewed, lack of involvement of kin in the care of elders reflects the demise of cultural values inherent in the move from homeland to the west. Often, larger kin networks present in older women’s home countries are not easily transported to the west upon immigration. These large kin networks of both nuclear and extended families who were often available to provide support to elderly family members in home towns, end up being replaced by smaller nuclear family arrangements in the west, forcing elderly women to rely solely on their children as replacements for valued extended kin relationships. This loss of extended family may be part of what is being expressed to workers in the form of disappointment regarding the lack of available family to provide care.

**“I notice here in the States, in the West actually, it’s very different from what we do culturally. Uh, we wouldn’t think of putting our elderly in a senior home. No, we look after our own. You know. We believe very much in an extended family. I am not talking about myself right now because I am, as I already told you, I am very exposed to Western culture as well. But as a community, we believe in extended families... Which is very different...almost not there...I mean this culture (Western) does not call for that kind of thing...young people, who are getting, who think that**

by trying to get away from their culture or religion they can get educated and become modern and westernized..” (Mrs. F., lines 102, 150).

“If I cannot manage, I may have to move in with my son. He will then support me. But I do not want to do that. My son’s mother-in-law is staying with him. It is hard for a mother-in-law to get along with a daughter-in-law. Because they are used to the Canadian way of life. My daughter-in-law was born in Canada. It is hard for two sets of parents-in-law stay together under one roof.” (Mrs. L., lines 88-90).

According to these community workers:

“we have an extended family system and you would have observed in [my country] houses that we would be an average of 5 to 6 people living in a two bedroom apartment so they live in such a you know poor condition and uh... most of the people, elders, they behave in the way they would have behaved back home. Here, young children of their children, they go to school and they almost behave in the Canadian way of life and they may not like these old people living in the house, they create problems and finally old people will have to get out of the house and they go to welfare and live with the minimum means. So, if they want to buy extra things like medication, some of them are covered under drug plan which is issued to them but most medical matters... it’s not covered under the drug card so they have to buy from outside. They can’t afford to buy because they don’t have the means to buy. So what ends up happening is they stop seeing doctors, they don’t go and tell all the problems to the doctor cause they end up prescribing medicines and finally what happens is that they can’t afford to buy it. So for those reasons they don’t go and see doctors and especially these very very poor. If the doctor makes an appointment to see them next time, they don’t go... and some of the old people complain that we want to go back cause we won’t be treated like that back home. So these are some of the complaints they are not happy. And this is the difference between [my people] that are brought up in their culture and those that take on the Canadian way of life” (Joe, line 18).

“For these senior people I think most of them depend a lot on their children but now, I mean the next generation, I mean the younger generation, they are changing. They already have their own family and they try to have their own... I mean some private life and working and family. That’s why sometimes you find some gap between the expectation of the senior and the younger generations own expectation. The seniors feel very lonely, they feel abandoned by their children. Now it’s changing, I mean the values, how to treat old people, it’s changing already” (Maya, line 17).

These quotes reflect a struggle between ethnic and “racial” minority peoples’ value regarding elder care and their perceived view of the demise of these values in the west. The incorporation or assimilation of western values regarding care are blamed for undermining valued cultural heritage. Some of the elders in this study reflected on their countries of origin and on extended kin relationships that would support the view that elders were traditionally taken care of by their families and communities. Although not practiced in the west and not clearly evident in the literature as the reality in these elders’ countries of origin, ethnic elders and workers from community organizations often talk about the limits of westernization in relation to elder care within the family. The experience of older women interviewed for the study exemplifies that they perceive their life in Canada as one in which a dramatic difference in values exist. Although wanting the best for their families economically, they experience a loss of fundamental values of community and family. Elders struggle with these notions as do ethnic communities. Elderly women and community organizers in ethno-specific organizations spoke about a loss of cultural values in the west and shared an experience of their values being undermined and undervalued in relation to western values.

By incorporating an “ethnics take care of their own” discourse, gerontologists have somewhat attempted to apply these home country ideologies and practices to ethnic communities here in the west, without success. There is a pull between elders’ critiques about the western system and the system’s expectation that they assimilate to it. For elders and ethnic communities, the western ways are expected to supercede their ways when accessing services. On immigrating, older ethnic and “racial” minority women often lose

their extended kin network and are forced, by this act of immigration, to replace the proximity of a large extended kin network of uncles, aunts, cousins, etc. for whom they often were able to rely on for help with the presence of only a small number of children. This is particularly true under sponsorship arrangements when, often, elderly mothers immigrate to be near one child who is directly responsible for their financial security. This is a dramatic distortion of the experience that ethnic people had in their country of birth, where an entire extended kin network or community may have worked together to support the elderly relative, not simply one or two children. When children, particularly daughters, are called upon to replace an entire extended kin network, then pressures on the family are bound to surface. In Canada then, the discourse of “ethnics take care of their own” reflects a value which, although central to older ethnic and “racial” minority women and their communities, in practice in elder care puts pressure on the nuclear family, contributes to family breakdown and renders ethnic and “racial” minority women further marginalized and oppressed.

The emphasis on family as connectors for older ethnic women to the formal care sector is interesting. Although on the one hand western families are not seen as “taking care of their own”, the formal sector expects family involvement. This begs the question, is family important because of the way institutions provide services or because of what older women want? Clearly, there will always be some people who want their family members or children to take over their care regardless of the way the system looks, but women in this study seemed reluctant to burden their children, believing that to make it in Canadian society, one has to work very hard, and they want their children to have the good life.

The link between the public and private is complicated. Older ethnic and “racial” minority women give two messages that reflect their own experience of being caught between two cultures. They miss and want the old ways yet can’t reproduce them here. They want their children to embrace the new world view because they want them to have the good life, yet want them to retain cultural values of family care which may be perceived as being more closely related to practices in their home countries.

Formal care providers bring their own political, social, cultural and institutional biases to the care relationship which sets up expectations that pull these old women between their two cultures even more. Workers state, “ask your family, they should help” and then expect women to acculturate by stating, “we do it this way here: our language, our values, our western ways”. Even those workers who have some sympathy with regards to older women’s valuing of home country ideologies around family care and their sense of western values undermining these traditions, still re-frame the efforts older women undertake to continue to receive care as manipulative and as wasting scarce resources; that is, that older ethnic and “racial” minority women re-frame themselves as “dependant” to influence their families to continue to provide care as well as to influence the system to provide care. In this sense, older ethnic and “racial” minority women re-create themselves as “dependent” in order to receive care from both public and private sources (Aronson, 1992).

By developing an analysis based on institutional ethnography methodology, the systemic forces which fundamentally shape interactions between workers, clients and their families, but which remain largely invisible in everyday practice, can be uncovered. Clearly, the everyday practices in elder care with ethnic and “racial” minority elderly

women, of involving family as interpreters and negotiators, whether articulated as policy or simply as an unwritten code of “the way things are done” result in a discourse which makes family involvement a primary function of the provision of adequate and appropriate services. This practice is both gendered and racialized resulting in the re-entrenchment of ethnic and “racial” minority female kin in the private sphere of the family.

The shape and nature of assessments and governing norms in the operation of care, in effect, require family involvement to smooth out processes of access. This is created and reinforced by government priorities which have, over the last many years, reduced health care and community services. The impact upon ethnic and “racial” minority elderly women is differential to elderly women generally, particularly since services such as translation, interpretation and advocacy at the community level have also been drastically reduced.

This chapter illuminates the struggle between older ethnic and “racial” minority women’s expressed desires regarding family care and the system’s operating norms regarding family care. These struggles are complex and often hidden from view. Operating norms are, of course, not as explicitly reproduced as policies, so that there exists a wide continuum among workers on the use and expectation of family involvement in the provision of care, particularly interpretation. There were workers who stated that they would never expect families to provide care or interpretation, just as there were workers who expressed the necessity of family involvement. What becomes important in this analysis is to look at the points of disjuncture between what women say and what workers say. From an institutional ethnography approach, it is within these points of disjuncture, these gaps, where state ruling practices become visible. These macro priorities of scarcity

have implications on everyday practices of agencies and it is within the everyday practices of agencies and the everyday interactions between workers and clients that these ruling ideologies are made manifest. In this instance, the everyday practice of involving families in care, stemming from an ideology of scarcity, result not only in burden among family members, particularly women who are most often called upon or available to provide care, but in the experience of struggle among elderly female clients. These struggles are all the more intense for ethnic and “racial” minority elderly women who may require their families to, not only provide care, but to negotiate, advocate and interpret interactions between workers and their relatives on a more frequent basis.

Finally, the practices which emerge out of the discourse of “ethnics take care of their own” work both for and against women in care. They work for, by enabling women to articulate their own set of values in and against those of the west, often seeing their indigenous ways as “better than” those of the west, thereby helping to buffer experiences of alienation and dissatisfaction that they experience in elder care services. In evaluating “care values and systems” in the west as inferior, older ethnic and “racial” minority women may be telling providers that there is a better way to provide care which can be incorporated into western values and practices. Unfortunately, the ideology of “ethnics take care of their own” is currently used by the system in a way which works against women, because it increases workers’ expectations that family, particularly female kin, “should” be providing that care and when they don’t to be perceived as deviant. Family care is, after all, what older women have expressed that they want.

But listening to older ethnic and “racial” minority women and incorporating a positive vision of extended kin which more accurately reflects older women’s values and

ideology might be a good response to the current pressures on families within the system. Encouraging the development of the advocacy, interpretive and accompaniment role of ethno-specific agencies might be a way to inform the system with the desires and values of older women. Through the creation of supportive “fictive extended kin” (Kamer, 1998), immediate, often nuclear family members, particularly women, might be partially relieved of some of the burden of providing some of these services. This would, of course, require significant funding by government to ethno-specific community agencies and would ultimately require an ideological shift from a medical to a health promotion focus. However, research has shown that investments in health promotion often pay off in the end with reduced need for medical care. Whether this is also true for a population of disabled elders already requiring health care remains to be seen. In the end, the establishment of fictive extended kin networks from a value stance consistent with ethnic and “racial” minority elderly women in the community would go a long way to shift current perceptions of health, health care and family involvement in operation in elder care today.

In the final analysis, workers must find ways to consider older women in decision-making even when families are used to interpret and negotiate care. This would mean that, even when professionals work in and through families, they need to keep going back to their clients themselves, communicating directly with them and laying the foundation of control in their hands. As one worker stated,

**“I have the opportunity...even if the senior person says to me I default to my child, as much as possible encourage the son... or the daughter, to communicate whatever is discussed to make sure that it’s communicated back to mom and if possible, if I’m around... it becomes a three way thing.**

So that what I would be discussing is involved with the person. So even if she said "Ok my kid's gonna look after whatever" you try and include her so she's not totally out there, you're not talking about her as if she's totally out of the discussion. And sometimes amazing things come out of that. You know a decision is made and she'll come back and say "No" because she was involved and she had the option to think it through and say ok what are the pros and cons of the situation. But again you know, time constraints... you can't do this all the time" (Ann, line 36).

It is essential to reiterate, however, that despite individual workers' capacity to engender care with older women's voices and incorporate older women into decision-making, the public elder care system continues to operate from an ideology of scarcity in which the private sphere of the family is seen as the most appropriate site of elder care. This invariably results in the marginalization and oppression of women, both as care receivers and as care givers. The oppression of women is also racialized as the experience of marginalization among ethnic and "racial" minority mothers and daughters is both more intense and fraught with a series of double binds. First, they are called upon to do service provision in the home, as are Anglo-Canadian daughters. They are also, however, required to do more institutional work, acting as interpreters and linkages between the private and public spheres; between their mothers and the elder care system. In effect, ethnic and "racial" minority children are forced to take on both the role of service provision and case management. Second, ethno-"racial" communities' experience of poverty and unemployment, particularly as recent immigrants, result in more strains and less time to devote to caring. This, coupled with older ethnic and "racial" minority women's intense historical struggles to provide a better life for their children, make the experience of burden and the desire to be undemanding all the more salient. Responding to this dilemma requires more than the commitment of increased resources for service provision and

**interpretation. It also requires a shift in ideology from one which claims the private sphere of the family as the most appropriate site of elder care. Only then will a more appropriate balance be struck between the role of public institutions, community agencies and families, which incorporates and sees as fundamental, the desires of elderly ethnic and “racial” minority women themselves. This will necessitate a restructuring of current models of elder care which, by emphasizing and making primary the involvement of family, contribute to the continued oppression and marginalization of women.**

## **Chapter 7: The Dilemma of Prolonged Engagement: Building Opportunities for Reciprocity in Elder Care Services**

The theme of reciprocity and relationship building emerged quite significantly in discussions with older ethnic and “racial” minority women interviewed for the study. In a variety of ways, older women expressed their desire and need for building and sustaining human connections through the sharing of personal stories, life histories, social activities and creating reciprocal “caring” relationships in attempts to remain “whole” persons in their contacts with the health care system. Women expressed the importance of having the opportunity to build and maintain relationships with those providing elder care services to them. These expressions were fundamental in women’s talk and included such components as: turning to “trusted” individuals when seeking to access care; remembering significant service providers but not the agencies these people represented; developing caring relationships with service providers; requesting opportunities for socialization; using a discourse of caring when speaking of what they need from health care providers; and reframing questions about health status to incorporate past stories about immigration and employment in order to inform health care providers about the larger context of their lives. Lastly, notions of independence were largely absent from women’s talk, particularly among those who were clients of the system. Instead the concepts of relationship-building and reciprocity were more common constructs about which older ethnic and “racial” minority women spoke regarding their desires of the system.

### **Trusted Individuals & the Experience of Access**

The notion or question of access is a central operating concept in the current study. As discussed earlier in this document, the notion of access is unevenly applied and

understood in gerontological literature. This is particularly true in research on and about ethnic and “racial” minority people, where definitions and conclusions about what makes elder care services accessible vary widely. (Please refer to Chapter 2 for a detailed discussion of these determinants of access). Overall, older ethnic and “racial” minority elders’ voices are missing from this research and as a result provides little illumination of the everyday experience of access, particularly that experienced by older ethnic and “racial” minority women. The current research seeks to redress this omission. Indeed the findings that emerge here from interviews with these older women point to dramatic differences between the way in which access is currently constructed and the way in which it is experienced by older women themselves. While research has tended to focus on such issues as older people’s lack of knowledge or education about available services and the means to get to those services (such as transportation or financial barriers), older women interviewed in this study have exhibited remarkable creativity and ability to “find out” about services through alternative means not often considered in the research. Older women interviewed for the study spoke about components of access rarely considered within gerontological research and practice and thus incorporation of their viewpoint has the capacity of informing the research considerably. Emergent in interviews conducted with older ethnic and “racial” minority women in this study is the central notion that the process of access to health care is largely achieved through interpersonal connections with trusted individuals, rather than as a result of more commonly understood institutional or systemic avenues such as outreach and education. Despite systemic efforts to increase access and to develop systematic methods for educating older persons on how to locate and manoeuvre through the system, access, as it is experienced in the everyday lives of

women, often operates as a complex series of chance encounters, with the initial contact setting the stage for future encounters. In addition, it is the presence of a trusted individual who acts as the key to older women's prolonged engagement with the entire system rather than older women's relationship to or understanding of the agencies which provide care to them, that makes the difference to them. While the first point of contact varies, the presence of an informed or trusted person usually results in the opening up of a web of available services so that if an older woman manages to identify one knowledgeable source, her chances increase that she will be able to find other resources either immediately or in the future, as long as that contact is maintained. For example, if an older woman accesses a caring individual through a community organization, this person will continue to serve as a point of contact for other services in the future. The more regular or prolonged the relationship between the elderly individual and the "trusted person", the more successful integration into the network of elder care services is likely to be.

Community workers, friends and neighbours are essential in helping people manoeuvre into and through the system. This is probably due to the fact that these persons are more likely to live nearby and be accessible to, develop ongoing relationships with, and reflect the cultural, ethnic and "racial" group of these older women. Without these access persons, older women describe feelings of isolation and lack of knowledge about how to get the services they need. It is through the identification of a human contact, a trusted individual that older women are able to access care.

Mrs. H.'s story exemplifies the often haphazard nature of referral sources. In this segment, Mrs. H describes how, by chance, her daughter encountered an old friend of Mrs. H. from the Caribbean, on the train. Mrs. H. had not been aware that her friend had

immigrated to Canada. Once this contact was made, Mrs. H. was introduced to her friend's church group and from there, Mrs. H. found out about other community services. The "Sarah" spoken of in the following segment is a community worker with a local agency that provides a congregate meal program for seniors once a month. Sarah visits the church group regularly to invite members to the congregate dining program. Mrs. H. stated,

**"Before I was alone. I didn't know what to do and I didn't know where to turn... And then my daughter met my friend from back home on the train once and tell her [about me] and give her my phone number and I just...and she said "Oh we are livin' very near". Yes and she visited me and she said "we have a group here and we have a group there" at her Baptist Church and all that. So I check with the group and I join the group down there...this centre where seniors go and meet and talk and we have recreation...so from there I get invited to Northlake by Sarah when they're having dinner and all that". (Mrs. H, lines 17-19, 21)**

Despite the presence of Mrs. H.'s daughter, who is herself a health care service provider, Mrs. H. describes how she did not know where to turn or whom to ask for help until her trusted friend from the same hometown appeared. In this instance we see the importance older women place on being referred to organizations by trusted persons and the need for culturally specific services. This process of entry is quite typical among ethnic and "racial" minority women. Further on in the interview, Mrs. H. described her ongoing relationship with Sarah, a community worker at Northlake and the central role Sarah continued to play in Mrs. H.'s life over the years. In the following quote, Mrs. H. refers to how Sarah helped her advocate on her own behalf with a doctor who had been refusing to send her to a medical specialist. It is Mrs. H.'s prolonged relationship with

**Sarah that enables her to go to Sarah with the problem she had with her doctor in the first place and to use Sarah's "voice" to advocate for herself. She stated,**

**"...So it was the coordinator from Northlake who said "you know Mrs. H., ask your doctor to send you to a specialist cause it's funny how you can't eat anything and feel sick". But he said he give me all this medical and I'm fine. So I ask him to send me to a specialist again but this time I tell him I was speaking to Sarah so that yes, he said ok..." (Mrs. H., line 31)**

**There is considerable research on access barriers to health care which describes older persons generally and older ethnic and "racial" minority persons specifically as lacking information and knowledge about formal care services (once again, please refer to Chapter 2 for a detailed account of this literature). It is posited that this lack of knowledge contributes significantly to access barriers. This analysis often blames the individual for "not knowing" and urges agencies and organizations to "beef up" outreach efforts in order to get more information out to elderly persons and their families regarding aging services. However, the general emphasis is on increased outreach but not necessarily on adapting the way organizations do outreach to more accurately reflect the ways in which elders seek out, share and assess the information they receive. It may be too simplistic to assume that older women do not know how to find out about available services. Rather, the way that they know might be very different from how current health care practice constructs the delivery and relevance of information. Women interviewed in this study did describe their lack of understanding about how the system itself worked. However, when they needed to learn about services, they located access points outside the formal care network in attempts to identify both appropriate and satisfactory agencies and trusted individuals who could help them identify where to go. This might mean that elderly women will rarely**

reach out to the local case management agency or health care centre, rather, they will seek out informal connections with friends and neighbours in order to obtain referrals to caring practitioners. This process of inquiry may be even more important for ethnic and “racial” minority women since the need to find a trusted person relates not only to the identification of caring practitioners but also those who can help them interpret western medical processes, who speak their language and/or who are familiar with and respectful of their cultural heritage. Given the dearth of ethnic and “racial” minority practitioners in the field, it is no surprise that older ethnic and “racial” minority women turn to friends, neighbours, family and local ethno-specific community organizations to find trusted individuals to help them with these initial contacts. The following quotes exemplify this reality:

“No, I didn’t have a family doctor...so across the street we knew this family...they were from the same community as us...and they helped us...they referred us to their doctor” (Mrs. T, line 34).

“When I first arrived in Canada, I lived in an apartment. One of my neighbours recommended him to me” (Mrs. L., line 136).

“My old neighbours where I used to live told me about him” (Mrs. Q, line 31).

As one community worker explained,

“I guess maybe that’s human nature that if you’re comfortable with someone... and let’s face it, we may be victims of that ourselves sometimes, that when we have that comfort level, that we know someone, and when you’re working through the details at the beginning and you’ve poured your heart out, they sort of want to come back and touch base, and it’s only human nature that I would call back and say you were going through a crisis and I hope that things have worked out... and it takes the right people out there as well, because we see it ourselves when we refer to other agencies, and if they built the connection with one of our coordinators here, they may still be calling back over here to get that pat on the back and

say I know what you've been through, it's been difficult and to be able to speak to someone that you've built that rapport and connection. And you have to nourish it... and maybe with the cultural diversities it may take a little bit longer only because they are dealing with the whole cultural aspect of it... first of all dealing with the environmental things, climate, changes, the people, the structure... so for the immigrant woman, I think it becomes even more complex" (Vera, lines 65-67).

The seeking out of informal routes to care, suggest that older ethnic and "racial" minority women are actively involved in accessing care and are not simply passive recipients of that care. It also suggests that, although their knowledge of the system may be limited, they know how to identify friends, neighbours and other trusted individuals who have used the system in the past, in order to get the information they need. According to this community worker:

"These women are very vocal, they speak their minds, they know where to go to get help, they call maybe friends and say "I have cancer" or whatever the case may be and they say "ok, check with your doctor and if he doesn't refer, check so and so". You see what I'm saying?" (Lois, line 47).

The following segment also exemplifies the point that older ethnic and "racial" minority women are seeking health care practitioners who are caring and to whom they can share personal, not only medical, problems. According to Mrs. R. health care means developing a relationship of trust with your provider and being able to share personal stories and difficulties with her/him. This contributes to the need to find not only a competent medical practitioner but also an empathetic and caring person.

"... like I said before my friend introduced me... you know I didn't know where to go and I didn't want to talk to just anyone about my family, you know... our personal lives and stuff" (Mrs. R., line 31 and line 37)

**This discourse of caring and empathy is present in much of women's talk about their satisfaction with health care professionals. In many instances, women talked about seeking out health care practitioners who are empathetic, caring, who give them time and listen to their emotional, psychological issues in addition to providing care regarding physical conditions. As Mrs. Q stated,**

**"My doctor is retired now. He was a wonderful doctor. He was like a therapist too, I could talk to him about my problems and we did this at times" (Mrs. Q, line 29).**

**Mrs. L. shares a story about an encounter with a caring hospital worker. In this story we learn the importance of identifying workers who can both share with the older person a sense of cultural understanding as well as take the time to support and comfort;**

**"My husband was admitted in the hospital... We saw a Chinese woman. She was not a nurse. She was a nutritionist. She saw me in the hallway and she encouraged me to cry. She said that I saw you suffering every day. You do not look well at all. Perhaps you would like to share with me what you are thinking. I told her that I worried about my husband and I did not know what to do. I hope that my husband will recover sooner. That woman was kind. I told her I did not know what was wrong with my husband. She explained to me that they operated in the same spot. She said that my husband had stones in his gall bladder... That time I had a nutritionist explain everything to me... I was walking around the hospital. Every day she saw that I was very worried, so she asked me what was the matter with me and asked if she could help me. I feel that the hospital needs this kind of people. They need people who care for the patients and their families" (Mrs. L., line 152-154).**

**Later Mrs. L. comments on what she considers important in finding a doctor. She stated,**

**"The most important thing is that the secretary in my doctor's office has to be kind and nice. My doctor should be empathetic and caring" (Mrs. L., line 116).**

According to Mrs. H., providing opportunities for sharing emotions and understanding are also essential to care:

“And so I know they have good care there. I know I could talk to them and tell them how I’m feeling and what I going through and they understand...”  
(Mrs. H, lines 17-19)

Mrs. T. describes a relationship with a service provider in which a discourse of caring is paramount:

“She was a really good woman...she would bring me soup from the store...a very caring woman” (Mrs. T., line 77).

One other woman interviewed for the study describes this caring relationship in terms of extended family, comparing the care received by professionals with that of family. This clear connection speaks to women’s desire to build connections with health care providers which are “family-like”, that is imbued with kindness, caring and a personal commitment.

“And there are times when a girl is used to the way I want to have a shower or whatever I want to have done in the house and suddenly someone else turns up and it’s not Valerie, it’s someone else, Patty or someone else and she doesn’t know what to do and I have to tell her where the brooms are or where this is, you know things like that. It’s difficult. It’s the agencies that have to be...That is where I would suggest they...uh...the idea of extended families come in.” (Mrs. F., line 121-122).

Mrs. F. suggests that the ever-changing worker syndrome interferes with her ability to achieve a level of comfort and understanding with service providers. Because of this difficulty, Mrs. F. brings up the issue of extended family to tell us that it is only

through a concept like extended family that we can achieve better relationships between service providers and clients. As one community advocate stated,

**“The continuity question is a very big question. Different people come in every day. You have to explain every thing all over again and also you don’t feel at ease. There is no opportunity for bonding or friendship which is... and isolation is one of the health problems of older people. They don’t have somebody coming in that they can be trusting and friendly with. It’s a real deprivation” (Sarah, line 14).**

It is important to note that in seeking out a trusted individual to access care, older women will not necessarily want to go to their own communities, particularly if there are no linguistic barriers between themselves and mainstream agencies. The key may not be in always being able to provide an ethnic match between provider and patient/client but to establish a trusted and caring relationship between them. In the following quote, we learn that not all ethnic and “racial” minority elderly women want to go to providers within their own communities and in fact, feel they receive more caring support from outsiders. As Mrs. T. stated,

**“We haven’t gone to them. We wouldn’t think of going to them... They just say nice things to look good. They never help. They say they will but they don’t. We get better care from “others”.”(Mrs. T., line 107).**

Workers have also confirmed that some ethnic and “racial” minority clients do not want to have service providers from within their own communities because of fears regarding confidentiality:

**“and similarly like some of the clients that we have um they don’t want to go to their ethno-specific agency. Um there’s, you know for some clients there’s a real fear that if they go to the ethno-specific agency, the knowledge about their illness, you know it’s a very small community that they don’t trust confidentiality and that’s happened in more than one different community, like the Greek community, the Ethiopian community,**

**the Somali community, they're very reluctant to go and use services when they're in our program 'cause they're scared that the knowledge of their illness is gonna get out" (Pamela, line 48).**

**Not all women interviewed for the study were able to identify a trusted individual to help them make their initial contact with the health care system. In these cases, women expressed frustration about locating resources and highlighted how difficult it is to find such resources on one's own. As one participant stated,**

**"Health care, if you..you have to go out and look for it. You can not expect..I mean, in the beginning I would expect people that I already knew here, living here for some years to tell me everything. Some people don't have the time or don't think it's important enough to lay everything... the cards on the table to say "well, you'll encounter this this this this this". They don't say that. So you have to find out for yourself" (Mrs. F., line 58)**

**What the above quotes exemplify is that the central component of accessing resources is the identification of a trusted individual who can share their expertise, introduce them to a caring individual within the elder care network and help to illuminate the processes and procedures for negotiating the system. This individual will need to pay attention to and understand one's cultural and linguistic heritage but need not necessarily be a member of one's own community, although most often older women do seek out support and help from within their own communities.**

**Older ethnic and "racial" minority women find out about the best place to go or the best person to see through the informal networks they create. This means that normal routes of outreach taken by organizations may not work with minority populations. For example, even if an agency sends older ethnic and "racial" minority women pamphlets they can read or understand, these might be irrelevant to them and not supply them with the**

information that they need, like who do I go to that will understand me and care about me. There are positive benefits to these informal referral sources for those who can develop and maintain them. However we must still keep in mind that this does not relieve elder care organizations of their obligation to do outreach. Rather it should tell them that their methods of doing outreach are irrelevant to many ethnic and “racial” minority women who prefer the human touch of referral and prolonged contact to ensure they encounter good providers and receive satisfactory care from the system.

Workers confirmed this notion of informal access routes and related their experience regarding the informal ways elderly people find out about the agency, specific workers in the agency and eligibility criteria. Workers shared feelings of frustration which sometimes surfaced regarding these informal processes. In one example, an intake worker explains how, since she is often the first point of contact with the system for many elderly women, and as a result of her friendly manner, she finds that some clients continue to call her when they have questions or problems or only remember her name, despite having been referred to and communicating with the client’s own case manager in her geographic area:

“Yah, I get a lot of call backs especially cause I’m a very informal type person and I’ll say to them “my name is Elaine”, I don’t even bother giving them my last name most of the times and I’ll get these calls for Elaine and I don’t know who it is and it’s from someone I put on the program last week and I don’t remember. And I think they write it down cause the initial contact and they’ll be calling Elaine back and I’ll just remind them it’s nice to call but I’m not the one to be calling any more and you refer them back to the person” (Elaine, line 67).

One ethno-“racial” minority worker described her experience of being identified by as a “trusted individual” by members of her own community and, as a result, being

**“targeted” by her community when elderly clients want to gain access to the service provided by the agency in which she works:**

**“I think also...uh... doing the interlinking with... so for example, when you talk about the woman who went through her church, got connected, because that’s my experience. What happens is, anyone that I help through the community will pass my name on to other people and I get inundated with calls. So I am nervous to tell people, give people my number cause the calls are just too... I cannot handle them myself. And then to spend the time to refer them to someone else. Once they’ve got somebody and you come recommended, that’s it. They don’t want to go to anybody else. And then you get stuck in a completely different situation” (Ann, line 10).**

**Community workers in ethno-specific agencies have also describes their efforts to identify and make contact with supportive ethnic and “racial” minority professionals working in the health care field. This is done in their efforts to help elders in the community smooth out the process of getting access to and receiving health care. As one community organizer stated,**

**“For example, there’s a woman doctor... a Tamil. They [older women] say you must go and see her. She sees the ladies, about 200 a day. We heard from some reliable sources in Canada she is in third place for having the highest number of patients because she is the only one. Being a lady, the... almost all the people, especially lady, they like to see her... And she used to say “how can I see all the people? It’s very difficult”. But from the point of view of the ladies, they are right because they can discuss with her very serious matters, they can even discuss family problems with her, with the doctor. They can discuss even family secrets with those lady doctors” (Joe, line 24)**

**Another worker goes on to state,**

**“We actually have some names of women’s health organizations and their telephone numbers. If some ladies ask us we give the telephone number to them. But the difficulty they have with them is conversation. Earlier they had a Tamil lady working in one of the women’s health centres so I used to give her name and she is now with some other job. So, it’s better to train some of them from all ethnic communities and give employment in some of**

these centres so even if it is far off, people would prefer to go there because they could discuss with them very freely and openly and solve their problems” (Mark, line 53).

Ethnic and “racial” minority workers have expressed the dilemmas they face when they live with the expectation that they will advocate for services within their own community, making it difficult to balance their professional work and their commitment to their communities:

“It’s really tough. And then you’ve got situations where they talk about you in the mosque “Oh she’s really good” and this other woman will say “No, she’s not, she was really snooty to me, she wouldn’t talk to me” that sort of thing (laughs)... you need uh... the consistency yes, but also we have to have the resources so recognize one person’s not enough to deal with a certain group of people? And being visible, going out there, doing the visitations that need to be done, going to mosques, explaining that this is the process, these are the.. This is how you access the service and you’re talking with the community volunteers, educating them as to how the hierarchy works here and they become the links instead of us... it’s really tough” (Ann, line 12).

Another worker talks about her role as advocate for her own community as follows:

“If I was answering the phone to a non-white elderly lady and she says “I need help with housework”. Now I, being of that origin myself, I may probe beyond that cause I really want to see if she is eligible for that service...” (Elaine, line 15).

Mainstream workers have also identified a similar dilemma, particularly those who do specialized ethno- “racial” community outreach. They describe finding that, once identified as trustworthy, ethno- “racial” community members and organizations will contact these mainstream workers in order to solicit their help in smoothing out the process of access for senior members of their communities:

**“But I found since when I hit the two year mark, all that seeds I had laid, I’m getting calls from everywhere, cause you make the connection even with private agencies. And they don’t know who else to call but they’ve seen you at these functions. So they start to call in to me to access things” (Melanie, line 71).**

**Workers have also commented on the “talk” within communities, particularly in buildings where a lot of elders live, and the resulting misunderstandings that occur when elders share stories about formal care being received and then complain to workers that they are not getting as much service as their neighbours. Workers find that this kind of “talk” makes it harder for them to create individualized care plans in buildings or communities and exacerbates the already existing problems regarding eligibility criteria. They have stated that they find that whole ethnic communities learn the “tricks” of accessing care, such as identifying a personal care requirement (i.e. bathing) in order to receive home care services and put additional pressure on the system needlessly.**

**“And you can never give them enough. And it’s not so much for personal care either, they want housecleaning. You know? Like mostly with the [ethnic group] when you go in for help, the primary reason that they’re calling is for housework. And they’ll say we need help with the bath cause they know that’ll get them housework. They learn very very quickly because it passes form one to the other, you know? And they know it’s the criteria and all of the referrals have ADL: help with the bath, home making: help with the bath. It’s amazing...it’s amazing”....but I don’t know where they find out... well it’s because they talk together...they’re a close community and they talk to each other and they go down to their lobbies in their various apartments and this is what they talk about... this one has homecare and this one has homecare, you know? This is how they get to hear about it.” (Elaine, lines 49-51, 55-57).**

**Despite older women’s efforts to establish relationships in order to smooth out the process of accessing and receiving care, the system is not set up to reward this type of process and in fact, renders workers frustrated and split in terms of job requirements and**

loyalties. Workers, in turn, experience pressures and pulls to respond to older ethnic and “racial” minority concerns, particularly when the system is not organized to prioritize and recognize these. The following focus group discussion highlights the dilemmas workers feel in attempting to respond creatively and appropriately to ethnic and “racial” minority elderly clients through adapting outreach to reach these women in an environment in which there is little time or institutional support. Workers discussed the issue regarding the adaptation of outreach efforts to conform to older ethnic and “racial” minority women’s desires and experiences:

“Worker 1 [referring to community clinics in her home country]: “it’s all happening in the same clinic and everybody had access to it.. it was walking distance, everything happened around the clinic. And uh... you saw people of your own colour there. But it wasn’t like going into a building... it would be in the community it wouldn’t be like you’d have to go downtown to an office building. It would be ground level. Like I think of this building, I mean we’re in Canada so it’s different but do you know what I’m saying? It’s ...

Worker 2: Let’s talk about [our institution here]. If people who live [here] who live in the community have issues they should come here. But how can minorities above 65 year old ladies they know that it exists here at [this corner of the street]? We did all the publicity everything. But who comes to the publicity? Mainstream, not the minority. The 65 year old and up lady sitting at home. Although the publicity is given, they don’t know.

Worker 3: But even if you sent them something... you can mail something in their language, to everybody, but they’re still not going to say “Oh this is free, I am going to go to the [home care agency]”. They are not going to do it. It’s a different mentality, it’s a Western...

Worker 1: I think if we were to have those social events with the ethnic food and the information was disseminated that way?

Worker 3: We have to do it in a way that they are comfortable...

Worker 1: Than it would make sense to them.

Worker 3: Yah, we need to do more outreach.

Worker 1: Talking to them in their language in their space as opposed to, having them... now you’re in Canada, you have to do what Canadians do, you have to adapt to the mainstream way of doing things? It’s too much to ask...

Worker 3: You can’t.

**Worker 1:** Like, to access this ... do it in their way.. Or find some middle ground. I'm not saying set up clinics, but look Uppermount has a clinic. They have a health centre and... it's closer to what I'm thinking of and it does work.

**Worker 2:** Who goes to the Uppermount clinic? Mainstreams, the people who know. I could say from my own experience out in the community. These older visible minority woman are most isolated and the most uh... people who needs the health care issue knowledge. They don't know what their rights are, what they can get... A whole lot of issues go along with minority woman, ok. They are not mainstream people in many ways. We cannot take them ... compare, ok?

**Worker 1:** You also have to keep in mind that when you're talking to mainstream clients... you're sort of at a level when you're talking the same language, so with ethnic and racial minority women you need more time... time... basically. We are dealing with people in the community, in specific minority women, the time that you allocate for visitation with the mainstream, say it's an hour. When you're out in the ethnic communities it's gonna take longer than an hour. That's a given. Maybe three hours. But I think we are very very limited with our resources...

**Worker 3:** It just hasn't been, I don't know we don't go out that much. I think outreach is one of the biggest things that's lacking" (FG, lines 136-164).

Clearly this dialogue points to the continued struggles in elder care services between ethnic and "racial" minority older women's desires regarding appropriate services, workers interest in adapting services to meet the needs of their ethno- "racial" clientele and systemic pressures, such as those related to practices of time and resource efficiency, which make adapting services, such as expanding outreach and lengthening home visits, harder to realize.

### **Women remember kind individuals, not the agencies they represent**

As alluded to earlier when discussing the discourse of caring in older women's talk, the concept of the primacy of relationships also emerges as a central theme between older women and their service providers beyond the point of initial access. Often, women spoke about "kind" or 'caring" individuals who worked with them without being able to

identify the agencies for whom these people worked. This points to the reality that older women are concerned more about who provides care, rather than from where that care is provided. Older women interviewed for the study rarely, if ever, remembered the agency or agencies that were involved in their care. Instead, they spoke of workers within those agencies who provided direct services to them and whom they regarded kindly. The following two quotes are from the notes of interviewers who conducted interviews with participants:

“Most of the services are received through agency x but they don’t know that agency x. coordinates the service for her. The provider is an agency but the client is not sure of the agency. They [the client and her daughter] think it is provided by the individual worker. They mention Debbie’s name but not the organization she works for. They were not sure about who referred them to the agency but feel that the worker found them and that she is a savior angel...” (Interviewer for Mrs. C, line 14).

“She was not aware of the fact that agency x was involved with her care. She only knew Karen’s name and referred back to her often” (Interviewer about Mrs. H, line 3)

The important connection for women is not the formal agency which provides service but the person who reaches them, reaches out to them and is seen as helping. When asked a question about a service agency, Mrs. Q responded directly about her individual worker, bypassing any mention of the agency:

“...well, my worker was Chris and now it’s Sonia because she went to a new position” (Mrs. Q, line 25)

What these quotes suggest is that when older women have the opportunity to develop relationships with those with whom they come into contact, they focus on their relationship to and with these individuals and continue to place little importance or have

little memory or understanding of how the system itself works or puts their care into place. This was confirmed by the fact that very few women interviewed claimed to have ever heard about the case management agency sponsoring the study, despite the fact that eight out of ten of these women were actively on the caseload of the agency and/or were referred to the study by their case managers. When asked where the women who come to their house are sent from, these older women responded:

“I don't understand who these people are” (Mrs. M., line 13).

“I don't know, what can I say?” (Mrs. Q., line 43).

“I don't know how they come... I don't know, my son knows all of this. Maybe you should ask him these questions” (Mrs. T., line 61).

For the most part, even those women who are “hooked up” to the system, have difficulty understanding exactly how the system operates, who is responsible for what component of their care or whom to call when issues arise. Only one woman was able to identify both the agency and the process of accessing care. Her experience differs markedly from other women interviewed for the study. In her own words, this difference might be attributable to her own class location. Mrs. F. describes herself as “westernized” from an early age as a result of her experience of being educated in western schools and of being from an upper class family. This, she said during the interview, has given her an advantage over other immigrant elderly women for whom western medical processes are entirely foreign. Thus issues of both class and exposure to western systems may have enabled this woman to be comfortable enough with these systems to gain an understanding of their operative norms and processes. As a result, she identifies with ease, how the service providers arrive at her door and the process of their involvement. Still, given all of

this, she is careful to qualify her statement with the words “I think” suggesting that it is she who figured it out on her own and was not told about the process by formal care providers. As she stated,

“It was almost immediate, about a week to ten days before she came... Because I think this [case management organization] has got different agencies and they get them to send these girls” (Mrs. F., line 80).

The experience of not knowing where service comes from but only the names of those who come to the house were reaffirmed by workers themselves. Time and time again case managers told us that elderly clients do not remember who they represent when they call or do a home visit and at times, do not even remember their names. Unless there are opportunities for frequent face-to-face contact, which are rare, older women forget who is managing their care. Workers stated that clients are most likely to remember only those who provide service on a regular basis, such as home care workers or visiting nurses:

“I think for the client, whoever they see more often they remember. Like the home maker. Whenever I ask they say “oh, you know, the person who comes to clean?” That’s why they remember, cause they see them more often. But they have no clue who sends this home maker” (Carol, line 9)

“Once they’re referred and we re-visit them they still don’t know who we [case managers] are, what we do, what is our role and how we could help them. And even once we explain it to them they say “Well, who’s the person coming in to my house twice a week?” They know it’s a nurse but they think that it’s the nurse who is the coordinator... they have everything confused (Hannah, line 13).

“Oh yes, definitely, all the time, all the time. Certainly have never heard of the agency, and very much have maybe heard of homecare. Yeah, yeah, it’s the best kept secret, that’s what we’re always told” (Pamela, line 72).

**“And in fact, most clients identify more with the providers than they do with Eldercare. It’s a fact of life it’s perfectly acceptable because don’t forget, they’re the ones... the providers are the ones that are going into the home. And if the clients don’t understand how all the system works it’s not that big a deal as making sure that they get the service that they need. So keeping that in mind, I’m sure this lady thought I was a social worker coming to visit but at the same time she also knew that I was the one who promised her a nurse to come in and help her with her medicines. So... that’s ok. It’s true it’s confusing to people. A number of times I’ve gone in and the person thinks I’m the home maker. “Now dear, the dishes are in the sink” (laughs loudly)” (Greta, lines 64-65).**

**“Cause again people don’t understand if they are getting a homemaker...they don’t necessarily know that it’s coming from us. So you know I would say some of the time people are already on the program ...they haven’t communicated or if they have, there’s been a failure of communication and in fact they need their whole services reassessed” (Melanie, line 10).**

**One worker related a story of a family who did not know where to turn during a crisis. She relates this story to the problematic of “contracting” services between the case management agency and service provider agencies, citing increased confusion by clients and their families regarding the chain of responsibilities:**

**“I would say that only about 10% of the clients actually call me. And this is probably one reason why I have difficulty contracting out all services. That’s not anything I can do about that. I have difficulty with it. It’s going to happen anyway, so I just have to try and make the best of it... the client tends to rely on that individual service, the client is given a name and phone number of that agency, they experience a frustration or a problem and they don’t know who to call... uh I could tell you that uh.. Yesterday morning I received a call from one of the sons of a client who has grown to rely on me quite a lot but he was still under the impression that I only worked Monday to Friday 8:30 to 4:30 and he couldn’t call in any time... The uh... nurse hadn’t shown up to give his elderly demented relative insulin. Oops, oh yes oops. And it didn’t only happen once, it happened three times and because there’s dementia... the son called the nursing agency, got voice mail, got frustrated, called the homemaking agency who kindly offered to send a nurse to see the client, which really they shouldn’t have done anyway, but they would have charged him for that.. the son ended up calling 911, the EMS faxed him something about getting in touch with the particular nursing agency... and then the son calls me up on Monday**

morning and says all this happened... the frustration was that the son couldn't get in touch with the agency involved, he didn't know the next step. The next step would have been to call us and we certainly could have put a fire cracker under the nursing agency. And follow it through and so on but we need the call. So these sorts of things do happen and it's just trying to ensure that they do happen very rarely" (Greta, lines 68-77).

One worker suggested that more information needs to be provided to clients regarding how the system works and who workers represent:

"I was on the program before and I had Mary. And I don't know who Mary is and I don't know which agency ... Mary. There's a lot of it too and I've learned this since going on intake that we really have to give them more information than we do and we should make sure on initial contact that they have it. Write this down... here's the agency and the number" (Elaine, line 73).

Yet this response may sound easier to do than it really is. As an interviewer remarks during one interview:

"I asked her if she knew who provided her care and she said she didn't but had it written down. She showed me the pamphlet that was left for her information but said she could not read it" (Interviewer about Mrs. H, line 1).

The confusion surrounding names of workers is exacerbated by of the myriad of different people with whom older women come into contact and the changes that often take place among workers. For example, in the last two years, one worker recalls having had her boundaries changed (geographic area for which she is responsible) four times resulting in transfers of cases between case managers:

"... because of the rise of the growth in the caseload, up to 180, some coordinators have that many, uh... we have to change [geographic boundaries and cases]. Many many times, yes. Ok I worked here four and a half years now and four or five now I can't recall. We just changed before

we went out before the end of December and I think that the team changed before that. I find it hard because we have some rapport with our clients. So with boundary change we may have to lose some of our clients we already know, we set up relationship with and we have to give the away and inherit some of the clients we don't know. So it's kind of uh... we don't like it but because of the caseload rising" (Kathy, lines 167-173).

In addition, workers talked about the many changes that occur with home care workers, resulting sometimes in different women appearing at a client's house every week for a long period of time; so that, on a regular basis, older women might see many different people in their home, even those that are meant to do the same job. This weakens opportunities for older women to simply become familiar with the person providing care, let alone develop relationships with them. It is no surprise then, that older women seek out trusted individuals with whom they can develop prolonged engagements and encounters in order to counter some of this flux that occurs regularly in the system and consequently in their lives. This attempt is made regardless of the trusted person's job description or professional status and although sometimes frustrating for agency staff, this strategy is essential for ethnic and "racial" minority elderly women to gain some control over their environments, particularly with reference to engaging with "trusted" persons, both inside and outside the system who are sensitive to and understanding of their language, cultural heritage and experience.

### **Befriending Home Care Workers**

One of the most significant ways that older women have themselves attempted to infuse the elder care system with "caring", build in the development of "relationships" and gain control over their environments is in interactions between themselves and their home care workers. Several reasons can be theorized as to why older women have focused

particular attention on the development of relationships between themselves and their home care workers. First is the reality that the service provided by home care workers is the most intimate and personal of all elder care service provision in the home and is centred around such tasks as bathing, cooking and cleaning, all of which are intimate tasks in the lives of elderly women and represent key components of elderly women's identity and sense of self in the home, rendering a greater sense of urgency to the need to develop relationships with these women. Second, home care workers are often the service providers who come into contact with clients most frequently, thus providing a more consistent basis for the development of relationships. Third, home care workers and ethnic and "racial" minority elderly women may share a more egalitarian relationship, despite their respective statuses of worker and client because of shared experiences as either working class women or immigrant women, since many of the women that are working in the field of home care are themselves immigrant women (Neysmith & Aronson, 1997). This shared status, identity and history may help to bridge gaps between these women, making the building of relationships between them easier and more fulfilling. Because of this increased egalitarianism, older ethnic and "racial" minority women may feel they can take more control in these relationships than with other health care professionals such as nurses or physiotherapists, who although also entering older women's private space of the home, enter with a professional status, a medical agenda and, more often than not, are white Anglo-Canadian, thus rendering them in control of the interaction. This will be discussed further in Chapter 8.

Older women talked frequently about their efforts to develop relationships with home care workers. This was expressed through stories older women shared about

kindnesses between themselves and home care workers. It is through these moments of kindness and reciprocity that older women gained a sense of comfort, importance and connection, infusing their relationships with their workers with a sense of equality and reciprocity. The following two quotes exemplify this:

**“Sometimes I find such nice ones to tell my stories to” (Mrs. H, line 54).**

**“Rosa sleeps here. She stays from Monday until Friday but the others don't want to stay and at the end of October she goes away. She won't leave me until I find somebody else who loves me, respects me and cleans me” (Mrs. M., line 36).**

**Mrs. M. and Mrs. T. describe their relationship with their home care workers:**

**“I tell her to sit down and we can speak and rest a bit... she is always doing something...” (Mrs. M., line 26).**

**“On Friday comes the older lady and she gives me a bath. She's sixty-four years old...and I believe she's going to get her pension in October. I feel sorry for the poor woman...she changes the sheets on the bed, puts the dirty sheets in the laundry basket and that's it. Then we sit here together until her time to go... and she leaves. I feel sorry for her...she's older and I don't want her to work too hard” (Mrs. T., line 67).**

**These stories reveal important information about older women's development of relationships with their service providers. First is the notion of empathy. Both Mrs. T. and Mrs. M. express empathy for the home care workers in the form of feeling badly about how hard they work and/or how difficult their lives are. Second, each woman does their best to get the home care workers to sit and rest as an expression of this empathy. Both women also suggest, although this is more evident on Mrs. T.'s case, that sharing stories and talking are important to them, enabling these women to develop trusting relationships with the home care workers and infusing the relationship with some element of reciprocity. That is, the home care workers do a great deal of work for the older women**

but the older women can contribute by lowering the work load, forcing the women to sit down and also by sharing sympathy about their home care workers' difficult jobs or life situations. It suggests that the older women can also act as confidante, friend and not only be seen as patient or service recipient. It also enables the older women to develop some sense of control over their care, if only in a small way by making choices as to whether or not the house gets cleaned or they have a chance to socialize a bit. It may provide these women with a sense of self that goes beyond their medical or functional limitations.

The idea of building more reciprocity into the system is a problematic one. This was clearly identified when the subject was brought up among workers in a focus group meeting. When the above quotes were shared with case managers, their reactions exemplified the tensions between what women want and what the system requires. Workers cringed when hearing about home care workers doing minimum work and then sitting down and talking. Discussion focused on the work that needed to get done and the fact that the service provider was being paid to work and not "to visit".

**"But we're paying this woman... (everyone laughs)" (Doreen, line 110).**

Earlier, a worker stated,

**"It's really hard to find the line between building that rapport and helping someone through a tough situation and then leaving...you know, closure. Moving on to the next case. Because that's what we're here for. But for them [older women], it's different..." (Ann, line 19).**

Another worker stated that older women might not be so quick to socialize with their home makers if they shared in the cost of the service, suggesting that it is simply as a result of the service being "free" that older women "took advantage" of the system:

**“So when you've got two hours of homemaking and you're paying one and I'm paying one, you care if that homemaker is sitting down having a cup of tea with you and eating her lunch cause she's going to the next client. Cause you're all of a sudden paying that hour. Cause that makes you say ok, I know you're hungry but I'm paying the two hours here” (Melanie, lines 134-136).**

**These data illuminate the tensions between older women's needs and desires, the service system's mandate and the workers' notions of responsibility. That older women want a reciprocal relationship with their home care worker is “recognized” by the workers but not valued in the system. The workplace value of “doing the job efficiently and effectively” takes precedence over relationship building and trust and in many cases, results in institutional operations which, in fact, undermine these human connections and interactions. In a system which is faced with constant pressures to respond to more and more clients, the focus on “moving on to the next case” is quite paramount. This is not only true in terms of response to medical need and then closing the case but also is paramount during home visits where there is an expectation for shortening the length of visits in order to respond to more clients in any given day. This sometimes results in very short visits between clients and service providers and among case managers these face-to-face interactions often occur after very long periods of absence. Commenting on these pressures, two workers stated,**

**“And the other part of it we know that there are less hospital beds open and people go in sooner so they're sicker at home and come back more frequently I feel. And they run out again so...and the people working with them are truly very stressed and strained so it makes for a very ...uh...trying working environment really on all sides” (Olive, line 66)**

**“Well that's what's really scary is it's becoming a counting thing and it's not really reflecting quality work. Just 'cause we do 20 visits a week, doesn't mean we're adequately serving twenty clients” (Pamela, line 186).**

**Although outreach and home visiting is increasingly being seen as a renewed priority in home care, there is still little institutional support for elongating these visits to allow time for building trust and developing relationships. Rather, it is an attempt to get workers to improve frequency of visits but not necessarily change the length or nature of each visit. The discourse around cluster care is a good example of the tensions between client needs to develop prolonged engagement and systemic efforts to improve efficiency thus narrowing opportunities for prolonged engagement.**

**“Some of what we'll look at doing is cluster care and it will be interesting to see what we do with those decisions. I mean I live in a condo with a lot of people are seniors. At least all of the original owners are. Probably of the 100 units ...I'm sure there are 60 anyway that are inhabited by seniors. Both of the big service provider agencies come there. So we pay twice for mileage twice for travel time...it's insane. And sometimes it might be a single address if it's a big building and sometimes it might be neighbourhood. Because that cuts down on travel time and mileage. But what it also does particularly with homemaking and cluster care..I mean homemaking right now, I think the least number of hours right now is 2 hours simply because the homemaking agency can't afford to pay you for an hour here and then ½ hour to get to ...you know it makes sense. But sometimes people only need 15 minutes. So, I can send you into a building for the whole day and you can see 15 people because 2 of them need 2 hours and all the rest need ten minutes. So again, it's a better use of resources...it does cut down on client choice and we will have to struggle with that and we'll always have to leave exceptions...” (Nora, lines 159-161).**

**As is evident in the above quote, often administrative discussions around improving home visiting gets articulated as a discourse of efficiency. But although saving the system time and money is certainly a priority, by doing so, the system may also be reducing opportunities which provide the basis of good, responsive care. Older women**

**talked considerably about how the notions of “time” and “efficiency” and how systemic pressures such as cutbacks have impacted upon the service they receive:**

**“There is a nurse that comes and she is here for ten minutes. The nurse checks her blood pressure, chest and her pills” (Interviewer for Mrs. C, line 9)**

**“Well how can they (do the sheets)... two hours, that’s all they have to do this work. It’s too much... not enough time. The younger one changes the sheets, gives me a bath, cleans up a bit and then goes to the kitchen to wash up some dishes... and clean the washroom... you know clean the toilet a bit, there it goes, two hours gone...like that” (Mrs. T., line 75).**

**Discussing her case manager, Mrs. T. later stated,**

**“I don’t know, maybe once or twice at the most a year...what can I say? She comes to see how I’m doing. Last time she saw me she said I was doing better, but I’m not. I wish to God I were better” (Mrs. T., line 57)**

**Speaking of her nurse, Mrs. M. stated,**

**“No the nurse comes here and gives me the pills and the injection. Before she was coming every week, but she told me she will come only every second week. The nurse told me that now I’ll have to go to the drugstore to get the pills and she won’t come here anymore. I asked a lady at the drugstore, she’s Italian but she is saying they don’t do that. Please don’t make her go away, make somebody come here. The government sends help to other people who need it. Why not to me? My son can’t do anything, please help me, I have only one son” (Mrs. M., lines 20, 46).**

**“One day she left because of the government cut backs and they offered her only five hours and it was not enough so she looked for another job” (Mrs. P., line 17).**

**Waiting periods and early hospital discharges, perceived often as resulting from changes due to health care restructuring, were of crucial importance to women and created barriers for health care access.**

**“If you need to go into a hospital with stones in your gall bladder, for example. They want you to leave the hospital in a short time. I think that**

if someone is older or even after a woman gives birth, you cannot tell people to leave too soon. When I get home, who will take care of me? Even if your neighbour is Chinese, he/she and I are both senior citizens. He/she cannot take care of me because he/she may have an accident while taking care of me. They should let us stay even one day longer. At least we have our meals in the hospital. Let's say if you are immobile...Yes... If one can wash herself or go to the washroom, I can do it as many times as I want. I do not want to trouble anyone. Of course if I am immobile, I need someone else to help me even if I do not want it. Don't you think they should let us stay longer? That would be my wish" (Mrs. L., line 261-263).

"Especially these days when there are so much cutbacks in the hospital, you wait and wait for hours on end before the doctor sees you and then he sees you for at most ten to fifteen minutes and you spent a good three to four hours there. I think it's disgraceful... the first time I went I was in tears because it was time for my medication...I was there for three hours before the doctor saw me, it was jam packed" (Mrs. F., line 70-72).

The notion of "caring" itself is related to time spent with clients, as is expressed by this daughter about her mother's medical care:

"Daughter: Yes. The doctor who put the tube in her arm was not a good doctor. He came into the room for a short time and then he left in less than five minutes. He did not care. For example, he would repeat what the nurse has just told us. He left the room quickly, shorter than five minutes" (daughter about Mrs. K., lines 119-121).

Mrs. L. recalled a similar experience with her doctor,

"At that time, he treated my stomach as if I had a stomach disease. I was sent to have X-ray and all sorts of tests. After all the tests, he told me that I do not have any serious problem with my stomach, it is only an old ailment. When I asked him a few more questions, he did not have the time to talk to me" (Mrs. L., line 15-16).

Indeed, workers themselves have described their frustrations around the lack of time available to them to spend with their clients and their desires to increase communication and develop caring relationships with their clients. When extra time is taken to do this, workers can also gain an added sense of satisfaction with their jobs and

create positive opportunities for developing relationships with clients. As the following ethnic minority worker stated,

“ I think that when I see older women, ethnic women, I tend to let them talk... I like to hear what they have to say I speak as little as possible, I try to listen and ... uh... become more aware of where they're coming from. Cause I know for them, wisdom is very important, making them feel like they know more than I do and I guess that it's maybe where I am coming from. You know sort of making them feel, you know that they're special... and that's why my interviews with them last so long. And I'm thinking people say it shouldn't be more than 30 minutes and I'm thinking why are my visits long, an hour and a half. We talk about family. You know, I went to visit this South Asian lady who is a single mom for as long as.. I mean 25 years and she was talking about it and she actually became very emotional, at one point she disclosed so much of her life that she became emotional and I was taken aback, I almost started crying with her and she was talking about her children and then sort of started talking about her daughter, she wasn't happy with her choice of mate. Daughter's choice of mate and she was saying "you know I wish she".. It was very important to her and suddenly I felt when I left... I felt so close to her because I heard... I allowed her to speak and I allowed myself to listen. About things that were not related to homecare or my reassessment (laughs). You know? It's interesting” (Hannah, lines 147-149).

Another example of this experience was related by a worker who struggles emotionally about a caring relationship she develops with a client:

“I saw a lady yesterday... I booked an hour, I should have booked two hours. Uh, we sat and talked about the bitterness about her move. She said, you know I haven't told anybody this before, I find you very easy to talk to. That I couldn't understand except that what she had to say, I wanted to hear. [The worker spends a great deal of time telling the older woman's story]. But the thing was that this was her priority, this is what she wanted to tell me. It wasn't my priority of what I wanted to talk about but... there you go. But that was her key and that was important. So I'll go back and see her in a couple of weeks. Maybe we'll see what else she needs... She's in her 90's, well she's 89... she looks about 70... uh, she looks as if she's really kept herself really well. You know how some people look young for their age, but she's also had a lot of things and uh her... But I certainly won't be a social visitor, I'll be a reassessor... to make sure that the service plan was helpful. I have to be detached (little bit sarcastic) can't take it home with me. There's lots of people in the past that I felt oh dear, poor

old soul I'd like to take them home with me but you can't do that so all I can do is what I can do. So..." (Greta, lines 90-99).

What this data suggests is that older ethnic and "racial" minority women want the elder care system to be developed based on the notion of reciprocal relationships, that time and resources be put in place in a way which would support the development of ongoing relationships with case managers and service providers, particularly home care workers. This would mean the allocation of more time for socialization and communication with health care providers. Case managers themselves have, at times, expressed their satisfaction with work when taking the extra time needed to engage meaningfully with these older female clients. Systemic pressures regarding efficiency and productivity have continued to govern the relationships between workers and clients and have acted to shape the way workers and elderly women interact, forcing them to a position in which medical and physical needs become paramount over social or emotional needs so that these latter needs are rarely given legitimate space. Despite workers' best efforts to make room for reciprocity and relationship building, the system continues to under-prioritize or under-value these. Instead the monitoring of these interactions is based on frequency, how many clients can be processed, visited or serviced in what optimum period of time. And although there is recognition that "care" is important, it is often subsumed by efforts to serve more people faster. In this environment, the "public, institutional" message to workers is that the system values face-to-face contact with clients and workers should reach out more often but more efficiently, more frequently. This puts workers in a dilemma and often creates situations in which they become frustrated with the ways clients attempt to create relationships with them because they still fall under the pressures of

doing more. Surely frequency of visits cannot stand on its own. It may also be necessary to consider how case managers and service providers visit and not only how often in order to respond to these dilemmas.

### **Central role of socialization**

One of the most common responses to the dilemma surrounding older women's needs to socialize with home care workers and the system's desires to develop more efficiency is for workers to suggest referring women to community organizations that provide socialization activities. In other words, the most appropriate place for engaging in the development of relationships and responding to older women's need for reciprocity and ongoing communication is through the avenue of grass roots community organizations rather than through home care agencies designed to respond to medical and functional need. Clearly older women themselves want more of these opportunities. When asked about additional services that older women would be interested in receiving, most mentioned socialization activities, particularly those which would allow them to get out of the house. This was particularly true for those women who are quite disabled rendering leaving their homes difficult without support. For these women, opportunities to socialize are rare. Since women want to be involved in reciprocal relationships, increasing opportunities for socialization may help respond to this need. Socialization activities often enable clients and professionals to relate on a more equal level, see talk and relaxation as important and allow participants to share of themselves and participate in a way which is not available to them when someone comes in to provide a service in their homes. Thus, if we talk about opportunities for reciprocity, socialization activities are paramount; however, socialization and recreation activities are not well funded in the current health

care system. These activities are components of health promotion, with a separate mandate from elder care home health services. Health promotion programs for functionally impaired or disabled elders are very few and far between in the current model of community health care. Socialization opportunities are currently not priorities within case management agencies and are also severely underfunded in the community.

“Ah...here I sit day and night locked in. In here everyday and sometimes I make it to the veranda with the walker...but it's painful to sit in a chair...that's a big problem...it hurts to sit in a chair. It would be nice if I could go out somewhere...anywhere. That would be really wonderful” (Mrs. T, line 91).

“I would like someone to take me out even once a month...that would be great. More than that would feel a bit hard...an ordeal to get down the stairs and into a car. But once a month would be great. Also I would like someone to do the cooking... enough for a few days worth of food and I would keep it in the fridge and just warm it up a bit. That would help” (Mrs. T., line 94).

“Before I was going out to the shops and I was happy. I was buying things, but now I don't shop” (Mrs. M., line 32).

“Mrs. C wants more outings. Often visits and service are only to have the nurse and doctor come in or to get an appointment or to go to the hospital. She wouldn't mind paying for outings” (Interviewer about Mrs. C, line 28).

The larger question remains, however, would increased opportunities for socialization have an impact upon reducing elderly women's needs to develop reciprocal and social relationships with service providers, particularly home care workers. The answer is, likely not. Expanding opportunities for socialization is important for older women but these, unless coupled with reciprocal relationships, would not change their needs of the provider-client relationship. These data suggest that the service system may need to be organized with multiple prongs to meet the different needs of older women in the community.

## **Core stories matter**

One of the other ways in which women have attempted to build reciprocal relationships and resist the compartmentalization of themselves as patients or clients is through the sharing of core life stories. During interviews and in participant observations of home visits, older women often redirected pointed questions about their health status or health care needs in order to provide themselves with the opportunity to talk about the stories that really mattered to them. For example, older ethnic and “racial” minority women often began interviews by sharing stories about their experiences of immigration and employment. These experiences or stories seemed more crucial to their sense of identity than their health or health care experience and actually provided a context from which to understand their current health care needs. Women’s core stories rarely reflected later life health difficulties. Rather, they often referred back to their stories of struggle which played a central role in defining their character as survivors. Older women wanted interviewers and case managers to know about these hardships as these stories more accurately described how older women felt about themselves than did their current physical or medical condition. These core stories of survivorship documented that older women have struggled a great deal through the experience of immigration. These stories documented life experiences of difficult, frequently underpaid work, poverty and struggles with accessing health care. They also tell a story that reflects older women’s beliefs about their contributions to Canadian society which makes them deserving of the help they are now receiving from the formal service sector.

Core stories were shared despite the interventions of case managers and interviewers. This is a very important point. Rarely is there room in interventions between

professionals and older women for women to share their own personal agenda, to be understood within the larger context of their lives or to be viewed as more than their health status. Older women often have to force this talk onto the agenda in between spaces, in between questions about how they are managing at home and how they currently feel physically. Often, health care professionals perceive older ethnic and “racial” minority women as passive recipients of care but in listening with different ears it is possible to notice that older women are asking us to hear their competence, their struggles and their survivorship. In writing about their initial encounters with participants, these two interviewers expressed how older women, from the beginning of the interview, attempted to divert conversation away from talk about their health status (each interview began with a question about how older women perceived their health status) to share stories of struggle. The interviewers’ notes described these first encounters with the women they interviewed:

“Immediately after I sat down, Mrs. R. began to describe when she came to Canada and that she came and immediately started working because she realized that she and her husband could not rely on her kids for financial support, so they began working” (Interviewer about Mrs. R., line 3).

“When I first asked her about her health care experience she said she had nothing to complain about compared to the experience of immigration... “It was a very difficult time in our life. We’ve been through a lot. More than anyone can ever really understand. I’m eighty years old and people tell me I don’t look it”” (Interviewer about Mrs. T, line 3).

When Mrs. M. was asked about her current health condition, she responded by talking about how healthy she had been all her life. This led her to relate a story about her early work experience in Canada:

**“I was always healthy. I worked for a man, a poor man who went bankrupt. I was getting paid 90 cents an hour. There was nothing around here, but then little by little they built the bank and the shops” (Mrs. M., line 30).**

**On the surface the two statements by Mrs. M seem to be totally unrelated and might even be interpreted as some form of memory lapse. In actuality, however, Mrs. M. might be trying to tell the interviewer something very important about herself, that despite her current need for formal care services, she was always healthy and strong. She remembers watching her community develop, she worked for a living, she struggled and she was a contributing member of society. In these few sentences, Mrs. M. wants the interviewer to know that she is a whole person, with something to offer, a history, an analysis and insight. This may be Mrs. M.’s way of attempting to establish a more reciprocal relationship from which to undertake the interview.**

**Mrs. Q responds differently to a question about her current health status, but does share some of her history in responding to the question:**

**“I’ve been through a lot, what with the war and suffering and losing my leg and I came to this strange new country and made a life and now in my old age to have to deal with this...” (Mrs. Q., line 51).**

**Once again, we are provided with information that helps us see the complete person, the history of the person and the suffering she experienced. Clearly experiences of immigration and employment are central components of these women’s lives, components professionals rarely give them the opportunity to share.**

**Employment histories and experiences of poverty are central to women’s talk about their health status. Older women interviewed for the study have expressed to us that**

immigrant women work until they are physically incapable of working. This directly links women's experience of their health in later life to their life long experience of work and by extension of race and class determinants of work. Mrs. T puts it well when she says;

“who had time for that? Who thought of doctors...we had no time for doctors...we just thought about work and surviving” (Mrs. T., line 38).

Women shared with us stories in which they worked until they were no longer physically capable of working. According to Mrs. F.,

“And I tried for jobs here too but my health was going down hill a bit. I couldn't because of my arthritis it was too much if I had to stand, if I had to stand too much, I had to sit. If I sat too much, I had to walk around...” (Mrs. F., line 92).

Mrs. T. shared her story of physical decline,

“I'm not sure...I remember I started getting a lot of pain...it must have been...back in '68...I was laid out in bed...that's how bad it was. First one leg started hurting, then I couldn't move my arms...so I said to myself...maybe I should quit work and stay home and get rested and recover from this...this tiredness. I remember it was Sunday...I felt good...it was my first day without a job...Monday I was ok also...but the next day...Tuesday I was totally immobilized...in bed...couldn't move, not at all” (Mrs. T., line 32).

Finally, Mrs. L. shares her story,

“I could not go back to work. After that accident, my right leg hurts and I cannot carry any heavy load. I do not want to trouble my children to take me grocery shopping. If I buy a bottle of soya sauce or a bottle of oil, I cannot carry both of them home. I can only buy the bottle of oil at one time. Sometimes my children pick it up for me. If I had to get a bottle of soya sauce, I would not be able to buy a lot of grocery. How can I go back to work? It was unfair for me” (Mrs. L., line 255).

Clearly, both core stories of work and immigration have a lifelong impact upon older women's health and their sense of themselves. But rarely do we provide opportunities to allow older women to share these stories with service providers. These

stories are so central to older women's experiences of their current health, we might wonder how we can truly service women properly without understanding the meaning they attribute to their health status. Often, and this is true even in interviews for the study, we force women into positions where they must struggle to find their voice so that we hear what they want to tell us (Devault, 1990). As a result, we see them as talking off subject, wasting our time or acting in a fashion which is non-compliant. Where language or cultural barriers exist, these interpretations of older women may be even more problematic. In several participant observations older people who attempted to find the space to talk off topic about their lives and experiences, found themselves being pushed back into discussions about their health status by well-meaning but time-strapped case managers. In one instance, for example, a case manager told a client that she was being referred by her sister. When the client found out that the worker knew her sister she became excited and began to share a story about the sister's struggle with cancer. At this point, the client started to cry. In response, the worker looked at her watch, patted the client's hand, said I'm sorry and proceeded to ask the client if she could walk unaided to the bathroom. The client immediately attempted to gain control of herself and demonstrate how she handled the walk from the bed to the bathroom. This exemplifies how, despite workers' understanding about women's need to share stories, systemic pressures on workers' time and the expectations to do more home visits with clients make it next to impossible to spend enough time with clients to allow for any additional "talk" between worker and client. Instead, continued pressures for efficiency shape worker-client interactions in a way which markedly separates the goals of monitoring health care from older women's desires to share the context of their lives with workers.

## **Who Speaks About Independence/Autonomy?**

Finally, reinforcing the notion of the centrality of “building relationships” is the virtual absence of a discourse of independence/autonomy from women’s talk. This is all the more striking if we consider how prominent this discourse is among workers. In fact, the notion of independence and autonomy for women who are currently receiving service within the system may be far from women’s minds. Instead, women may be placing priority on the development of reciprocal relationships within the confines of declining physical health rather than struggling with maintaining independence. Perhaps maintaining relationships is what gives them a continued sense of belonging, purpose and identity. Those women who used the terms of independence were those who resisted entering into the formal service sector, not those who were already in some way reliant on services. For example, Mrs. R. is an elderly women in her 80's who has, for a long time, refused to accept formal support services into her home. She lives on her own and now must walk with a walker. Despite being approached by a nurse in the facility where her husband lives about going for an assessment, Mrs. R. feels she is still managing on her own. She stated,

“But I didn’t think it was necessary to get somebody to come in and help me. I was able to help myself because I’m not a person to give up easily...Getting help would... mean well, ok, you are giving up now and you are going to fight to the last. So go and when you cannot do it anymore I wouldn’t fight it... fight it bitterly” (Mrs. R., line 15).

Another participant, Mrs. F., did have a homemaker coming in to her house once a week after falling but she canceled this because she felt that she needed to do things on her own to improve her functioning otherwise she would lose her capacity to take care of herself.

**“I don’t think...maybe a few years down the line I might need this. I am beginning to go down in my health but up to now I still like to do...I stopped the worker coming. They were surprised but I said I don’t need her anymore because I am supposed to try and help myself...Yah, I prefer to be very independent. I am a very independent person” (Mrs. F., lines 96, 100).**

**These stories differ markedly from those voices of women interviewed who are currently receiving formal support. These other eight women did not mention the concept of independence at all. Perhaps entering the formal service sector requires women to rethink notions of priority or resign themselves to making a shift from “independence” to “relationships”. As exemplified in the above quotes, perhaps the maintenance of independence is a more important concept for those who are not yet clients in the system. If this is so, a dual purpose is required in elder care services, which recognize both older women outside the system who wish to remain independent and older women who are inside the system who want to develop reciprocal relationships. In this case such issues as health promotion for the very old would take a central place in the former arena and adapting services to allow for the building of relationships needs to take prominence in the latter arena.**

### **Conclusion**

**The primary pattern emerging in these data is that women in care are looking for expanded opportunities for relationship-building and reciprocity. Older women want to be valued as human beings first and not as decontextualized “passive recipients”, “patients” or “clients” in their interactions with the health and elder care systems. Older women interviewed have resisted these definitions of themselves in a number of ways. First they**

avoid approaching service providers unless recommended through a trusted resource. Second, they attempt to influence visits by talking “off the subject” about their own lives and experiences, relating experiences of employment and immigration seen as central to their current health capacity. Although opportunities for reciprocity are rare, older women have attempted to develop reciprocal relationships where they have some control and this is made manifest most often with home care workers. In addition, they expressed less concern about the agency that provides care than with the people with whom they interact on a regular basis. Finally, older women expressed a desire to shape their care to allow for socialization. In terms of providing service to women already in care, the data reflect this desire for reciprocity over and above discourses of autonomy or independence. The women interviewed implied that they could be physically dependant but still maintain some level of life satisfaction and satisfaction with services if given the opportunity to build and maintain relationships. The fundamental root of women’s experience is the desire to remain a whole person while in care. The question then shifts from how can I maintain my independence to how can I maintain myself and my integrity while in care.

The challenge, of course, is for practitioners and policy makers to find a way to integrate this reality into the health care system. In its current form, elder care services are not designed to recognize this discourse of reciprocity and in fact jeopardize efforts between workers and clients to develop reciprocal relationships on a daily basis. As a result of demands for cutting costs, using resources efficiently and responding to the increasing needs for community elder care services pressures are continually put into play which pit agency or systemic priorities against client desires and at times, worker desires. Larger caseloads, changing geographic boundaries and high turnovers of service providers

result in a system where clients rarely see their case managers and come into contact with many different and shifting service providers. This often results in discontinuous, meaningless interactions between clients and workers. In addition current efforts of outreach may not reflect the ways in which older ethnic and “racial” minority women seek care and thus do not have an impact upon them.

We may have to consider that there is a fundamental conflict between women’s need to build and sustain relationships and the elder care system’s focus on the development of efficient and cost effective services. The data presented in this chapter reflect that older ethnic women expend a fair amount of energy attempting to develop relationships with formal care providers and health care professionals and resisting attempts by these professionals to decontextualize them. In addition the data suggests that workers struggle with the increased demands placed on them to become more efficient with their time and the value they often also place on maintaining contact with their clients. In a system which continues to devalue reciprocity and relationship building, workers end up focusing on medical and functional status and becoming frustrated with clients who attempt to redefine their relationships and place greater demands on service providers and case managers to “be caring”. Prolonged engagement is key to meeting the needs of older women, but increasingly, opportunities for prolonged engagement are narrowing within the system. As pressures increase to meet the needs of a growing number of older persons requiring more acute care medical services, fewer opportunities may present themselves for clients and workers to develop relationships. These data reflect the complexities involved in delivering services that meet the needs of clients within a framework which prioritizes cost effectiveness and efficiency.

## **Chapter 8: Relations of Ruling in Elder Care Services - Influences of the Medical Model on the Interactions Between Worker and Older Woman**

The previous chapter focused on older ethnic and “racial” minority women’s experiences of elder care services with a particular emphasis on their expressed desires to build reciprocity into these services. This chapter intends to expand this discussion in order to infuse it more concretely with workers’ (case managers) own experiences of providing care, their analyses of the processes by which care is provided and the ways in which these processes are shaped by models of medical efficiency. In general, an attempt will be made to concretize the ways in which medical discourse gets enacted in elder care services by examining the everyday working processes of the home care institution with an emphasis on workers’ analyses of their interactions with ethnic and “racial” minority elderly clients. This discussion will expand upon and illuminate the dilemmas of adapting the system in order to incorporate the concept of prolonged engagement and discuss how older ethnic and “racial” minority women are themselves constructed by their health status within current gerontological practice in such a way as to limit their capacity for self expression and self control. By focusing on interpretations by workers themselves and experiences workers have within the institution in which they work, one can connect the ways in which both workers and workers’ work are constructed and the impact this has on their interactions with clients.

### **The Prominence of the Medical Model**

In current elder care services, the medical model features prominently as the underlying value or perspective from which services are delivered. This occurs in a variety of ways including: (1) referral sources; (2) eligibility criteria; (3) assessment; (4) the

regulation of work through forms; (5) size of caseload; and (6) reliance on service providers to communicate between clients and case managers. Together, these create a very strong focus on the construction of older ethnic and “racial” minority women as “patients” or as “ill”, a construction, as was demonstrated previously, that older women themselves resist.

The prominence of medical discourse is made manifest through institutional processes founded on a model of scarcity of resources within elder care generally. Once again, shifts in population demographics resulting in a larger proportion of “old” (75+) persons in the population requiring more intensive medical care, restructuring in health care resulting in earlier discharges and more day surgeries and lower rates of institutionalization are all “reasons” used to create boundaries around who receives services, how often and under what conditions. In the end, institutional processes in elder care are developed which shape and limit care. In the current political climate this has meant that more elders are provided with some form of community services but under strict guidelines and criteria. A focus on efficiency, reducing overlap and duplication, sharpening criteria for eligibility, establishing guidelines for what constitutes efficient use of time and promoting the involvement of families are all ways in which the government has influenced both how care is provided and how workers and clients interact. As discussed in the theoretical chapter, in a system in which scarcity is the prominent operating feature, delimiting and narrowing criteria are often based on “need” determined by medical and functional health status. As one manager stated,

**“We are doing more high tech stuff, we are treating people in their acute phase of their illness. My understanding is that sort of philosophically,**

that's not supposed to disenfranchise others but who knows whether in fact that will be the case" (Jean, line 35)

Workers in the system have confirmed this reality in interviews. They expressed that their interactions are limited by a medical focus and that assessments prioritize medical and functional status over psycho-social issues. As one worker stated,

"It's like working in the hospitals and there's this persistent, not everywhere in the organization, but there is this view of the [psycho-social issues] being a luxury and not really really essential and that kind of thing. I think a lot of it has to do with the medical model. Um, I think that it's probably improved some, I mean with hiring social workers as coordinators. There was a lot of apprehension that social workers wouldn't be able to do this job. Because of the lack of medical knowledge... you gotta win them over" (Pamela, lines 114-126).

These community workers stated,

"Their funding is spread so thin at this point that particularly older women who are not critically ill are getting the short end of the stick. The people coming out of hospital get quite good care, I think, for a short time, a very short time, because there are monthly quotas of how many hours you can have and they give you a lot of hours at the beginning and then they put you off very quickly. But the people who are crippled by arthritis or other chronic conditions or who have other issues and need help to stay in their homes are getting very little care... and the "Eldercare" would like to do more but when you have very sick people on your hands you have to respond to them" (Sarah, line 3).

"The whole policy is just, you know, our orientation is a medical model. I don't really buy this model because you assess the services, you just assess the functional aspect, the medical aspect, and sometimes it's only so-so, it is more social related. But you cannot get a service if it's just the social aspect. That's one big problem with the Ministry...because we belong to the Ministry of Health, right?" (Maya, line 125).

According to another *Eldercare* worker,

"... it's so medically focused that the concern is that the wound is draining blah, blah blah.. And how about how the client is living at home? What are the supports? What are some of the other issues that the client is facing? Are there any marital problems? Uh... we ... we don't get that picture.

Financial problems? What are some of the stressors in that person's life? Uh... you know is that person an alcoholic? What is the client faced with? You don't often hear that. All you hear is the wound is opened to a certain diameter and I'm cleaning and I'm doing this and that. Yah I think it's hard but I think it's up to the coordinator to ask those questions... If I see from the notes, initial during intake I see something like family very unsupportive, uh... client hardly sees children. Then I would ask that question "Have you seen any of the client's children?" you could ask those kinds of questions. But the nurse wouldn't mention that, you see? I don't blame her, that's her focus... the client's wound and she's there for one thing... Well, I'm ... I'm really relying on my trust. You have to trust nurses. You know it's this trusting relationship you have to have with the providers. You have to because you're relying on their reports to see how they're doing to see how the client is progressing..." (Hannah, line 64-71).

This latter quote is quite interesting for several reasons. First, the worker explains how the system itself is designed to be medically focused so that the emphasis for access to care is on acute care medical needs such as wound drainage. This marginalizes other issues such as those that are psychosocial in nature. Second, the worker infers that this focus is reinforced by the way in which case managers and service providers actually interact with clients. Here, the case manager is expressing some frustration around opportunities to assess psychosocial needs. She states that it is the service provider, not the case manager, who has ongoing contact with the client, so that case managers, who may have an eye on larger contextual issues (and here I say "may" only) are often totally reliant on the service provider to "pick up" on these issues and report them to case managers. After all, the service provider is often in more regular face-to-face contact with the client than is the case manager. In addition, the case manager also discusses her problematic role as gatekeeper of services. In her attempts to monitor service requirements she ends up in a position of needing both to police service providers and rely totally on their analysis of client situations. In most cases this situation is made more

complex because case managers do not, in fact, often speak directly to the service provider, but rather, rely on written reports and when conflict arises, communicate with the service provider's supervisor. This results in a wider separation between case manager and client. The following quote is from a worker describing a situation in which she was not informed about cancellation of service to a client until many months after the fact. This story exemplifies the difficulties that sometimes occur when case managers and service providers do not talk directly:

"Uh... what was happening with this particular agency, the individual who was taking the messages retired. Someone else took over and that individual wasn't of the highest caliber, shall we say? And was fired. The person who was doing the scheduling was very stressed because of this individual not being of the highest caliber and having to take on more work... uh the scheduling clerk eventually left, the new supervisor had to get to know the situation and the new scheduling clerk arrived. So you can just look at it... and I'm the only constant but I didn't hear anything. But I was out of touch. OK. Homemaking services directly? No. We don't speak to the homemakers" (Greta, line 107-109).

The case manager's face-to-face interactions with the client are often infrequent, based on initial assessment and evaluative follow-up and this occurs, at most, every three months or so. This, according to workers is clearly a best case scenario. With current pressures on case managers and case load limitations, sometimes case managers do not see their clients for much longer periods of time:

"I would say 60% are seniors requiring homemaking. [We wait] Uhm, between 4-6 months for reassessment. Yah every time after we made a home visit we would extend for 24 weeks usually so I would try to make a visit two weeks prior to the planned discharge date. That's the maximum that we can extend it. We try not to extend it beyond because the client will need a home visit. It means it is time up and we need to do another home visit. And at the meantime we will get like reports, not really reports but if there are any concerns or problems, usually the homemaking agencies, they are quite good" (Kathy, lines 63-67).

**“...I think I set my record at a year and a half. That’s too long and I don’t like that. It’s far too long. I try and do this calling in between but even sometimes then we just don’t have the time. So, it’s a well known fact that you spent 90% of your time on 10% of your case load. And the rest of it... so sometimes you’re not able to serve the client like you’d like to. And in those situations, sometimes I’ll come across some things that I really don’t like such as here I am picking up the pieces. It’s been a year and it might have happened anyway, but I might have picked up on it earlier if I had been visiting every six months” (Greta, lines 101-102).**

**Or sometimes not at all:**

**“And because you don’t do initial visits, you know, you’d never know until after 3 months till you see them, after 3-4 months. Sometimes we don’t see them at all because nurse comes in and out, and hey, discharge is done... I think it’s because it’s very medically focused. It’s... it’s... relies on a medical approach to care...” (Hannah, lines 131-137).**

**What these data suggests are that older female clients are rarely directly in touch with their case managers and when in contact with them, much of the interaction revolves around medical care. This leaves little room to develop trusting prolonged relationships between the client and the health care professional designated as primary care manager. Those clients who have acute medical care needs that are short term in nature may not even meet the professional organizing and managing her care. As well, clients whose care is long term but chronic and stable may also not have steady continued access to or communication with their case managers. Clearly, there is a hierarchy of service provider agencies and individuals which makes it difficult for clients to keep track of who provides what care and from where does this care come. One client may be receiving service from two service providers (nurses and home makers) from two separate agencies. These providers have two supervisors who report back to their case manager who is from yet another agency. This may further exacerbate the dilemmas, as experienced by older ethnic**

and “racial” minority women interviewed for the study, of infusing elder care services with consistency, reciprocity and relationships of prolonged engagement.

### **Eligibility**

Case managers discussed the concept of eligibility as another way in which medical discourse shapes who gets access and how. This is articulated through institutional processes which define need solely in terms of medical diagnoses and functional status and prioritize medical referrals over community ones.

The previous chapter highlighted the ways in which older ethnic and “racial” minority women access health care and their desires to create health care systems in which the concept of “caring” is paramount. This is reflected in older women’s attempts to build relationships with case managers and service providers and to infuse the interactions they have with these professionals with a sense of reciprocity and “caring”. To this end, older ethnic and “racial” minority women attempted to use “alternative” means of accessing care when needed. In terms of home care, this has meant that older women seeking out services have identified trusting individuals who provide much needed information not only about where to go to locate appropriate services but also whom to go to in order to locate “caring” professionals. For older women “caring professional” are those individuals who can engage in prolonged relationships with their clients and who have some understanding of the linguistic concerns and cultural values of these women. In general, however, most older ethnic and “racial” minority women are not accessing home care on their own. The vast majority of the current case load in public home care agencies are not self, family or community referred; they are referred by the hospital. It is only a small

minority of clients who access services on their own (about 20% according to administrators in the system) rendering the majority (80%) reliant on hospitals and hospital health practitioners to help them gain access to the system. As a result, public home care agencies have assigned a growing number of case managers to work directly in hospitals in order to improve their presence in these locations, educate hospital personnel about the role of community elder care institutions and speed up the process of referral. This process, then, both shapes and is shaped by the medical discourse which remains prominent in elder care services so that, in the end, hospital referrals are quick, efficient and operate more clearly than community referrals. This contributes to the legitimization of prioritizing acute medical care services over psycho-social services. This reality is also reflective of current federal and provincial policy in Canada regarding health care restructuring. As a result of hospital and bed closures, emphasis has been placed on returning health care to the community. Thus, money and resources have been reinvested, to varying degrees, in homecare and community health institutions and organizations to offset the cutbacks in hospital care. Rhetoric has centred on developing new and improved partnerships between acute hospital care and community health care in order to create a coordinated continuum of health care services in the community. This rhetoric has strongly shaped eligibility criteria through the lens of acute medical care needs.

Eligibility criteria have functioned to shape and legitimize medical care services over psycho-social services. One worker describes her feelings about the current eligibility criteria:

**“It's been from the beginning, the rigidity of our whole eligibility criteria, that was the first thing. It's the getting through the phone system and then**

trying to talk to someone on the phone, who you wondered if they were really listening to what you were saying. But sometimes you go by your guts, you know that this person needs something .... you don't exactly know what service and you're trying to describe it to someone who's screening it over the phone and they'll go "Well, it sure doesn't sound like there's anything we can do, call back when you have some more information, da...da..da.." That, a lot of times happens, it does, I hear it a lot and I just cringe and I feel so ashamed. And you know what? I often feel if you just go out and I know that it may not be physically possible because of the numbers, but it's never what it sounds like over the phone, Never. Or very seldom...I was talking with this nurse about the woman who is just constipated, she was just discharged from the hospital, they could have made a referral thinking that she's eighty something years old, maybe she could use a little support..." (Melanie, lines 47-49).

The same worker later stated,

"I'm not...I don't think I'm really really generous in regards to the homemaking. But I think that I'm not stringent when I think that...let's look the other way, let's really give this a try. But our criteria is there must be a personal care component or else you're ineligible. I think that's silly" (Melanie, lines 115-117).

These community workers stated,

"Because right now they have the need for professional [medical] care... that is the most they need to get services... so before even the meal preparation they can take into consideration but right now they can't. I don't know why that is..." (Rona, line 61).

"...emphasis is on personal care [such as bathing].... we find out that many seniors do not need personal care, they don't really need you to help with the bath or to eat, but they need, we have to do the homemaking, but you cannot just provide a homemaking service because the emphasis is on personal care, that's why now I find they have difficulty to do the homemaking service but we cannot provide it for them" (Maya, line 19).

This discourse around referral sources and eligibility is directly tied to professionally-driven definitions of need. Priority for service is determined by acute care medical need defined largely by hospital referrals. This focus is made manifest in agency texts, particularly assessment forms which itemize medical problems and medical goals for

treatment, such as returning to self-care, returning to functional level, healing of wound and which require a medical referral form be filled out even when there was no physician referral for care, but provide no distinct place to itemize psycho-social issues.

As a result, assessment is based solely on physical need. But physical need as defined by whom? Clearly, “need” gets defined and interpreted by health care professionals who have the power over the allocation of scarce resources and who can determine whether or not people’s expressed “needs” match those which are prioritized by the institution itself. This results in the limitation of services based on eligibility criteria which are narrowly set in terms of medical focus and pre-existing or available social support:

“We will focus on diagnosis and what they need for care. And we will assess if there is family support. We will assess if there is a doctor, if they have medical supervision” (Kathy, line 177).

“Perhaps also our or the institution's perceptions of what their needs are or how they manage at home or how they look after each other...I think that might be sometimes a barrier” (Olive, line 8)

What is important in the above quote is the worker’s reference to the institution’s perceptions of “need” as the essential factor in receiving care, rather than the client’s expressed need. Often times, workers express that these needs may be in conflict with each other:

“It does tend to sometimes be a challenge in terms of being able to provide what we think is needed but then the focus isn’t on what we think is needed it’s what the clients feel they’re needing too and then we have to balance it out and it’s difficult...” (Greta, line 14).

In the following quote, the worker expresses what type of “need” gets attention. This is quite telling because they are identified as “personal care need” (a euphemism for significant limitations in functional status which require physical assistance supervision and/or coaching, such as bathing or toileting and/or behavioral cueing related to the management of personal care) and “professional need”, meaning needs which require intervention by a health care professional. These may be in conflict with needs as defined by clients and their families themselves:

“So if they feel they've identified a personal care need or a professional need then immediately that person is encouraged to speak to me, either in person over the telephone, whatever” (Melanie, line 5)

In situations where professional needs are in conflict with clients' expressions of their needs (lay needs) it is those with the power to hand out resources that will ultimately be given institutional legitimacy in determining and prioritizing needs:

“Because again, because of language and if not language I think that even people who are from this country have difficulty sometimes understanding what their true need is..” (Melanie, line 8).

Why is it that this worker feels that people have difficulty understanding their “true need”? This paternalistic response highlights how professionally-defined needs are often not understood or articulated by older ethnic and “racial” minority persons. This gets constructed by professionals as ignorance on the part of the older ethno-“racial” minority person. As the same worker says later:

“[I] went out to do a presentation and it was interesting when I was asking people if you wanted to stay in your home, what do you think you might need in terms of services...dead silence. So I tried to have some participation and no one did anything but it was obvious that some needed

**mobility aids and that some needed personal care sort of thing, but they didn't know how to ask for it" (Melanie, line 63).**

**Is it that they didn't know how to ask or that they were unfamiliar with the way to ask, or they asked in a way unfamiliar to professional discourse, or what they wanted was not available? Another worker intimates that conflict between professional and client needs results in a kind of blaming of the client for misusing the system:**

**"But if you advertise your services by being specific of what the service is supposed to provide for you - and you're sure that you let them know that there are services there to assist - not to take over. Take for instance, homemaking or personal care: a lot of people who've had it have somebody coming in to clean their homes and so they think that the government is giving them a maid - paying for a maid for them- they treat them like maids and 90% of them - that's what they're looking for, and that's what they're getting" (Fay, line 20).**

**The struggle between "providing assistance" and "taking over" is quite commonly talked about in elder care services. Within the practice of elder care, there is a general fear of creating dependence within client populations (Ahroni, 1989). This is fundamentally rooted in a scarcity model of service delivery in which receiving services are viewed as a privilege which is finite and supplemental. As a result, persons who make demands on the system which are outside these time and resource boundaries are treated in a subtly accusatory manner. Often clients themselves get blamed for wanting too much or not staying within the prescribed boundaries of "illness equals service", yet there is little recognition that clients may simply not know how to ask for service in a way which will be understood or accepted by the system. What happens to elderly ethnic and "racial" minority women who call on their own and can't express this "need" in a way that is understood by the health care professionals or matches the criteria of the institution? Older**

ethnic and “racial” minority women must learn how to ask properly if they are to manage to get access to home care. This reality reflects quite clearly the ideology of “expert discourses of need” outlined in Chapter 2. According to several theorists (Aronson, 1992; Dill, 1993; Fraser, 1989; Kaufman, 1994), expert definitions of need are paramount in state processes of defining public problems in a way which shapes them into administrative categories which are more readily controlled by the state. As a result of this control over defining need, social problems are rendered more manageable and non-threatening to status quo discourses and practices, like those embedded in the medical model. In the field of gerontology, expert definitions of need are paramount and have sustained systemic legitimacy marked by a high degree of control over access and treatment. This control is maintained by institutions which require elders to articulate techno-medical definitions of need in order to gain access to care. This makes it absolutely necessary for elderly ethnic and “racial” minority women to become familiar with this discourse and process of operation if they are to access services on their own. It is no surprise then, that elderly ethnic and “racial” minority women must locate “trusted individuals” within the community to teach them about what to ask and whom to ask in order to be “heard”. In the end, most older women require a health care professional, adept at speaking this hegemonic language, to make contact with home care institutions for them:

“And I do not think at this point many of the senior know about the drop in refer themselves, it’s mainly through the doctors” (Kathy, line 27).

Those that arrive on their own without a medical referral must learn the “medical discourse” and apply it. If one is not familiar with this medical discourse, then she might find these institutions inaccessible. According to these workers:

**“The only people that refuse service really are the ones that come right out, honest with you, and say “you know I need help with my vacuuming I can’t do it myself because I have a bad shoulder or leg or something”. And when we’re talking refusing service we’re strictly talking about homemaking. Because all the other professionals services, nursing physio, they’ve all been identified by a physician. Sometimes the physician will call and say this person needs homemaking too. But just cause he calls and says she needs it doesn’t mean she needs it. And even if the physician calls and says this person needs help with her vacuuming because she can’t do it, we say sorry but that’s not a service we provide and then you refer them to other agencies. So the ones that are refused service are the ones that are not eligible because of the need and that would be that they don’t need personal care” (Elaine, line 90).**

**“uh...people who it's felt...I was going to say we felt... do not need the service that we provide. For example they don't need a professional service like they don't need nursing or physio or O.T. or they are going to outpatient for those parts but they feel they need housekeeping or you know preparation. So we generally have to refuse those people. But we suggest other ways of managing like hiring Meals on Wheels or a house cleaner” (Olive, line 81).**

**The issue about knowing what to ask for is fundamentally racialized:**

**“...like the non-ethnic people know the language better, they know the terms to use and they know what to...what... they know the strings...they know the system and they basically know...especially a lot of them are asking for home..for help with personal care and homemaking and they know. The white Canadian average know to get home making they have to say they need to have a bath. So straight away they’ll say “I can’t bathe myself, I’m afraid of getting in and out of the tub” and they know that will link them to a homemaker. Whereas the non-white older person, they don’t know that and they’ll say right up front I can’t vacuum my floors or I can’t do the washing and then you have to go beyond that to them and say do you need help with personal care?, Do you need help with your bathing? And then sometimes they’ll say “Oh yes, I need that” but their first call is because this is what they really want this is what they ask for. So sometimes you have to go beyond that to really get the help that they need.[Question: So sometimes people don’t get help?].Because of the way they ask for it? Yes. And I mean, it depends. If I was answering the phone to a non-white elderly lady and she says “I need help with housework”. Now I, being of that origin myself, I may probe beyond that cause I really want to see if she’s eligible for the service. Whereas maybe another...white**

coordinator may not go beyond that...they'll just say...may just say, I'm sorry we can't give you the help, your not eligible for help with the housework and not bother to go one stop beyond to see that there's anything else that they need. I mean it does happen. It does happen." (Elaine, lines 13-15).

As the above worker stated, case managers have a crucial role to play in the lives of older ethnic and "racial" minority women attempting to access care. They must translate what older women say into terms acceptable within the institutional discourse. Without the "good will" and "cultural intuitiveness" of these individual workers, many ethnic and "racial" minority elderly women fall through the cracks. Clearly institutions are in control of what gets counted as knowledge. This is largely equated with education regarding western medical practices. Indeed, one ethnic minority woman was referred to the study because she was perceived as being "on the ball". As it turned out "on the ball" referred to this woman's ability to articulate her thoughts and ideas in a way familiar and comfortable to the worker. The woman interviewed was western educated and from an upper-class family, or in her own words she "came to Canada with money" and did not find it difficult to adapt to life in the west.

"Yes but I have always been very Western oriented. Well I was brought up in a British colony, India. The colonization days where I was educated there...And I was educated and those days English was very important...I had a lot of exposure to my advantage actually. I came with money into Canada" (Mrs. F., lines 31, 33, 37).

One worker describes this reality when she talks about older women and their families being able to express their "need" to the intake worker:

"And even when language is not a barrier it is perhaps how they are able to express themselves, perhaps even accent. Even if they have some language

...how they are able to express what their needs are and tell some story of what is happening at home. So education has a lot to do with it too (Olive, line 16).

At times, ethnic minority persons who may not have language capacity or knowledge about the formal system, western health practices and processes or “education” about these may be able to rely on their ethno-specific agencies to guide them through the technical processes of accessing care. The institution studied is in an area with a large, well established Chinese community in which there is sizeable infrastructure of ethno-specific agencies and institutions. So Chinese elders can rely on community agencies and professionals to help mediate access to mainstream institutions and advocate for them:

“I think usually they can get help through the community social service agency. We get quite a lot of referrals through the Chinese social service agency. There are also in the Chinese paper, like Yee Hong is a big Chinese community organization and they also had a column on the paper once before to provide some information about how seniors can access different service like supportive housing, in home service, Meals on Wheels, that sort of thing. So, Chinese community service organization have their own organization tools or means to provide information to their own target group. So if it is a new immigrant who doesn't know the community at all, doesn't know services available, I think it won't be too hard if they access some of the social service organizations” (Liane, line 32).

In addition, knowledgeable community workers learn how to “translate” need to help their clients access care, thus exaggerating illness in order to meet criteria set out by these institutions:

“I will try... I mean for one case or two cases they will [extend services] but you have to know how to say it, how to emphasize it's [the situation is] really dangerous, it's very unsafe...” (Maya, line 54).

Without these supports (trusted individuals, advocates, medical practitioners), older ethnic and “racial” minority women may not be able to fully articulate their needs in

a way which will be understood by health care practitioners. This, in fact, will create fundamental barriers to care and limit opportunities for older women to get what they need.

### **Ruled by Processes: Phone, Paper and Computer-generated Relations**

Case managers interviewed for the study have spoken about the importance of doing home visits both to “eye-ball” cases and to keep “up to date” with the status of their clients in order to evaluate them properly. They also spoke of the importance of developing relationships with clients in order to understand their situations more accurately, as discussed in the previous chapter. However, because of time constraints, case-manager-client interactions are dominated and structured around the telephone.

“Communication is usually by telephone’ (Olive, line 55).

According to this manager,

“...when I first walked into the old office which was larger than this in terms of square footage... I thought I’d walked into the reservation centre at Air Canada, or something like that. Here are all of these, and they are predominantly women, sitting there in these cubicles with headphones on talking, talking, talking. What is this? Is this a market survey thing? What is this? And this is what our coordinators spend a lot of their time doing and I think that...number one, I can’t see how one gets a huge amount of job satisfaction from that and number two, I don’t know that it’s the best way of servicing clients. Everything is being done at a distance and if their caseloads were down more they’d be able to be out there meeting with clients, a picture’s worth a thousand words, have that contact, ask... you know something twigs your interest you can ask a question, but you don’t get that over the phone...” (Jean, line 43).

This reality limits workers’ capacities to fully engage with clients and assess their situations. Workers, themselves, have expressed their preference for face-to-face contact over telephone work. As one worker stated,

**“You see in a lot of people's minds they feel they can get accomplished on the telephone what I can get accomplished in person and I don't believe that's so... It doesn't normally happen, I can't say and uh...but again I'm probably being unrealistic by saying that we can in fact visit everybody, but ...the satisfaction of you actually doing the right thing rather than sort of guessing is really rewarding cause you can really slot things in appropriately. Ands it feels really good when you get a report back that says ah you put the right things in. And of course [over the phone] you make mistakes...the rigidity of over the telephone may not pick up that little wavering of what is the right service” (Melanie, lines 20, 54).**

**Later in the interview, she expressed feelings of great unease about the institutional processes which define how a client communicates with the agency:**

**“I felt so ashamed about us because what they were saying was very true...they had someone who was a coordinator pretending and they'd ring a bell [phone] for the coordinator and she'd go ...uh...I'm sorry, your coordinator's not available. All the frustration that people do experience...that was one thing, the inaccessibility, they didn't know who their homecare coordinator was which is often the case, uh...you know there was just a whole thing.” (Melanie, lines 73-75).**

**Two other workers confirmed the difficulties which arise when the majority of work with clients is done over the telephone:**

**“...there's a client who's getting nursing services once a week plus physiotherapy once every other week and occupational therapy. It does get very confusing. Especially... I don't want to be biased... when you get to a certain age. You know an 85 year old client is seeing all these people coming to his or her home... her home, I guess we're talking about... it's very confusing... You know I think that every time we get an intake, a new file, the coordinator should be out there with a pamphlet, should know already who the providers are, who's going in and going to the client's house and explaining to them “you know you're going to be getting physiotherapy and this is who it's going to be, you're going to be getting occupational therapy because of this” and explaining everything and you know once you leave, the client should have with them, to put on their counter, a pamphlet, explaining all the services...what a nurse does and why... you know explain to them who will be in there and how often. Cause most of them... all we get is... all... the process right now is that we**

get an intake, we plan the service, then the file goes to the coordinator and that's it. No one explains to the client what he or she is getting. Maybe initially on the phone. But an 85 year old client who may have some cognitive impairment will not remember that" (Hannah, line 48).

And another worker stated,

"...Because sometimes we're talking to people on the phone and we get a gut feeling there's more. Either they need more service or you know they're just pulling wool over your eyes in needing help with the bath, you know? And sometimes I've gone out there and I was right you know where uh...they needed more. The ones I gone out to see..." (Elaine, line 79).

The telephone can also operate to cause struggles between workers and clients. In the following example, the worker shared an experience in which she inappropriately blamed a client for being non-compliant because she was not able to communicate with her over the telephone. In the quote, the worker expressed how she had done work to set up the service and did not receive any feedback from the client or her family about these services. What this suggests is that when workers and clients do not have the opportunity to know each other and visit face-to-face in an atmosphere of prolonged engagement, then problems arise which can result in the unfair labeling or treatment of some clients:

"Well I was glad to hear she was in hospital but then here I am thinking "I made the referral I made all these calls, nobody's getting back to me, how irresponsible" and I was ready to label them as irresponsible and ignorant and there they were having a crisis in the home. So you really sometimes have to get out there and see what's going on to know what people are dealing with" (Elaine, line 80).

This unfair labeling and treatment can also result when a potential client is discovered to have refused care on a previous occasion. As related in this participant observation:

"I asked Elaine about the category "patient/family refused". I wanted to know if people get treated differently the next time they call if this category

is ticked off on their record. Elaine said this shouldn't be but it does happen. People say "Why is she calling again? She refused before". She said "people are human and they make judgements, I know cause I hear it all the time. The check offs are vague so you can write or tick off something else less damaging. Like this guy refused but to his credit cause he really didn't need the service, so it's to his credit"" (Elaine, PO 11).

In the end, telephone contact shapes and defines relationships between workers and clients in a way which narrows opportunities for relationship building. This is also true of relationships between case managers and service providers. Often frustrations around phone contact arise when case managers attempt to do inter-disciplinary work with front-line service providers such as nurses or physiotherapists over the telephone, as is often the case with case conferencing. In referring to her experience of doing telephone case conferencing, this case manager stated that she felt,

"...frustrated and left out. You know you feel like you have something to offer about planning for the patient at home or not to be having the patient at home. But you know, when it comes down to it there isn't enough time in our day" (Olive, line 60).

Paperwork is another arena for shaping interactions between workers and clients. Paperwork serves both to reinforce medical criteria and "manage" workers' time in such a way as to render relationship building and reciprocity next to impossible. Paperwork in the form of assessments and service contracts are heavily regulated by the government ministry responsible for funding home care, the Ministry of Health. This results in an emphasis on medical criteria for assessment and short-term medically-oriented goals of treatment. Assessment forms are, once again, a good case in point. Each assessment form package which is filled out by an intake worker at the time of initial contact includes a variety of forms which serve to regulate how and why clients "get on" the service. These

forms include a communication-administrative form which serves as the bulk of the assessment tool, a medical referral sheet which provides medical information, a service requisition sheet which indicates which service is required, a sheet which provides a communication link to the hospital if the referral is being made from the hospital and a referral control sheet which provides space for the intake worker to indicate special instructions for internal control between intake worker and worker responsible for arranging service providers. Several items on these forms indicate clearly the medical and short term priorities of formal care provision. First, the medical referral sheet indicates clearly under service provision that "treatments will be taught/reduced unless otherwise indicated" suggesting the goal of treatment is to ultimately remove the need for professional support. Indeed, on the main form, treatment goals are itemized as follows: healing of wound; return to self-care; return to former functional level; return to total self care; reintegration into community; teach treatment protocol; adjust to altered functional status; delay or prevent deterioration; assess level of care required. Each of these are medical goals, most of which are acute in nature with an expectation of short term or reduced treatment once adjustments to health status are met. There is currently a designation between acute and chronic programs within *Eldercare* as outlined in their text on eligibility guidelines. The guidelines around the differentiation between the two programs are simple. The acute program is based on illness recovery, increased mobility, increased or restored competence and a length of stay on the program of under 60 days. The chronic program is based on progress towards clinical treatment goals, delay or prevention of deterioration, delay of transfer to an institution and a length of stay over 60 days. However, the official ministry form contains a category entitled "reasons for non-

admission” which is in direct conflict with “softer” institutional protocols and, as a result, are quite problematic. For example, one of the criteria for check-off underneath the category reasons for non-admission is “no progress expected”. This is quite a peculiar designation considering the high proportion of elders with chronic care conditions on *Eldercare*’s caseload. One worker stated during a participant observation,

“This is a bad one. Lots of seniors are not expected to progress. It is not realistic for this population and should be removed. I never check off no progress expected for example. It is a small way of advocating for a client” (Elaine, PO 12).

Case managers have talked about the huge amount of time paperwork takes up in their day, which, in the end, does function to shape the work they do both in the office and with their clients. For as long as paperwork takes up as much time as it does, this will mean both that workers have less time to interact with clients and also have to shape their conversations by what is required by the Ministry of Health for their paperwork. The following quote exemplifies how workers’ work is governed by paper:

“Oh that’s too many. There are many. The thing we need to do is the client’s case documentation where we have to record every call, every conversation or communication with everybody regarding that case, something that is an open case, right... something that is in the system already... a client in the system already. There are also forms which are for intake and crisis which is also like a fact sheet a snapshot of information for that crisis and how like... why we think that this is a crisis, what’s the situation, what’s the contact person, how do we process it and what is the resolution. So it’s a brief form. And because of so many changes from before ... and... there are a lot of forms where we used to do before, right now we are still doing and things are modifying a little bit and uh... that’s for the case part, the case work part. For the bed offer part when we need to coordinate with the facilitates... when we are doing the bed offer, we have to document every call that we make with regard to that bed offer and then we have to count how many calls we made for one bed vacancy. Oh I made a record... I made a record of over 100 calls for one bed vacancy. So that kinds of forms are necessary for us to fill out. And after bed was filled,

we fill out another authorization form so that the nursing home can get the money. That's the form that go into the Ministry. And we also have to fill out some statistic? Like every month we have a list of all the calls... all the bed vacancies... like how we go by each bed vacancies. I can show you later... like on certain day we receive that bed vacancy... like it's a table that we fill out each month. And then after each one week... we used to fill out a summary of bed vacancy for that month which is a brief summary of the total bed vacancies in that facility ... average call we make for each bed vacancies and so on. That we used to do. I think some workers are still doing that. I'm not sure whether everybody is still doing it. Cause it used to be the statistics that we report to the Ministry. And they keep track of how many calls we are making for each bed and maybe they use that to figure out how much staff we needed... that kind of thing. So those data... I think is useful for the Ministry to plan ahead the funding or whatever. But I don't know now... I still do that...I still do that. But here, because I'm still relatively new here so I don't know if all the paper chasing process are still the same...uh... and whether it's still... somebody will look at it. I spend so much time just filling out my forms. And we have another form which is called the intake tracking sheet just to record all the incoming calls, the inquiries, general ones. Because we have the caseload one which is documented in the case file... and then we have the crisis and then general calls. So basically I think... oh there are a lot more but those are the basic ones that are needed to fill lout all this. Oh (sigh) I got used to it already. I got used to it already. A lot of documentation" (Liane, line 71-77).

In commenting about competition between doing home visits and completing paperwork, the following worker had this to say:

"But at first it used to get me really nervous, you know you felt like you needed to be in two places at once. I felt like I could only be you know a couple of hours away at one place and then I had to rush off a couple of hours at the other? And because the whole idea is to be out here and to be visible and accessible so you shouldn't be back there worrying about paper. But unfortunately it's a reality in our job, paper work is critical. So I have come to terms with and I will do what I need to do. If I can stay away longer, I will do it. But if I have to go back in a row, because I had tons of paperwork to get organized, I will do it cause there's no other solution at this point in time. So that I can see is the only difficulty at present" (Melanie, line 37).

Another worker stated simply,

"We're getting more like secretaries" (Elaine, PO 12).

Paperwork and government ministry regulations also determine what is important and what is irrelevant information, guiding and instructing what workers ask clients about and what is deemed important for interactions between worker and client:

“But there’s nothing about... like the way they have it... they don’t have it like... the assessment form, when I get the intake, there’s nothing about social, mental, family... all it is is about medical you know? There’s no category of family situation, family dynamics or social and mental... condition... you have to... on the ball.. You have to put it... the assessment tool, it’s not there... but if it was neatly categorized you can flip through that page and see social, family network, culture. You know you would find all that. Finances. Any thing, financial situation. The client is on welfare. The client is on welfare and I would never know cause it’s not on the intake” (Hannah, line 131).

“But generally the way I do my recording (takes out form) here is where I have to write everything in this little square and I start with admitted on such and such a date, diagnosis, previous medical history and I put currently and I put a big paragraph on what is happening currently, the bottom I put social and I try to find out as much as I can about what’s going on, what kind of housing they live in, how many children they have, are they supportive or not... sort of an odd question, are they supportive, do they help you, do they pop in and do groceries...and you know how much information I can get about that and pop it in there... future plans they have regarding staying home or have they considered placement...purchasing extra help.. I write very small if there’s a lot (laughs)” (Olive, lines 142-144).

“Well you know it’s cause we’re providing health care and the health care comes in all languages, I guess. I don’t know maybe the feeling is that if you ask... some time ago...we’ll say before my time...there used to be questions on these forms for race and stuff and then it was thought that because that was seen as racism. But then that was stopped so then there’s no place on the form for it” (Elaine, line 139)

Assessment tools at the agency fundamentally shape the determination of eligibility priorities at *Eldercare*. As the workers allude to above, space is provided to include psycho-social components such as family support, social activities and psychological well-

being, but it is done so in a way which often marginalizes these issues in comparison to medical need. For example on the assessment forms of the agency there is one small box which indicates "other support/agencies" and an additional space for "additional information". It is in this latter area that most workers described attempting to "fit" psycho-social information that has a bearing on service plans.

Conversations between worker and client, already defined and shaped by a lack of prolonged engagement, are further ruled by the guidelines and questions which must be filled out on forms to meet governmental requirements. This happens despite the fact that both workers value home visits which provide opportunities for them to speak with and learn about their clients and clients' desires to be more fully recognized as people by their workers.

How is paperwork used? Clearly it often defines the work case managers do over and above what they themselves consider useful or important. The following quote exemplifies the complexity of the use of paperwork and the ways in which paperwork serves the interests of both government and institution, rather than those of worker or client:

**"But for the chronic cases they often get admitted back and go out and get admitted back in again. So often those people we tend to get to know. And we pass pieces of information to hospital, something like this, from my colleagues in the office. They fax this to us when the clients come back in the hospital, telling us what services are already in, then we...so that's a reminder to us that so and so is already a client? So over time we get to know the revolving door type of clients who use the service continuously. And they can be in the hospital for 10 working days with the chart remaining open in our office. And supposedly after 10 working days they are supposed to close that chart and we have to do a new assessment. But there are occasions when we close it immediately...if they came in for a completely different reasons or there was a major surgery or if there were complications at home they say look we're closing it we'll look at it afresh.**

**But if there's a lot of equipment in the home then it gets quite complicated. Because theoretically we're supposed to pull it out, get the equipment from the home. Yah because of billing. It's wasted in the home because we're still paying rent. But sometimes we don't know from day to day or week to week. [and then closing and opening a case is sort of] a waste. It can be. It sort of sometimes is good for statistics" (Olive, lines 47-51).**

**Often interactions between case management agency and service provider agency are dictated solely by paper. There are a myriad number of forms whose sole purpose is to inform other agencies about service requirements. Case managers may never talk to service providers unless a crisis develops and even then may only talk to the service provider's supervisor. This complicates and reduces opportunities for sharing client information, problem solving and developing relationships between case management institution and provider agency or various types of workers.**

**"... Yes...uh...everything I do for my new client today, once I've completed everything, my papers go to head office as you might be aware by now they get faxed out if I order nursing, they get faxed out from there to the nursing agency...faxed out to other home making agencies if it's that. Or I have to fax out myself if I need home making fast. So I have already set it up by the time it goes in" (Olive, line 55).**

**Relations between professionals are formed by paper. In discussing a list of the language capacities of workers at the agency, one worker stated,**

**"There's so much paper in this place that nobody... nobody...nobody... could just pull out of their hat exactly where something is located. But if as long as you know the bits and pieces or the places to look you can always ask. Uh.. You're ok. It begins with information and manuals, that's one place you can look, we have a drawer full of paper which is all different resources which is another place we can look. I know we have some stuff in my drawer" (Greta, lines 49-52).**

**Computers have begun to replace paper contact within and between agencies. The shift from paper to computer has added a further layer of alienation to the work done**

among health care professionals and for the short term, at least, contributes to worker strain, anxiety and loss of time spent in interactions with clients. Learning to use computers, managing government ministry requirements and dealing with ongoing changes and problems with government ministry software have all contributed to this sense of strain among workers:

“Now, if we have a very good computer system, things may not be that bad. But... the problem is our system aren't working well and we are even losing information... crucial important information... a lot of times, everything we enter is gone and we can't even communicate like through the bed vacancy screen. It's too non-user friendly. So.. Yes I do. Especially with the computer... it could be quite straining and uh... but uh... hopefully you know, after the turmoil we can have some light...” (Liane, line 88).

“in terms of the computers and our uh we get like a, we get like an activity log, the providers, that has all of our cases and we get this date that says if you are still seeing this client past this date, you owe a progress report to the coordinator you know, what's happened with the case and if you want an extension of authorization for visits and there's some kind of computer glitch that's not printing out those dates. And what that means for us is that we don't have sort of a reminder that oh, I'm overdue for a progress report now so then the coordinators get maybe annoyed with us 'cause we're not staying on top of giving them a progress report 'cause they don't know that we don't have this cue and then we put in a billing and the team assistant goes to enter it and it gets rejected because it's not authorized so the team assistant has to come back and say can you go back to the coordinator and you know see what happened with this authorization. So it just slows down all of that stuff” (Pamela, line 100).

One worker talked about frustrations she had getting a meeting together with her supervisor. Instead, she was referred back to her computer and asked to engage with the supervisor via email. This produced frustration in the worker.

“So I was in the office for maybe five minutes and I said “can I just quickly take five minutes of your time just to let you know about one of my cases?” “Oh, could you do me an email?”. I don't have time to do an email. I had to stay, I was late for the next client visit to write up for a half an

hour, this case. And I got, you know, this reply, "thanks for the email. It doesn't sound like it's [a problem for us]" (snorts). No like, wow that sounds like a heavy case, wow, you know, are you ok, you know... like , I guess we're not here to get support like that. What it says is that you have to go for that support to your colleagues. You don't get it from your manager. At least I don't get it from my manager.... you know she cut through all this stuff about the case and said "oh it doesn't look like it's gonna be our problem" (laughs)" (Pamela, line 196-198)

Elder care institutions are largely ruled by technology. In efforts to increase efficiency, technology has been used as a panacea. Phone assessments of clients, faxing service orders to provider agencies, trouble-shooting via phone or fax, updating and evaluating cases via reports and telephone case conferencing, and emailing are all ways in which work gets speeded up to the detriment of developing human relationships, trust and familiarity. Unless problems arise, case managers may often rely solely on phone contact with clients between long intervals of silence. Home visits, while deemed important by all, occur rarely for those clients with stable situations. Clients themselves may lose track of whom to call during a problem as several layers of hierarchy exist in service provision; provider, provider's supervisor, case manager. Not only clients lose out in this scenario. Workers also express feelings of isolation, stress and lack of control over their jobs. Phones, paperwork and computer work rule elder care services and as such, rule relationships between supervisors, workers, providers and clients. Once in place, these tools are difficult to remove or reduce; after all, speed and efficiency are necessary in order to provide services to a growing number of clients. Each of these technologies serves to reinforce medical criteria for care, shaping how workers and clients interact, what is seen as important information and how much time is available for talk outside the defined parameters of physical need.

Caseload size plays a part in reinforcing this focus. Caseload size both shapes interactions and limits frequency of contact. This contributes, alongside an emphasis on technology for communication, to a discourse which under-prioritizes such interactions as follow-up visits and over-prioritizes medical functioning.

**“But I would say I would hope to see the ratio, the caseload ratio to be lowered. We barely have any chance to do the follow-up. And follow up is part of our job. Follow up is always viewed as as the lowest priority...” (Liane, line 83-84)**

**“And unfortunately some people have to be... because if you’re willing, if you’re a coordinator that’s willing to do that [spend longer with some clients and allow them to talk about their personal lives] you have to accept that some people will be left out because you can’t see everybody. Unfortunately I base it on diagnosis. Something that’s quite severe like cancer or COPD.... respiratory problems or cardiac problems or onset of MS, you base it on... Especially if it’s uh...cardiac.. If there’s a cardiac problem....Because those are more likely to be rehospitalized” (Hannah, lines 151-157).**

According to other workers:

**“Everybody has their areas of interest or expertise. My big area is palliation. And uh I do tend to pay attention a lot to these individuals simply because their status can change so quickly. There’s a lot of issues and stress” (Greta, line 57).**

**“Uh, that is the ideal to see the client right away but it doesn’t usually happen. Because of the caseload. So I will assess what the problems first, what the diagnosis. If it’s just like a simple dressing, a straightforward dressing, if it is an acute case, then I might not be able to see the client, like even if the client is discharged. But if it is... a client with a palliative client with a diagnosis like cancer or leukemia then I try to see the client as soon as I can. Two or three weeks I would say. Like if it is really palliative, you know I have to do an emergency assessment... Well if a palliative client is admitted to the program, the doctor will say the client has an expectancy less than three months I will need to do an assessment to see if there’s any more service the client will need. I will try and do a home visit to meet with the client to explain to them, like to see what the needs are. Because the client, at that point it might be more homemaking, especially for supports at that time. So we try to do that. But otherwise if it is just a chronic case I**

would try to fit them into my regular home visit schedule to see if I can see them” (Kathy, lines 51-57).

In the above quotes, the workers describe how they perceive themselves as making “personal choices” to prioritize the more acute and pressing medical needs of palliative patients when determining whom to see on a face-to-face basis. This expression of “personal choice” exemplifies how larger systemic discourses of medicine get rendered invisible and re-conceptualized as personal choice by the worker in relationship to the management of their time and workload. In both the above quotes, what is apparent is that more critically ill individuals, such as those that are palliative, are given “individual” priority. But this “personal choice” reflects governmental and agency priorities which are invisible to these workers. Based solely on referral source (80% of clients are referred through hospitals), it is not hard to imagine that worker preference for prioritizing palliation may also be reflected in institutional priorities, regardless of whether or not it gets articulated as such. In institutions, worker practices are often not perceived as evolving from larger administrative-medical discourses but rather are reconstituted as worker priorities. This gives workers some sense of having control over their jobs, albeit in a limited way. When workers have talked about control over their jobs, they often did so from a micro-perspective, rarely referring to macro changes which have contributed to increases in case load or changes in processes which regulate contact through technology. Indeed job control is largely about whom to visit with, whom to confer with and to whom to provide service. Workers see themselves as “adapting” the rules in order to service their clients better, develop relationships with them and manage their time as much as possible, to suit their schedules, their clients’ needs and their own personalities and values.

**“you see, I've never worked well with a person with a thumb on me making it like I can't breathe. I will always give more than what is expected, that's just the way it's always worked. So telling me I can't go to the washroom or I have to be back at one minute, is not appropriate for my character. I used to...like when I started saying that I participated in [community outreach]...I used to tell my supervisor I'll be here...here and I'm going to this and I'm doing this. And the response I got was "Is this for personal?". Do you know what I mean? And I basically couldn't...I couldn't believe it. So I stopped telling him. Because I said to myself I know what I'm doing and I would not be wasting my time this way if I didn't think there were benefits... But I enjoy it so much that I'm willing to put up with that negative aspect of things...just don't talk about it cause I don't intend to change. So that's that...” (Melanie, lines 81, 148)**

**“But sometimes you wind up providing a little bit more service than you really feel is necessary, but you can't do much about that. Well because there's also anger and distress and we're in a position where we are supposed to be trying to assist and if what we're doing is creating anger and distress, you have to measure all these things against what you are ultimately trying to make happen. And if one hour of homemaking is making the difference, what are you going to do? Are you going to take that hour away and cause a whole lot of distress or you going to leave it there knowing full well that you'd like to see this person manage with a little less” (Greta, lines 25-27).**

**“I recognize that compared to some other settings that I could be working in, I still have a fair bit of control. This is what I have to keep telling myself when I feel...negative. I still can basically get up in the morning and say I want to see Mr. Brown, Mrs. Smith and Mr. Jones today, but I certainly do not want to see Mrs. Black... like we can say this is a really heavy duty visit so I'd better go see this person 'cause I'll be wiped after this one or um you know this is some time that I can do paperwork, so you know the actual time management part is still relatively within my control” (Pamela, line 165)**

**“It gives me more control over my person. I don't know about my job but my person. I feel very secure in myself ... you know, I feel ... to be quite honest, that tomorrow morning they can come and say you're done and that would be ok with me but I'm going out on my terms. That's the way I feel. If I have to go out fighting I will but they're going to have to know how I feel when I'm going. I will not go silently (laughs)” (Elaine, line 184).**

**“OK, sometimes like... ok lets say ok putting in a home some equipment? Like putting in a bed, a hospital bed, because sometimes I need some**

support from my peer to give me advice to say ok, go ahead, put the bed in (laughs), yah. Yah it's a big investment and I want to make sure it's appropriate to put in for palliative clients. Although sometimes the client, the term palliative the client has less than three months to live. But sometimes the client, it might not be as sick for just three months but I feel that his or her condition is kind of deteriorating then I will say I would tend to put in a bed for the comfort of a client. So I need to listen to my peer to actually see if it's ok" (Kathy, lines 115-117).

Institutions do support this kind of flexibility so that workers are not necessarily going against the rules when they make adjustments to their schedules, the services their clients receive or whom they prioritize for home visits. In fact, these are normal components of their everyday work. As one manager stated,

"I think that if you presented a case scenario to a bunch of coordinators and they were allowed to ask questions and get information, I think you'd find that they came up with quite a range of service plans for getting the same information... My hesitancy around that is that you should never lose sight of the individual and no matter what... how good a form, a program, whatever, there has to be some degree of flexibility around how these things are determined. Otherwise you don't need these people, you just buy some more computers and press in, you know, if you're diabetic press 2 and get this number of hours of service" (Jean, line 41).

However, workers often perceive themselves to be "bending the rules" when they make these kinds of changes, going outside the boundaries of what is considered "normal work processes" or when making decisions which have resource or monetary implications. This may have something to do workers' perceptions regarding a lack of institutional support for these decisions. This is quite complex. In reality, managers support self-regulation, control and peer support, but in the actual everyday lived reality of workers' lives, there is little time for these activities in people's work loads. Often workers are simply "surviving", working at a frenetic pace to keep up with their current case load and

do not feel they have adequate time for visiting clients, doing case conferencing or getting advice from colleagues about their cases. Reducing case load size is the top priority of the home care institution under study. However, even once workers are hired to reduce case load size, work is still disrupted as a result of exchanges of clients between workers due to geographic boundary changes. In addition, the demand for service is so great that workers have stated that giving up clients to new workers has simply resulted in the addition of new clients to their case load. In the end, when perceptions regarding job performance, (based on individual workers' capacity to handle and create control over their jobs) and ruling processes (which shape how able workers are to both handle and control their jobs) are made totally invisible, then workers, suffering under huge caseloads and time constraints, are more likely to perceive that institutions do not support or value their efforts and ways of working. This is felt in terms of the lack of managerial sympathy for the pressures workers are working under, a lack of focus on creating larger change through advocacy and a lack of education and resources for workers. As these workers stated,

"We're not getting a lot of relief and we're not getting support and high case loads...you go out to make a home visit the work is still coming while you're out there..it's not stopping when you go out to make a home visit" (Elaine, line 86).

"Um, well we've never had an active PR campaign that I'm aware of in the history of the organization. I think historically it's been a very traditional, conservative agency, it's not been an activist kind of an agency, um it used to frustrate me to death... I would really like to see us becoming more involved, not that it would become our sole mandate but as part of , as an adjunct of the services we provide to clients, I'd like to see us do more of the community development stuff... Case by case you can't rabble rouse, you can't, you can't stir the pot, you can't, you just do your little advocacy thing on that particular client and then you go on to the next one" (Pamela, lines 74-78).

**“and I will never suggest that there has not been an attempt to try and ensure that that information is available because it is, and it has been over the years, you get lists circulated, when you have new staff, they are supposed to be added to the list. But it’s a matter of priorities and if uh... somebody’s performance review is due and this list has to go around and you have a crisis with a client, guess which is going to come first. There are just so many hours in a day” (Greta, line 55).**

**This reality suggests that there is a link between institutional processes and individual choices. Work processes are not so much about individual worker energy, priorities, values or preferences but about how institutions structures procedures, how they shape such processes as time and communication, and as a result, fundamentally shape possible choices workers have regarding control of their jobs and subsequent interactions between “worker and client” and “worker and worker”. Yet, preferences regarding who gets seen, when and why are viewed as individual choices made by workers and not as a construction of systemic ruling apparatus. What happens then is that administrative conclusions get made about workers’ capacity and performance based on “individual work”. This is particularly true in the situation of home visiting. Workers that do more home visits or outreach are viewed more positively by the agency. Energy, flexibility and adaptability to new operating guidelines and procedures are seen as qualities to be rewarded. This sets up a competition between workers in which, often newly hired employees are regarded more positively and seen as more “adaptable” and “productive” than employees who have been around for a long time.**

**“They really have a really challenging job and very difficult a lot of times. Some of them could be a little more flexible but part of it is the old culture from the other agency where everything was very laid out. Tick every dot in every box and every “I”. It’s easier for the newer people coming in but**

people that have been around for a long long time, it's been more difficult for them" (Rhonda, lines 138-140).

"Older" workers, however, may simply be refusing to adapt or having difficulty adapting to the new model of community care with its narrower eligibility criteria, larger case loads and a technologized work environment. The impact of governmental changes on work conditions can leave workers confused, isolated or frustrated, particularly as this has meant increased pressure on workers in community care to "pick up the slack" of hospital closures while at the same time becoming more efficient and cost-saving in their work, thus rendering their everyday work experience pressured and their relationships with clients even more contested:

"The thing is that there's been a lot of changes in time. When I first started to work here, I mean we gave taxis out like candy. Got all strict... opened up... got all strict again... opened up. Just keeps happening, back and forth, back and forth, back and forth... and depending on what was going on in the government, depends what was going on in terms of the philosophy of the current people in power and uh.. You just get used to the fact that what we say today may not be true tomorrow. Sometimes I have to qualify what I say and say "well, right now this is how it is, it may not always be this way, but this is how it is right now" and uh... I think those things you learn by having gone through this and learning to be not really really rigid in what you're doing. Trying to be flexible and trying to consider how best we can see what is needed and figure out how we can do it within the confines. That's all. Sometimes you get bent a little bit but never broken. I mean you have to be creative but you have to be flexible but you have to be sure that you can justify what you do. As long as you're sure that you can do all those three things you got it made. But that's taken a long time to figure out how to do that. We often don't know what the experience of these people are when they come here but we are continually having to watch our pennies, make sure that the services we are providing are appropriate based on the guidelines from the Ministry and sometimes that doesn't fall into the idea that these individuals have. So that can sometimes struggle to be a big problem. [We do] a lot of negotiating" (Greta, lines 83-86).

**“But the problem is having so many kinds of changes, is hard for everyone to catch up. So, it may take time to get everybody know how we operating these days” (Liane, line 37).**

**“But sometimes it’s - and it’s not even us and the workshops that we necessarily put out - very often when the government (and again it’s political) give the [institution] ten dollars, they go on the radio and they say, “Well you know, homecare - ...all of these dollars and we can do all of these programs”... People hear that and they think, ‘Hey, there’s some free dollars going to homecare so we can come and get anything that we want”, so the message... it’s the wrong message going out...” (Fay, line 24).**

**“I think it's more to do with um...the um the funding structure and um the fear of you know us being perceived as and I appreciate this politically I mean we can't be perceived as pointing the finger and blaming, we have to be perceived as doing something cooperative and collaborative...it's like sometimes we know what our limitations are given what the Ministry of Health can give us and we almost sometimes unconsciously or consciously welcome somebody to stir the pot 'cause we know that we have problems but we're not in a position to sort of, certainly not in a position to publicly take it out and say you know we get all this money, but here's the gaps, this is what we need” (Pamela, lines 82-84).**

**These quotes attest to the difficulties workers experience in their daily work as a direct result of governmental actions. As worker Pamela above stated, it becomes difficult to critique the current model and gaps in service when one works for a publicly funded agency. Workers express the dilemmas of “biting the hand that feeds you”. Within the current climate, there is little room for this debate within institutions. Instead the larger political discussions regarding health care restructuring and its impact upon the everyday working processes of agencies and worker-client relationships, get shifted back to the individual worker in terms of working performance, productivity, adaptability and agency loyalty. Here then, the philosophical stance of medical prominence and resource scarcity vis-a-vis government gets articulated at the agency as individual worker’s choice.**

## **Conclusion**

The data presented in this chapter examine two central and related ideologies at the root of the current model of elder care services, namely medical-dominance and scarcity of resources. Relationships between health care professionals and elders are predominantly shaped by the ruling ideologies of governments as articulated through the everyday practices and processes of public elder care agencies. In turn, these practices and processes shape professional perceptions and constructions of elders and, as a result, what is counted as legitimate “need” for service. In the current climate, this has meant that elder care services operate almost exclusively from a medical perspective, shaping and limiting elderly clients in terms of their medical or functional status. This is achieved in a number of ways. First, the most common point of entry is through the hospital, which accounts for almost 80% of new caseloads. Second, eligibility criteria are almost totally medical in nature. This is even true of home making where “personal care” criteria limit who can gain access. Third, paperwork in the form of assessment and evaluation are severely regulated by the Ministry of Health which funds home care. Fourth, caseload size plays a part in both shaping interactions (because of emphasis on time efficiency, leaving less time for “open talk” and building trust in which psycho-social needs often get articulated) and limiting frequency of contact so that only the most medically serious cases are given priority. In addition, case managers need to rely almost exclusively on service providers to tell them when changes occur in the status of their clients. These service providers, particularly nurses and physiotherapists, are trained from within a medical model and so may be limited in their capacity to assess psycho-social needs. “Non professionals” like homecare workers change so often so that there is little consistency from which to assess

changes in clients over the long term. Medical discourse acts as a “professional lense” through which “need” is interpreted in the every day as medical or functional impairment so that only those who speak from within this discourse are heard and legitimized. That means that the prioritizing of medical “need” is articulated in the form of “technical language” to which only medical professionals and other “insiders” gain access, leaving the boundaries around who receives care and under what conditions in the tight control of case managers. Still, the fact that this discourse is operationalized in the every day by case managers themselves, enables the macro structures inherent in the relationship between discourse and practice to remain invisible. Only the relationship between worker and client is visible, thus leading the public to believe that worker “personal choice” is responsible for the prioritizing of “need” as medical.

These everyday realities have a very large impact upon older female clients, primarily constructing them as “patients”, “passive recipients” and as “ill”. Older ethnic and “racial” minority women have expressed resisting medical constructions of themselves and have attempted to be understood not only for who they are, but also for who they were; women who have struggled with experiences of hardship, whose experiences of immigration and employment helped shape their lives as survivors. Workers have also, at times, expressed attempts to resist the boundaries placed upon them by ruling practices in elder care. They do this through stretching what they perceive are the boundaries of their work, putting in extra service even though it may not be required or doing additional outreach without informing supervisors. Together, worker and client efforts to resist medical domination may have a quite limited effect given that ruling relationships inherent within the ideologies of medical-dominance and scarcity of resources so prominent in our

**current elder care system remain largely invisible and, therefore uncontested. As a result older women's wants and needs may continue to be met with institutional disapproval.**

## **Chapter 9: The Limits of Multiculturalism**

The following chapter addresses the question of how discourses of “race” and racism are articulated in elder care services. In order to examine the ways in which “race” and racism are understood and experienced and the ways in which institutions practice multiculturalism, the stories of older women, workers in the system and ethno-specific community workers will be analyzed. Central to the current analysis is an examination of how each of these differently situated stories and experiences are reflected in and reflective of everyday practices of access and how discourses of “race” and racism are made manifest through agency policies and procedures on multiculturalism, particularly as they are made manifest in the treatment of communication services (interpretation<sup>3</sup>) as the fundamental construct through which barriers to care are understood. It is through these everyday practices, policies and procedures on multiculturalism, that discourses of “race” and racism get molded, articulated and shaped, thereby having a substantial impact not only on how older ethnic and “racial” minority women gain access to and are constructed by elder care services but also on how ethnic and “racial” minority and mainstream workers see and experience their work. In the case of workers, an examination of how both ethnic and “racial” minority workers and mainstream Anglo-Canadian workers both construct themselves and are constructed by ruling practices and the impact this has on the

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<sup>3</sup>In the current context, the term “interpretation” is used specifically to identify both language translation and cultural interpretation (i.e. the explanation of cultural norms and practices which exist independent of language). Cultural interpretation is often embedded, invisibly within language translation services but forms a central component of the task of interpreters who are responsible for “communicating” between worker and client. Workers, in speaking about this communication, may move between the terms “interpreter” and “translator”. It cannot be assumed, therefore, in the quotes included in this and other chapters, that they are referring in the former instance to the larger definition of interpretation as conceptualized by the author. Rather, given the primary focus on language discourse in the institution under study, “interpretation” most likely means “language translation”, unless otherwise articulated by the worker as “cultural interpretation”.

work they do with their ethnic and “racial” minority elderly female clients, will be explicated.

### **The Primacy of Language**

The least contested terrain in multicultural policy and practice in elder care relates to language. All participant cohorts agreed that language acts as a fundamental barrier to access for both clients and their families. There appears to be a clear institutional priority regarding language services which operates to enable elders to receive services, in at least some capacity, in their mother tongue. Where institutional priorities do exist to deal with ethnic and “racial” minority clients, the focus is largely on language responsiveness. This does not necessarily mean that the institution backs up this priority with financial or other resources. In fact, part of the practice of language responsiveness is to rely almost exclusively on families to provide interpretation. However, within institutional discourse, consensus does exist around the need for linguistic sensitivity in care, even when and if that response is limited. Language-matching issues for example (when clients are matched up with workers who speak the same language as they do) are particularly present in people’s “talk”.

Older ethnic and “racial” minority women themselves spoke of the potential for language difficulties to create barriers to access and to the provision of health care:

“When the doctor, the physiotherapist and the doctor had a meeting, they asked me to attend. I sat there like a piece of wood and I did not understand their conversation. I did not know what has happened, I just sat there like a block of wood...” (Mrs. L., line 170).

She later stated,

“I think because I do not speak and comprehend English, if the technician told me to breathe, to turn left or right... the technician becomes impatient

and his attitude was poor. I think that the hospital or any Canadian doctor should have a Chinese nurse" (Mrs. L., line 220).

"It was difficult but language is a great thing. It's good to know languages cause you don't feel foreign... But for the other people, for the elderly of the ethnic communities, definitely you would need people who were able to speak their language. Because for the elderly it is very difficult for them to learn English at that age, you know... I think language is very important, extremely important" (Mrs. F., lines 136, 165).

"No, she [the nurse] doesn't [speak Italian]. I would prefer an Italian nurse, but there are none" (Mrs. M., line 22).

"We don't know anybody. There are only English people here and we don't speak English" (Mrs. P., line 27)

"I can hear the Chinese nurses who speak Chinese. But I cannot hear what the Caucasian nurses are saying...They always tell me to learn to speak English. I am so old now, how can I learn a new language?" (Mrs. K., lines 67, 112).

"If there was no interpreter available, even when she said that it hurt nobody understand her. If Chinese staff were available, they could understand her. If her arm hurt, she could tell the interpreter. If she complained nobody understood her and they would "force" the needle into her arm. It will be for the best if they have Chinese nurses who can help her" (sister about Mrs. K., line 110).

In speaking about language as a barrier to care, both Mrs. F. and Mrs. K. refer to the treatment they received at the hands of health care professionals who insisted that they try to learn English. This centers and shapes those who do not speak the mainstream language of Canadian health services as "deviants". Practices such as these formulate language barriers as client problems rather than institutional ones (Kaufert & Pusch, 1997).

Workers have also identified language as the fundamental barrier to care among ethnic and "racial" minority women:

**"I think from my past experience because of the language barrier, some of them will [think that] because [they] cannot speak the language...they do not try to seek assistance" (Kathy, line 3).**

**"I think the major major barriers for Chinese seniors to access nursing home would be language area... a barrier which is another language, a different language, a second language would be ...very big obstruction and it varies for them to access. It provides them a psychological resistance... they are afraid to communicate in a different language and they also find it very insecure if they are put in a setting where a lot of people around them are not speaking their language. It would be particularly difficult when the senior are frail, having lots of physical or psychological issue, like depressed or physical problem because that would be hard for them to verbalize how they feel. So I think language is a big issue for them to access the care..." (Liane, lines 5-6)**

**"The issues... uh...accessing health care, as like any other service we access or buy, if their language isn't our language or we cannot communicate, then I think that is one of the hugest things that will impede them" (Olive, line 7).**

**"I think... uh... the main issue is the language barrier. The issue that uh sometimes people who are being served by homecare services, trying to get someone who understands what their needs are and giving them the opportunity to make their needs known to the individual." (Greta, line 7).**

**Hospital and community workers have also expressed this priority:**

**"I think the most important difficult problem is the language barrier" (Maya, line 7)**

**"The first issue that comes to mind is language. I deal with elderly patients that don't speak English and so they rely on interpreters who may not be home during the day. So if they don't have someone who speaks their language, then that is a problem" (Ginette, lines 3, 7).**

**Why is language comprehension seen as the main priority in elder care? One of the central reasons relates to the fact that a language barrier is one of the most tangible barriers to care. When a client and worker do not speak the same language it is immediately visible and concrete, giving it shape. Because it is so visible, it can be dealt**

with in a relatively straight forward way; locate someone who can interpret between worker and client. This renders the response simple and achievable. As one worker stated,

**“So the ones that can’t speak you know straight away that you can’t talk to them. They go “Eh? Eh? Eh?”. So you know you’re not going to get anywhere with that one so you know you have to go and get a Chinese coordinator to interpret it for you. So I find language to me is not a big problem cause the ones that I can’t deal with, I take it to somebody else” (Elaine, line 23).**

Despite the fact that language is perceived as the most tangible direct source of access barriers experienced by older ethnic and “racial” minority women, the way language services are delivered are not unproblematic. There are currently not many financial or human resources put into interpretation services. The most common approach for dealing with language barriers is to call on family to provide translation or interpretation. The current system puts a great amount of pressure on families to interpret, thereby reducing the need to pay for professional, interpretive services. This was discussed at length in Chapter 6. When no family is available to provide interpretation, more formal approaches are considered. However, according to workers, there are no clearly identified agency policies around interpretation, so often workers are on their own to decide how to proceed with a client who does not speak English or French. This leads to a great deal of variability in regards to people’s perception of and the value attributed to interpretation and language-matching, both of which are directly linked. Workers are not always in agreement with how to handle the “problem of language capacity”. Generally, in considering the interactions between client and case manager, most workers followed a “loose” guideline around interpretation which, although not formalized by the agency, was commonly understood:

**“Um, what we do try to do in terms of language and easing some of the access is, we sort of have a hierarchy I guess you've probably heard about this where um if it's inappropriate to use a family member to do the interpreting uh because of the nature of the work... the next line is we try and use a staff to kinda go and do a joint visit with us [or interpret] over the phone and if that's not feasible we can make a case to our manager to pay for an interpreter and uh I have used [a service]. We used to have a contract with them, I'm not really clear on whether we still do...And we you know, in general, we try to make do with accessing staff that we know like we , like I've hit on people...that you know are from some of the African countries, can you help me understand this case? Um, you know for sort of peer support and supervision almost but um it's usually piecemeal and we have to make do with what we can access here” (Greta, line 63-67).**

**The above quote suggests that, overall, family is considered to be the first option regarding interpretation. If family is not available or “appropriate” (workers mentioned only abuse as the case in which one should not use family to interpret) then other staff are sought out to aid in interpretation. This seems the most common source after families. In order to get a paid interpreter, the manager or supervisor is called in for consultation. However, worker Greta, the one most forthcoming about the hierarchy of choice regarding interpretation, could not remember if this practice still applied, suggesting it is not used very frequently at all. Confirming this, she states that finding interpretation is a “piecemeal activity” in which “workers make do” with what is at hand. This suggests that there is little institutional emphasis placed on or institutional resources provided for interpretation services. This is despite the fact that it is the most uncontested access barrier, that is, everyone names language as the primary barrier to care facing ethnic and “racial” minority elderly women. This lack of resources has an impact upon and shapes**

everyday working processes, so that, eventually, newer workers understand the formal process of deciding how to proceed on interpretation in the following way:

**“My understanding is this. Provision of... you go through the mainstream way but if the language is holding you back, then you provide the language service. Not to give it in their own language [if they speak English] because we are told we are in Canada, the main language is [English]... if they can speak the main language then by all means we should provide the service in English... if the person’s mother tongue is x and they speak English, although there is a worker available who speaks x, I don’t think we should cater to that language” (Carol, line 174).**

Since ethno- “racial” minority staff are most often called upon to “deal with” interpretive problems between mainstream or Anglophone workers and their clients, the next question begs, how do workers locate these ethno- “racial” minority staff and what institutional supports are given to those workers who provide interpretation to help them deal with the added pressure of helping out on other people’s cases while maintaining their own case load? The first question was answered by workers when they referred to a “language list” that is circulated about the agency. There was a great deal of talk by workers about this list of staff and their corresponding language capacities. Many, if not all workers interviewed made reference to this list. However, at the time of the study, no one could pinpoint where that list was actually kept suggesting that workers rely on their own personal contacts and connections rather than a formal process to identify staff interpreters. That might mean that certain workers are called upon more often than others to interpret or that certain workers make themselves more available to provide this interpretation. One minority worker confirmed this:

**“I think we have that list but I think because this is such a small department here and everybody knows everybody. So when they know somebody that needs a Chinese interpreter then they will come to us. Like I know if there’s French or any other languages, Italian, then I will know where to go” (Kathy, line 137).**

**“People know who speaks [what] pretty much. In your own team you know who speaks Greek, Italian, Chinese...” (Doreen, line 153).**

**In some cases, there is only one minority worker on staff who speaks a certain language. This can sometimes put a strain on workers in relation to managing their own workload alongside providing interpretation on colleagues’ cases. However, workers have a loyalty to their ethnic communities and to reducing language barriers so they “fit in” this interpretation as an expression of their values and commitment:**

**“I am happy to translate because helping a person who is vulnerable, somehow to get the message across. Not like you know, they don’t want to repeat over and over to too many people. So I am very happy. I can squeeze it in” (Carol, line 158).**

**Other minority workers, however, have expressed difficulty with this dual role:**

**“While I was the only [language] worker, it was overwhelming. I didn’t go around advertizing the fact that I speak the language...I thought it was too much. I don’t mind putting myself on the list but what was happening was... it’s like they said, the [community organization] will find the ethnic community person, that’s what was happening to me. I was the only one. I was it for everything. I was getting calls even in the evening and everybody was expecting you to respond by the next day” (Ann, lines 164-171).**

**“From my past experience, yes my visits with [my ethnic community] families are longer... one thing about [my ethnic community], that once they find an [indigenous] speaking coordinator or any professional, they become very demanding. Very demanding. Like “Oh this person understands me, so I will [go to them for help]...”” (Hannah, lines 163, 177).**

Clearly there is a cost to relying on informal interpretation as the major communication link between worker and client. This cost is felt not only by ethnic and "racial" minority family members but anyone who provides this essential service, including ethnic and "racial" minority workers. Currently there is little institutional support for these ethno- "racial" minority workers. The practices by which workers get assigned to clients might also exacerbate this problem. To date, the assignment of cases is geographic in nature so that any client who presents herself or is presented to the agency is assigned a case manager responsible for the geographic area in which the client lives. This is efficient and cost effective. Without geographic boundaries, workers would have to travel greater distances to reach clients and spend more money on gas. While efficient and cost effective, ethnic and "racial" minority clients "lose out" in terms of being assigned case managers who speak their language. For although, for example, there might be a Greek speaking case manager at the institution, their assigned area might be geographic area A. The unilingual Greek client in geographic area C will not have direct access to her, unless the Greek worker volunteers to act as an interpreter and even then this will occur under very distinct conditions (i.e. client has no family to translate) and only for a short period of time (to do an initial assessment for service). So while ethnic and "racial" minority workers are available in the sense that they are working professionals at the agency they may not be readily available to assist those from their own ethno- "racial" backgrounds. There are a number of issues embedded in this dilemma. First, even though the institution places considerable importance on the hiring of ethnic and "racial" minority language speaking staff, these ethnic and "racial" minority language speaking workers may not directly benefit ethno- "racial" minority clients. Second, ethnic and "racial" minority language

speaking workers might end up with “extra” invisible workload as interpreters to clients even though these clients are not on their caseload. In these cases they might face indirect pressure by the institution to provide interpretation for little benefit, through pleas to workers’ sense of good will, their values and loyalty to the agency and their own ethno-“racial” communities. Third, families will be prioritized even more in these cases, despite the presence of ethnic and “racial” minority speaking workers because the prolonged institutional relationship will still be between a case manager and client who do not speak the same language. This is a complex dilemma for all persons involved. Women do not want their families involved unless totally necessary because they don’t want to burden them. Families would not need to be burdened as much if already available ethnic and “racial” minority language speaking workers were assigned to their cases. The result is that despite the existence of these workers and their gradual increase as a proportion of total staff, institutions continue to marginalize the experience of ethnic and “racial” minority elderly women because of the primacy of efficiency and cost effectiveness based services largely centred around geographic boundaries. The agency studied is currently experimenting with crossing geographic boundaries through “directed case loads” within the Chinese community. There are several reasons for this. First, there is a high proportion of elderly persons in the Chinese community in Area P, the majority of whom do not speak English or French. Second, the Chinese population in Area P is quite large. Third, there are a sizeable number of workers of Chinese heritage working in the agency, so, there is critical mass to support a “Chinese caseload” which spans geographic boundaries, both inside and outside of the agency. This is an important effort and the success of this project may provide justification to apply it to other similarly situated communities. However,

those communities with little critical mass within and outside the agency may not be able to advocate for or support this kind of initiative regardless of its perceived importance. One thing that is important to consider, however, is that ethnic and “racial” minority workers are already breaking geographic boundaries when doing interpretation as “volunteers” but not receiving institutional support for their efforts in the form of reduced caseloads or receiving extra time to undertake this work.

The issue of language-matching between client and service provider is also considered an important feature of the provision of language services. Once again, there is no formal policy on how to approach the issue at the agency but many informal practices are in operation. Case managers consider language-matching differently for different functions, rendering it not a value-based decision but a functional one. The inconsistency among workers is based on the question of whether or not they offer to language-match clients and service providers or wait for the client to ask for it:

“If we can do it, I would offer” (Carol, line 129).

“I usually ask first... I think it’s sort of a ... I don’t know any worker who doesn’t try [to offer to match language of client and service provider] but I don’t know every single worker. I think it’s sort of an unwritten rule” (Doreen, line 150).

I don’t, I don’t unless... if they ask. If they ask. Uh... because there’s so many agencies I wouldn’t know who has. Through time you discover, ok this agency has some Italian speaking, this agency has some Greek workers... uh.. Greek speaking workers, so through time you discover where you could find them (Hannah, line 117).

Sometimes the decision to wait for clients to ask depends on the perception workers have of the ethno- “racial” community being served. The quote below suggests that the worker perceives both the Chinese and Italian communities to be particularly

vulnerable to language difficulties in which case she is more likely to offer or put in the language-match regardless of whether or not the client requests this:

**“If the client requests it, try by all means to meet it. If they don’t, no. ...If I hear a voice on the phone...well we don’t have any control over the person that goes in as intake coordinators. We contract with the agency and they send the worker out. Now unless the client say to me I only want someone from [my ethno- “racial” group]... and even then I try to tell the clients we cannot guarantee it... Language is different cause you really gotta have somebody you can communicate with. And if you can’t communicate with them it’s not going to be any fun working with them. But Chinese we know for sure we do try to send Chinese homemakers in and nurses. Cause if they’re just speaking Cantonese you know? But most, as you say, of the other nationalities speak enough English to be serviced, not perfect but enough to be serviced. Whereas some of the elderly Chinese ...nothing at all. They don’t communicate at all in English. Some Italians too. You know the older ones that live in the little Italian communities. They’ll just be able to say “No English” “Me no speaka the English” and I’ll say “Me no speaka the Italian” (laughs)” (Elaine, line 29).**

Sometimes there is priority given to language-matching only for certain kinds of service. For example, nursing is perceived as a less important service in which to provide a language-match than home making because of the medical task-oriented nature of nursing care:

**“Usually I will take into consideration depending what the tasks are... And as far as a nurse is concerned, if they speak English, it doesn’t matter. A nurse is going in to do whatever, wound dressing, so it doesn’t matter. But if they are doing personal care and meal preparation... then that requires more work” (Doreen, line 132).**

Despite the lack of institutional policy, resources or guidelines regarding the treatment of the issue of language resulting in variability in perceptions about the importance of language-matching and decisions regarding when to use interpretation and language-matching, most workers believe that language functions as a barrier and must be

addressed. Another one of the reasons for this is that one can easily separate out language comprehension from the category of discrimination, thus rendering language barriers as an individual problematic rather than a systemic one. Although institutional practices become more recognizable as forms of institutional racism when a lack of resources are applied to the problem and when fiscal restraints are used to explain why institutions can not be better prepared to deal with language, the concept of language still often resonates as an issue centered in communication between individual workers and their clients. This contributes to another form of pathologizing of ethnic and “racial” minority elderly women. When the system puts pressure on ethnic families and ethno- “racial” minority workers to deal with these immediate problems of communication, it renders the whole concept of control invisible, that is the problem is seen as resting with ethnic assimilation rather than in the processes and decisions of the institution regarding resources. This places the blame squarely on ethno- “racial” elders and their families, as problems of “the elder cannot speak” and “the family is not available”. Rarely is the “problem” constructed as “the institution is not prepared or responsive”.

There is also another problem when we focus only on language as the fundamental barrier to care among older ethnic and “racial” minority women. As was outlined in the Census data analysis, not all ethno- “racial” groups have similar limitations with regard to knowledge of English or French. Black persons, for example, have experienced a history of exclusion in the health care system, none of which is centered around lack of language proficiency. On the contrary, the majority of Black persons and Black seniors in Canada speak English or French. The “Black experience” of health care is not about language but about racism. When agencies respond to the “ethnic” question by prioritizing and

developing language-specific services, they invariably continue to marginalize and exclude English or French speaking ethno- “racial” communities like Black communities from their agendas. What needs to be considered to ensure the inclusion of ethno- “racial” communities generally and seniors in specific, is a broad spectrum of services which include language, culture, ethnicity and “race” as indicators for inclusion.

Only one worker interviewed, herself a visible minority woman, began her analysis regarding access barriers and the primacy of language from an institutional or systemic level, rather than situating her discourse in the primacy of the individual. She linked institutional priorities to a political agenda and as such, suggested the response to institutional issues such as the lack of culturally relevant services, needs to be located at the systemic level. What is clear here is that “where you see the problem is how you find the solution”.

“Resources are not available to them [black elders]. And in the programs that are available that they are able to access, are not sensitive to their needs; they’re not culturally based, and I think part of the reason being that they assume to know their needs without some kind of survey or something. And they also don’t necessarily, (and if they do, very rarely) hire ethnic minorities that would be sensitive to their needs. Resources are just not available. I personally don’t think the government has it as an agenda item to look at ethnic minorities and particularly, black persons, the way they look at a lot of other minorities. And that may very well be because we’re not as politically active as we should be... So I think that some of it has to do with voicing our own opinion and going out and doing something about it” (Fay, line 3).

This quote is very important to the present analysis. First, Fay makes a connection between institutional and governmental support and locates the problem as one of a lack of intent and as a result, a lack of resources. She places the blame on the system itself. She then points to the lack of critical mass and community organizing so that changes are not

forced upon the system. Once again the notion from the previous chapter comes into play here regarding institutional responsiveness rather than proactiveness; if Black persons aren't being serviced and they are not pounding on the door, then they won't be perceived as having a problem of access and thereby won't be targeted for outreach. This is highly problematic. Fay continues to reinforce the point about the importance of including culture in considerations of service delivery over and above language:

**"There ought to be other things but I think um, so long as they can get somebody to speak their language the assumption is that the need will be met. But you can speak the language without being culturally sensitive. They don't look at the total picture - they just look at the fact that I am able to communicate with this person - that I'm coming to "give you a bath" and you, be specific that I'm going to do this and I'm going to do that. The rest of you can go by because that's not my focus and I don't have to focus on that because all I have to be able to do is to communicate with you what you need in terms of physical care, and that's it" (Fay, line 27).**

The reasons for this medical focus are complex but are partially based on financial and time constraints that often appear at the forefront in discourse around services so that often the best way to provide service is perceived as the cheapest and fastest way. Another worker stated,

**"So then the criteria we use is language only. That's what we keep coming back to. I think it is because of time constraints. Well, when you're doing it the way it is supposed to be done, it takes longer than five minutes on the phone. It takes longer than five minutes. When we started, we were supposed to provide service in their language even if they spoke English... the whole culture you take into consideration. However the time constraints... the restraints are such that you just can't do that. So that's what we resorted to is if the person can't speak English, can't cope then they get the [interpreter]. It's only in situations where you really have a problem with language barriers, then you get someone" (Ann, lines 173, 175).**

The result of this emphasis on language and its construction as an individual problem is that some ethno- "racial" communities are serviced better than others. It also results in the framing of some ethno- "racial" communities as "deserving" and some as "undeserving" of attention and adapted services. This creates tensions between ethno- "racial" communities as they vie for a space within mainstream institutions and compete against each other for scarce resources. In the end, ethno- "racial" communities have less leverage, as a whole, to target the state for designing elder care resources from a model of scarcity in the first place. Those ethno- "racial" communities that end up with the designation of deserving are those that "go after" changes on their own, that is advocate on a community level for mainstream agency responsiveness, those that can provide ethno-specific care on their own to supplement or compliment public care thus ensuring the mainstream public system that they won't put too much pressure on services, those that have a larger infrastructure from which to garner support, and those that have a critical mass for change both outside and inside the agency. These communities need also claim a large enough elderly population than cannot communicate in English or French. It is these ethno- "racial" communities, over others, that gain institutional and state legitimacy from which to make a claim for resources and shape organizational priorities and practices. This is essential but may make it more difficult for others to claim territory and be heard. Advocating for changes in the system also becomes a full time job for ethno- "racial" community organizations, which may limit their capacity to take on other, more immediate tasks:

**“...but being able to unite and come forward and advocate on what’s happening, maybe sometimes the external forces need to be brought home to say we really have a need and we really have to band together and we really have to push for it and advocate to make sure it happens, because i’m only one person voicing it but this is as far as it will go unless you have a united front that will take it further, and I guess it’s like that in many other cultural groups as well, it’s not just our own community that when you want things to happen and change and take place, it’s almost full-time work where you have to advocate and push” (Vera, line 130-131).**

**An example of the struggles which exist between ethno- “racial” community groups may be visible, to some degree among Chinese and Black communities in Area P. The Chinese community in Area P is highly organized, has a strong and unified infrastructure and resources for elders. Given these strengths, the Chinese community has been able to make claims on public resources and develop shared avenues for adapting services to meet the needs of it’s population. Black communities in Area P, on the other hand, while sizeable and visible, have not been able to make the same claims on public sector elder care resources. The reasons for this are many but include the fact that Black communities do not have an equitable infrastructure in Area P, are not organized in a monolithic way (there are many Black communities serviced by smaller organizations often based on home country origins), and do not have access to financial and other resources from which to gain power and legitimacy. This most disenfranchised of ethno- “racial” communities may not fight back against the system to make demands upon it. This is exacerbated by the fact that, within Black communities, the proportion of youth is much higher than that of seniors, resulting in the prioritizing of youth services over elder care services on community agendas. The Chinese community, on the other hand, has a large population of elders, resulting in a more focused energy directed at developing aging**

services and linking to elder care organizations. This experience is confirmed by Black and Chinese agency workers:

**“But I have definitely heard ...and I have no proof of this is that the Chinese clients and the Chinese community...I’ve heard this through coordinators...get lots of service. I’ve heard that. Whether it’s true or not, like I said I haven’t even attempted to look at it... Because we have the [elder care services] and all kinds of Chinese organizations that meet their needs. And in terms of that I think that Blacks tend to be the most disadvantaged because they don’t have these cultural groups out there. [it would be good] to see if these people are getting adequate services or to see if they have enough supports or advocating for them. Or if they are just left out there to try and fend for themselves because they don’t have these other supports, you know?” (Elaine, lines 148-151).**

**“going after M.P.s and M.P.Ps and local M.P.s and M.P.Ps but also I mean, I mean, you know, if you’re in a predominantly Portuguese district, it seems to me that there will have to be a lot said to the government for them to be aware that this is predominantly this type of group and so we need to put something there to meet the needs of this group. And it’s the same thing like the area that I’m in - it’s a predominantly West Indian population, but there’s absolutely nothing... but there again I think the whole approach is, if it doesn’t affect me then I can turn a blind eye - the government do it, the police department do it -everybody do it... it’s huge - what they call - “money speaks money”. If you have money you can start what you like, or you can also scream a lot and people will listen because they feel, well you know, you have money to do something about it. Or politically you are in a position where they have to listen because they will suffer politically if they don’t listen to you because you have the resources to get them , you know, the vote or where they want to go, and if you don’t have that kind of a resource behind you then it’s much more difficult...So if you have a predominantly Black or West Indian group that you service that you ought to be able to cater to that group, just the same way that you would, say, if it’s a predominantly Chinese, uhm, area that you expect that there is some cultural mix in there that would meet their needs, i.e. either somebody whether they be Chinese or somebody who is able to speak Chinese to cater to their needs. That kind of thing. That’s all that needs really to happen. ” (Fay, lines 10-15).**

**“Most agencies they are able to provide for a Chinese speaking client, most of them. But the other minority it is not... Well they cannot get a worker, really that’s the main... although they send out a list that they have an Armenian, Portuguese, Polish speaking but there might only be one worker... and the Chinese we try to advocate a bit more. Cause like the**

people at [the Chinese elder care agency] they are kind of, they try and advocate..." (Kathy, lines 145-150, 274-281).

Given this debate, what should be the responsibility of the institution? To date, elder care institutions largely work from a responsive rather than pro-active stance so that only those communities with legitimate voice can make change happen. Those communities that are more disenfranchised and less likely to fight will rarely be put on the agenda. Perhaps instead, these institutions should focus more attention on responding to the needs of those ethno- "racial" communities which have a smaller voice in the arena:

"I think that the people that are brought to our attention are assessed in an equitable way I feel, I can only speak for myself and the people I work with...uh... and that they get..and the services are at least set up fairly within the mandate and the levels we can give based on their other supports and the situation etc. And then what happens out there...who knows (Olive, line 158).

"They will respond, yah, but they're not going to go and seek it out.. probably because of where we came from and where we have been brought up... the providers, we haven't done that and we don't feel the need maybe? Let people come to them as opposed to going out and offering. They probably feel we have the service, we're giving you the service, we have the service. If you want, you kinda gotta come get it. Yah. Rather than going out to them. Maybe I should form an alliance with the Black people up here and [fight]... (laugh)" (Elaine, lines 156-158).

How do institutions incorporate a broader anti-racist framework within the context of a multiculturalism focused on individualism and cross-cultural (language) communication? How can concepts such as "race", ethnicity and culture get included on the agenda? At the moment there is little understanding about what culture means in everyday practice. One of the first tasks is the incorporation of cultural constructs in

matching clients and service providers, rather than simply focusing on the language match. Once again, the system is set up to make these matches next to impossible. There are just not enough ethno- “racial” service providers in the system. What happens then is that workers practice “carefulness” in their everyday work, often preferring not to mention the possibility of providing an ethnic match to clients, in case they cannot find an appropriate service provider to match with the client. In other words, workers are wary of offering up ethnic matches for fear of not being able to provide them. Only those who can ask for this match, those with this “technical knowledge”, will have the opportunity of receiving a service provider from their own ethno- “racial” and cultural community. Most clients are left with few options and never find out about the possibilities regardless of how rare they are:

“Where is that line? And the line is for me, personally, right or wrong, it’s probably wrong, I don’t know...you don’t offer it. I don’t offer a culture... the person will ask for it if it’s important to them. That’s how I feel” (Elaine, line 143).

“Of course it would be uh... most ideal if they can get into the Chinese nursing but you know the places are very limited. Right now the two Chinese nursing homes have a waiting list of more than three years so it would be very difficult for them to get in. And a lot of time now, I can only suggest to family to apply or get into a non Chinese home which has more Chinese resident. And they are getting more and more non Chinese facility which provide a Chinese unit on a certain floor which pool most of the Chinese resident together so they can concentrate and manpower the Chinese worker on that unit. And they provide some Chinese food although it may not be authentic Chinese food although it’s better than nothing” (Liane, lines 12-15).

“... there’s another client who’s Greek and only speaks Greek, she’s palliative and the family keeps asking me “can you please find a Greek home maker, can you please find a Greek nurse?” so... of course I don’t blame them...There’s someone there you could identify with and you could relate to and disclose your problems...” (Hannah, line 113-115).

**“In terms of what’s out there - actually there’s nothing. It’s funny because I recently had a situation where there was a question of our beliefs in our West Indian family, and in order to have the social worker go out, and be able to identify properly the problem or get any information at all, I felt the need [to find a West Indian social worker]... but there’s no such thing as West Indian-type social workers, which is a huge thing that we need that would be able to address that issue - or these kinds of issues from a cultural perspective, because you know culturally how the person will behave and what’s considered normal and what’s not, in that particular society or based on that particular culture. And that’s just not out there. Uhm, I looked too, to find some kind of a support group or system out there that would be able to, I mean, there are support systems out there, I mean , there are caregiver, stress groups all over the place. But if you have a caregiver stress group that’s not going to be there culturally to that person - because what I consider to be stress for me, will not necessarily be stress for the other person. So, if you don’t have those kinds of things that would be culturally defined, and have somebody from a cultural perspective being able to be sensitive to those needs, then it’s no good and it’s just not there. ” (Fay, lines 6-8).**

**Another issue that makes workers wary of offering an ethnic match is that it takes more time and ground work to set up. This includes developing relationships with ethno-specific communities and/or agencies that have ethno-specific workers in order to fill the requests of clients for ethnic matches. Given the time pressures that workers are currently working under, it is no surprise that efforts to provide ethnic-matches are undermined:**

**“If I wanted to detail to the service provider that I am looking for someone who speaks Greek or Italian or whatever, you can easily mark that in the service order. This gets faxed to the agency cause it specifically orders the service that you’re requiring and in special instructions you’d say it. But what I like to do in those cases is personally call those agencies and explain what kind of person I am looking for and ask them to search and if they have that person to get back to me before I actually go through the process? I don’t like to be told “I’m sorry but we’ll get someone as soon as we can”. If it’s part of the plan that I’m trying to make I’d rather see it done at the beginning” (Melanie, line 128).**

**“And you know we can identify that an individual requires a certain homemaker or nurse or whatever but even when we do that, that’s not always provided and when ... like the agencies say they have these people but when you go to access these people, they’re not there... Well I think**

it's partly because it's expedient to say yes you have these people to provide these kinds of services but you have to remember that I'm dealing with a little tiny area. So for instance over time I've gotten to know which homemaking agencies I'm more likely to get a Cantonese speaking home maker, which nursing agency I'm more likely to get an Italian speaking nurse, this sort of thing. And whenever possible I just sort of gear in on to these people and try to work it that way. That's the way I try to deal with it. If we all tried to deal with it that way it wouldn't be too good (laugh)" (Greta, line 8-9).

The further integration of the larger concepts of ethnicity, "race" and culture into discourse of language is also undermined by the fact that workers themselves are not familiar with these concepts and what they mean:

"If the client requests for that worker. But I wouldn't... unless when I do the reassessment I find that this woman cannot understand at all, could not speak at all in English...uh... [Question: it would mostly be to do with language rather than culture...] I don't understand... [Question: for example, most Black women speak English so you wouldn't necessarily put in a Black home maker or Black nurse...] No.. No it would only be based on language. Like Tamil... Tamil? Like if a client asks for a Tamil speaking individual, requests for that specifically then I will call different agencies to request that. Well, Mrs. B. asked me for a coloured woman. She specifically asked for a Jamaican woman (laughs) cause she felt that "she would understand us, understand what we're going through and who we are"" (Hannah, lines 117-122).

In this quote, the worker has difficulty understanding the question which compares language to culture and then laughs uncomfortably when relating the story of the Jamaican woman's request. Clearly this is not an easy discussion for her.

Workers also are not familiar with theories or models of "multicultural" practice and often rely on their own personal experience to inform their work rather than specialized knowledge. When asked if they use any special knowledge, theory or experience in working with ethnic and "racial" minority women, workers responded:

"(Long pause) I don't." (Hannah, line 143).

**"No... I don't [use] that at all. Uh..." (Melanie, line 89-90).**

**"I have some personal knowledge...my husband comes from [another country]...so you know... I know...and I see people who come from that country...for them there are so many racial groups that come from that country, there are so many religious groups within that country ...and it's really a tiny country. And so as such...I mean my colleague asked me the other day actually, "oh would you know, she said, if a Muslim mom, a new mom, if she had a third girl would that be sort of a terrible calamity for them"? You know a lot depends on their religion. I think she said [the country's name], that was it and I said "well, it depends on the religion". You know I have knowledge of my family are Catholic, and people of all different Christian religions and Muslim and Buddhist...it would just depend and also within the religions it depends how much education they've had, how Westernized they are or are not...it's so hard to generalize" (Olive, line 22).**

**"Older Chinese women specifically? ... mmm... I think it's the cultural background that I'm familiar with that sometimes I know that they are relatively submissive? So I have to help them to build up their own confidence to say no and like ask them to look after their own needs and that's the area... and it's not a particular knowledge or skills but it's something that I think I may have to do something on it to help them to verbalize what they need and sometimes what I call confirm and consent...uh... like a senior may say "oh ok, I'll accept that... well, I'm no use anyway, I'm a burden to the family anyway, why bother so I will take that". You know that kind of feeling? And this is I... will try to help them although it is a difficult decision anyway, I will try to help them to understand the family is not abandoning them and try to let them see another side of the picture. Uh... want possibly to accept the placement. I think that's the thing that I particularly work from here" (Liane, line 102)**

**"Ooooo.... what special knowledge...I... I... mean I think the only... the only... knowledge and experience, I wouldn't say it's a theory that I use is what I said before about how uh... I try to ask culturally sensitive questions... they came out with this document called something about asking culturally sensitive questions. It was all about you know... how do ask questions about the view of the illness within that culture without sounding like a bigot. Uh.. And it was very practical, very hands-on and that sort of stuck with me? Uh.... so I use... I mean that's always in the back of my mind, trying to help the client tell me their story from that perspective? So I think that... I use that in that... hopefully it builds a rapport with the client and builds a certain trust...uh... you know that you're actually asking those kinds of questions... they like to be in that**

position of being the teacher? You know, I'm born in Canada, I've traveled a little bit, I've never been to your particular country. Uh, sometimes if I have... I use my four month Europe stint quite a bit. I remember when I was in Italy, dah...dah...dah.. And I remember it was like for me, was it like that for you? And you know try and get them to open up that way? When they find out that you've been to their country of course, you ... you're in there like flint right away. And if you haven't been to their country, the other thing I do sometimes is I talk, "you know I have this other client and this is the situation, is that what it was like for you?" "Was it different for you?". And they like that, they like being able to relate" (Pamela, lines 216-222).

The use of workplace documents reinforces this perspective. While both managers and front-line workers expressed pride regarding the fact that *Eldercare* publishes pamphlets in a variety of languages, these pamphlets are, in fact, rarely used. One worker referred to pamphlets available in other languages but when asked if she uses them stated,

"I... haven't. I think it's sometimes not because they cannot read but maybe the fine print because they all have impaired vision... not all but many have impaired vision. [Question: so what do you do in those cases?] (Silence)...Uh... I don't think that it's any specific theories, I just do when the need comes up. I just use my experience, I just explain to the client to give her any information, any resource that I will be able to give them regarding about what to call, whom to call, any other service in community they might need. As you have mentioned, the pamphlets have just in English. Is that discrimination?" (Kathy, lines 200-209).

Most workers interviewed referred to these pamphlets but did not know where they were stored, reaffirming their relative under use at the agency in the everyday work of case managers. One worker was finally able to locate them for me in a box in a locked storage room.

Forms, particularly assessment forms, the most crucial of the institutional texts as they fundamentally shape interactions between workers and clients, do not specifically address ethnicity, "race" or culture. In fact, there is no space on these forms to even

indicate language, the most often delineated barrier to care. This both reinforces its marginalization in the everyday working processes of the agency and as an institutional priority. The result is that workers are left with the responsibility of indicating these identity criteria if and when they consider them important. In reviewing client files with workers in order to locate appropriate candidates for participation, it became evident that the way workers identify even the most simple indicator of language is not consistent across the agency. Some workers put language capacity and mother tongue right up-front in the file, while others do not. In most cases, workers had to sift through entire case records in order to locate the language or cultural group of the client. Most often, however, only language was indicated with little reference to cultural group. With no clear space to indicate these components of identity or language capacity and no separation between categories of language, ethno- "racial" group or cultural group, workers are not institutionally encouraged to see these items as central to the experience of ethnic and "racial" minority clients or to understand the differences between them.

Where there was some reference to or knowledge about multicultural service it was related most prominently to models of cultural competence in which workers attempted to understand or learn about the individual practices, beliefs and values of specific ethno- "racial" communities in their efforts to communicate better with them and understand how meaning is attributed to their health and health care. It is through this "cultural inventory" that workers were taught or felt that barriers between themselves and their clients could be reduced:

**"Some years ago there was some attempt to address it, we did, and in the branch that I worked in and I think that all the branches were given a**

project to do per month or some sort of a topic to put on display and to do...it was in the resources centre we called it...and ours was multiculturalism. Our team was about, I don't know, 15 or 20 people. That's a number of years ago. We had basically got a lot of information and statistics of the make-up...of the city. Uh...one cute little thing we did was put up a map of the world and the staff... well no we invited all of the people from home care then to come up and put a little sticky red dot on the part of the world where they came from or where their roots were and you could just glance and it was all over and maybe it made people realize that we were from all over the place. We brought in foods, we had a day for bringing in different type lunch or whatever. (Olive, lines 108-114).

"I try and remember what I learned. The thing is you learn as you go along, because all these people are individuals. It's nice to know a little about what's normal for a culture. But you know I don't know what's said about people who speak English and are born in England and so on and so forth but uh... that's supposed to be my background and all the people I've met from my own background are all different. And this is one thing that I can remember when speaking about cultural sensitivity we had to try and not lump people and say groups, so if they looked like they were Chinese you had to feed them rice. That's so wrong. So we have to try and give each person an opportunity to say what's important to them...And in fact, over the years we've been handed pieces of paper with very simple phrases, how to communicate in French or Mandarin or Cantonese or Italian. But quite frankly I don't find those pieces of paper that useful because if the person doesn't have any command of the English language, the simple phrases aren't enough to get to points I need to make. I have to have something a little more in order to serve that person well" (Greta, lines 53, 125).

"Cultural, culture is the main thing too. Unless you understand, you know and understand the culture of that person, you cannot better service unless you know. And last year I attended a focus group on making a book that will contain the Chinese culture and superstition and culture. Hopefully uh... it's for distribution at the hospital or any service providers so that they will have a better understand of the Chinese culture. So I think culture enters in and that will help us" (Kathy, line 237).

"I don't think there's any doubt that we have to do more in terms of specific awareness about specific population norms, rituals, this kind of thing and also having the provider staff who can meet the needs" (Jean, line 63).

The limitations of a focus on multiculturalism as model of cultural competence has previously been theorized in Chapter 3. What is made evident here, in practice, is that a multicultural model based on cultural competence tends to reduce problems of access to those based on cultural misunderstandings between individuals who both give and receive care. This limits institutional responses to training workers to better understand the “folkloric practices and beliefs” of ethnic and “racial” minority seniors and leaves systemic barriers, priorities and resources intact and invisible. Clearly, the variability of worker responses to ethnic and “racial” minority clients and unclear institutional practices, suggest that workers do need to enhance their practice through the addition of training and resources. For example, given the primacy of language and the focus on interpretation currently in practice at the agency, simply training ethnic and “racial” minority workers on how to provide interpretation would improve consistency of interpretation services. Education has been cited as an emerging priority by agency managers. Workers spoke about efforts to provide educational opportunities:

“No I don't. And I think we're lacking in that [training]...But with regard to the first question are we doing anything to teach about diversity or to be able to serve the needs of the make-up of the area...you know, no it has not been brought up at all since we [came here]. I think, yah, it's got to be part of... I think what we do has to change a little bit, how we think about people and the future and services for people and acceptance. I don't know. It is just something that is not mentioned at all. And it may be, is it something that is of lesser importance now....getting the [agency] up and going, you know we're not a year on our own yet. But I mean the statistics that were revealed a couple of months ago, that Toronto will be more than 50% visible minorities in 2000...You see some little attempts say in this hospital in [the area]...signs put up in English, they've always been in English and now they're in Tamil and Cantonese” (Olive, lines 108-114, 124).

**“Well I’ll say this. In the past coordinators have created their own opportunities in terms of what we feel is important and we would have monthly branch meetings. In fact, if we wanted to learn something we would seek out ourselves and invite this individual to come speak to us. And that’s one thing. And uh... it’s really, professionally speaking, it’s really important to be able to identify your own learning needs? And so it has been addressed and every once in a while if there is something someone wishes to offer to the group they can present it to the group. Now with four different teams, we’re still in a process of defining how often we need to be meeting, you know, what’s the most important to be discussing, this sort of thing. So lately, there’s been so much going on that we haven’t had the opportunity to do this but there has been in the past” (Greta, line 127).**

**“I think there’s opportunities, it’s uh... it relies on the initiative of staff to develop and ask for and you know we’re still in the settling in mode so I don’t think too much of that has happened yet. But I definitely think, you know it’s not that the agency would deny us the opportunity.... It’s not being done right now so much that I’m aware of. Most of the stuff we’ve had presentations on, that I’m aware of has to do with service, community resources. Not so much our relationships with... No they’re just, they’re just.... we just get a voice mail saying there’s a person coming from this agency or this agency. And I don’t know how those are being spearheaded. I mean we used to have a staff development coordinator who would spearhead those kinds of things. I don’t think we have that designated person right now?” (Pamela, lines 235-237).**

**Staff have expressed quite frequently that the institution should be given some leeway to get itself organized to provide more educational opportunities and support. Having only decentralized one year ago, staff feel that there will be shifting emphasis in the future to include this kind of training material. There exists an informal sense of good will from most workers interviewed that the agency considers training and education one of it’s top priorities. One of the things that must be kept in mind however, is that, despite these new efforts, both the nature of cultural competence models of multiculturalism and the primacy of ruling relationships that govern the way institutions operate (i.e. pressures to remain cost effective and efficient, workload issues and the shaping of relationships through paper) often render these efforts difficult to maintain or make attempts to shift to**

models which critique or make changes to institutional and systemic policies and practices difficult, if not impossible, to undertake.

### **Discourses of “Race” and Racism in Elder Care Services**

This section examines the ways in which the experience of racism is articulated in the everyday worlds of both ethnic and “racial” minority elderly women and ethnic and “racial” minority workers and through institutional working practices. Given the proliferation of individualized notions of cultural competence in operation within institutional practices through which such barriers as language get problematized at the level of individual interaction, it is not surprising to find that racism, when articulated at all, gets constructed as an individual act. Issues of “race” and racism are, on the whole, forced underground in elder care and rendered invisible in the everyday experiences of workers and clients. There is little room for the expression of the experience of racism or in the articulation of an anti-racist agenda within a multicultural perspective focused on individual interactions and communications between workers and their ethnic and “racial” minority elderly clients. In order to do justice to these issues, it is important to separate out the experiences and voices of older ethnic and “racial” minority women, ethnic and “racial” minority workers and mainstream procedures and practices.

### **The Experiences of Older Ethnic and “Racial” Minority Women**

Racism was, in itself, rarely named explicitly by older ethnic and “racial” minority women. At most, stories about acts of discrimination were couched in terms such as “rudeness”. What this suggests is that, in seeking to understand how older ethnic and “racial” minority women experience racism, gerontologists may need to go beyond

**“professionalized” terms and definitions (even terms such as racism) to hear how women themselves articulate this experience of discrimination. As related by an interviewer:**

**“Being an ethnic and racial minority senior woman with health problems is difficult. It was difficult for them to look for services; they were not aware of anything but the social assistance. Now that they use services it feels easy but at the same time they are scared that they might be treated badly, in fact sometimes doctors and nurses in the hospital are very rude and do not attend to them at all and they feel it is because they are women of colour. Mrs. C had a rude nurse in the hospital who did [not want] to give her a bed pan” (Interviewer for Mrs. C, line 17)**

**This quote exemplifies how one might mis-label this story of racism simply because the word “rude” was used instead. On the surface “rude” does not imply racism, but Mrs. C. explains that the rudeness she experienced was related to her skin colour thus firmly entrenching it as an act of racism. One ethno-specific community worker confirms how terms like “rude” are used by older women from her community to articulate experiences of racism.**

**“...many languages don’t even have that word. You know? There’s no word. You have to use it in a sentence form, you have to explain it, there’s no such word as anti-racism and if there is it’s like, you know, when you don’t have a word for it in English, you borrow it from Latin or you borrow it from the French language and it’s there. So, talking about the mass of people who have service[s], I mean, they might interpret that phrase but it is not a word from their language...They don’t say it is racism, they see it as something else. They read it as “oh this white woman came to my house to help, how can she understand? How can I speak her language?” They talk about it this way “this white woman came to me”... I don’t think they use the word the word racist, they might say the doctor was rude and I will not go back. OK? We would not say “I think the guy was a racist”. You won’t hear [our] seniors saying that” (Lina, lines 65-69)**

**It is crucial for both professionals and researchers to understand this point that, for many ethnic and “racial” minority elderly women, the discourse or concept of racism is foreign and as such, they use other terms to identify and explain their experiences. This**

shift in the discourse of racism will contribute to the process of rendering visible older ethnic and “racial” minority women’s experiences of racism, which, to date, has been largely absent from discussions about elder care access.

For the most part, when asked direct questions about their experiences of racism, older women stated that they had not experienced racism or discrimination. The following are examples of older women’s experiences:

“I haven’t, honestly I haven’t [experienced racism]. And that is also because of my outlook on life. I haven’t felt it. Even if I was dark skinned...I don’t think it would have made any difference because of my own approach to people and to life...I like meeting people from different cultures, I can adopt to any cuisine...it’s from childhood actually, all my brothers and sisters, we’re all that way...But I’m very happy here. I’m very happy here. I have never felt an alien or felt an outsider. And I think that’s because, personally it’s because of my approach and my exposure as a family I can say not even mine...as a family...our exposure to different groups. It was very good” (Mrs. F., line 140-146).”

Mrs. R. stated,

“I have never ... never any discrimination whatsoever. I’ve always been accepted as who I am and that is something I’m very proud about. Yes. My doctor... doesn’t feel... I’m not only his [patient]. He says “I love you. You’re just like a friend. And you can call me anytime you’re not feeling well. You just call”. So as I said, I don’t really...There’s nothing really, up to this moment that I have found not to my liking... But you see... everybody’s experiences are not the same. And uh.. I can only speak of mine. And I try to tell people. And people come to me and tell me they were discriminated [against], some of my friends and they don’t know why. I said “it was just what you think” I said, I worked with people and I know if I was not doing something right, I have to be told about it and I accept that. But I don’t think anything like that. I worked among doctors... and uh... I’m proud to say doctors are all very nice to me. I have family... doctors in my family and they are very very good” (Mrs. R., lines 53-57)

She continued later on during the interview,

“Canada is my home. I call it my home, there is no other home. I’m happy in Canada. There is never no... I really can’t say about...No-one has ever said in the health care. And I worked in the hospital, there were a few

coloured people that uh... did not go along with me as to that. I try to talk to them and explain to them it's not their colour, no no. Don't ever think that. It's something you may have done, that you didn't do it right and just your being talked to about it and you must accept that from your superiors...Uh...I... don't know if I should say this but I remember it very well. The remark [back] from the young woman was "it's because your kids are all married to white people" and I was very upset... she says, because of that I'm going to defend this nation. But it's nothing of the kind. I went through this and I know it's just who you are. And it's just your character which is the most important thing of all. So I... And all the things that I have spoken to you this morning about... it's nothing but the truth. I give you from the bottom of my heart. I'm a very contented woman too, very contented." (Mrs. R., lines 66-74).

Mrs. H. discussed her experiences of racism. The following quotes follow in the order that Mrs. H. shared her stories and provide rich detail for analysis:

"I get to know people and to mix with every different kind of people, the Jew, the Gentile and whatever. And I like everybody. And that was the first thing that when I going to get a job. I say "Do you specialize in people?" and they say "No everybody, everybody". And I cope with them a whole lot...I have everybody as friend. Yes everybody, cause I see everybody as one" (Mrs. H, lines 51, 72).

"Yes, when I work, when I was working, some of the Jewish people, no hard feeling, like they don't like me. But working with them for long, I let them like me. Because there was one lady, I think she had Alzheimer anyway, you know sickness and all that. Whoa! We could not get along and she don't know one thing about me and we couldn't get along. And she tell me off and I looking around and I was take it and never complain. And one day she said "and you don't come back!". So I didn't go back there. And my supervisor call me and I said I not doing anything so I don't go back. And this lady calls and says "where's my homemaker?" So I went back. And then my supervisor call me and said "Mrs. H., that is very good cause some would stick it out and say they're not going back and that is the beauty of it... I want to get her to know me, yes! And my supervisor said "if you're not comfortable and not getting along, you don't have to stay" And then the lady say "I want you to stay!" (laughing). So from there we were best friends. We were such good friends.. So that's how I try to get along with them...But one Jewish lady threw me out completely. And I call from a payphone outside and they say Ok Mrs. H. And I didn't know that they knew that she don't like us. She said why don't you go back to your Jamaica!". I say I am from Jamaica, I have a lot of kid here, they are

working and supporting this government and I am working for this government... I am doing service in this country (laughs) and then I didn't have to go back to she" (Mrs. H., lines 76, 78).

Mrs. H. responded to a question about discrimination in the health care sector:

"But with me I make people like me. If you don't like me when you come to me well you's hard, you's hard. I think I get along with everybody. Just the smile and the laugh" (Mrs. H., line 80).

There is a lot of depth and richness evident in the above quotes. Clearly older women are expressing some shared perceptions, regardless of whether or not they shared stories of experiences of racism or felt that they had experienced racism in the health care sector. This may be partially explained by the previous analysis which theorized that older ethnic and "racial" minority women do not use the same framework or the same terms (such as racism) when speaking of their experiences, preferring instead such terms as "rudeness" or "dislike". Second, older women said that they worked hard to get people to like them and that this helped buffer potential acts of racism. Third, they treated everyone the same or liked everyone regardless of "race", ethnicity, religion and this also helped to avoid, reinterpret or buffer experiences of racism. Fourth, older women spoke in a way which reflected a need to defend their status as Canadians, to defend their rights and entitlements as Canadians. When conducting member checking with visible minority workers in the agency under study, older women's responses were reviewed and ethnic and "racial" minority workers, in confirming these data, provided some insight into the older women's responses and shared similar stories of their own. These workers' responses helped to contextualize the statements made by older women:

"But then I think part of the thing is that we sort of grew up - the majority of us, and the older ones who grew up in the Caribbean and then

immigrated later where you were sort of socialized to believe that the government is there for you and they'll do the best for you - systems are there for you and they will do the best for you - so you don't question the system and you sort of accept that the system is taking care of your needs to the best of their ability - which is really not so. Uhm, if you're taught, though, to, say, my children now - they would be a lot more vocal about that and will look more at pushing to get these kinds of systems in place and I guess because they, sort of, didn't grow up in that sort of - laid back, accepting of the status quo. Sigh" (Fay, lines 5-6).

"Uh... I guess they feel... off the top of my head, personalizing this a bit... they probably feel if they're nice and they're accepting of everybody, nobody's going to put them down? So of course I haven't experienced racism, I'm accepting of everybody, how could they be? I'm nice. I'm not going to buck the system or annoy anybody or put myself in a position... I don't know, this may be it, they're very nice out there, they're kind to everybody, they're just a nice person so everybody will be nice to you...And their terms of not having racism is maybe not having somebody call them names or say anything to them and for a lot of people that's where racism ends. You know, with somebody calling you Black or nigger or... that's it. They don't think of how they're being denied or treated or anything generally. And that's how most people feel...So I just think that person that feel that way because they are nice, accepting, kind and generous or whatever, that people would not put them down or say anything bad to them or about them so that they wouldn't experience racism. But... you need to rock the boat to get services and if that person rock the boat, she'll see where racism comes in, very quickly...be told how dare you! You from another country go back where you came from... Very kind of subservient accepting people. Like most people who are subservient don't have any problems because whatever's dished out to you, you take" (Elaine, lines 104-111).

"I could relate to some of that myself. You're just smiling and... you're always on guard! And I think in situations like that you're constantly being the nice person, you're really not getting very close to anybody... it's very much on the surface... Avoid conflict. Avoid any kind ... it's it's harder for someone to pick on you if you're being very nice all the time, right? Basically it's an avoidance mode. You can't really buffer acts of racism... I could see myself in the areas where I was the only person of colour or one of few so that would be a way of avoiding conflict of any kind. The other thing of course is being better than everybody else, like smarter in every sense of the word, whatever that means... so you just worked so much harder than everyone else around you so nobody pointed a finger at you, that type of thing?" (Ann, lines 127-131).

These data bring up many important issues. First, they provide a “race” analysis regarding why ethnic and “racial” minority women do not complain about service and take what they can get from the formal sector. Past experiences of discrimination may force older women to accept the status quo in order to avoid rocking the boat or calling attention to themselves. This is so because it is as a result of complaint that racist responses from the public sector are revealed or emerge. Older women articulate this as a fear of repercussions, a fear of losing access to services; however, this fear of reprisals is not colour-blind, it is fundamentally both racialized and gendered. Ethnic and “racial” minority elderly women have little institutional and social power and as such, have little control over both the shaping of services and their interactions with workers. Intersectional experiences of sexism, ageism and racism, which have historically shaped older ethnic and “racial” minority women’s relationships to the state and to health care institutions fundamentally drive women’s capacity for agency in these milieus. Women’s resistance is therefore limited to the creation of themselves as “non threatening”. They are forced into using their personalities, their charm, as a means of protecting themselves and as a tool in fighting against individual acts of racism. “Being nice”, “liking everyone”, “always smiling” are some of the only means at elderly ethnic and “racial” minority women’s disposal for resisting racism. Because of their positions of disempowerment, love and acceptance become accessible strategies to resist oppression and survive. Older ethnic and “racial” minority women’s past experiences of oppression suggest that they need to remain “passive” in their interactions with mainstream institutions. This gets articulated as giving thanks, accepting meager support and blaming themselves when conflicts arise. Older ethnic and “racial” minority women learn not to call attention to themselves in order

to convince everyone that they shouldn't be harmed. This response, contributes to the masking of the impact of racism on older ethnic and "racial" minority women in the health care sector.

Can or should institutions expect ethnic and "racial" minority elderly women, particularly immigrant women, to name the racism they experience? These women are, after all, the least powerful within these institutions, rendering it difficult for them to speak out against individual and institutional acts of racism. Once again, it might be more relevant to look beyond what older women say to uncover experiences of racism. Simply speaking from a defensive posture regarding their rights to service as Canadian citizens and as contributors to Canadian society is in itself a struggle against racism. Racism is often invisible and therefore harder to name and identify. This reinforces the need to move beyond the articulation of individual acts of racism by clients in efforts to respond to racism. Without doing so, the system can more easily hide behind the perception that racism does not exist. After all, ethnic and "racial" minority women are saying that everything is fine. At most, racism is experienced as an individual act. Since systems focus on cultural competence and multiculturalism models in efforts to understand cultural groups, the role of racism in shaping historic and current responses to ethnic and "racial" minority clients in health and elder care is largely invisible. Given that older ethnic and "racial" minority women themselves do not have the space to articulate their experiences of racism, particularly that which goes beyond individual acts of racism, how will those acts which are institutional and systemic in nature ever reach a public forum for discussion? In this situation, we become more reliant on workers to articulate racism as a problem. How realistic is this?

Generally, there is little room within institutions for a systemic analysis of racism. Workers interviewed for this study tended to react to questions about “race” and racism with defensiveness, insecurity and discomfort. Racism was defined or interpreted as a “dirty word”. There was little safety around discussions of racism and little knowledge about how to dialogue. Workers clearly did not know how to verbalize these issues. These quotes are from two white ethnic minority workers:

“You know I am aware of a lot of stuff that goes on, not just here but ...[Question: What kind of stuff?](Laughs and pauses) [Question: You knew I was going to have to ask that question!] Yes I knew! Just...you know...(sighs and whispers).....discrimination. [Question: From who?] I think ...certainly from individuals .... some more than others (Olive, lines 114-120)

“(Long pause) well, I think that... I don’t know if it’s something that I... but I find that a lot of them... a lot of ... I find that... I have some [minority] clients and I find that the medical system tends not to focus on their care as much as someone who would be Anglo? And I don’t know if it’s hidden...hidden discrimination or something like that (laughs nervously) but I find that when I compare who’s involved, especially palliative, I’m talking palliative now, I find that the ethnic... ethnic... the ethnic female who’s under palliative care has less, there’s less attention focused on her care than there would be an Anglo... Anglophone... Anglo... Canadian woman. Yup. I find that and I find that... and it’s not frequent that I see that, but the two cases that I have occurring... I find that the care is not as intense or as focused than a client who is Anglo. You know what I’m trying to say? It’s not as organized or something is miss... there seems to be always a gap in there, in the service plan...I don’t know. It could be that they’re very intimidated... it could be that they’re very intimidated by the medical system, the ethnic women and they don’t ask questions, they don’t actually take initiative to say “what do I need” or “I need a doctor to see me”. Maybe it’s because they don’t understand the system that they don’t bother to ask or they don’t take that first step? Rather than the Anglo female, because she knows what is there, what is in the community, she’s more motivated to get it. You see? [Question: and when you say discrimination, what do you mean by that?] (Long pause at the end of which is no response)” (Hannah, lines 91-94).

Two things are happening here. First, these two workers are hesitant, embarrassed and uncomfortable saying the word discrimination and do not respond with the word racism, even though the question was originally asked using the word racism. Second, both workers individualize these situations as representing isolated and individual acts of discrimination or lack of knowledge about the system. In the latter quote, the worker shifts her analysis from one of discrimination to one of client lack of knowledge, thus embedding the blame for discrimination in the client's behaviour. Racism, constructed from a discourse of multiculturalism (in which language and communication are seen as primary) is primarily viewed as an individual or relational problem, so that when institutions talk about racism, they continue to search for the individual source of the problem. This invariably will effect the way clients are viewed:

"But let's put that in perspective. Racism and the health issues. Minority do they feel because of the racism they are not getting the health care? Ok, I don't know. Some people the 65 and up, they are first of all, very hesitant to ask for help especially the ladies because they don't know their rights, they don't know.. So the knowledge... the knowledge base... has ... when people are knowledgeable I think racism is not much ...uh... much stance. I am OK you are OK. I mean this is my thinking but people don't have the knowledge this can be coloured as a racism. I mean I needed the help so many times and I did not get it. I didn't not get it cause of the racism, I didn't get it because you didn't ask the right person, the health care professional, the right resources for the help. You know what I am saying? This knowledge ... is just trying to focus on the knowledge base. OK this is the reason... the system is for everyone... the system is being used by the mainstream because of the language because of the knowledge, they know the services best.. (Carol, lines 132-136).

The responses of the following workers to problems of access are rooted in an analysis of the individual "pathology", that is, beliefs and practices of cultural groups. This is fundamentally a racist discourse:

**“I think too it depends on the background where the person is coming from? Because some backgrounds tend to be... more focused on having more services from the government, funded programs. And then some types of backgrounds tend to be less focused on getting services and want to be more independent...” (Greta, line 14).**

**“I think it’s culture... I think it’s attitudes in the culture... I think that’s what it is. Going back to the fact that even though they need the service they don’t accept it, I think it’s all... it all has to do with the culture. It’s where they’re coming from, the attitudes, the philosophy of seeking help” (Hannah, line 103).**

**“Um, I would say probably one of the main issues, and this is um a very generalized stereotyped kind of statement um would probably have to do with expectations in terms of health and social services. For example, um, I have run across a series of clients um who have extremely high expectations that they come to Canada and if they fall through the cracks the social safety net is gonna take care of them. You know some of them are disappointed by wait lists and you know an inability to access service promptly when they need it. Um, other clients...come to Canada and they don’t have such high expectations and they are actually bowled over by the amount of help and support they can get from social and health services. So I’ve sort of seen the two extremes. Um I guess when I’m mentioning about um one of the issues is you know how realistic are their expectations? ...Another issue that I see in terms of accessing service has to do with various cultures’ view of illness and in particular an ill female, a disabled female member, where certain cultures you know almost discard their member when they become ill or disabled um and I do, I do a lot of interviewing with clients um again I’m not, in my head I’m not just thinking of elderly people I’m just thinking of some of the ethnic minorities I work with. I try and get at some of these questions by asking questions like you know if you had the same illness or disability and you were back in your own country, what would life look like? And I have them sort of describe and you know it’s, it’s amazing how common it is that sometimes they say that oh well it wouldn’t be an issue because I’d have my extended family around me and they would be taking care of me and I wouldn’t have to rely on the formal services so much. But then other times, they’ve, other people, like I’m thinking one client in particular right now from Ethiopia, um, they said that they would be uh it’s almost like a leprosy, they would be completely rejected by their fr- their family, like their family would come and visit them but their family wouldn’t take care of them uh of course they wouldn’t have the social supports and health services that we have here... It was a really really awful and I mean that’s a very blatant example of this**

kind of ostracizing that certain cultures seem to go on, so... ” (Pamela, lines 16-17, 28-30).

“I think ....minority women, perhaps they haven't been here all of their adult lives and working lives...perhaps they have come here later sponsored by their children or what have you. So sometimes they feel also like they're not entitled. Also there is some ignorance to what is available, they feel that they're not entitled. And depending on what culture they are actually from, if it's an... they feel their role is... to manage the home, to manage... perhaps to continue to be the matriarch if it's a matriarchal type situation. And also the expectation is that the family will look after them...but that's very general cause there are so many different cultural groups...” (Olive, line 20)

By saying that access barriers are all about cultural behaviours around help seeking, lack of information or education, even if these issues are partially responsible for creating access barriers, institutions and health care workers construct and respond to ethnic and “racial” minority elders in such a way as to pathologize and blame them for their plight. It assumes that once older ethnic and “racial” minority women incorporate or engage children who have incorporated a western ideology of health care and help-seeking behaviours, their barriers to care will be resolved.

Workers who do articulate or share experiences of racism are also limited by an individual framework; acts of racism are often made tangible only through the individual:

“I would have clients who are serviced by a White - particularly a homemaker. And not necessarily just a homemaker, to some degree, where what they're required to do when they get out there, they don't want to do, they refuse to do, or they have to because for whatever reason they probably don't feel that they should be servicing that person. You know, I've had complaints where it's supposed to be personal care - it's supposed to be a shower - but the shower's not being given - there's all kinds of reasons for it - the service is supposed to be for 2 hours, they come for 1 hour and leave them. Those kinds of things. And I'm not saying that it doesn't happen necessarily for other groups, but I find more complaints when it seems to be [a client who is] a West Indian-type person” (Fay, line 55).

In the following quote, a worker struggles to make a connection between racism and care:

“So the coping mechanism is either they try to please them or they try to keep quiet.... But I have to make a remark, I’m not sure that bad experience they have in the home is strictly related to racism. It may not be. It could be that the worker there are burned out and frustrated. I never have a way to verify which side is right or wrong. Yah... I mean my role, I cannot do any investigation in the home. When I receive this kind of complaint, the only thing I can do is to suggest and advocate or help the family to access the complaint officer. Usually I will suggest to them, talk to the unit nurse, complain to the unit nurse if someone do this to you. If that doesn’t work go to the administrator. If you still couldn’t get your answer or if the issue still not resolve then go to the complaints officer and jot down all the information, all you observation, make sure the time, date, person in there... Some family can do that. But uh... they may not want to go to that far. But I don’t know if it’s related to race.” (Liane, lines 104-110).

Other workers identify racism:

“I think so and I hate to be pointed fingers at my environment but you hear it...I hear it all the time ...I hear it as another worker within the organization and I hear comments from my peers you know? How they relate to ethnic people on the phone. Like comments are made like “Oh they just come here and they don’t do anything and they want all the service” and this type of thing. So you have to know that if these people are servicing ...they’re not going to be as receptive and they’re not going to offer as much cause they don’t...accept it. They doesn’t accept them as they probably accept the White person. And... I don’t know... I would hope, I would really hope that they’re not denied services but I think they don’t get the same level of service...I really feel that they don’t get the same level of service or they don’t get it with the same respect that others get it. Oh I get very angry. I get very angry and I had occasion to speak to a couple of people. Just this morning we were talking about it actually, it was the first thing “They come and they don’t...they just want this” and I say “We all came...we all came” and I have no problem with [telling people what I think]...” (Elaine, line 35-37).

“... and then another day this week... and I felt really bad after this had happened and I felt really bad cause I didn’t tackle it at all...it was over the

phone and I was referring someone out to homecare and...uh...the surname was Singh and I got the intake person I don't know if it was a clerical or a coordinator person...she was taking the details and I gave the name ... she had this impression that all the Singh's live down the street and I said "Actually, no this is it". "Oh! Oh ok" and then we carried on and went through the thing. I don't why my flesh was crawling and when she asked is there any family or contact and I said "Yes, there is a husband" She was younger than me this client, and "yes, her husband lives with her" and I went on to say "and her parents-in-law and three small children". And she said, "Oh, of course there would be loads of them in their house"...(sighs). Well I don't know if people would be so direct or bold [to the client's face about their attitudes], perhaps not. But if it's an older person, then perhaps [the worker] might be a bit more brazen" (Olive, lines 131-138).

A community worker also stated,

"I am hoping that there isn't [racism in health services] but I'm thinking that I may be naive to say there isn't any racism, but I guess you try to prevent that from happening through education... all I could say, getting back to our own organization and seeing the workers that we have, everyone has their own biases and you hope that the staff that you hire on is more sensitive and more aware... probably I am going to be very naive to say there isn't any of it but we're hoping times have changed and people are educated and we may be a little higher up on our levels and that... it's not acceptable anymore, and if we see any of that, that we bring it to the attention of the coworker, whoever is evidencing or maybe has that bias that we say to them that in a field like this where humanities take place and when it's client-focused, that it's not acceptable and to be able to put a stop to it" (Vera, line 133).

This focus on individualism, articulated either as blaming clients for their lack of acculturation or assimilation to western health care practices, blaming misunderstandings on lack of communication between worker and client or lack of worker knowledge about cultural practices, or confining racism to individual acts by ignorant professionals, determines institutional response. These responses get limited to educating clients and workers alike about cultural norms and practices. This model of cultural competence does little to extend analyses beyond cultural norms and behaviours and reinforces solutions

which are based on individual notions of assimilation and integration (Adams, Bell & Griffin, 1997; Dominelli, 1988; Tator, 1996). It has proven weak at linking experiences together, rather it approaches conflict one incident at a time so that racism never gets articulated as the root of these conflicts or struggles:

**“...we often find ourselves in power struggles with some certain clients from certain ethnic backgrounds and certain socio-economic backgrounds and the speaker that came did the sort of cultural interpretation and she sort of verified that you know validated that you know it wasn't that we were being prejudiced, it was in fact, you know, their expectations of what Canada was going to be able to give them” (Pamela, line 20).**

Another example is found in the racist struggles which occur between white elderly clients and homemakers of colour. The next two quotes discuss experiences of workers mediating racist conflicts between white elderly clients who refuse to receive homemaking from service providers of colour. These racist incidences are common experiences in elder care and are frequently resolved like the ones below:

**“Oh well that comes up a lot and the agency has been really quite good at handling that. We have numbers of cases where we just say “What is it about the work that the person is doing that you don't like. Don't tell us about her skin colour..” uh and we reinforce, that's one thing we're very clear on... we are not providing you with a white Anglo-Saxon home maker. We are providing you with a home maker to do the work. If you have a problem with some of the work, tell us some examples. And people are aghast. Usually they back out and claim “Oh it's not that I'm prejudiced” which is exactly what it is. And we just say, you know, we can't support... you know, we're not going to change home makers just because you don't like the colour of her skin” (Pamela, lines 224-227).**

**“Well, you call the agency and you try to find out what the problem is, and you have to be very careful not say that it is what you may perceive it to be until you've investigated the whole thing. Very often what they do - they Band-Aid the problem by saying “We'll change the homemaker to a different homemaker”, so they themselves don't really deal with the problem effectively - they just put a Band-Aid on it” (Fay, line 59).**

The second worker points to the problematic of treating these racist incidences from an individual perspective. When white clients express racist ideologies, all that is done by the agency is to change the homemaker or worse force the homemaker to stay in a racist environment in an effort to teach the client that racism is unacceptable.

By taking an institutional stance that racism occurs only at the interaction between worker and client, institutions themselves become racist, forcing both worker and clients to remain in racist environments and be continually disenfranchised and marginalized. In the case of service providers they also have the added experienced of being invalidated by their employer. Given this reality, it is no surprise that over the course of their lives, ethnic and “racial” minority people, as both clients and workers stop bringing these issues into public and professional discourse and internalize them. One worker clearly articulated this latter point:

“And then really, you yourself - you’re being prejudiced too, by firing the worker because they’re racist - because really it’s because your prejudice against them not thinking the way you’d like them to think. So it’s a catch 22 situation...” (Fay, line 64).

People are differentially situated within the system and this shapes their own personal experience with racism and therefore their responses to it. Ethnic and “racial” minority workers who have themselves experienced racism or who come from ethno-“racial” communities in which racism discourse gets articulated and analyzed are more likely to identify racism in the health care system. Others, in positions of power or dominance and who may benefit from the system as it is, have difficulty articulating or understanding racism. The following focus group discussion highlights these differing

positions quite well. Worker 1 and 2 are immigrant people of colour, while worker 3 is an Anglo-Canadian. Clearly, worker 3 has more difficulty understanding and discussing if and how racism gets articulated in health care:

“[Question: Had workers ever seen or experienced racism in the health care sector?]

Worker 3: In the context of our jobs?...

[short discussion with other workers]

Worker 3: I don't know I'm a little bit confused too. Were these people that you were talking with staff? And you were asking them about racism in the client group, ethnic elderly minority?

[Question: I asked them if there was, in their opinion, racism in the health and social service sector]

Worker 3: Themselves?... [Because] I don't know if they could answer that. Because you are asking them to answer how another person is feeling or experiencing and how could they know that? ... I don't know...

Worker 1: you could see in the hospital if you think there are any...biases...

Worker 3: Oh institutional biases... oh... (silence)... Well I don't know...

[Question: does anyone here ever talk about that?] (Silence)...

Worker 2: It's not a term that people are comfortable with because we don't want to poke it up sort of bring up but again... For the professional, I think it depends on how liberal you are. I certainly don't mind saying or talking about racism.

Worker 1: But would that be if you are talking about racism in the system, then you are pointing a finger at your colleagues, would that be it?

Worker 3: I don't think you'd find it overtly. I don't think I find in any of my colleagues, somebody not being...

Worker 2: racism is always subtle. It is never prominent, ok? Are you going to tell me you hate me because of my colour? You are not going to tell me...

Worker 3: That's a huge question. Like you could say... my first instinct would be no, we all try not to be... but people can't speak for every single solitary human being that's out there. And uh... I don't know...

Worker 1: How about the question being, is our system the way it is... uh... are there avenues for people to feel free to report it?

Worker 3: Well there are but maybe people don't feel free. But there are avenues. But see, a lot of people don't know... this is everybody... a lot of clients, young, old, don't know that they can call up and say "I don't like my... homemaker" and you can change her. They don't know they can do that. When we know, we'll do it. It's not a problem. We'll just ask what's the problem and ok we can do that. We'll even change agencies. You know? If it warrants it. But lots of times they don't tell us. They just don't tell us.

**Worker 2:** I must just say, with the professional, I'll be very honest... if you look at an institution you look at the numbers of the employees. Do they represent the mainstream, do they represent the ethnic?

(Silence).

**Worker 3:** What here at [our agency?]

**Worker 2:** Any institution... I mean there has to be. Institutional racism is there, it is subtle. And nobody's going to come out and say I hurt you because of race.

**Worker 3:** No no. So how would it come out though? Withholding services? I don't think so.

**Worker 1:** Withholding information. Maybe...

**Worker 3:** But what benefits does that have for anybody? To withhold information. I mean that has no benefit?

**Worker 1:** Ok, for example? It's not a real live thing that I have seen but if there is a feeling out there, ok that people are coming in from out of the country, then new immigrants are getting all these services... I have had comments made like that. "They've only been here for two years and look they're already taking a lot from us".

**Worker 3:** Yah you know where I hear those kinds of comments? I've heard those comments a lot too but not from other providers, but clients. From other clients... I'm not saying I haven't heard it but I'm saying I heard it much more from other clients than I have from service providers...

[Question: So why are workers answering so tentatively?]

**Worker 3:** I don't know and I don't know why they didn't put it in context either. Cause it's so hard to say who they're talking about exactly. They should have given examples. Like you could interpret that... It's so hard to know what they are talking about.

**Worker 2:** A couple of weeks back I was speaking to an older lady... she was from Jamaica. I didn't say anything. I was going to give her assistance according to the need. But she said, "listen darling, I put my sweat into this toil". I did not say anything. I was going to provide the services according to like I said... yes or no. But she said "listen darling, I put my toil into this soil. When I was healthy I worked like anything. Now I'm not here to beg you for services. I think I need to get the services that I am supposed to". So I said "ok, that's what I'm going to discuss with you. What your needs are. We are here to provide the service to meet the needs. I am going to explain to you". But where would she get that impression to come up with that to me. I put my sweat into the soil. She's used to saying that. Something in the background where that came up for her. So she is just forewarning me. So I believe there is racism, ok. I did not believe that there was such a thing but from the people's point of view or thought I do believe there is. Though I don't feel it maybe because I have been [used to the western ways], but being with the people I feel they think there are differences and that sometimes they don't get what other people get. So they have to bring it to the forefront.

**Worker 1: Yes, actually that has triggered something for me with the discharge planner in the hospital 1994. And uh it was overt ... it was this attitude that you know, you are immigrants and I was bunched in with the immigrants... uh but you know they are coming and taking services from the hospital.**

**[Question: Is this a subject that people can talk about at work?]**

**Worker 1: I think it would be loaded.**

**Worker 3: I guess it depends on the context. It means a lot of things to different people. And just to talk about it for the sake of talking about it. There should be a reason. People would find it uncomfortable yah. But it could be done but it is loaded. It's a loaded word.**

**Worker 1: How do you deal with situations if somebody makes a comment like that? It would make a stance, fine. But where would you go with that information? How would you deal with a discharge planner...?**

**Worker 3: Call her supervisor. And just say you know this happened and it concerned me and I just wanted you to know it happened. Let her deal with it.**

**Worker 2: Never put it under the carpet because if there is racism it should be dealt with" (FG2: Workers 1, 2 and 3, lines 63-125).**

The above dialogue reinforces the concept that racism is so difficult to talk about as people are coming from very different spaces with different understandings and experiences of racism. While Workers 1 and 2 articulated their understanding of the subtle forms of racism apparent in health care, Worker 3 had real difficulty understanding and accepting that racism exists. In addition, as racism is identified solely from an individual perspective, naming racism becomes potentially dangerous, for it exposes individuals, perhaps colleagues, to scrutiny. Instead, as exhibited by worker 3, it is easier to target clients' racist viewpoints rather than engage in a process of individual and institutional self reflection. There is little institutional safety in addressing racism despite the awareness that acts of racism should be dealt with. This makes it all the harder for institutions to develop ways to talk about "race" and racism. Indeed, addressing all forms of racism, be they individual, institutional or systemic, is a long-term and time consuming process which

requires a level of safety and common understanding between and among workers at all levels of the organization. Since workers' own locations and experience shape their understanding of and comfort with discussing these issues in a public format, addressing the issue of racism within institutions are fundamentally "loaded" and thus avoided.

Representation is one of the areas where institutional racism does get more concretely understood and articulated because it is the responsibility of managers and thus of institutions to hire workers, whereas it is still seen as the responsibility of individual workers to bridge gaps of understanding and miscommunication between themselves and their ethnic and "racial" minority female clients. Representation is seen as an important issue in the delivery of appropriate service. It is often ethnic and "racial" minority workers who have identified a sense of disenfranchisement about their experience of representation and as a result, decision-making power in agencies. Below, two visible minority workers and one white ethnic worker share their understanding of representation as an issue of institutional racism:

"The other thing too, of course, is to hire a lot more [ethno- "racial" group] people to deal with these areas. I mean, when you look across this particular agency you probably can hand pick us on one hand, you know, and yet the area that we're serving is very very... with the population. So we need to do something... Nothing [has been done] that I could put my finger on. I, I think the managers... and I don't think that they deliberately exclude [ethno- "racial" group persons] per say, but I think that one or two of them I know of, have been sort of trying more to at least hire one or two more [ethno- "racial" group persons]. Not a lot but maybe one or two. I think that they could do a lot more work.... I don't know if I want to go there...I don't want to go there because you don't even have to look - you can see it for miles; you can see it all over the health care system - in the hospitals, here, wherever you go, do we have a manager that's a Black manager in any of the [institutions] apart from [one or two]? No. None. We have a few coordinators and that's about it. And even if the qualifications are the qualifications that they're looking for, the majority of

even those of us who are here, have those qualifications. Well did they hire any manager that are Black apart from maybe one? I think it may also start with the whole hiring process and getting the right people in with the right groups and the appropriate research and what have you too, then bring out what is required and then get the money and get on with it" (Fay, lines 65-70).

"We talked about hiring practices. And like it's very noticeable that since we first been out here we've hired so many people and none of them until last week were non-White. And I said to him we just have to be aware of this because we are servicing a non-white community. And all the managers here are White and almost all the coordinators are White and believe it or not, whether you want to accept it or not there is racism in the workplace. Now nearly all... almost all (whisper) the clerical people, the paraprofessionals, are non-white. And the professionals, almost all of them are white. And that to me, is racism. All of the managers are that's racism. Not consciously maybe, but it's there. [They] wasn't aware even. You see they don't think...So I said there is a definite feeling in the organization, wrong or right, that there's racism and you want to keep the top white, you know?" (Elaine, lines 121, 174).

"But if you look at the institutions, say our office. I look at us and say do we really reflect the community that we're serving. Is there much, if we call it, employment equity here? What are the hiring practices? Are there any real efforts to recruit people? From other backgrounds? Whether it's because of their language or their knowledges? I don't know if there's... I don't what the legislation states any more" (Olive, lines 120).

These women, once again, are better able to articulate a "race" discourse. This is probably a result of their own experience, their values and beliefs and/or their exposure to "racial" discourse. Those workers who are familiar and comfortable with discourses of racism will more likely identify and name racism where they see it.

Flowing from the issue of representation is the theory of critical mass. As stated earlier, often a critical mass is required to provide a sense of security about and adequate representation to advocate for institutional change. Without adequate agency and community representation, workers feel disenfranchised and unable to produce change for their community or themselves. Workers fear and experience stigma with minimum

representation. They also describe reduced morale and a sense of helplessness. This may account for some of the differences in workers' responses to and expressions of joining together to advocate for institutional change:

**"I think it's more informal. There's really nothing set up. But then there's not enough of us really to make enough noise about it. And that's part of the problem. Well, yeah, if you have more coordinators and you can say, "well, you know, as a group we require and we would like 2 or 3 people - I don't even think we have 6 coordinators...and, I mean, this is an improvement by the way...it's getting beyond tokens. Well, lets say we are trying to get beyond tokens; we still have tokens. But we're trying...I've been with home care 4 years now. But I've been in the medical field for over 20 years. And the same problems I face now are the same problems I've faced over the 20 years as a nurse in an institution. We deal with it. It's like everybody else here - you bite your tongue and you scream sometimes. I've screamed over the years. All you do is get labeled as being a troublemaker, there's a stigma. But there aren't enough people to form a group to say, "Well, we're not just going to scream - we're going to do something or else". And so what can you do? You just do as much as you can with whatever you're working on. Oh I still make trouble! ... I scream when I need to scream. They probably call me a troublemaker more - I'm the QT? now - but it's still the same ... It's not that I'm uncomfortable making noise, it's just that I wouldn't get enough people to make enough noise to matter. Because there aren't enough....if you have 50 workers and 25 decided to go on strike, you'd probably sit up and take notice. But if 2 wanted to go on strike, they'd say, "Well, that's ok - the other 23 can handle the job"...it's the numbers... [Question: would other people walk out with you?]You know, from every other perspective, there probably will be but the question they'll probably be asking themselves is, "Should I be sticking my neck out here?" Yes I do agree - but ...yes you'll find some people that will - but I don't think it will be significant.." (Fay, lines 43-52, 72-73).**

**"No we don't [meet together]. No we don't and I don't know why. Maybe cause there's not enough of us and we're so spread apart. But I will sometimes go seek out Fay or Bob to talk to them if I hear anything but no we don't. There's really not enough of us" (Elaine, line 135)**

**Aside from the dilemma of a lack of a critical mass, stigma also gets experienced as a result of work constraints, so that advocating for institutional change around such issues**

as representation and other organizational practices are seen as too difficult to undertake by visible minority workers:

**“It’s almost like uh... I think this issue of the system has been approached earlier and I get the sense that people are just resigned to the fact that this is what we have and so what do we do with what we already have. It’s like advocating for what we could have and what we should have... there’s no hope cause given the restraints, the budgetary restraints, etc. I mean, most of us are carrying a heavier caseload than we felt we can handle so we have little energy to fight” (Ann, lines 3-5).**

On the other hand, some ethnic and “racial” minority workers, who have a greater degree of representation and specialized services to meet the needs of their communities have not felt that great a need to meet together to advocate for change:

**“I don’t know about the others but let’s say the Chinese, because there are few of us sitting in the same team, the same quad not regularly but like Friday, let’s say they go out, they go out to have lunch. But it’s not necessarily just Chinese, we have invited others as well to join us. And it’s not only Chinese food. We have tried to go to Mother Tucker’s. So I would not say just us. [Question: are there issues you think that you together should could need to talk about in your work life?] You mean among the Chinese staff? I don’t think so. [Question: or let’s extend that to the Chinese staff and the black staff or the ethnic staff. Do you think there are things that have to happen here for yourselves?] I don’t think so. Personally no. OK but one thing I forgot to tell you that last year, the Chinese New Year, we went out to have lunch, the Chinese (laughs). We asked the clerical staff, and PCS staff, whoever like to join us because it’s Chinese New Year and we are all working on the New Year and we feel sorry for ourselves so let’s go out and have a good lunch so we went to a Chinese place to have lunch” (Kathy, lines 267-272).**

The data presented here point to the need to provide training regarding racism. According to workers and managers, this kind of training is currently on the agenda of the institution, although it has not, at the time of the study, been undertaken. According to one worker:

**“and I mentioned this about that person saying... not directly but it was brought to me after... about uh... these people that want so much I wish they would get back on a plane and go back where they come from. Somebody actually heard that, a coordinator saying that and they told me about it and he did talk to her about it after. And he said we should have some education here about racism and homophobia. So I found the name of a person and gave him and he’s supposed to come in and have a little chat. So that’s one step.” (Elaine, lines 121-125).**

## **Conclusion**

**These data presented in the two chapters on the limits of multiculturalism provide evidence for a need for gerontologists to make a fundamental shift in their current understanding of multiculturalism as it operates in the everyday practices of elder care agencies. This shift must incorporate what ethno- “racial” communities, particularly ethnic and “racial” minority elderly women and ethnic and “racial” minority workers tell us about the experiences of “race” and racism in elder care institutions.**

**Multiculturalism in elder care institutions is largely practiced from a cultural competence model in which the primacy of language narrowly constructs institutional priorities in elder care services, defining communication between workers and clients as the site of access barriers and fundamentally situating problems of access in the capacity of clients to speak the language of mainstream institutions and in the availability of families to intervene when communication between mainstream agency and older ethnic and “racial” minority woman is not possible. Locating the “problem” in the individual renders the role of systems and institutions in creating this problem, invisible. Whether or not institutions are adequately prepared to support and service these clients and whether or not governments and institutions prioritize the needs of these clients through the provision of adequate resources, the development of policy and guidelines around such issues as**

interpretation services, the adaptation of textual documents such as assessment forms to include a place to identify language and culture, matching strategies and training of workers, are not addressed. In fact certain practices such as relying on ethnic and “racial” minority families and workers to translate “for free” puts a great deal of strain and pressure on ethno- “racial” minority persons, mostly women, to pick up the slack where governments have left off. This analysis which has been made quite articulately by feminists writing in the field of “caring” (Aronson, 1991; Chappell, 1993) has not adequately addressed how “race” complicates this experience. Institutions then, become inadvertently responsible for the continued oppression of ethno- “racial” minority women, despite their best efforts to provide translation services in a context of scarcity of resources. That is, given the lack of resources for interpretation and the lack of priorities of government to provide funding for these services (as it visible both through the lack of identification of textual documents such as policies and guidelines that reinforce the legitimacy of identifying language and the loss of funding to ethno-specific agencies for interpretation services), institutions have little choice but to rely on the good will and commitment of ethnic and “racial” minority women, as both families and workers, to provide this service for them, thus putting them in a position of doing more work without any tangible benefits. Institutions have a responsibility to problematize their relationships with ethno- “racial” communities and to render visible the ways in which everyday working practices contribute to the oppression of women as both families and workers. In the latter case, this is easily done through providing training to workers who take on the task of interpretation on a regular basis and by institutionally recognizing their role as interpreters through reduced workload or other forms of compensation. Otherwise these

workers can easily become agency tokens. In the case of choices between using families or workers to interpret, institutions must begin to develop protocols and guidelines for workers to help smooth out or render visible the process of decision-making in these cases. It might also be relevant, through this process, to shift the priority of interpretation so that families are not seen as the first viable choice for interpretation, but the second, if and when professionally trained interpreters from the agency are not available. This might mean: changing the way boundaries are identified so that ethnic and “racial” minority workers could be available to clients from the same communities not only as interpreters but as case managers; recognizing that building relationships with ethnic and “racial” minority elderly women, who have been totally disenfranchised from mainstream institutions their whole lives, will take more time and thus have an impact upon case load; supporting the fact that representation becomes more crucial to these efforts; and that institutional priorities need to reflect the experiences of ethnic and “racial” minority elders and workers, thus requiring shifts in representation at all levels of the institution. Finally, texts which shape interactions, such as those of assessment forms, must be adapted to highlight the central place of culture in the process of giving and receiving care. This will help to identify, in the everyday, that workers themselves must be concerned with these issues of identity, of language, culture, ethnicity, “race” and religion, amongst others on a routine basis and not only in cases where communication barriers render the interactions between worker and client a “problem”.

By focusing on cultural competence alone, with an emphasis on language, several other things happen. First, where important efforts to provide community outreach and adapted services are undertaken, these are done only within those communities that have a

significant “language problem”. This inevitable leads to the identification of “deserving” and “underserving” ethno- “racial” communities. That is, those communities with a large proportion of seniors who do not speak either English or French get identified of deserving of additional institutional support, while those communities with a smaller proportion of seniors who do not speak either English or French are not seen as institutional priorities for adapted services. This leaves ethno- “racial” communities in competition with each other in their efforts to alter institutional arrangements and shape service delivery. Losers in this battle, that is those that have little influence over institutional priorities are rendered further marginalized and oppressed by mainstream services. Workers from these ethno- “racial” communities feel this marginalization and experience additional oppression in their work environments.

Second, experiences of racism and oppression, whether those of older ethnic and “racial” minority women or ethnic and “racial” minority workers are rendered invisible. If these experiences do not fit within the construct of language and communication, they have little space to be articulated. Racism is clearly a “loaded word” in elder care and this is exhibited in both clients’ and workers’ avoidance of these terms and discussions. Institutions have a responsibility to provide space for these discussions and need to listen with expanded ears to older women’s stories in order to shift discussion from “there is no racism” or “racism is only located in individual acts” to “what are the institutional and systemic roots of racism and how can these be institutionally addressed?”. Given the fact that governments have little interest in exploring these questions and have continually shaped the discussion of access barriers around “questions of language”, it becomes more imperative for institutions to enter into and provide space for these discussions. This

undertaking requires some education around and common understanding of the intersectional nature of oppression. This does not mean that current efforts to provide multiculturally sensitive services should be discarded. In fact, the opposite is true. Efforts such as those to provide ethnic sensitive services to target communities, to problematize and discuss the role of families in translation, to provide education to incoming staff, to develop outreach strategies, to adapt forms, should all be encouraged and supported. These efforts, however need expansion, the articulation of guidelines, the shifting of everyday practice and the broader training of staff so that they become entrenched in everyday practice and “talk” within the institution and render a common experience possible from which to begin to explore the more contested terrain of “race” and racism.

## **Chapter 10: Discussion and Conclusion**

The present study explores the impact of ruling relations on ethnic and “racial” minority women’s experience of access to elder care. It attempts, through this exploration, to create a more profound understanding of access, one which is based on broader definitions than those currently used by gerontologists and which is more reflective of older ethnic and “racial” minority women’s experience. It explicates the practices and processes by which access is currently being defined and how actors both reproduce relations of oppression and counter or resist those relations. These practices are textually-mediated and, as such, the current study examines those texts which shape relations between individuals in the everyday experience of access. These include assessment and eligibility guidelines and policies, referral practices and policies and, procedures concerning the delivery of services to ethno-“racial” communities. Finally, interviews conducted with clients, front-line workers, managers, ethno-specific community agency, multicultural agency and hospital workers articulate how everyday practices are made manifest through institutional and individual relations.

The current inquiry can assist the larger project of adapting health care in Canada to better meet the needs of older people. First, by illuminating institutional processes of access which serve to shape and render problematic the experience of those who have historically faced inequities in care, gerontological theorists, policy makers and practitioners can begin to reconsider how access operates in the everyday against the interests of these people. Second, these same decision-makers can learn a great deal about the ways in which institutional processes impact upon those differentially (and often less problematically) marginalized but who are, nonetheless, still subject to ruling relations in

elder care, such as elderly Anglo-Canadian women and elderly ethnic and “racial” minority men.

The discussion which follows traces the problematic of access for ethnic and “racial” minority women through the lens of a “conceptual map of power”. This “conceptual map” highlights and makes visible the patterns of relations of ruling prominent in elder care services and serves to expose how state ideologies, particularly those of scarcity and medicalization operate in the everyday practice of elder care institutions. The findings of each of the main chapters will then be synthesized and positioned collectively in order to reveal the coordinated pattern of ruling which functions to marginalize and oppress older ethnic and “racial” minority women. Once this has been achieved, the discussion will turn to theoretical, public policy, program and practice implications of the current study and suggestions for future research in the area.

### **Mapping Relationships**

The first task of the discussion of the current project is to map the direction of relationships of ruling in elder care services to ethnic and “racial” minority women. This pictorial diagram provides explicit description of how state ideologies operate as concrete practices which serve to exclude and marginalize older ethnic and “racial” minority women as they attempt to access elder care, and will situate the discussion that follows. Smith (1987) describes the process of mapping relations as simply “making a design” (Smith, 1987: 170). This design is meant to provide conceptual clarity and is not intended as a static theoretical model. The process of mapping relations of ruling is intended as a fluid tool to identify and mark these relations for public scrutiny. Although borders are defined and made visible, they represent complex relations and interactions which are constantly in

flux. This leaves room for the addition of other components of ruling relations to emerge as they are exposed in the everyday practice of organizations.

Figure 1 depicts these ruling relationships. The state, as represented by the largest square, is situated at the top of the map. Positioning it so serves to reinforce the reality that the power elite, through apparatuses of the state, is exclusively responsible for translating ruling ideologies into professional discourse and institutional practice. As is consistent with the institutional ethnographic approach, one end of the state box is left open to suggest correlations to the political economy and to larger political and social ideology which, although influenced by state practices and policies, are not wholly situated within them. Predominantly, but not totally embedded within the state, is the community. Here the community broadly refers to the entire geographic area which is served by *Eldercare*, but which constitutes many communities, including ethno- "racial" communities and community organizations. Although largely defined by their relationship to the state, through funding arrangements and policy, the community is differentially impacted upon by the state. For example, some organizations are able, through independent funding, to exist more tangibly outside of state ruling apparatuses and thus critique, expose and work against the state more concretely. This is rare in elder care and within the confines of state funding, thus little space has been left outside of the state box in which the community resides. Mediating state relations with both the community and the *Eldercare* institution is a box entitled "Professional Discourse". This is meant to symbolize the extent to which state ideology is enacted through professional discourse which fundamentally shapes public elder care services. As discussed previously, discourse within the field of gerontology is almost exclusively professionally defined. Unlike other

fields, such as the disability field, in which activists have been able to shift professional discourse so that previously professionally-defined, passive recipients of care have found space to articulate need and shape services, the field of gerontology has had few such influences. State ruling ideology has therefore been more firmly entrenched in elder care. State ruling ideology is made manifest through textual relations, particularly state requirements of eligibility and this is pictorially described in the box entitled texts which sits parallel to and partially inside the professional discourse box. The *Eldercare* box also largely rests within the community. This is meant to exemplify how geographically-based these services are. However, a portion of the *Eldercare* box is situated outside of the community box and is meant to suggest the marginal place ethno-“racial” communities have in the development and operationalization of elder care services. It is in that space that these marginalized ethno-“racial” groups are located. Finally, the box on family rests between the *Eldercare* box and the older women box. This picture speaks for itself. Clearly, as has been articulated time and again in the current study, older ethnic and “racial” minority women experience elder care in and through their families, particularly when language and cultural communication between older women and mainstream institutions is impossible. As such, their voices are largely absent in service development and maintenance. Older ethnic and “racial” minority women require their families, by design, to mediate and interpret these services to them. This works both ways so that workers, as representatives of *Eldercare* services can also only interact with older ethnic and “racial” minority women through their families. What this picture suggests is that older ethnic and “racial” minority women’s relationship to state apparatuses, themselves ideologically-driven, is entirely invisible. Given that there are so many mediators of the

relationship of women to the state, it is no surprise that ruling ideologies become so permanently entrenched as common-sense practice. In the end, older ethnic and “racial” minority women’s experience of access and their everyday interactions with workers become entirely constrained and fragmented. To describe these relationships in greater detail, we now turn to a discussion of key findings and the public policy, program and practice implications that emerge from these.

### **Emergent Concepts**

The current study illuminates the central processes of access which serve to shape and delimit elder care through and from ethnic and “racial” minority elderly women’s standpoint. To this end, analysis remained rooted in elderly women’s own conceptions and expressions of experience, lending credibility to the findings and infusing the study’s direction with women’s location and voice (Devault, 1990). The concepts that emerged are situated in women’s standpoint and explore how the state, through the everyday practice of elder care both distorts women’s voice and renders women passive recipients of care. Three primary concepts have been articulated here, they are 1) the primacy of family, 2) the dilemma of prolonged engagement in the context of the primacy of the “medical” (acute health care) model and, 3) the ideology of multiculturalism. These concepts are not abstract ideologies but rather, they represent concrete practices which are enacted in the everyday processes of access. The concepts are linked by a common thread, that is, the manifestation of a disjuncture between elderly ethnic and “racial” minority women’s desires regarding the provision of elder care services and state practices of ruling in elder care.

The first set of institutional practices illuminated in the current study revolved around the concept of the primacy of family. These data suggest that the involvement of family in providing care and in mediating the relationship between institution and elderly ethnic and “racial” minority client is highly problematic. On the surface, the practices which make family primary in elder care seem ideologically neutral. In fact, often elder care institutions and the state point to the mutual benefits of involving family in the provision of care to elders, stating that both direct service agencies and elderly clients themselves express higher levels of well-being and satisfaction when family members are involved in their care on an ongoing basis, thus reinforcing the popular view that there is no gap between what elderly women want and what the elder care system offers. In fact, elderly women in this study also pointed to their need to involve families in their care and their desires to be taken care of by their kin. However, these realities and desires are fundamentally mediated and constructed by current practices in elder care and do not themselves suggest that the state can forego the provision of services when family are present to provide care. The conclusion derived at by state institutions is a distortion of women’s expressed desires. What remains invisible in the expression of positive benefits of the involvement of family is the ideology of scarcity underpinning this model of elder care and the fundamental practice of race and gender exclusion and marginalization embedded within it. In their everyday operations, elder care institutions entrench family involvement through the myriad of practices in which families are not only encouraged, but required to “pitch in”. This enables the reduction of the public provision of service and results in a spiraling effect in which, as fewer resources are made available, families are increasingly required to do more and, as families do more, governments can justify more reductions in

service; so the practice of family involvement becomes a means for public institutions to control and delimit the provision of care and shift care onto the backs of families. This ideology gets made manifest, not only in the actual practices of agencies but in the value-stance of the institution and its workers, so that, when families do not participate but are perceived as being capable of participating, they sometimes become labeled as abusers of the elder care system. This reinforces ethnic and "racial" minority women's and their families' marginal position as actors and decision-makers in the provision of care. These practices highlight the entrenchment of an ideology of scarcity in which the private sphere of the family is seen as the most appropriate site of elder care. The root of this practice is both sexist and racist. The gendered nature of caring has been well articulated by feminists working in the field of gerontology and will not be elaborated on here. For these argument see Aronson (1991), Chappell (1993) and Neysmith (1997). The current research expands this debate to incorporate an analysis of the intersecting nature of oppressions in the structure of "elder caring". A model of elder care which defines family as the most appropriate site of elder care oppresses ethnic and "racial" minority women in unique and multiple ways. The experience of marginalization among ethnic and "racial" minority mothers and daughters is both more intense and fraught with a series of double binds. First, they are called upon to do service provision in the home, as are Anglo-Canadian daughters. They are also, however, required to do more institutional work, acting as interpreters and linkages between the private and public spheres; between their mothers and the elder care system. In effect, ethnic and "racial" minority children are forced to take on the multiple roles of service provision, interpretation and case management. Second, ethno-"racial" communities' experience of poverty and under-employment, particularly as

recent immigrants, result in more strains and less time to devote to caring as they search for means to establish themselves. The reality of women's participation in the home-work economy (Gabriel, 1999) further problematizes ethnic and "racial" minority women's role as carers. From the point of view of institutions, ethnic and "racial" minority daughters who perform home-based work, such as the needle-trade, are "at home" during the day and thus are perceived as being able to take on responsibility for providing care. Their activity in the labour market through home-based employment is relatively invisible to elder care workers for whom the primary task is simply assessing the extent and capacity for family participation. This serves to render these women targets for reduced service provision at a time and within a social location in which their need of public service is more acute. Finally, the practices which emerge out of the discourse of "ethnics take care of their own" work both for and against ethnic and "racial" minority women in care. They work for, by enabling women to articulate their own set of values in and against those of the west, often seeing their indigenous ways as "better than" those of the west, thereby helping to buffer experiences of alienation and dissatisfaction that they experience in elder care services. Unfortunately, the ideology of "ethnics take care of their own" is currently used by the system in a way which works against women, because it increases workers' expectations that family, particularly female kin, "should" be providing that care and when they don't, to be perceived as deviant.

By infusing the debate on the primacy of family with women's standpoint, it is possible to illuminate how women's experience of family involvement is not as uncontested as elder care organizations and gerontologists would have us believe. In fact, in the current study, older ethnic and "racial" minority women have expressed their

discomfort with having to rely on their families to provide care. Rather, older women have attempted to relieve pressure on their children by taking care of themselves and demanding less from their children. This attempt to be undemanding confirms previous research which suggests that being undemanding is one of the only ways elderly women have to mediate relationships between themselves and their caregiving daughters (Aronson, 1991). This experience may be more problematic for ethnic and “racial” minority women because of their intense historical struggles to provide a better life for their children, making the experience of burden and the desire to be undemanding all the more salient. Exposing this reality enables the positioning of the strategy of reducing demands on family as an act of resistance. Finally, older ethnic and “racial” minority women attempt to articulate a lack of family care and to pathologize their experience of family to workers in the system as a strategy of obtaining more care from the public sector. This strategy is premised on an understanding of the primary focus their workers place on family involvement and their experience that those with less family help receive more attention from the public system.

The second problematic made evident in the current study highlighted the disjuncture between older women’s experience of creating opportunities for reciprocity and trust-building in their relationship to state workers and the primacy of the ideology of medicine in elder care services. This disjuncture or problematic illuminates how essentially older women’s desires and state ruling apparatuses are in conflict. The primary pattern emerging in these data is that women in care are looking for expanded opportunities for relationship-building and reciprocity. Older women want to be valued as human beings first and not as decontextualized “passive recipients”, “patients” or “clients” in their interactions with the elder care system. Older women interviewed have resisted these

definitions of themselves in a number of ways. First they avoid approaching service providers unless recommended through a trusted resource. Second, they attempt to influence visits by talking “off the subject” about their own lives and experiences, relating experiences of employment and immigration seen as central to their current health capacity. Although opportunities for reciprocity are rare, older women have attempted to develop reciprocal relationships where they have some control and this is made manifest most often with home care workers. This latter experience is fundamentally racialized. Anti-racist feminists have elsewhere pointed to the problematic of appealing to notions of “family” in the provision of domestic work by women of colour to white women and/or white institutions (Neysmith and Aronson, 1997). According to Brand (1999),

It is a well-known joke among Black women in domestic work and institutionalized domestic work and other areas of Black women’s work that employers, when trying to exact more work from them or when Black women reject disrespectful treatment or assert themselves, make an appeal to family... the derision with which Black women view these statements is a recognition of the attempts to “work them to the bone” while extracting that “free” (read unpaid) labour which stands for kinship, blood relations, and familial duty. Black women often remind employers that they have their own families where enough “free” labour is given up. (Brand, 1999:92)

Clearly, the fact that the current study has illuminated how ethnic and “racial” minority women also make appeal to “family-like” relations of reciprocity and caring in their desires of the elder care system, renders an analysis of the above argument more problematic. When white institutions appeal to ethnic and “racial” minority home care workers to take on more work as an expression of caring, they are coming from a discourse of racism. Given the paucity of ethnic and “racial” minority service providers in the system and the efforts to ethnically match clients and service providers, this appeal to

ethnic and “racial” minority home care workers is not an uncommon occurrence. However, in the current study, relations between ethnic and “racial” minority home care workers and ethnic and “racial” minority elderly women clients, particularly visible minority women, may be an expression of empowerment and resistance, rather than one of racism. In this instance workers and clients may share a more egalitarian relationship, despite their respective statuses of worker and client because of shared experiences of racism and sexism. This shared status, identity and history may help to bridge gaps between these women, making the building of relationships between them easier and more fulfilling. Because of this increased egalitarianism, older ethnic and “racial” minority women may feel they can take more control in these relationships than with other health care professionals such as nurses or physiotherapists, who although also entering older women’s private space of the home, enter with a professional status, a medical agenda and, more often than not, are white Anglo-Canadian, thus rendering them in control of the interaction. Ethnic and “racial” minority workers may also find a place of peace and rest within the homes of older ethnic and “racial” minority women unlike their contested experience of domestic work for white families (Brand, 1999). Thus, when ethnic and “racial” minority women align themselves with their home care workers through the use of comparisons to family it is not to engender more work from these home care workers but to establish opportunities for social relationships; for talking and building reciprocity.

Elder care services are not designed to recognize the discourse of reciprocity and in fact jeopardize efforts between workers and clients to develop reciprocal relationships on a daily basis. This differentially impacts ethnic and “racial” minority elderly female clients who, because of their marginalization within white supremacist and andro-centric

institutions, may need to develop relationships as an expression of resistance to the sexism and racism they experience. As a result of demands for cutting costs, using resources efficiently and responding to the increasing needs for community elder care services, pressures are continually put into play which pit agency or systemic priorities against client desires. Workers in the system have also expressed the importance and satisfaction of relationship-building and often struggle with their own desires to spend more time with clients in an environment which places pressure on them to do more and do it more quickly. Larger caseloads, changing geographic boundaries, high turnovers of service providers and the intrusion of texts and technology such as forms, phones and computer programs all serve to rule the interactions between workers and ethnic and “racial” minority female elderly clients. The outcome is a system in which clients rarely see their case managers and come into contact with many different and shifting service providers. This often results in discontinuous, meaningless interactions which do little to satisfy older ethnic and “racial” minority women’s needs for prolonged engagement with their workers and serves to alienate and oppress them.

These institutional practices reflect the articulation of the central and related ideologies at the root of the current model of elder care services, namely medical-dominance and scarcity of resources. In the current climate, this has meant that elder care services operate almost exclusively from a medical perspective, shaping and limiting elderly clients in terms of their medical or functional status. Medical discourse acts as a “professional lense” through which “need” is interpreted in the every day as medical or functional impairment so that only those who speak from within this discourse are heard and legitimized. That means that the prioritizing of medical “need” is articulated in the

form of “technical language” to which only medical professionals and other “insiders” gain access, leaving the boundaries around who receives care and under what conditions in the tight control of case managers (Aronson, 1992; Dill, 1993). This practice is almost exclusively textually-mediated. Eligibility requirements and assessment forms serve to shape how workers perceive, identify and manage elderly ethnic and “racial” minority female clients. These texts also serve to render ethnic, “racial” and cultural identity relatively meaningless to these interactions. Elderly ethnic and “racial” minority women, themselves farthest located from sites of professional power and control in elder care services and the least familiar with western models of health care are unlikely to articulate their needs in a way which can be understood and legitimized by professional discourse. This renders them invisible within these institutions (Fraser, 1997). Finally, state orchestrated relations remain hidden in this environment so that only the relationship between worker and client is visible, thus leading the public to believe that worker “personal choice”, not state priorities, is responsible for the prioritizing of “need” as medical. This is particularly problematic for ethnic and “racial” minority workers whose attempts to build alliances with ethnic and “racial” minority elderly women in order to combat racism, may be threatened when a prioritizing of need is masked as individual choice rather than located as state ideology.

Multiculturalism is both an ideology and a practice. The articulation of multiculturalism represents a broad range of values and practices which are highly contested in academic and public policy arenas (Das Gupta, 1999; Newfield and Gordon, 1996, Ng, 1991). It is within the framework of multiculturalism that the third and final problematic, addressed in the current study, emerges. Elder care institutions, in

articulating multicultural ideology and practice, do so from a position of cultural competence (Mama, 1992; Yuval-Davis, 1994). This translates into a series of institutional practices which are aimed at individual adaptation and focus primarily on increasing understanding of the beliefs, values and health care practices of individual cultural communities and expanding opportunities for communication between worker and client. As a result, elder care services identify language as the primary barrier to care faced by ethnic and “racial” minority women. On the surface, this is not a contested reality. All constituents interviewed in the current study stated that language acts as the most frequently encountered barrier to care. However, it is within this ideology of multiculturalism, in which the primacy of language narrowly constructs institutional priorities in elder care services, that the point of disjuncture becomes visible. The primacy of language acts to define communication between workers and clients as the site of access barriers and fundamentally situates problems of access in the capacity of clients to speak the language of mainstream institutions and in the availability of families to intervene when communication between mainstream agencies and older ethnic and “racial” minority women is not possible. Locating the “problem” in the individual renders the role of systems and institutions in creating this problem, invisible (Das Gupta, 1999). Whether or not institutions are adequately prepared to support and service these clients and whether or not governments and institutions prioritize the needs of these clients through the provision of adequate resources, the development of policy and guidelines around such issues as interpretation services, the adaptation of textual documents such as assessment forms to include a place to identify language and culture, matching strategies and training of workers, is not addressed. In fact certain practices such as relying on ethnic and “racial”

minority families and workers to translate “for free” puts a great deal of strain and pressure on ethno-“racial” minority persons, mostly women, to pick up the slack where governments have left off. The gender component of this analysis, which has been made quite articulately by feminists writing in the field of “caring” (Aronson, 1991; Chappell, 1993) once again, has not adequately addressed how “race” complicates this experience. Institutions then, become inadvertently responsible for the continued oppression of ethno-“racial” minority women, despite their “best efforts” to provide translation services in a context of scarcity of resources. That is, given the lack of resources for interpretation and the lack of priorities of government to provide funding for these services (as it visible both through the lack of identification of textual documents such as policies and guidelines that reinforce the legitimacy of identifying language and the loss of funding to ethno-specific agencies for interpretation services), institutions have little choice but to rely on the good will and commitment of ethnic and “racial” minority women, as both families and workers, to provide this service for them, thus putting them in a position of doing more work without any tangible benefits (Brand, 1999). These issues must be considered in policy and programmatic responses in aging services.

By focusing on cultural competence alone, with an emphasis on language, several other things happen. First, where important efforts to provide community outreach and adapted services are undertaken, these are done only within those communities that have a significant “language problem”. This inevitably leads to the identification of “deserving” and “undeserving” ethno- “racial” communities, with “deserving” communities being identified as those for whom English language comprehension is lacking. This leaves ethno-“racial” communities in competition with each other in their efforts to alter

institutional arrangements and shape service delivery. Second, experiences of racism and oppression, whether those of older ethnic and “racial” minority women or ethnic and “racial” minority workers are rendered invisible. If these experiences do not fit within the construct of language and communication, they have little space to be articulated. Racism is clearly a “loaded word” in elder care and this is exhibited in both clients’ and workers’ avoidance of these terms and discussions. As such, racism becomes so embedded in everyday practice that it becomes common sense, the way things are done. Workers in the current study attested to this reality. This makes efforts to unmask and expose institutional racism highly improbable and thus contributes to the maintenance of status quo operations in elder care.

The data presented in the current study provide a rich and detailed picture of the problematic of access to elder care from the standpoint of ethnic and “racial” minority women. The principle ideologies which emerged, namely those of the primacy of family, medical dominance and a philosophy of multiculturalism rooted in cultural competence, are made manifest through concrete institutional practices which shape how services are delivered and ultimately how elderly ethnic and “racial” minority women are themselves constructed, oppressed and marginalized. Underlying these ideologies is a meta-narrative of resource scarcity which connects the practices of elder care institutions to their relations within the political economy of the state. Resource scarcity as a meta-narrative drives institutional practices and priorities through funding arrangements so that cost-effectiveness and efficiency become the primary operating focus of elder care institutions. While appearing gender and “race” neutral on the surface, each of these practices is fundamentally sexist and racist and reflect totalizing ruling relations between the state and

ethnic and “racial” minority women in elder care specifically and in Canadian society generally. Older ethnic and “racial” minority women are multiply oppressed by and within elder care institutions. Yet, the practice of locating the “problems” faced by these women in their capacity to adapt, their ability to speak the language of the institution, the availability of their children to participate or the pattern of communication between themselves and their workers, serves to make the ruling apparatuses which shape their oppression, utterly invisible. Since racism and sexism are experienced as “common-sense” practices, older ethnic and “racial” minority women’s experience of oppression literally disappears from view. Ironically, it is these women who will most likely be the targets of institutional efforts to improve access at the same time as their voices remain absent from debates regarding how access should be re-constructed and how care should be delivered.

#### **Implications for Public Policy, Programs and Practice in Gerontology**

The following sections examine the implications of the findings of the current study on public policy, programs and practice in the field of gerontology generally and in reference to ethnic and “racial” minority women specifically. These discussions are focused around two concepts central to the current project, namely “access” and “equity”. Notions of access and equity are intrinsically tied together in public policy and professional debates in elder care. As such, an examination of these terms, through an exploration of the ways they are defined, operationalized and experienced, can contribute to a fundamental re-examination of elder care policy and practice. It is important to state that what is called for here is a paradigmatic shift in the current construction of what constitutes equitable access in the field of gerontology, not in its removal from public policy debates entirely. Equitable access is an essential goal to strive for in the provision of

elder care in Canada but is currently poorly articulated in public policy discourse and as such, is open to easily corruptible interpretations. Rather than deconstruct to remove, the project here suggests deconstructing in order to redefine with more precision, elaboration and commitment to incorporating the voices and experiences of disenfranchised elders into public policy debates. It is with an explicit commitment to re-shaping the paradigm of equitable access from the experience of ethnic and “racial” minority elders that we can truly begin to develop a responsive and appropriate system sensitive to principles of equity and justice. Gerontologists must begin to engage in a dynamic discussion with all constituents, including those most disenfranchised in the current system, to more adequately articulate the fundamental principles of equitable access. By doing so, gerontologists can create environments in which the needs, desires and visions of all elders requiring public care can be realized.

### **Rethinking “Access”**

The findings articulated in the previous section point to the necessity of critically re-thinking public policy and practice in relation to the definition and delivery of services to elderly persons in Canada. This is particularly true if services are to appropriately and sensitively reflect the desires and experiences of a variety of disenfranchised populations, including ethno- “racial” minority communities and women.

As a first step, gerontologists must revisit the notion of “access” as a central operating principle in the articulation of elderly people’s relationship to state services. At the present time, “access” fundamentally shapes how we think about and consequently how we design, services to elders, particularly to those who have been historically disenfranchised and who, as a result, have become recent targets of public policy and

program initiatives to improve access. The findings of this study suggest that a paradigm shift in public policy which dislocates an essentialized notion of “access” as the sole operating principle from which to theorize care, may be required if we are to develop services more in line with older people’s experience. The current study enables this endeavor by calling into question long-held and popular assumptions about what constitutes access and, by extension, what constitutes equitable access. What becomes clear in the present study is that, despite policy makers’ consistent use of the term, no one definition of access is universally recognized or accepted. A review of the vast array of theoretical and research literature in the area of health care access, both in Canada and the United States has turned up confusion rather than consensus on the subject of what constitutes access. In the current study, these disagreements become most salient in comparisons between professional and lay definitions of access. Access, as it is currently constituted by public policy and professional discourse is largely centred on the singular act of “getting to the door” of elder care services (the most popular references are made to transportation, cost and knowledge of services in the articulation of “getting to service”). As a result, public policy in the area of access to elder care has focused on easing entry to the vast array of elder care organizations through the development of single entry access points. Since “getting to the door” is the fundamental problem and too many doors make for confusion, it has been postulated by public policy makers that one door would simplify access enough to encourage more equitable usage. This rhetoric has fueled an agenda marked by the centralization of community services, reduction in service duplication, cost-cutting and efficiency-based criteria for service provision. There are two fundamental problems to this public policy direction. First, it suggests access is a problem

only at point of entry, thus directing little energy to adapting the actual provision of services to those facing barriers to care. In other words, only the route to care must change and not the way care is delivered. Second, it suggests that single entry models will make it easier for all elders, particularly those who have been historically disenfranchised, to access services.

At minimum, the current research calls these uncontested notions into question. In reality, the paradigm of access as it is currently being constructed by public policy makers and professionals in gerontology, may hinder equity in the system more than help it. This is particularly true for ethnic and “racial” minority elderly women interviewed for the study who have expressed that access is more fluid and complex than previously identified. In these women’s daily realities, access is a process in which decisions about how to enter the system are continually adapted as a result of advice received, over time, by trusted individuals who serve to direct them to the most appropriate and sensitive workers. This development of trust matters more to the positive experience of accessing care than does the particular organization of information and services and attests to the lack of culturally sensitive services generally. The likelihood of developing these types of relationships which ease access increase when older women have ongoing opportunities to come into face-to-face contact with “facilitators of access” in a social environment of reciprocity in their local neighbourhoods. Recognizing older women’s priority for locating sites of trust as central components to accessing equitable and sensitive care would require the shifting of points of access from single to multiple locations and from central to localized sites, thus enabling women to gain further control over to whom they go for information and from where they get advice, prior to making decisions about their use of elder care

resources. Entrenching access in localized and diverse organizations would in fact support, rather than impede, access for elderly people, particularly for ethnic and “racial” minority women whose communities, interests and experiences are not necessarily reflected in the operation of mainstream elder care agencies. As such, local ethno-specific and neighbourhood agencies may be better prepared as sites from which to provide advice, information and services to members of their communities. This recommendation suggests a dramatic shift in public policy in the area of access, namely that of coordinating access through centralized case management agencies.

The current study attests to the false nature of the claim that the problem of access is rooted in the problem of “getting to the door”. Access is not, in fact, a single point in time, but rather, a fluid and changing series of encounters built upon over time which, when positive, establishes a concentric string of linkages based upon trust built between people which can serve, again and again, to ease interactions between clients and the organizations that provide services to them. There are several factors which lead to this building of trust, not least of which is prolonged engagement with people, knowledge of people’s histories and strengths and the elaboration of culturally sensitive relationships. Trust does not occur in a single point in time or space. Trust must be earned and shared. Access can therefore be reinterpreted or reconstituted as a series of acts, and not as a point in time and place. For public policy makers, this would result in a system which recognizes the diverse ways in which elders seek care and make commitments to decentralized and diverse opportunities for linking more aligned with the experiences of elderly clients.

Also required in attempting to recognize fluidity, longevity and the process-focused nature of access in elder care is a loosening of the emphasis on medical criteria for eligibility. As explicated throughout the current study, elder care has operated significantly from an ideology of medicine. What this means in everyday practice terms is that elder care priorities, particularly in relation to access, are driven by the acute health care system's agenda. Community elder care is, for all intents and purposes, an extension of hospital care. After all, it has been demonstrated that over 85% of referrals to community care originate in hospital and are related to discharge planning. The small remainder are community referred, either by family physicians, community agencies, families or elderly people themselves. Those referred as a result of hospital discharge planning tend to be highly medical in nature, resulting from immediate acute health care needs. Those referred via the community network often require long-term support, as a result of chronic physical conditions, in which social support figures more prominently, alongside medical need, in the development of care plans. There are therefore, two very distinct modes of access which are related to two very distinct service models; the acute health care system and the chronic social support system. Although community health care agencies service both kinds of clients, public policy does not currently guide the appropriate balancing of institutional priorities between acute care and chronic care clients. What results is a strong emphasis on acute care service delivery. This is particularly true in the current climate of health care restructuring in which hospital closures and shorter bed stays have resulted in increased pressure on organizations such as *Eldercare* to provide immediate acute medical care to elders in their homes. As a result, only the acute medical care needs of clients are prioritized, with an observed lack of articulation of the value of social support in the health

and well-being of elders who enter the system as a result of chronic care conditions, a group largely made up of elderly women. Public policy makers in aging must begin to think about how to strike a balance in institutional and agency priorities in relation to the two models of care, to ensure that the social support needs of chronic care clients do not completely disappear from the agenda of elder care services.

At the organizational level, one more point is worth making in relation to current parameters of access which cause significant barriers to care in Ontario. This relates to the criteria of “personal care” in gaining eligibility to the system and fundamentally exemplifies the lack of articulation and understanding of the value of social support in elder care services and exposes the grey area which exists between medical and social constructions of home care (Twigg, 1997). In Ontario, “personal care” criteria are one of the central foci of eligibility for those elders who access services through community referral. Personal care, although including activities of daily living such as dressing, feeding and bathing, has largely been articulated through “requiring help to take a bath”. This means that only people who need help with personal care will gain access to other needed services which are essentially supportive in nature, such as cleaning services. In the current study both older women and workers attested to the central place of the “social bath” in accessing care. The “social bath” is a highly problematic area of community care which has been central to recent debates in the provision of care (Twigg, 1997). As Twigg (1997) has pointed out, the “social bath entails aspects of being and social exchange that have not been traditionally part of the standard, rationalistic and disembodied account of social policy” (Twigg, 1997, 211). Still, the “social bath” functions as a highly targeted area of access and as such, cannot be ignored as a crucial dimension of social policy. This point of

access is particularly problematic for ethnic and “racial” minority elders for whom bathing is not only a very intimate act but also requires some common understanding of cultural rituals and trust between worker and client in order to reduce the experience of intrusiveness and shame often associated with this body management function of service delivery. In the current system, few opportunities to build prolonged engagement or to engage ethnic and “racial” minority workers, increase the likelihood of a negative experience in “social bathing”. This acts as a serious barrier to care and should be reconsidered as an access criterion for other homemaking services.

Expanding notions of access to incorporate the diverse experiences of elderly people, to recognize the fluid and complex process of access centred in trust building and prolonged engagement and to ensure older people’s integral involvement in decision-making around care is a central challenge for public policy makers in the field of aging. Shifting public policy in favour of decentralized access calls for a re-examination of single entry access. Current directions in public policy in Ontario and elsewhere are entrenching single entry access as the only model from which to provide service. The creation of single entry access centres, although opened in a number of geographically distinct locations across Ontario, are far from neighbourhood-based. While responsible for a particular catchment area, they are relatively large organizations which are bureaucratically designed and situated in large buildings which are not necessarily visible to the public. This intensifies a precarious relationship with local community organizations and populations. As such, relatively few neighbourhood organizations know of *Eldercare* agencies’ existence, let alone have influence on the design and delivery of services. It is, for the most part, larger institutions such as hospitals which have the largest impact on service design

and delivery. This reality is in opposition with women's expressed desire for the development of prolonged relationships in local settings as a means of facilitating access. Single entry models were supposed to resolve the perceived confusion facing elderly people who had difficulty maneuvering within the myriad of elder care services and programs by instituting one site that would take responsibility for facilitating care plans and providing information; in effect, to create a one-on-one relationship to care. This simplification of the system has not materialized. In fact, according to the women interviewed in the current study, the system now seems to be equally if not more confusing. Women, for the most part, do not develop ongoing relationships with their case managers, in fact, they rarely see their case manager, let alone understand what organization she represents. It seems as though the development of *Eldercare* organizations has simply added another tier to already complex relationships between elders and the formal care system.

Compounding this problem is the fact that front-line service providers do not work for *Eldercare* organizations but for other agencies who enter into contractual relationships with *Eldercare* to provide direct service. This means that disconnections, not only between workers in the same agency, but between case managers, service providers and their supervisors who work for different agencies, become more commonplace. This was expressed by workers interviewed for the current study. With increasing levels of hierarchy between clients and their case managers, come increasingly distant communication in the delivery of care which is fundamentally mediated by the telephone, fax machine and computer. This results in more, rather than fewer, opportunities for disjuncture in communication and in relationships between all players; clients, case

managers and service providers. This is an important area for future research and policy initiatives.

In addition, confusion over to whom to go for what services is increased because *Eldercare* organizations do not, in fact, facilitate access and arrange care for all types of aging services, only for those related to physical limitations in the home, namely nursing, physiotherapy, occupational therapy, home making and the like. Other services, such as meal programs, day programs and support groups are not funneled through *Eldercare*. This reality further marginalizes social support as an integral component of care plans.

Public policy makers in elder care may need to question if the rhetoric of simplified access actually works in everyday practice. According to older women, simplified access does not only remain confusing in relation to who workers represent but corresponds little to the way older women actually attempt access to the system, that is, through prolonged engagement with trusted individuals. While there do remain local provider agencies with whom older women come into contact in their neighbourhoods, these organizations have been placed further from their view in the current system. Since the Ministry of Health has positioned *Eldercare* agencies as the sole mediators of service provision, the relationship between older people and their service provider agencies becomes increasingly distant and inaccessible.

It is important to reiterate here that, while the current study did not explore the experience of front-line service providers on these and other issues but rather, sought to explore relations of ruling in elder care from the standpoint of ethnic and “racial” minority women and case managers in *Eldercare* agencies, it is not meant to suggest that the experiences and standpoint of service providers are not central to an understanding of

these relations. Future research in the area should seek to incorporate and juxtapose the experiences of front-line service providers with those that have been explored presently in order to further expose the dilemmas experienced by *Eldercare* and service provider agencies in the current system.

The contracting out process may increase the dynamic of distance and inaccessibility by regulating the size and shape of provider agencies and by weakening articulations of what constitutes “quality” in elder care. In the current elder care system in Ontario, *Eldercare* organizations are designed as program management agencies and do not employ front-line service providers, such as nurses and homemakers, directly. Instead, *Eldercare* manages care and contracts out service delivery to not-for-profit and for-profit agencies under a managed competition system (Williams et al., 1999). Contracts are worked out through a process called Request For Proposals (RFP) in which service provider agencies submit proposals to *Eldercare* organizations for the rights to provide services to clients of the public organization. *Eldercare* organizations currently base contracts on a combination of highest quality-lowest price criteria, the proportions of which vary slightly from one organization to the next (highest quality could go as high as 80%). The operationalization of what constitutes “quality”, however, is currently weakly articulated and lacks explicit definitions of outcome measures, does not define how standards will be met and does not provide for training of staff to carry out the role necessary to ensure quality is being met (Williams et al., 1999). The balancing of cost and quality is highly problematic, particularly with the introduction of larger for-profit service provider agencies who will be competing for contracts with not-for-profit agencies. The Ministry of Health recognized that non-profits that historically provided services to the

community might not be able to compete with private for-profit agencies in securing contracts. To deal with this problem the Ministry was giving non-profit agencies (like the Victorian Order of Nurses) three years to “get competitive”. In the first year of operation, non-profits with historic contracts through the homecare system were guaranteed 90% of their previous contracts. In the second year, 80% and in the third year, 70%. But after this time, it was assumed that they could get competitive and will be offered no guarantees of contracts. This has a profound impact on who will get contracts and subsequently, what kind of service one might receive. The only way to compete with for-profit agencies is to begin to act like them and the only way to make a profit in the labour-caring field is to reduce labour costs (Mead, 1998). Non-profit agencies, with a history of union contracts, a commitment to fair wages, full-time jobs with benefits and to hiring skilled employees, may have to restructure themselves in the shape of for-profit agencies (part time jobs, fewer benefits, lower wages, de-skilling) to remain alive in this marketplace health care system. This system also opens up more space for large-scale American companies to move into Canada and vie for contracts with the government to provide services to elders. These companies can potentially undercut the ability of locally owned and controlled agencies to compete, since large for-profit American companies can rely on substantial resources, in the short term, in order to lower costs enough to “push out” smaller agencies and when achieved, reassert lower standards and higher costs in a less competitive market (Williams et al., 1999). Elders will have no choice but to go with the agency contracted with the *Eldercare* organization if they are to receive public services, regardless of the cost-quality design of that agency. In the first year, change-overs have sometimes been quite traumatic for elders who, after years of receiving services from one agency are

forced to make the switch. Williams et al. (1999) has also noted the impact of managed competition on barriers to co-operation between allocation and provider agencies. The authors state;

**“To the extent that quality becomes a “competitive advantage”, there are disincentives to providers sharing their best practices and improving the community-based long term care sector as a whole. Also noted were the tensions experienced by case management agencies in attempting to work with providers while maintaining an “arms length” relationship as purchasers of their services, further limiting the ability for collaborative action to improve quality”. (Williams et al., 1999, 143)**

Privatizing will alter quality of care and may mean even less consistency and commitment to multiculturalism practice in care. The impact of the RFP process on relationships between service providers and *Eldercare* agencies, particularly those small ethnically based agencies which cannot compete economically with larger companies may be tremendous. Thus, local neighbourhood service provider agencies who handled small caseloads but who were locally responsive may entirely disappear from the elder care landscape.

What this all means for public policy initiatives in elder care is threefold. First, gerontologists must consider entrenching a philosophy of access which is more in line with older people's experiences and desires. The philosophy underpinning health promotion strategies amongst well elders may provide some insight for use in designing and delivering care to older people who are in need of elder care (German, 1994; Glor, 1991; Hall, DeBeck, Johnson, Mackinnon, Gutman & Glick, 1992; Noble Walker, 1994; Schmidt, 1994; Young, 1994). Health promotion programs and policy in the field of aging have grown in prominence over the last decade in Canada. Initiatives in the field of health promotion have successfully entrenched the idea that healthy aging necessitates that elders

become involved in self-care strategies, both at the individual and community level. Within this framework of health promotion and/or seniors' independence, models of self-care, decentralized programs and services and prolonged engagement with health care practitioners as a means of ensuring optimum health and well-being among well elders, as they age, are accepted norms. Social support in the form of recreation, socialization and local control of programs are prominent features of health promotion programs and notions of choice and partnership are more commonly understood and accepted within the realm of public policy in health promotion for the well elderly. Unfortunately, once an older person becomes sick and/or experiences a loss of autonomy, these ideals for program and service delivery become quickly lost to the goals of maintenance and protection from risk. Health promotion as a paradigm for disabled elders has yet to be adequately explored. Since health and well-being are often defined in terms of "independence" and "autonomy", the goals of health promotion are often seen as beyond the reach of people who have become physically or cognitively disabled and who are seen as treading down a progressively steeper slope of illness and disease. Creating alternative models of health promotion for disabled elders, through social as well as medical programs, would require gerontologists to reframe goals that are reachable by these elders themselves and which are adapted over time in recognition of the changing nature of illness and functioning. In developing a model of health promotion for elderly people who have experienced a loss of autonomy, gerontologists can encourage the prolonged health and well being of disabled elders as well as promote their central involvement in decision making around care. This would contribute greatly to a countering of the conceptualization of older people as dependent and in an opening up of access criteria

more in line with the experiences of older people themselves. It is also important to point out that a health promotion focus would allow for more concrete, diverse and changing articulations of cultural values and practices in the delivery of health care services. This is so because ethnic and “racial” minority elderly people, as partners in defining the goals of health, healthy environments and health care treatment will, by design, have a space opened up in which to outline the components of their identities and social environments which they see as central to achieving health and healthy relationships. As a result, gender, ethnicity, “race” and other components of people’s identities which have been historically ignored, may find place in the development of elder care agency agendas, partnerships with ethno-specific and other community organizations, outreach efforts to communities and individual care plans.

Second, in decentralizing services, several parameters become important. First is the creation of local neighbourhood-style, visible agencies. Second is the requirement that service provider agencies and case management agencies work more closely together, perhaps even through the hiring of service providers within agencies to reduce the separation between case management and service provision functions. Case managers, when they are needed to organize and facilitate care, should be in direct contact with service providers. The easiest way to ensure smooth communication and ongoing contact is to have case managers and service providers working together in one environment. Because agencies would already be defined and administered locally, they can more easily avoid becoming too large and bureaucratic. This would ensure greater local ownership and responsiveness and increased communication between workers, thereby ensuring more opportunities for prolonged engagement and the building of reciprocal relationships.

Third, both case management and service provider agencies must become more centrally involved, as partners, in the articulation and operationalization of what constitutes "quality" and to entrench these definitions as separate from the influences of cost, so that quality does not become a luxury in an environment of capped budgets and resource cutbacks. With the articulation of what constitutes "quality", the development of outcome-based measures for ensuring quality is met and maintained becomes easier to facilitate. Ethno-specific community agencies must be included in the development of these initiatives in order that the priorities and needs of ethno-"racial" elders are seen as central.

Finally, policy makers need to become more comfortable with duplication in the system in order to ensure that a diverse group of elderly people's needs are met, particularly those who have been historically disenfranchised. In this regard, the field of gerontology can take a few lessons from the disability movement. Independent Living Movement activists, for example, have not been preoccupied with service duplication and efficiency as have those in the field of gerontology. In fact, Independent Living Movement activists have praised a multiplicity of services which may be duplicated in different neighbourhoods and for different populations in order that individuals can meet their own particular needs. What has been labeled duplication in aging services has often been called diversity in disability services. Issues of diversity may be more easily ignored or marginalized within a single entry system which tends to develop standard operation procedures for access more removed from people's own articulations or preferences. While cases may be more easily managed within the case management approach, elderly people may lose even more control and choice than what had been previously available to

them. What is important here is not to enter into dichotomous thinking in relation to elder care services. Individuals with different experiences, levels of energy and desires regarding their involvement in decision-making could all be respected in a system which is multi-dimensional and which provides local neighbourhood services. It is in such an environment that support for localized, highly sensitive ethno-specific and multicultural agencies and services are most likely to emerge.

Transforming the system to decentralize and incorporate diversity is not without inherent conflict. It has been suggested previously by policy makers and practitioners in the field of community care that merging the functions of resource allocation and service delivery can put public agencies in a conflict of interest with themselves, as these agencies both determine what services are needed and distribute resource dollars for those services. As such, programs that run from this model run the risk of escalating costs, although they may more easily engender consumer responsiveness (Williams et al., 1999). As an alternative to totally re-designing the system in favour of models which incorporate program management and service delivery in the same agency, it is possible to achieve similar ends from within the current design of the managed competition model in place in *Eldercare* services in Ontario. The *Eldercare* organization studied had developed one off-site location in a local neighbourhood organization and was piloting another off-site location in an ethno-specific organization at the time the research was being undertaken. Most workers pointed to these off-site initiatives as examples of positive efforts to develop outreach with communities and respond to the local needs of ethnic and "racial" minority elders. The continued expansion of these satellite offices as an alternative model to centralized and highly bureaucratic centres should be encouraged and supported

through their articulation in public elder care policy. This must be undertaken concurrently with efforts to articulate what constitutes “quality” in these settings.

It is important to reiterate here that making these policy changes requires a significant commitment of financial resources. The transfer of funds saved through hospital closures to the community sector has not been adequate, resulting in continued under-servicing of elders residing in the community (Chappell, 1993; Keating, Fast, Connidis, Penning & Keefe, 1997). This has resulted in an increasing burden on families, particularly female kin, who are providing more hours of care as the gap in community care services widens. This is a significant health policy issue and has been elaborated on by feminist gerontologists over the past decade. In consideration of ethnic and “racial” minority women specifically, the concurrent reduction in funding to ethno-specific agencies has made women’s caring significantly more problematic. As reported earlier in the current study, ethno-specific agencies used to play a role, alongside families, in providing advocacy and interpretation services for elderly members of their communities. This was an essential resource for elderly people who needed such advocates in order to ensure appropriate care was delivered in the health care system. These organizations have experienced tremendous cutbacks in their budgets particularly related to advocacy and interpretation services. As a result, the support families received from these agencies in relation to their elderly members’ care has disappeared. This puts added pressure on families, mostly women, to take on this role. The combined effect of cutbacks to health care and to community services has had a detrimental impact upon women as care givers and care receivers. Clearly, no shift in the way access is operationalized can be successful without a public commitment of resources.

The articulation of a National Home Care Policy is an important public policy initiative which must be implemented in order to develop stronger standards of accessibility in elder care services. Home care currently falls outside the realm of the Canada Health Act. This has resulted in a weaker articulation of standards for home care and has eased the emergence of two-tiered service models in elder care. There is a growing market of private purchasing in elder care. Because of large increases in the caseloads of elder care agencies, narrowing eligibility criteria and the growing emphasis on acute health care needs, the capacity of elder care agencies to provide adequate services is drastically reduced. As a result, elderly clients are receiving fewer and increasingly discontinuous services from the public sector. In the growing gap, private not-for-profit and for-profit agencies have emerged to meet the needs of elderly people who are not getting what they need from the public sector and who can afford to pay privately for the services they require. There is a great amount of "topping up" which occurs in elder care services resulting in a two-tiered system. In this environment, class acts as a fundamental access issue. While the data that emerged in this study did not address this particular point, they do not detract from its importance. Future research and practice initiatives need to explore the nature of this phenomenon, its impact on ethnic and "racial" minority women's access to care and how national standards might serve to control the problem of class inequities in home care across the country.

The development of national standards through the entrenchment of home care in Canada's Health Act, can contribute greatly to the development of best practice policy in the area of accessibility. According to the Canadian Association on Gerontology (1997), major national policy bodies and associations in the field of aging have all reached

consensus on the importance of developing comprehensive community-based health and social support services and that these need to be fully recognized as essential services within the Canadian health care system (Canadian Association on Gerontology, 1999). This would help to ensure the availability of more equitable and comprehensive health care to seniors across the country. This would have a considerable positive impact upon the lives of older women specifically and older people generally (Neysmith, 1999). In entrenching home care in the Canada Health Act, policy makers may need to expand definitions of health to more concretely include social support in order to widen its applicability beyond acute health care models. This would serve to bring community care inside the boundaries of national health standards and would more accurately reflect the health needs and desires of all Canadians.

Finally, gerontological theorists and practitioners generally and in *Eldercare* specifically, must develop stronger partnership with national and local advocacy organizations. Organizations such as Care Watch and the Older Women's Network have a long history of advocating on behalf of elderly people and have developed research and practice initiatives which assess and monitor elder care services for barriers to care. Increasing opportunities for mainstream public services and non-profit organizations to sit around the table together and exchange information and ideas will benefit all older people.

### **Re-Thinking "Equity"**

Notions of equitable access in elder care are rooted in an ideology of multiculturalism premised on individual adaptation and communication. As examined throughout the current study, this emphasis results in little room for the articulation of the multiple and intersecting systemic and institutional causes of oppression such as those of

racism and sexism and the impact of these on ethnic and “racial” minority women’s everyday experience. In the absence of such articulations, policy and programs developed to address equitable access remain narrowly focused on the dynamics between workers and clients and weakly tied to the real lived experience of elderly ethnic and “racial” minority women and by extension all those who experience oppression, leaving white supremacist and androcentric institutional practices intact. This study has pointed to the damage this causes to ethnic and “racial” minority women’s experience in the system, both as clients and workers. Although experienced in the everyday, between individuals, oppressive practices are, in fact, systemic and institutional in origin. Articulating this is one of the central first steps in defining programs and practices which address inequities in access and service delivery.

Enakshi Dua (1999) opened a recent publication on Canadian feminist thought with a discussion on the intersections of racism and sexism in the social articulation of a national identity. In theorizing these interconnections, she states,

While the excursion into national identity [draws]... on notions of hybridity, fluidity and dislocation, it also illuminates the structures that organize race and gender in Canada. As anti-racist feminists have pointed out, the social and political definitions of who is defined as Canadian reflect the race and gender underpinnings of Canadian society. (Dua, 1999: 7)

There is no better place to begin a discussion of the issues of institutional oppression which emerge out of the present study than by reflecting upon Dua’s words. For within the particularized and localized site of elder care, as with excursions into national identity, who gets socially and politically defined as “participant”, as “insider”, is also fundamentally racialized and gendered, reflecting totalizing ruling relationships between the state and ethnic and “racial” minority women in Canadian society generally.

The social organization of knowledge (Smith, 1987) in elder care, as in the larger society, is premised on andro-centric and white supremacist ways of knowing. That is, political and social definitions of inclusion-exclusion are fundamentally articulated and entrenched by those in power. In elder care, as is true within the larger Canadian context, it is the white male power elite who define and shape what gets counted as legitimate (Mama, 1995). Institutions, such as those that provide elder care services, act as local sites from which andro-centric and white supremacist ideologies are perpetuated, organized and maintained. It is through these institutions that oppressive gender and race inequalities translate state ideology into everyday practice thus entrenching them in social and political consciousness as “given”. State discourses of race and gender are thus reconstituted as processes through which the ideas of race and gender inferiority come to be known and understood as hegemonic.

Anti-racist feminists have spoken about the impact of the “normalization” of sexism and racism through state processes of entrenchment of ideology in practice on our ability to identify oppression. According to Bannerji (1987),

The most difficult aspect of talking about racism in Canada was that it was so common sense - so embedded in everyday life...because racism was so embedded in the diffused cultural practices of Canadian society it was erased. As a result, there were gaps and silences, that people like us were never present... (Bannerji in Dua, 1999: 14)

The act of rendering state ideologies, such as sexism and racism, as everyday practice makes oppression hard, if not impossible, to detect (Mama, 1995; Neysmith and Aronson, 1997). Ideology as practice simply becomes a normal part of everyday life, embedded silently within “acceptable” political discourse. In the case of elder care services, public discourse is largely centred on the ideologies of resource scarcity and

medicalization. While not always visible themselves, these more common discourses have provided a veil through which andro-centric and white supremacist ideologies are made even more invisible. Bannerji (1987) points to the resulting gaps and silences that result from this process of rendering invisible state ideologies within everyday processes. As such, those who are most predominately oppressed are not *rarely* heard, they are *never* present. As was made evident in the current study, older ethnic and “racial” minority women, located socially and politically far from sites of power and authority in elder care, are fundamentally absent as knowers, creators and subjects; rather they are acted upon as objects of illness and disability. Thus, this process of “removing” and silencing is both gendered and racialized.

The current study has exposed the ways in which practices of cultural competence have been ineffective at addressing needs of elderly ethnic and “racial” minority women and have, at times contributed to their further marginalization both as workers and clients. Anti-racist theorists have highlighted the commonplace nature of these institutional practices in the health and social service sector, labeling those institutions which function from a model of cultural competence as add-on multiculturalist (Henry, Tator, Matis & Rees, 1995; Tator, 1996). Several features of add-on multiculturalist institutions have been theorized, most of which are apparent in the current paradigm of *Eldercare* services and priorities. They are worth outlining here as a means of emphasizing their taken-for-granted status in health care. According to Henry et al. (1995), the most salient features of multiculturalist institutions are: making limited modifications in organizational life (such as periodic recruiting of visible minority staff or translating documents) without altering fundamental structure, mission and culture; reacting to demands rather than proactively

addressing issues; tokenizing and ghettoizing visible minority staff by drawing on them to assist in the translation of material or to work with members of their own culture but continuing to offer them little power and limited control; considering racism as distinct from the day-to-day life of the organization and as such rendering racism invisible; dealing with the needs, interests, and perspectives of racial minorities on an ad-hoc basis; delegating responsibility for change to the front-line worker, who may then function in an unsupportive environment with little education and guidance; developing training centred on helping workers understand issues of diversity without attempting to create new workplace norms and organizational procedures that would promote access, participation and equity, and eliminate discrimination (300-301). Ethnic and “racial” minority women and workers interviewed in the current study attested to the commonplace nature of these practices.

In order to advance the cause of equity, public policy in gerontology must move beyond the notion of simply understanding culture to address, head on, institutional and state practices of sexism and racism that contribute to barriers in the first place, and to the intersecting nature of these. This means articulating policies and practices which are rooted in anti-racist practice (Henry, et al., 1995; Tator, 1996). This would result in a fundamental shift in both how institutions develop policies and practices regarding their work with ethnic and “racial” minority elderly clients and what those policies, programs and practices look like. It would also mean a re-shaping of ethnic and “racial” minority workers’ and clients’ relationship with and to the elder care institution and by extension, to the state. There is a great deal of research and theory on adapting health and social service organizations to address anti-racism which can serve to guide the development of

policy, programs and practice in the field of gerontology (Henry et al., 1995; Tator, 1996). In the context of *Eldercare*, several key areas for policy and program development have been highlighted throughout the study. These include: the committing of resources to interpretation services so as not to force ethnic and “racial” minority families and workers to do this work for free; developing anti-racist training programs; providing opportunities for ethnic and “racial” minority workers to come together and voice concerns; hiring representative numbers of ethnic and “racial” minority workers in positions of power (management) and supporting their integration; developing programs to help existing ethnic and “racial” minority workers advance in the agency; creating alternative program models that target ethno- “racial” clients which cut across geographic boundaries to ensure that ethnic and “racial” minority clients have access to already present ethnic and “racial” minority case managers; encouraging proactive outreach strategies which target ethno- “racial” communities under-represented as clients and as decision-makers and not only responding to those who make it to the door; creating services which are based on expanded notions of ethnicity, “race” and culture and which are not limited to restrictive notions of language as the sole operating principle, and; involving ethno- “racial” community organizations in decision-making at the agency level.

Central to the development of anti-racist practice and over-arching the above listed program suggestions is the necessity of articulating notions of equity from the point of view of those who have largely been excluded from the project of defining how care is accessed and received. Within this framework, unmasking racism becomes a process of acknowledging that racism permeates individual, institutional and system relations and that these are made manifest in everyday practice. This would require explicating how acts of

racism, which are embedded in societal norms and cultural values, are transmitted in and through everyday organizational practice and how these have a detrimental impact upon the experience of ethnic and “racial” minority workers and clients. In exposing these realities, institutions must become engaged in a broader commitment, not only to improving equity in one component of the organization but to ending discrimination and oppression within and without the organization, at individual, institutional and systemic levels. These efforts must be undertaken in conjunction with local organizations who have advocated on behalf of their communities and who can aid in articulation of needed changes. It cannot be understated that these efforts will be more successful if and when governments re-commit resources to ethno- “racial” community organizations in order to facilitate the freeing up of time and energy to engage collaboratively and in a meaningful way with public institutions. Developing partnerships, networks and engaging in larger coalitions to end discrimination must be seen as a central mandate of public institutions. *Eldercare* is involved in the beginning stages of such initiatives through the development of a task force on minority health which is intersectorial and multidisciplinary and which includes community organizations alongside public sector organizations around the table. These efforts should be applauded and supported. By engaging in these efforts, institutions will be better prepared to respond to the needs of all older people.

The task of developing anti-racist institutions is fraught with conflict. To engage thoughtfully and successfully in this project, the commitment and support of management and mainstream workers is essential. Organizations can not and must not put the onus of responsibility for anti-racist change on the backs of ethno- “racial” minority workers. Doing so further marginalizes and oppresses them. Mainstream practitioners, who hold

positions of power in agencies and in society have a particular responsibility to engage in change efforts. The issue of developing alliances between professionals and communities is critical to the advancement of ethno- "racial" people in gerontology. This requires mainstream workers to reflect upon their positions of privilege inside and outside the agency and to share power. The process of reflection and action can feel quite threatening to some, but is a necessary task of creating anti-oppressive agencies. The fears associated with opening up discussions about race and racism cause many organizations to dismiss change efforts. Indeed, as articulated in the present study, one of the reasons for the invisibility of articulations of race and racism in organizations currently is that there is little understanding of these terms and as such, they are seen as dangerous and threatening to expose. However, it is important to reiterate that status quo practices continue to marginalize ethnic and "racial" minority workers and clients, despite the fact that they are not made explicit. Moving from tokenizing models to substantial equity and inclusion is a significant process which takes time and resources to realize (Minors, 1996). Recognizing this may help to ease the concern of staff and institutions who are concerned about the impact change will have on services and on the feelings of threat experienced by mainstream workers in the short term. Understanding that institutional change is a slow process which will invariably result in shifts and uneasiness but which will, in the end produce positive change for all involved can contribute to the lowering of resistance to these change efforts. Situating responsibility for change at the institutional level, rather than in individual workers, and recognizing the important role of supporting staff during the change process may also contribute to easing resistance. Finally, organizations must be prepared for the reality that the anti-racist project is ongoing; that there is never a point in

which one can state “the work is done” and so, become complacent. Embarking on a project of anti-racism requires vigilance in terms of the evaluation and monitoring of policy and practice initiatives and in the continued effort to involve community in the change process. As long as racism and sexism exist in society generally, mainstream organizations will be challenged to expose how these ideologies are made manifest in their everyday practices and policies. Moving from a naïve multiculturalism to a critical multiculturalism in elder care requires the support of government, institutions and the input of communities and people who are the targets of equitable access in order that racist and sexist relations of ruling are not reproduced in access and service delivery models to elderly people.

### **Conclusion**

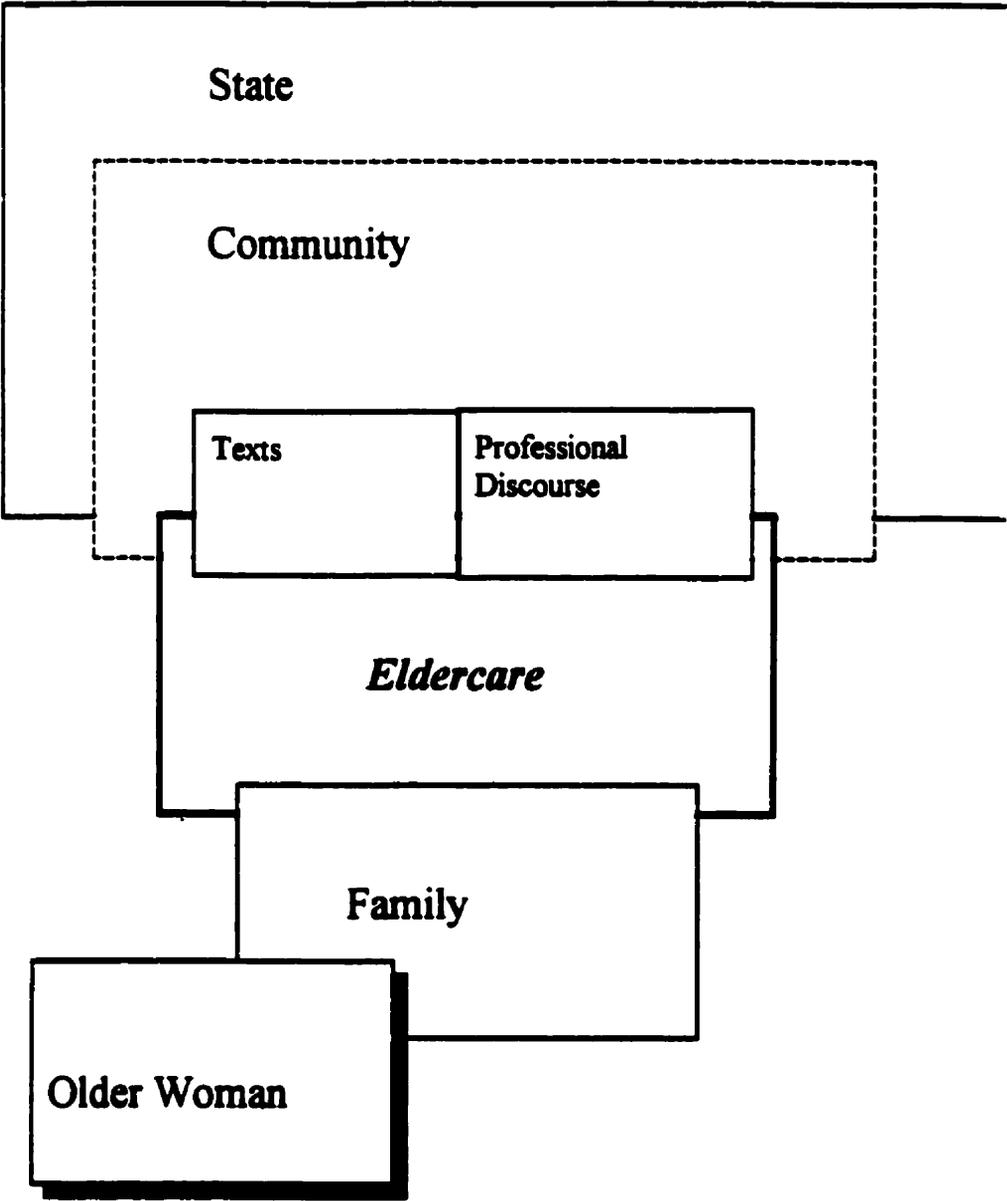
The current study has explored the everyday processes of access to elder care from the standpoint of ethnic and “racial” minority elderly women. Although situated in one local site of public elder care service, it is essential to reiterate that what was uncovered in the local site is not unusual or unique. All elder care agencies, particularly those located in large multicultural centres, face similar problems and dynamics in the delivery of services to ethno- “racial” minority people and communities. The data presented here are not meant to be seen in an isolated context, but rather, to serve as a point of departure for the explication of relations of ruling embedded within institutional practices and processes across sectors. Although the details may differ, the roots of the problematics of the everyday are structural in nature, right down to the level of practice. This encourages gerontologists to understand the causes of these problematics as situated in state decisions and priorities and societal ideologies which are played out in institutions through

relationships between workers and clients. There exist tremendous good intentions on the part of workers in the system who struggle daily under huge constraints (financial, bureaucratic, resources, time) to provide appropriate and sensitive service with little guidance as to how their practice should be adapted to address racism and sexism in the system. This is a struggle which manifests itself differently depending on many factors including level of power, autonomy and privilege one has in the agency and in society. Of course, elderly ethnic and “racial” minority clients have the least of these and as such, uniquely experience oppression both in access and service delivery, as do their families and communities. Adapting services to incorporate their experiences and needs will benefit all people in the system.

The current study attempts to render the voices of older ethnic and “racial” minority women, and the processes by which their voices are made invisible, visible. By doing so, it contributes to an anti-racist feminist project intent on critiquing, exposing and shifting the dominance of state orchestrated ideologies which operate to shape the experience of women who are multiply situated on the margins and who are continually oppressed by andro-centric and white supremacist state institutions. The practice of doing institutional ethnography research is critically transformative. The political nature of this research is particularly relevant to the field of social gerontology, in which professional and state ideologies of scarcity and medicalization are firmly entrenched and in which the voices of elders, particularly those of ethnic and “racial” minority women, have been historically marginalized. This has contributed to the continued invisibility of sexist and racist practices of institutions and to the oppressive social construction of ethnic and “racial” minority elderly women. Exposing these relations to public scrutiny means that

they can be more readily contested and challenged. To date, changes that are being undertaken in elder care are meant only to give the illusion of innovation. This is so because while money is being reinvested to some degree in elder care services in Ontario, the macro structures and ideology of that care remain intact. In this context, access as a paradigm from which to focus service adaptation continues to be embedded in ruling relations which oppress those to whom both governments and institutions claim to be most intent on improving services, that is, ethnic and “racial” minority elderly women. It is hoped that this study contributes to the shifting of this paradigm.

**Institutional Ethnography Conceptual Map of Ruling Relations in Elder Care From the Standpoint of Ethnic and “Racial” Minority Elderly Women**



# TABLES

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## **Tables - Chapter 2: Review of the Research Literature**

### **Table 1: Medical and Social Service Journal Search**

<p><b>Advances in Medical Sociology</b></p> <p><b>Affilia</b></p> <p><b>American Journal of Public Health</b></p> <p><b>American Psychologist</b></p> <p><b>British Journal of Social Work</b></p> <p><b>Canadian Journal of Psychiatry</b></p> <p><b>Canadian Social Work Review</b></p> <p><b>Canadian Family Physician</b></p> <p><b>Families in Society</b></p> <p><b>Gender and Society</b></p> <p><b>Geriatric Nursing</b></p> <p><b>Hastings Centre Report</b></p> <p><b>Health and Social Work</b></p> <p><b>Health Care</b></p> <p><b>Health Care Financing Review</b></p> <p><b>Home Health Care Services Quarterly</b></p> <p><b>Hospital and Community Psychiatry</b></p> <p><b>International Social Work</b></p> <p><b>Journal of Health and Social Behaviour</b></p> <p><b>Journal of Health and Social Policy</b></p> <p><b>Journal of Case Management</b></p> <p><b>Journal of Health Politics, Policy and Law</b></p> <p><b>Journal of Social Policy</b></p> <p><b>Journal of the American Medical Association</b></p> <p><b>Medical Care</b></p> <p><b>Millbank Memorial Fund Quarterly</b></p> <p><b>Pride Institute Journal of Long Term Care</b></p> <p><b>Public Health Reports</b></p> <p><b>Social Problems</b></p> <p><b>Social Science and Medicine</b></p> <p><b>Social Work</b></p> <p><b>Social Psychology Quarterly</b></p> <p><b>Social Work in Health Care</b></p> <p><b>The Forum</b></p> <p><b>Women and Health</b></p>
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**Table 2: List of Gerontological Review Literature**

<b>Title</b>	<b>Variable Name</b>	<b>Value</b>
<b>CAT (Category)</b>	<b>COMP (included with Provider-Patient relations in analysis)</b>	<b>Compliance Literature</b>
	<b>DEL</b>	<b>Service Delivery</b>
	<b>PHYS</b>	<b>Provider-Elder Patient</b>
	<b>RACE</b>	<b>Ethnicity and/or "Race"</b>
	<b>RESAL</b>	<b>Resource Allocation</b>
	<b>UTIL</b>	<b>Utilization</b>
	<b>WOM</b>	<b>Women</b>
<b>CTY (Country)</b>	<b>CAN</b>	<b>Canada</b>
	<b>Neth</b>	<b>Netherlands</b>
	<b>UK</b>	<b>United Kingdom</b>
	<b>US</b>	<b>United States</b>
<b>METH (Methodology)</b>	<b>THE</b>	<b>Theory including policy, description or review.</b>
	<b>QUAL</b>	<b>Qualitative</b>
	<b>QUANT</b>	<b>Quantitative</b>
	<b>QUAL+</b>	<b>Multi Method</b>

**Table 2: List of Gerontological Review Literature**

Author	Title	CAT	CTY	YR	METH
Abramson, J.	Enhancing Patient Participation: Clinical Strategies in the Discharge Planning Process	DEL	US	1990	THE
Adams, P. & Dominick, G.	The Old, the Young and the Welfare State	RESAL	US	1995	THE
Adelman, R. et al.	Issues in Physician-Elderly Patient Interaction	PHYS	US	1991	QUAL
Ahroni, J.	A Description of the Health Needs of Elderly Home Care Patients with Chronic Illness	DEL	US	1989	QUANT
Applegate, M. & Morse, J.	Personal Privacy and Interactional Patterns in a Nursing Home	PHYS	CAN	1994	QUAL
Applewhite, S.	Curanderismo: Demystifying the Health Beliefs and Practices of Elderly Mexican Americans	RACE	US	1995	QUAL
Aronson, J.	Old Women's Experiences of Needing Care: Choice or Compulsion?	WOM	CAN	1990	QUAL
Ascione, F.	Medication Compliance in the Elderly	COMP	US	1994	THE
Baker, D. & Pallett-Hehn, P.	Care or Control: Barriers to Service Use by Elderly People	UTIL	US	1995	THE
Barer, B.	Men and Women Aging Differently	WOM	US	1994	QUANT
Barker, J.	Pacific Island Migrants in the United States: Some Implications for Aging Services	RACE	US	1991	THE
Bazargan, M. & Hamm-Baugh, V.	The Relationship Between Chronic Illness and Depression in a Community of Urban Black Elderly Persons	RACE	US	1995	QUANT
Beland, F.	Patterns of Health and Social Service Utilization	UTIL	CAN	1989	QUANT
Belgrave, F. & Moorman L. Deborah	The Role of Social Support in Compliance and Other Health Behaviors for African Americans with Chronic Illnesses	COMP	US	1994	QUANT
Biegel, D. et al.	Overcoming Barriers to Serving the Aging/Mental Health Client: A State Initiative	DEL	US	1989	THE
Biegel, D. et al.	Unmet Needs and Barriers to Service Delivery for the Blind and Visually Impaired Elderly	DEL	US	1989	QUANT
Binstock, R.	Changing Criteria in Old-Age Programs: The Introduction of Economic Status and Need for Services	RESAL	US	1994	THE
Binstock, R.	Old Age-Based Rationing: From Rhetoric to Risk?	RESAL	US	1994	THE
Black, J. & Mindell, M.	A Model for Community-Based Mental Health Services for Older Adults: Innovative Social Work Practice	DEL	US	1996	THE
Blakemore & Boneham	Age Race and Ethnicity	RACE	UK	1994	THE
Blandford, A. & Chappell, N.	Subjective Well-being Among Native and Non-Native Elderly Persons: Do Differences Exist?	RACE	CAN	1990	QUANT
Bolaria, S. & Bolaria, R.	Immigrant Status and Health Status: Women and Racial Minority Immigrant Workers	RACE	CAN	1994	THE
Bonar, R.	The Experience of Italian Women	WOM	CAN	1994	QUAL
Branch, L. & Hoening, H.	Measures of Physical Functioning	DEL	US	1997	THE
Brill, R. et al.	The Three R's of Long Term Health Care for the Elderly: Regulation, Rationing and Railroaded	RESAL	US	1991	THE
Browne, C.	Empowerment in Social Work Practice with Older Women	WOM	US	1995	THE
Browne et al.	Individual Correlates of health Service Utilization	UTIL	CAN	1990	QUANT
Burton, L. et al.	The Structure of Informal Care: Are There Differences by Race	RACE	US	1995	QUANT
Burton, L. et al.	Creating Culturally Relevant Ways of Thinking About Diversity and Aging	RACE	US	1991	THE

Butler, R. et al.	Health Care for All: A Crisis of Cost and Access	RESAL	US	1992	THE
Calasanti, T.	Bringing in Diversity: Toward an Inclusive Theory of Retirement	RACE	US	1993	THE
Calasanti, T.	Incorporating Diversity: Meaning, Levels of Research and Implications for Theory	RACE	US	1996	THE
Calasanti, T.	Introduction: A Socialist-Feminist Approach to Aging	WOM	US	1993	THE
Calsyn, R. & Roades, L.	Predicting Perceived Service Need, Service Awareness and Service Utilization	UTIL	US	1993	QUANT
Camp, C. et al.	The InterpreCare System: Overcoming Language Barriers in Long-Term Care	RACE	US	1996	THE
Canetto, S. et al.	Typical and Optimal Aging in Women and Men: Is There a Double Standard?	WOM	US	1995	QUANT
Cantor, M. et al.	The Importance of Ethnicity in the Social Support Systems of Older New Yorkers: A Longitudinal Perspective (1970 to	RACE	US	1994	QUANT
Capitman, J. et al.	Diversity Assessments in Aging Services	RACE	US	1991	THE
Chadiha, L. et al.	Post-Hospital Home Care for African-American and White Elderly	RACE	US	1995	QUANT
Chambers, L. et al.	The Impact of Home Care on Recently Discharged Elderly Hospital Patients in an Ontario Community	UTIL	CAN	1990	QUANT
Chappell, N.	Home care Researcher: What Does it Tell Us?	UTIL	US	1994	THE
Chipperfield, J.	A Longitudinal Analysis of Perceived Respect Among Elders: Changing Perceptions for Some Ethnic Groups	RACE	CAN	1992	QUANT
Clark, P.	Geriatric Health Care Policy in the United States and Canada: A Comparison of Facts and Values in Defining the Problems	RESAL	US	1991	THE
Cohen-Mansfield, J. et al.	Underutilization of Adult Day Care: An Exploratory Study	UTIL	US	1994	QUANT
Congress, E. & Lyons, B.	Cultural Differences in Health Beliefs: Implications for Social Work Practice in Health Care	RACE	US	1992	THE
Coward, R. et al.	Residential Differences in the Use of Formal Services Prior to Entering a Nursing Home	UTIL	US	1994	QUANT
Cowart, M. et al.	Health Promotion for Older Rural African Americans: Implications for Social and Public Policy	RACE	US	1995	THE
Cox, D.	The Influence of Class on Aging Policy: Why Catastrophic Was Repealed	RESAL	US	1993	THE
Cox, C. & Monk, A.	Strain Among Caregivers: Comparing the Experiences of African American and Hispanic Caregivers of Alzheimer's	RACE	US	1996	QUANT
Cox, E. & Dooley, A.	Care Receivers' Perception of Their Role in the Care Process	RACE	US	1996	QUAL
Crowell, S. et al.	Use of Home Care Services Among the Elderly in Eastern Canada	UTIL	CAN	1996	QUANT
Crystal, S.	Health Economics, Old Age Politics and the Catastrophic Medicare Debate	RESAL	US	1990	THE
Cutler, N.	Targeting and Means Testing Aging and Need	RESAL	US	1991	THE
Damron-Rodriguez, J.	Multicultural Aspects of Aging in the US: Implications for Health and Human Services	RACE	US	1991	THE
Davies, B.	Caring for the Frail Elderly: An International Perspective	DEL	US	1993	THE
Davis, K. et al.	Alone and Poor: The Plight of Elderly Women	WOM	US	1990	THE
DeCroix Bane, S.	Rural Minority Populations	RACE	US	1991	THE
Denton, M.	The Linkages Between Informal and Formal Care of the Elderly	RESAL	CAN	1997	QUANT
Denton, M. & Spencer, B.	Population Aging and the Economy	RESAL	CAN	1988	THE
Depoy, E. & Butler, S.	Health: Elderly Rural Women's Conceptions	WOM	US	1996	QUANT
Diwan, S. & Moriarty, D.	A Conceptual Framework for Identifying Unmet Health Care Needs of Community Dwelling Elderly	UTIL	US	1995	THE

Diwan, S. et al.	Composition of the Home Care Service Package: Predictors of Type, Volume and Mix of Services Provided to Poor and Aging and Ethnicity	UTIL	US	1997	QUANT
Dreidger & Chappell	Gender, Race and Class: Beyond the Feminization of Poverty	RACE	CAN	1987	THE
Dressel, P.	Daughters Caring for Their Aging Mothers: A Midlife Developmental Process	WOM	US	1996	QUAL
Eckert, J. & Shulman, S.	Utilization Patterns of Clients Admitted or Assessed but not Admitted to a Long-term Care Program- Characteristics and Community Interventions for Helping Isolated and Underserved Seniors	UTIL	CAN	1990	QUANT
Ellis, J.	Service Providers' Perceptions of Immigrant Well-Being..	DEL	US	1996	THE
Ervin, A.	Privitization, System Membership and Access to Home Health care for the Elderly	RACE	CAN	1994	QUANT
Estes, C.& Swan, J.	Access to Long Term Care: Race as a Barrier	RESAL	US	1994	QUANT
Falcone, D. & Broyles, R.	Ethnic Aging in Canada and the United States: A Comparison of Social Policy	RACE	US	1992	THE
Filinson, R.	Medical Power and Women's Bodies	WOM	CAN	1994	THE
Findlay, D. & Miller, L.	The Social Construction of Noncompliance: Implications for Cross-Cultural Geriatric Practice	COMP	US	1991	QUAL
Fineman, N.	Health Care Providers' Subjective Understandings of Old Age: Implications for Threatened Status in Later Life	PHY	US	1994	QUAL
Fineman, N.	How Japanese Families Cope with Fragile Elderly	RACE	US	1990	QUAL
Freed, A.	Implementing the Patient Self-Determination Act (PSDA): How to Effectively Engage Chinese-American Elderly	RACE	US	1994	THE
Fung, LW.	Sociodemographic Correlates of Health Beliefs Among Black and White Community Dwelling Elderly Individuals	RACE	US	1994	QUANT
Galanos, A. et al.	Functional Health of Older Women: Three Dimensions	WOM	US	1994	QUANT
Gale, B.	The Impact of an Educational Program on Provision of Services to Ethnically Divers Elders	RACE	US	1993	THE
Gamel, N.& Yeo, G.	Alzheimer's Care and Service Utilization: Generating Practice Concepts from Empirical Findings and Narratives	UTIL	US	1994	THE
Ganzer, C. & England, S.	Women and Aging	WOM	CAN	1987	THE
Gee & Kimball	Trends and Forces: Influence of Immigration, Migration and Acculturation on the Fabric of Aging in America	RACE	US	1991	THE
Gelfand, D.& Yee, B.	Rural-Urban Differences in the Utilization of Care by the Elderly	UTIL	Neth er	1990	QUANT
Gerritsen, JC et al.	The Health, Labor Force and Retirement Experiences of Aging Minorities	RACE	US	1991	THE
Gibson, R. & Burns, C.	Ethnicity and Aging	RACE	US	1992	QUANT
Giordano, J.	Age-Based Policies and the Oldest-Old	RESAL	US	1995	THE
Gonyea, J.	The Paradox of the Advantaged Elder and the Feminization of Poverty	WOM	US	1994	THE
Gonyea, J.	A Minority-Feminist Perspective on Women and Aging	WOM	US	1989	THE
Gould, K.	Promoting Women's Health: Insights From Recent Research	WOM	CAN	1994	THE
Green, K.	Older Patient Satisfaction with Communication During an Initial Medical Encounter	PHY	US	1994	QUAL
Greene, M. et al.	Decision as a Process: A Conceptual Model of Black Elders' Nursing Home Placement	RACE	US	1994	QUAL
Groger, L.	Limit of Support and Reaction to Illness: An Exploration of Black Elders' Pathways to Long-Term Care Settings	RACE	US	1994	QUAL
Groger, L.	Aging and Exchange: Differences Between Black and White Elders	RACE	US	1995	QUAL+ QUANT

Hagan Hennessy, C. & John, R.	American Indian Family Caregivers' Perceptions of Burden and Needed Support Services	RACE	US	1996	QUAL
Hamm, V. et al.	Life-Style and Cardiovascular Health Among Urban Black Elderly	RACE	US	1993	QUANT
Hammond, J.	Multiple Jeopardy or Multiple Resources? The Intersection of Age, Race, Living Arrangements and Education Level and the	WOM	US	1995	QUANT
Hannun R.	A Life Course Perspective on Health Threats in Aging	DEL	US	1991	THE
Hardy, M. & Hazelrigg, L.	Gender, Race/Ethnicity and Poverty in Later Life	WOM	US	1995	QUANT
Hardy, M. & Hazelrigg, L.	The Gender of Poverty in an Aging Population	WOM	US	1993	QUANT
Harrington-Meyer, M.	Gender, Race and the Distribution of Social Assistance: Medicaid Use Among the Frail Elderly	WOM	US	1994	QUANT
Harrington Meyer, M.	Family Status and Poverty Among Older Women: The Gendered Distribution of Retirement Income in the United	WOM	US	1990	THE
Hart, V. et al.	Strategies for Increasing Participation of Ethnic Minorities in Alzheimer's Disease Diagnostic Centres: A Multifaceted	RACE	US	1996	THE
Hartman, A.	Aging as a Feminist Issue	WOM	US	1990	THE
Haug, M.	The Interplay of Formal and Informal Health Care: Theoretical Issues and Research Needs	DEL	US	1990	THE
Haug, M.	Elderly Patients, Caregivers and Physicians: Theory and Research on Health Care Triads	PHY	US	1994	THE
Havens, B. & Bray, D.	International Comparisons of Long-Term Care: Canada, with Specific Reference to Manitoba	RESAL	CAN	1996	THE
Health Services Utilization Commission	Waiting Time for Nursing Home Admission in a Voluntary Single-Entry System	UTIL	CAN	1997	QUANT
Hogan, D.	Impact of Geriatric Consultation Services for Elderly Patients Admitted to Acute Care Hospitals	PHY	CAN	1990	THE
Hughes, S. & Guihan, M.	Community-Based Long Term Care: The Experience of Living at Home Programs	DEL	US	1990	THE
Hyde, J. & Torres-Gil, F.	Ethnic Minority Elders and the Older Americans Act: How Have They Fared?	RACE	US	1991	THE
Ishii-Kuntz, M.	Formal Activities for Elderly Women: Determinants of Participation in Voluntary and Senior Center Activities	WOM	US	1990	QUANT
Jecker, N.	Age-Based Rationing and Women	WOM	US	1991	THE
Johnson, C.	Determinants of Adaptation of Oldest Old Black Americans	RACE	US	1995	THE
Johnson, R. & Wolinsky, F.	Gender, Race and Health: The Structure of Health Status Among Older Adults	RACE	US	1994	QUANT
Johnson Jackson, J.	The Plight of the Older Black Woman	WOM	US	1997	THE
Jones Morrison, B.	A Research and Policy Agenda on Predictors of Institutional Placement Among Minority Elderly	RACE	US	1995	THE
Jorgensen, L.	Public Policy, Health Care and Older Women	WOM	US	1993	THE
Kaden, J. & McDaniel, S.	Caregiving & Care-Receiving: A Double Bind for Women in Canada's Aging Society	WOM	CAN	1990	QUANT
Kamikawa, L.	Public Entitlements: Exclusionary Beneficence: Class vs. Race as Essential Variables in Policy Formulation	RESAL	US	1991	THE
Kapp, M.	Legal and Ethical Issues in Home-Based Care	DEL	US	1995	THE
Katz, P. & Karuza, J.	Service Delivery in an Aging Population: Implications for the Future	DEL	CAN	1992	THE
Kaufman, S.	Decision Making, Responsibility and Advocacy in Geriatric Medicine: Physician Dilemmas With Elderly in the	PHY	US	1995	QUAL
Kenney, G.	Is Access to Home Health care a Problem in Rural Areas?	DEL	US	1993	QUANT
Kirk, A. & Rittner, B.	Old and Poor: Comparison of Female and Male Meal Program Participants	WOM	US	1993	QUANT
Kramer, J.	Urban American Indian Aging	RACE	US	1991	THE

Kramer, J. & Barker, J.	Ethnic Diversity in Aging and Aging Services in the US: Introduction	RACE	US	1991	THE
Krassen Maxwell, El. & Maxwell, R.	Insults to the Body Civil: Mistreatment of Elderly in Two Plains Indian Tribes	RACE	US	1992	THE
Krause, N. & Wray, L.	Psychosocial Correlates of Health and Illness Among Minority Elders	RACE	US	1991	THE
Kutza, E.	Medicaid: The Shifting Place of the Old in a Needs-Based Health Program	RESAL	US	1995	THE
Lanoie Blanchette, P.	Progress in Geriatrics: A Clinical Care Update and a Look at the Future	RESAL	US	1996	THE
Laws, G.	Understanding Ageism: Lessons From Feminism and Postmodernism	WOM	US	1995	THE
Leigh, P. & Fries, J.	Education, Gender and the Compression of Morbidity	WOM	US	1994	QUANT
Leirer, V. et al.	Elders' Nonadherence: Its Assessment and Medication Reminding by Voice Mail	COMP	US	1991	QUANT
Lew, L.	Elderly Cambodians in Long Beach: Creating Cultural Access to Health Care	RACE	US	1991	THE
Liska Belgrave, L. et al.	Health, Double Jeopardy and Culture: The Use of Institutionalization by African-Americans	RACE	US	1993	THE
Liska Belgrave, L.	Discrimination Against Older Women in Health Care	WOM	US	1993	THE
Loomis, R. & Thomas, C.	Elderly Women in Nursing Home and Independent Residence: Health, Body Attitudes, Self-Esteem and Life	WOM	CAN	1991	QUANT
Lowe, M. et al.	These Sorts of People Don't Do Very Well: Race and The Allocation of Health Care Resources	RESAL	US	1995	THE
MacAdam, M. et al.	Targeting Long-Term care for the Frail Elderly: Models From the Social/HMO Demonstration	DEL	US	1991	QUANT
MacLean, M. et al.	Institutional Racism in Old Age: Theoretical Perspectives and a Case Study About Access to Social Services	RACE	CAN	1987	QUANT
MacLean, M. et al.	Health Realities and Independence: The Voice of Elderly Women	WOM	CAN	1994	QUAL
MacLean, M. & Sadakis, V.	Quality of Life in Terminal Care with Institutionalized Ethnic Elderly People	RACE	CAN	1989	QUAL
Markides, K.	Risk Factors, Gender and Health	WOM	US	1990	QUANT
Masi, R. & Disman, M.	Health Care and Seniors: Ethnic, Racial and Cultural Dimensions	RACE	CAN	1994	THE
McCabe, M.	Long-Term Care and the Navajo Elder	RACE	US	1995	THE
McLaughlin, D. & Holden, K.	Nonmetropolitan Elderly Women: A Portrait of Economic Vulnerability	WOM	US	1993	QUANT
Mercer, S.	Navajo Elders in a Reservation Nursing Home: Health Status Profile	RACE	US	1994	QUAL+
Mindel, C. & Kail, B.	Issues in Research on the Older Woman of Color	WOM	US	1989	THE
Miner, M. & Crose, R.	Identifying Barriers to Services for Low-Income Frail Elders	UTIL	US	1996	THE
Minkler, M. & Robertson, A.	The Ideology of 'Age/Race Wars': Deconstructing a Social Problem	RESAL	US	1991	THE
Minkler, M. & Stone, R.	The Feminization of Poverty and Older Women	WOM	US	1985	THE
Minkler, M. & Robertson, A.	Generational Equity and Public Health Policy: A Critique of Age/Race War Thinking	RESAL	US	1991	THE
Mitchell, J.	Service Awareness and Use Among Older North Carolinians	UTIL	US	1995	QUANT
Monk, A.	Health care for the Aged: The Pursuit of Equity and Comprehensiveness	RESAL	US	1990	THE
Moon, M.	Public Policies: Are They Gender Neutral?	WOM	US	1990	THE
Morrison, J.	The Black Church as a Support System for Black Elderly	RACE	US	1991	QUAL
Morrow, D.	Improving Consultations Between Home-Health Professionals and Older Clients: Implications for Pharmacists	PHYS	US	1997	THE

Morrow-Howell, N. et al.	Adequacy of Discharge Plans for Elderly Patients	DEL	US	1991	QUANT
Mui, A.	Self-Reported Depressive Symptoms Among Black and Hispanic Frail Elders: A Sociocultural Perspective	RACE	US	1993	QUANT
Mui, A. & Burnette, D.	Long-Term Care Service Use by Frail Elders: Is Ethnicity a Factor?	RACE	US	1994	QUANT
Mui, A.	Correlates of Psychological Distress Among Mexican, Cuban and Puerto Rican Elders Living in the USA	RACE	US	1996	QUANT
Muszynski, A.	Gender Inequality & Life Chances: Women's Lives and health	WOM	CAN	1994	THE
Mutschler, P. & Callahan, J.	Utilizing Client Experience in Developing New Service Models for the Care of the Aged	DEL	US	1990	QUANT
Myles, J.	Neither Rights nor Contracts: The New Means-Testing in US Aging Policy	RESAL	US	1995	THE
Nelson, M.	Race, Gender and the Effect of Social Supports on the Use of Health Services by Elderly Individuals	UTIL	US	1993	QUANT
Neugebauer-Visano	Marginal Women	WOM	CAN	1995	QUAL
Newhouse, J.	Do Unprofitable Patients Face Access Problems?	RESAL	US	1989	QUANT
O'Connor, P.	Salient Themes in the Life Review of a Sample of Frail Elderly Respondents in London	DEL	UK	1994	QUAL
OGrady LeShane, R.	Older Women and Poverty	WOM	US	1990	THE
Ozawa, M.	Solitude in Old Age: Effects of Female Headship on Elderly Women's Lives	WOM	US	1993	THE
Palo Stoller, E.	Gender and the Organization of Lay Health Care	WOM	US	1993	QUANT
Parkinson, C. & Howard, M.	Older Persons with Mental Retardation/Developmental Disabilities	DEL	US	1996	THE
Penning, M. & Chappell, N.	Ethnicity and Informal Supports Among Older Adults	RACE	CAN	1987	QUANT
Penning, M. & Strain, L.	Gender Differences in Disability, Assistance, and Subjective Well-being in Later Life	WOM	CAN	1994	QUANT
Perkins, K.	Recycling Poverty: From the Workplace to Retirement	WOM	US	1993	THE
Perry, C. & Johnson, C.	Families and Support Networks Among African American Oldest-Old	RACE	US	1994	QUANT
Quinn, P. & Keys Walsh, S.	Midlife Women With Disabilities: Another Challenge for Social Workers	WOM	US	1995	QUAL
Rabiner, D.	The Relationship Between Program Participation, Use of Formal In-home Care and Satisfaction with Care in an	UTIL	US	1992	QUANT
Rantucci, M.	Health Professionals' Perceptions of Drug Use Problems of the Elderly	COMP	CAN	1989	QUANT
Reinharz, S.	Friends or Foes: Gerontological and Feminist Theory	WOM	US	1997	THE
Risteen Hasselkus, B.	Three Track care: Older Patient, Family Member and Physician in the Medical Visit	PHYS	US	1994	QUAL
Risteen Hasselkus, B.	Physician and Family Caregiver in the Medical Setting: Negotiation of Care	PHYS	US	1992	QUAL
Rivas, E. & Torres-Gil, F.	Politics, Diversity and Minority Aging: A Delicate Balance is Required	RACE	US	1991	THE
Robert, S. & Norgard, T.	Long-Term Care Policy Based on ADL Eligibility Criteria: Impact on Community Dwelling Elders Not Meeting the	UTIL	US	1996	QUANT
Roberts, C.	Conflicting Professional Values in Social Work and Medicine 14(3), 211-218	PHY	US	1989	THE
Rodeheaver, D. & Datan, N.	The Challenge of Double Jeopardy: Toward a Mental Health Agenda for Aging Women	WOM	US	1988	THE
Rosenthal, M. & Morith, N.	Women and Long Term Care Planning: The Adverse Impact of Women's Perceptions	WOM	US	1993	THE
Rosenthal, E.	Women and Varieties of Ageism	WOM	US	1990	THE
Ross, J.	Health: Who's in Control?	RESAL	US	1992	THE

Roy, Lonnie, Dietz, Tracy & John Robert	Determining Patterns of Formal Use Among Mexican American Elderly: Improving Empirical Techniques for Policy	RACE	US	1996	QUANT
Russell Hatch, L.	Effects of Work & Family on Women's Later Life Resources	WOM	US	1990	THE
Sadakis, V. & MacLean, M.	The Role of the Social Worker With Ethnic Elderly People in Geriatric Day Hospitals	RACE	CAN	1993	THE
Saldov, M. & Chow, P.	The Ethnic Elderly in Metro Toronto Hospitals, Nursing Homes and Homes for the Aged: Communication and Health	RACE	CAN	1994	QUANT
Saldov, M.	The Ethnic Elderly: Communication Barriers to Health Care	RACE	CAN	1991	THE
Sanders-Phillips, K.	Health Promotion Behaviour in Low Income Black and Latino Women	WOM	US	1994	QUANT
Saxon, S.	Pre-Retirement Health Needs of Women	WOM	US	1993	THE
Schneider, J. et al.	Elderly People with Advanced Cognitive Impairment in England: Resource Use and Costs	UTIL	UK	1993	THE
Schoenbaum, M. & Waidmann, T.	Race, Socioeconomic Status and Health: Accounting for Race Differences in Health	RACE	US	1997	QUANT
Schoenberg, N. & Coward, R.	Attitudes About Entering a Nursing Home: Comparisons of Older Rural and Urban African-American Women	WOM	US	1997	QUAL
Schoenberg, N. et al.	Screening Community-Dwelling Elders for Nutritional Risk: Determining the Influence of Race and Residence	RACE	US	1997	QUANT
Schulz, R. & Williamson, G.	Psychosocial and Behavioural Dimensions of Physical Frailty	DEL	US	1993	THE
Shea, D. et al.	The Health-Wealth Connection: Racial Differences	RACE	US	1996	QUANT
Shenk, D.	Older Rural Women as Recipients and Providers of Social Support	WOM	US	1991	QUAL
Shoemaker, D.	Health Care, Cultural Expectations and Frail Elderly Navajo Grandmothers	RACE	US	1990	THE
Simmons, H.	The Nation's Least Understood Healthcare Problem-The Quality of Medical Care	RESAL	US	1996	THE
Slivinske, L. et al.	Predicting Health and Social Service Utilization of Older Adults	UTIL	US	1994	QUANT
Sloane, P.	Experiences and Expectations of Government Services: The Older Soviet Immigrant	RACE	US	1991	THE
Sokolovsky, J.	Ethnicity, Culture and Aging: Do Differences Really Make a Difference?	RACE	US	1985	THE
Sook Lee, M. et al.	Social Support and Depression Among Elderly Korean Immigrants in the United States	RACE	US	1996	QUANT
Spector, W. & Kemper, P.	Disability and Cognitive Impairment Criteria: Targeting Those Who Need the Most Home Care	UTIL	US	1994	QUANT
Spence, S. & Atherton, C.	The Black Elderly and the Social Service Delivery System: A Study of Factors Influencing the Use of Community-Based	RACE	US	1991	QUANT
Stanford, P. & Gwynne Schmidt, M.	The Changing Face of Nursing Home Residents: Meeting Their Diverse Needs	RACE	US	1995	THE
Stanford, P. & Yee, D.	Gerontology and the Relevance of Diversity	RACE	US	1991	THE
Starret	Self-Reliance	RACE	US	1992	QUANT
Stump, T. et al.	The Structure of Health Status Among Hispanic, African American and White Older Adults	RACE	US	1997	QUANT
Taira, F. & Taira, D.	Patient Dumping of Poor families	RESAL	US	1991	THE
Tanjasiri, Sora, Wallace, Steven & Shibata, Kazuo	Picture Imperfect: Hidden Problems Among Asian Pacific Islander Elderly	RACE	US	1995	THE
Tarman, V.	Age and Gender: The Missing Analysis in Long Term Care Reform	WOM	CAN	1994	THE
Tennstedt, S. et al.	Unmet Needs Among Disabled Elders: A Problem in Access to Community Long Term Care?	UTIL	US	1994	QUANT
Ter Meulen, R. et al.	What Do We Owe the Elderly?: Allocating Social and Health Care Resources	RESAL	US	1994	THE
Tran, T.	Language Acculturation Among Older Vietnamese Refugee Adults	RACE	US	1990	QUANT

Tran, T. & Dhooper, S.	Ethnic and Gender Differences in Perceived Needs for Social Services Among Three Elderly Hispanic Groups	RACE	US	1996	QUANT
Tran, T. et al.	Acculturation, Health, Stress and Psychological Distress Among Elderly Hispanics	RACE	US	1996	QUANT
Trippel, S.	Being Aware: The Relationship Between Health and Social Support Among Older Women	WOM	US	1991	QUAL
Trype, J.	Gender Based Mortality and Morbidity Patterns and Health Risks	WOM	CAN	1994	THE
Ujimoto, V.	Racial and Ethnic Dimensions of Aging: Implications for Health Care Services	RACE	CAN	1994	THE
Victor, C.	Continuity or Change: Inequalities in Health in Later Life	UTIL	UK	1991	QUANT
Vinales Cunningham, C.	Reaching Minority Communities: Factors Impacting on Success	RACE	US	1991	THE
Waizkin, H et al.	Narratives of Aging and Social Problems in Medical Encounters with Older Persons	PHY	US	1994	QUAL
Waldrum, J.	Cultural and Socio-Economic Factors in the Delivery of Health Care Services to Aboriginal Peoples	RACE	CAN	1994	THE
Wallace, S.	Community Formation as an Activity of Daily Living: The Case of Nicaraguan Immigrant Elderly	RACE	US	1992	THE
Wallace, S.	The No-care Zone: Availability, Accessibility and Acceptability in Community-Based Long-Term Care	RESAL	US	1990	QUAL
Walls, C.	The Role of Church and Family Support in the Lives of Older African Americans	RACE	US	1992	QUANT
Wan, T. & Ferraro, K.	Assessing the Impacts of Community-Based Health Care Policies and Programs for Older Adults	DEL	US	1991	THE
Ward-Griffin, C. & Ploeg, J.	A Feminist Approach to Health Promotion for Older Women	WOM	CAN	1997	THE
Wasson, J. & Jette, A.	Partnerships Between Physicians and Older Adults	PHY	US	1993	THE
Wenger, G.	Introduction: Facing Frailty	DEL	UK	1990	THE
Whetstone, W. & Crusie, M.	Community Partnerships: Home Health Care for Elderly Minorities	RACE	US	1995	THE
White-Means, S. & Hammond, J.	Health Insurance and Disability Levels for Older Black and White Women in the South	WOM	US	1993	QUANT
White-Means, S.	Informal Home Care for Frail Black Elderly	RACE	US	1993	QUANT
Wilson-Ford, V.	Health Protective Behaviours of Rural Black Elderly Women	WOM	US	1992	QUANT
Wilson-Ford, V.	Poverty Among Black Elderly Women	WOM	US	1991	THE
Wister, A.	Residential Attitudes and Knowledge, Use, and Future Use of Home Support Agencies	UTIL	CAN	1992	QUANT
Woodruff, L. & Applebaum, R.	Assuring the Quality of In-Home Supportive Services: A Consumer Perspective	DEL	US	1996	QUAL
Wotherston, T.	Colonization, Self-Determination and the Health of Canada's First Nations Peoples	RACE	CAN	1994	THE
Wray, L.	Public Policy Implications of an Ethnically Diverse Elderly Population	RACE	US	1991	THE
Wyke, M. & Haug, M.	Multicultural and Social-Class Aspects of Self-care	RACE	US	1993	THE
Wyke, M. & Musil, C.	Mental Health of Older Persons: Social and Cultural Factors	RACE	US	1993	THE
Yeatts, D. et al.	Service Use Among Low-Income Minority Elderly: Strategies for Overcoming Barriers	RACE	US	1992	THE
Yee, B. & Weaver, G.	Ethnic Minorities and Health Promotion: Developing a Culturally Competent Agenda	RACE	US	1994	THE
Yeo, G.	Ethnogeriatric Education: Need and Content	RACE	US	1991	THE
Yeo, G.	Ethnogeriatrics, Cross Cultural	RACE	US	1996	THE
Young Chung Pang, K.	Self-Care Strategy of Elderly Korean Immigrants in the Washington DC Metropolitan Area	RACE	US	1996	BOTH Q

Zong, L. & Li, P.	Different Cultures or Unequal Life Chances: A Comparative Analysis of Race and Health	RACE	CAN	1994	THE
Zweibel, N. et al.	Public Attitudes About the Use of Chronological Age as a Criterion for Allocating Health Care Resources	RESAL	US	1993	QUANT

**Table 3: Percentage of Gerontological Literature Dealing With Access Issues**

Access Form: Catalogued As:	Service Delivery	Resource Allocation	Utilization	Access Explicitly Defined	Provider- Patient Relations	Other	Total
Provider-Patient Relations and Compliance					18		18
Utilization			26				26
Resource Allocation		29					29
Service Delivery	23						23
Women	2	22	15	5		18	62
"Race"	15	6	30	13		33	97
Total	40	57	71	18	18	51	255
Total - Other = % Articles Dealing with Access	19.6%	27.9%	34.8%	8.8%	8.8%	NA	255-51=204

N used for percentages refers only to review literature which deals with access in some way.

**Table 4: Gender Approach (Eichler, 1987) of Gerontological Literature**

<b>Gender Approach: Catalogued As:</b>	<b>Sexist</b>	<b>Non-Sexist</b>	<b>Woman Centred</b>	<b>Feminist</b>	<b>Total</b>
<b>Provider-Patient Relations and Compliance</b>	18	0	0	0	18
<b>Utilization</b>	23	3	0	0	26
<b>Resource Allocation</b>	27	2	0	0	29
<b>Service Delivery</b>	22	1	0	0	23
<b>Women</b>	2	9	24	27	62
<b>"Race"</b>	85	9	1	2	97
<b>Missing</b>					1
<b>Total %</b>	177 (69.4%)	24 (9.4%)	25 (9.8%)	29 (11.4%)	255 (100.0%)

**Table 5: Gender Inclusion of Gerontological Literature**

<b>Gender Inclusion: Catalogued As:</b>	<b>None</b>	<b>Minimal</b>	<b>Variable Only</b>	<b>Integral</b>	<b>Total</b>
<b>Provider-Patient Relations and Compliance</b>	7	1	10	0	18
<b>Utilization</b>	4	1	21	0	26
<b>Resource Allocation</b>	23	2	4	0	29
<b>Service Delivery</b>	16	2	5	0	23
<b>Women</b>	0	0	7	55	62
<b>"Race"</b>	49	5	37	6	97
<b>Total %</b>	99 (38.8%)	11 (4.3%)	84 (32.9%)	61 (23.9%)	255 (100.0%)

**Table 6: Inclusion of Ethnicity and/or "Race" Issues in Gerontological Literature**

"Race" Inclusion: Catalogued As:	None	Minimal	Variable Only	Integral	Total
Provider-Patient Relations and Compliance %	14	2	0	2 (11.1%)	18
Utilization %	18	4	3	1 (3.8%)	26
Resource Allocation %	20	3	2	4 (13.8%)	29
Service Delivery %	19	1	2	1 (4.3%)	23
Women %	25	13	7	17 (27.4%)	62
"Race" %	0	2	2	93 (95.9%)	97
Total %	96 (37.6%)	25 (9.8%)	16 (6.3%)	118 (46.3%)	255 (100.0%)

**Table 7: Use of Ethnicity and/or "Race" in Gerontological Literature**

**Defined-Undefined: Do(es) Author(s) Attempt to Define Their Usage of the Categories of Ethnicity & "Race"?**  
**Diversified-Essentialized? Do(es) Author(s) Homogenize or Essentialize Ethnic and/or "Racial" Groups by Lumping Diverse Groups Together Within the Same Category?**

Use of "Race": Catalogued As:	Defined Diversified	Undefined Essentialized	Defined Essentialized	Undefined Diversified	Total
Women	2	33	1	1	37
"Race"	40	41	11	4	96
Total %	42 (31.6%)	74 (55.6%)	12 (9.0%)	5 (3.8%)	133 (100.0%)

N used for table refers only to review literature which includes, to any extent, issues of ethnicity and/or "race".

**Table 8: Organizational Approach to Ethnicity and/or "Race" (Tator, 1996) in Gerontological Literature**

<b>Organizational Approach to "Race": Catalogued As:</b>	<b>Monocultural</b>	<b>Add-On</b>	<b>Multicultural/Anti-Racist</b>	<b>Ethnospecific</b>	<b>Total</b>
<b>Women</b>	1	1	2	3	7
<b>"Race"</b>	4	20	10	11	45
<b>Service Delivery</b>	22	1	0	0	23
<b>Total</b>	27	22	12	14	75
<b>%</b>	(36.0%)	(29.3%)	(16.0%)	(18.7%)	(100.0%)

N used for table refers only to articles which deal with service delivery or ethno-organizational issues.

## Tables - Chapter 4: Methodology

**Table 1: Problematic Constructions of Access & Research Design Implications**

<b>Problematic Area</b>	<b>Design Implication</b>
failure to define the nature and parameters of access	incorporate complexity and remain open to competing definitions of access
narrow focus on reductionist (individual and relational) barriers to care with a corresponding lack of focus on structural or ideological issues; no emphasis placed on understanding the relationship between these barriers	explore the ways in which systemic dynamics of power are enacted/experienced in the everyday practices of organizations (i.e. the relationship between macro and micro forces in the everyday experiences of access)
little recognition of older women's differential experience of access	incorporate women's voice and begin from women's standpoint
essentialist categories of ethnicity and "race" which are rarely defined; folkloric focus	maintain sensitivity to diversity within and among ethnic and "racial" minority groups and categories; focus on individual, institutional and systemic practices and not on ways specific ethnic groups "cope" or "adapt"
posits the experience of gender, ethnicity, "race" and class as hierarchically ordered	explore interlocking oppressions
focus on monocultural or add-on models of ethno-geriatric service delivery	address models of care with organizations and institutions
definition of "need" based on physical or mental criteria for determining accessibility	explore the social construction of elders and highlight the processes by which this takes place

**Table 2: Comparison of Institutional Ethnography and Grounded Theory Approaches**

<b>Institutional Ethnography</b>	<b>Grounded Theory</b>
<b>Epistemology</b>	
Mapping Terrain	Developing Theory
Start From Women's Standpoint	Ground Research in Data/Experience
Move Beyond Individual Experience	Conceptual Transcendence
Rooted in Everyday-How Things Operate	Explore What's Going On in the Everyday
Explicate Relations of Ruling	Influence of Structural Conditions on Behaviour
Focus on Social Relations of Ruling	Interactional-Interested in Patterns of Action
Analysis Driven by Pre-Existing Theoretical	Orientation or Understanding Can Be Based on Theoretical Elaboration, but Not Common Approach
Explication	Conceptualization
Emancipatory - Consciousness Raising	Expand Knowledge
<b>Method</b>	
Multiple Methods	Multiple Methods
Bracketing Procedures So That Theory or Ideology Does Not Drive Data	Emergent Fit to Incorporate Pre-Existing Theory
Purposive Theoretical Sampling	Purposive Theoretical Sampling
Iterative-Inductive-Deductive	Constant Comparative-Iterative
Development of Diagram of Social Relations of Ruling	Conditional Matrix Map
Methods of Analysis Not Specified	Three Stage Analysis Method to Identify Categories
Complete Transcription to Retain Complexity of Women's Voices	Initial Complete Transcription. Second Stage Selective Transcribing

**Table 3: Description of Older Ethnic and “Racial” Minority Women Participants**

<b>Ethno- “Racial” Group</b>	<b>Age</b>	<b>Living Arrangement</b>	<b>Date of Arrival in Canada</b>	<b>Knowledge of Official Languages</b>	<b>Perceived Health Status</b>	<b>Interview with...</b>
<b>Black</b>	<b>83</b>	<b>Alone</b>	<b>1969</b>	<b>English</b>	<b>Arthritis/ Back Problems</b>	<b>Alone</b>
<b>Black</b>	<b>75</b>	<b>Alone</b>	<b>1986</b>	<b>English</b>	<b>Cancer</b>	<b>Alone</b>
<b>Chinese</b>	<b>67</b>	<b>Alone</b>	<b>1988</b>	<b>Neither</b>	<b>Below Average</b>	<b>Alone</b>
<b>Chinese</b>	<b>77</b>	<b>Homemaker</b>	<b>1992</b>	<b>Neither</b>	<b>Poor</b>	<b>Daughter</b>
<b>Greek</b>	<b>82</b>	<b>Spouse</b>	<b>1953</b>	<b>Neither</b>	<b>Severe Arthritis</b>	<b>Husband</b>
<b>Greek</b>	<b>72</b>	<b>Spouse</b>	<b>1960</b>	<b>Neither</b>	<b>Poor</b>	<b>Alone</b>
<b>Iranian</b>	<b>68</b>	<b>Alone</b>	<b>1983</b>	<b>English</b>	<b>Arthritis/ Osteoporosis</b>	<b>Alone</b>
<b>Italian</b>	<b>83</b>	<b>Other Family Member</b>	<b>1960</b>	<b>Neither</b>	<b>Diabetic</b>	<b>Alone</b>
<b>Italian</b>	<b>68</b>	<b>Spouse</b>	<b>1960</b>	<b>Neither</b>	<b>Arthritis</b>	<b>Alone</b>
<b>South Asian</b>	<b>81</b>	<b>Daughter</b>	<b>unknown</b>	<b>Neither</b>	<b>Poor</b>	<b>Daughter</b>

**Tables - Chapter 5: Setting the Context: Socio-Demographic Characteristics of Ethno- "Racial" Minority Elders in Area P**

**Table 1: Ethno-"racial" Group as a Percentage of the Total Population by Area**

Ethno-"racial" Group	Canada	% of total	Toronto CMA*	% of total	Neighbourhood CSD**	% of total
Total Pop.	28390680	100.0	4218470	100.0	553860	100.0
Black	570165	2.0	273445	6.5	55055	9.9
South Asian	669060	2.4	329120	7.8	75345	13.6
Chinese	857370	3.0	334315	7.9	92205	16.7
Greek	203005	0.7	80255	1.9	18035	3.3
Italian	1197495	4.2	411185	9.7	24700	4.5

Census 1996 - Special Tabulation

\*Census Metropolitan Area

\*\* Census Sub-Division

**Table 2: Percentage of Ethno-"racial" Group Living in Neighbourhood CSD\***

Ethno-"racial" Group	% of Toronto Group Living in CSD*	% of Canada Group Living in CSD*
Total Population	13.1	2.0
Black	20.1	9.7
South Asian	22.9	11.3
Chinese	27.6	10.8
Greek	22.5	8.9
Italian	6.0	2.2

Census 1996 - Special Tabulation

\*CSD- Census Sub-Division

**Table 3: Age Breakdowns - Canada, Toronto, Neighbourhood CSD\* by Ethno-  
"racial" Group**

Ethno-"racial" Group	Canada			Toronto			Neighbourhood CSD*		
	0-17	18-64	65+	0-17	18-64	65+	0-17	18-64	65+
Total Population	24.9	63.6	11.5	24.1	65.5	10.4	23.7	65.0	11.3
Black	35.2	60.5	4.3	34.1	61.9	4.0	34.7	61.0	4.3
South Asian	29.9	64.6	5.5	30.0	64.7	5.3	30.2	65.2	4.6
Chinese	24.6	66.6	8.8	23.7	67.0	9.3	22.1	67.5	10.4
Greek	23.7	67.5	8.8	21.7	69.2	9.1	21.6	70.3	8.1
Italian	27.5	62.5	10.0	25.0	64.8	10.2	23.4	65.4	11.2

Census 1996 - Special Tabulation  
\*CSD- Census Sub-Division

**Table 4: Gender Breakdowns Among the Elderly by Ethno-"racial" Group**

Ethno-"racial" Group	Canada		Neighbourhood CSD*	
	Male 65+	Female 65+	Male 65+	Female 65+
Total Population	43.3	56.7	42.8	57.2
Black	35.4	64.6	33.8	66.2
South Asian	47.8	52.2	48.3	51.7
Chinese	44.7	55.3	45.6	54.4
Greek	49.0	51.0	54.3	45.7
Italian	49.9	50.1	53.3	46.7

Census 1996 - Special Tabulation  
\*CSD- Census Sub-Division

**Table 5: Percentage of Neighbourhood CSD\* Ethno-"racial" Group (Total, 65+) Unattached**

Ethno-"racial" Group	% of Total Population Unattached	% of 65+ Population Unattached
Total Population	8.8	22.2
Black	9.5	25.4
South Asian	3.5	9.7
Chinese	4.5	6.5
Greek	3.6	10.2
Italian	5.9	16.5

Census 1996 - Special Tabulation  
\*CSD- Census Sub-Division

**Table 6: Percentage of Neighbourhood CSD\* Seniors Who Are Recent Immigrants (1976-1996) by Ethno-“racial” Group**

<b>Ethno-“racial” Group 65+</b>	<b>Percent Who Are Recent Immigrants</b>
Total Population	26.0
Black	47.4
South Asian	85.7
Chinese	82.0
Greek	10.2
Italian	2.9

Census 1996 - Special Tabulation

\*CSD- Census Sub-Division

**Table 7: Percent of Neighbourhood CSD\* Seniors Who Do Not Know Either English or French by Ethno-“racial” Group**

<b>Ethno-“racial” Group (65+)</b>	<b>% Who Do Not Know English or French</b>
Total Population	16.9
Black	1.5
South Asian	28.2
Chinese	68.4
Greek	40.6
Italian	31.3

Census 1996 - Special Tabulation

\*CSD- Census Sub-Division

**Table 8: Percentage of Neighbourhood CSD\* Seniors Who Live Below the Low Income Cut Off Line by Ethno-“racial” Group**

<b>Ethno-“racial” Group (65+)</b>	<b>All 65+ Who Live Below the Low Income Cut Off</b>	<b>All Unattached 65+ Who Live Below the Low Income Cut Off</b>
Total Population	25.8	58.2
Black	43.6	84.9
South Asian	35.9	73.1
Chinese	34.1	80.8
Greek	27.3	60.0
Italian	25.9	65.9

Census 1996 - Special Tabulation

\*CSD- Census Sub-Division

# **APPENDIX 1 AUDIT TRAIL**

### **Audit Trail - Journal of Process and Decisions:**

This journal was created in order to enhance dependability of the research. I used it as an audit trail to follow the process of decision-making throughout the data collection and analysis stage.

I began by interviewing the Executive Director. My intent was to get a firm grasp of the macro and mezzo issues in the development and operationalization of the agency. I developed a series of questions (interview guide) focusing on organizational development, Ministry and agency relations, inter-organizational relations and the impact of diversity on these items. The purpose was to broaden my understanding of the development of the agency, including Ministry procedures, the process by which "Eldercare" contracts with service provider agencies, history and board development and, their relationship to the community and in specific to ethno-racial community agencies. This interview served as the preparation stage for beginning my inquiry of older women's experience (*prolonged engagement*).

My entry point was that of interviews with older ethnic and racial minority women, to begin from their location and experience. Participant recruitment took a long time and a great deal of effort. I began spending time at the agency in order to familiarize myself with the environment and to spend time explaining the project to staff in order to earn trust and begin recruitment (*prolonged engagement*). Staff were not forthcoming with names of people to interview at the beginning and it took about one month of intense time here to earn enough exposure and trust to begin getting referrals. I relied heavily on a couple of staff to get names of appropriate women for interviews. The staff then called these women or their children to ask if they would be willing to be called about participation. Children

often acted as their parents' protectors and did not want their mom bothered. Going through the child was partly the result of the nature of those I was searching to interview and partly due to culture of the agency in which children often served as point of contact for the case coordinators. Given the length of time it took to get these women, I spent a lot of time hanging out, presenting to teams at staff and team meetings, training interviewers and waiting. This proved to be extremely valuable time because it gave me an opportunity to become familiar with and involved in the "culture" of the agency, identify people to sit on an advisory group and network (*prolonged engagement*).

Once I had 4 older women's interviews for analysis (*open sampling*), I began analyzing and developing themes (*Grounded Theory (GT) constant comparative method*). Many of the older women had to be interviewed by indigenous interviewers because of language requirements. I decided to go for indigenous interviewers rather than getting a translator for various reasons, most importantly because I wanted the interview to be smooth in order to allow for a conversational, open-ended, qualitative style. I felt that the use of translators would force the conversation, make it halting and also would mean that the older women's voices would be submerged underneath the translator's voice. Now I recognize that in translating the transcript (*referential adequacy*), this would also submerge the voice of the older woman, but I felt that it would be less so if older women could talk freely in conversational style with an interviewer who knew their language and culture rather than one in which the older woman was trying to simplify her responses so that I could understand. It proved a good decision. All of the women were really happy to have someone to speak to from their own cultural background and who spoke their own language. They felt more "at home" to talk about issues they faced. I, in fact, encountered

a little resistance when doing interviews with women not from my cultural group. One Black woman was disappointed to see me and said she was hoping that a woman from the Caribbean was coming to interview her. One of the things I found in the study was that women I spoke with often defended their rights to service and expressed great satisfaction about choosing Canada as a place to live and some of this response could have been that they felt it necessary to tell the white girl Canadian that they love Canada to reinforce that they are also Canadian to me. I wonder what would have happened if the English speaking women were interviewed by a person from their own cultural group (*reflexivity*). Of course the negative is that I had to rely on interviewers who may or may not have been able to move the interview in a way that I wished at the time of the interview itself. I had trained these interviewers in the method and asked them to add or change questions depending on the advance of my theories (*theoretical sampling*) (for example by focusing on such issues as control over decision-making, family involvement or experiences of racism) but they worked to a more or less degree depending on the interviewer and the culture of the interview (for example, one Chinese interviewer focused quite a lot of her interview on health status rather than health care access). However it is important to note that all interviews contained useful and rich data for analysis, so none was discarded.

Once these 4 interviews were done, I began interviewing staff, using preliminary analysis of women's experience to delve into issues with staff. I chose staff from various places to get a representative sample on several points. I started with two points: potential jobs at the agency in which staff interacted with clients (i.e. off site coordinators, hospital coordinators, providers, case coordinators for in-home services and placement services) to get a broad understanding of the roles of staff in clients' lives, and minority and majority

workers (to test if personal and professional merged) and later added length of time working for the agency's predecessor agencies as well as those newly hired at the agency because old timer and newcomer status, in addition to colour, appeared to informally separate workers and alter worker relationships (front-line to front-line as well as front-line to manager) at the agency. In relating women's experiences to staff in the interviews, I concentrated on a few themes such as the notion that women remember kind individuals but not the agencies they work for, meaning attributed to relying on families to advocate for care, women's desire to remain social beings, and buffering acts of racism. In particular, the arrangement for service between "Eldercare" and provider agencies was very complicated for women so I spoke to workers about this.

Recruiting staff to interview proved a daunting task. Very few people volunteered despite my attempts to describe the research and the interview (as well as reassuring staff about confidentiality) at team meetings. I had to develop a more aggressive stance, personally approaching staff to be interviewed. This I began doing once I got a handle on how the agency as a whole worked and who had which positions. Informal discussions also helped to identify participants, particularly those that were seen as "leaders" at the agency, who were identified as "having very relevant information to share" or who were either identified as "long timers" or "newcomers". I also relied on one of the women of colour at the agency who, herself being "politicized about issues of race at the agency" was able to identify and recruit other women of colour at the agency who might have otherwise been unsure about participation.

At this point I also sought out an interview with a mainstream senior woman who is active as an advocate in several mainstream advocacy agencies for seniors in the health

community. One of these agencies is very actively following *Eldercare*. This is a woman I had heard speak at a conference about the agency and wanted her input into the study to see how mainstream advocates think about the agency and if they understand issues of race alongside the political issues which they address. This organization had been collecting stories of complaint about the agency over the summer and we discussed this as well.

By interview #4 I had already adjusted the guide to include some of the results from the previous interviews (*selective sampling*). It was particularly important to do this checking at the time of this 4<sup>th</sup> interview because I chose this person to be slightly different (*negative case analysis*) from the other interviews in order to test out emerging themes (*member checking*) I had found in the previous 3 (*constant comparative method*). The first 3 interviews were done with women who perhaps were not well aware of the services available in their area or who had language barriers. Although two were chosen by convenience (referred to me by case coordinators because of their ethnic status primarily and also partly because of their situations: Elderly South Asian woman who lived with her daughter and does not speak English and who has had some “difficulties with the system” as was put by the worker and one Greek woman who did not speak English and was “bedridden”), one interview was purposely chosen (*purposive sampling*) to be someone who has not historically been connected to the agency (*negative case analysis*) (she was referred by a community organization and had only recently accessed agency services) (Interview #2, case #003). None of these three women were considered by staff to be “knowledgeable about community services or the agency” and therefore faced particular problems. I wanted to chose, for my fourth interview, someone who, in the eyes of staff,

had a good understanding of the services offered to compare and contrast with those people who had no idea how to get to services (*selective sampling*). Interview #4 (Case 005) was such an interview. She was referred to me as someone who is “on the ball and has a lot to say”. What does “on the ball” mean in comparison to those others I interviewed? This would become another theme to look at and discover. Some of the adapted questions, therefore referred back to some of the findings that emerged from the first 3 interviews (*constant comparative method; revising questionnaire; member checking*). In particular though I wanted to get an understanding about how someone who was seen as “knowledgeable” accessed services in comparison to others . I also asked about or paid attention to the following themes (*working hypotheses*): 1) the idea of being gregarious to avoid racism or discrimination; 2) Also asking if she feels different with the cutbacks because this came up in other interviews as well; 3) Also ask about the idea that some people really need family to help to get services and find out if that was this woman’s experience; 4) Ask her why her experience of advocating for herself was different from others; 5) Also confirm question about immigration and employment as core experiences.

Interview #1, case #002 was an interview which was not tape recorded and in which the daughter also participated. They were of South Asian origin. So of my first four interviews I got a broad spectrum of people, 2 visible minority women (one South Asian (interpreted), one Black woman (I did the interview) and two white ethnic women (one Greek interpreted interview and one Iranian I did the interview) (*description of sample to enhance transferability*).

After these interviews were done and preliminary analysis completed, I began interviewing other constituents. Interviewed 5 agency staff and one community advocate during this phase (*theoretical sampling-selective*).

I scheduled a RAG meeting. I used my preliminary analysis with older women to introduce to focus group and discuss (*triangulation; peer debriefing; member checking*). This group served as a kind of verification process for me, also a means of getting further understanding of issues from the standpoint of workers in the agency. So it was both a means of collecting data and furthering my analysis and understanding of issues and checking out analysis. Discussion which resulted explained, expanded and adapted future questions and analysis.

I then went to interview other older women, agency staff and persons working in ethno-specific agencies to confirm, disconfirm concepts and categories (*member checking; negative case analysis*). At this point I adapted the guide (*dependability*) to include some of the concepts I had discovered in the preliminary analysis.

It was also at this point that I decided not to interview families. The culture of the place was so focused on families that I did not want to contribute to this. In fact, I did not want to rely on family to interpret for older women. In some cases, family members did attend the interview with their elderly family member. This was, of course, the choice of the older woman and was allowed.

It must be stated that I often went with participants, talking about what they wanted to talk about and simply guided the interview at several points. This sometimes led to information which was not useful but more often than not, it led to a deeper understanding of where the women were at and what their experience was. For example, a

theme that emerged was that women wanted to be seen as more than just their illness, they in fact saw employment and immigration experiences as more core or central to their life history and central to their experiences in Canada's health care system than the act of being sick was. If I had simply focused on my guide I would have missed this central point (*subjectivity*).

I chose to continue interviewing staff despite having reached my initial maximum of 5-7 staff. I did this because I had felt that I had not achieved theoretical saturation and needed to go back to interview others to talk about these themes (*constant comparative method*). They included such things as experiences of racism and discrimination, agency processes and practices of multiculturalism and the construction of language interpretation. These items were particularly relevant because there appeared to be little consensus around such issues. In order to understand how these practices were shaped and understood and reflective of agency procedures, guidelines and philosophy as well as systemic ideology and governmental priorities, I felt I needed to ask a few more workers some of these questions (*negative case analysis*). I was also intrigued by the way workers responded to questions about what theories or experiences they used in working with ethno-racial minority clients. These answers were vague and unclear, as though they had never considered these kinds of questions (although this was not consistent) before so that I needed to address this issue more (*triangulation*).

During and after interviewing staff, I began to do more PO of home visits and intake, and informal discussions around the office to get a feel for how it practices operates versus how they are talked about (*triangulation; prolonged engagement*). I also wanted to test out the issue of how the "medical model" applied to the everyday work

with older ethnic women. I also did some PO of Management and Board activities and how the board operates to get an idea of the link between management and policy and client service and access. So I attended the Annual Meeting, some team Management meetings and then got permission to attend Board meeting after the summer was over. Also from there decided to attend a committee meeting which deals directly with ethno-specific communities in outreach and membership (*prolonged engagement*). From this PO meeting, I felt I needed to interview a couple of Board members who had seemed to me to be directly impacted by ethno-racial issues. I also found out about an Ethno-Racial Council run by all 6 *Eldercare*s and decided to PO that as well.

I wanted to get a feel for how the community handled these issues of race. One of my interviews with a community representative had stated that little work is done in this area and that few minority communities are represented on coalitions. She invited me to a senior's umbrella organization meeting to verify this (*prolonged engagement*). At this meeting I talked to several people and realized that many of these organizations consider themselves multicultural and feel that they have a specific take on "diversity" different from that of ethno-specific agencies. They also feel they represent minority communities around the table, even though these communities are themselves not present. I realized that many feel there is a difference between the roles and experiences of ethno-specific versus multicultural agencies and so I decided to do an interview at another multicultural agency to talk about what this might mean for clients in getting to care (*discriminate sampling, triangulation*).

Finally, it became clear that the primary community player for "Eldercare" is the hospital, as hospital referrals are the most common point of access and so I felt it

necessary to interview a constituent person, who was not a staff member of the agency, (hospital worker) to get their opinion about the process of access for ethno-racial clients (*discriminate sampling; triangulation*). This completed my data collection.

**1. #1: Do interview with ED - May 28**

**begin collecting documents:**

**Information on agency, governing documents, Bills and Laws around LTC, agency by-laws, values papers, organizational chart, newspaper articles, letters and reports about divestment, documents passed out at Team Management meetings.**

**2. DO 4 interviews with older women June 27- July 6**

**#2: 1 non-English speaking visible minority, referred by agency staff, with daughter, not well connected**

**#3: 1 English speaking visible minority, referred by outside community agency, not well connected, just got on agency service**

**#4: 1 non-English speaking, white ethnic origin, not well connected, referred by agency staff**

**#5: After 3 wanted one interview of woman who staff felt were "connected" or "knowledgeable". English speaking, white ethnic minority**

**3. #6: Do 1 interview with white elderly woman who is advocate in the community to politicize understanding of development of agency and see how white advocacy organization conceptualized ethnicity and saw older women's stories also to see if white elderly woman saw some of issues similarly... July 7**

**4. Begin interviews with staff July 16-July 21**

**#7: Off-site coordinator, white woman working in agency for medium time.**

**#8: Off -site hospital coordinator, white woman working in agency for long time.**

**#9: Visible minority woman working for agency long time.**

**#10: Visible minority woman working for agency long time.**

**#11: White woman working for agency medium time.**

**PO:**

**Up to this point, I did some PO work. While I would have preferred to wait to begin my PO until having gained a handle on the process of work through interviews, I needed to go with what was happening at the agency and in my research endeavors. These Pos, therefore, occurred at this point primarily because of scheduling. For example I wanted to attend the Annual General meeting and this occurred early on in June. I also went on a home visit with one of the off-site coordinators and observed two meetings between the off-site coordinator and provider nurses.**

**Document Collection:**

**I began collecting intake and assessment documents, placement documents, and a document entitled "the rationale for referring to social work". I began asking around for any documents on eligibility criteria. The only document I was able to locate was given to me by one of the Team Managers and it was not what I was after. It was a paper that gave very generalized information on eligibility but did not lay out how eligibility actually operated. I finally found what I needed later on during a PO with an intake worker and found a detailed description of eligibility criteria on her desk.**

**5. Focus Group 1. Talk about older women transcripts. July 23**

**6. Expand Inquiry. July 31- September 14**

**#12: Older woman, English- speaking, visible minority receiving no services. July 31**

**#13: Ethno-specific organization (South Asian) August 4**

**#14: Ethno-Specific organization (South Asian) August 21**

**#15: Visible minority worker September 12**

**#16: Multi-cultural organization (Greek worker) Sept. 14**

**PO starts in earnest here:**

Up to this date, I had done participant observation at 2 Management Team Meetings, Annual Meeting of the Board, One Home Visit, One Off-Site meeting with provider nurses. But once I have saturated, to a greater degree the way people talk about their work and the process of servicing older women, wanted to expand data collection through PO. Community Resources meeting, Intake (\*2 times), more home visits. Get an idea of agency work and Community thinking in the area.

**Documents Expanded to Include:**

**Guidelines for assessment of eligibility for in-home services, occurrence report forms, re-assessment forms.**

**7. Older women interviews August 7- August 25 to get ethnic representation and to ensure that I had a majority of non-English speakers interviewed as the issue of language is central to access. Received Sept. 15**

**#17: Older woman, Chinese ethnic origin, non-English speaking**

**#18: Older woman, Chinese ethnic origin, non-English speaking**

**#19: Older woman, Italian ethnic origin, non-English speaking**

**#20: Older woman, Italian ethnic origin, non-English speaking**

**#21: Older woman, Greek ethnic origin, non-English speaking**

**8. Second Focus Group: Staff Interviews Analysis September 15**

**9. Expand Inquiry September 15-November 5**

**#22: Team Manager, white male**

**#23: Team Manager, white female**

**#24: Visible minority worker**

**#25: Ethno-Specific Organization, Chinese agency**

**#26: Ethno-Specific Organization, Multi-cultural agency, Black program**

**#27: Multi-cultural agency**

**#28: Focus Group, 2 board members**

**#29: Multicultural agency, focus group meeting with staff**

**#30: Hospital Workers**

**10. Final Research Advisory Group Meeting - November 10- Census data**

**During this period I also did several POs with basic intent of seeing board in action (Board meeting, committee meeting), community in action (umbrella organization) and the 6 *Eldercare*s and how they deal with diversity (Ethno-racial Council meeting).**

**Documents here expanded to include:**

**Minutes from board of directors' meetings, budget statements, minutes of ethno-racial advisory committee, hand-outs from meetings attended.**

**APPENDIX 2**  
**TABLE SPECIFICATIONS: CENSUS 1996**

## TABLES ON ETHNICITY

**Census:** 1996

**Geography:** 5 areas, including Canada, the province of Ontario, 2 CMA (Toronto, Montreal) and 1 CSD (Scarborough)

**Universe:** Total Population in **Economic Families** within private Households (20%)

**Table 1:** Population in Economic Families by Economic Family Structure showing Sex variable (3) by Age variable (4) by Year of Immigration variable (4) by Knowledge of Official Languages variable (3) by Visible Minorities variable (6) by Ethnic Origin variable (5) by Income Status variable (3).

(12,960 cells)

**Universe:** Total Population of **Unattached Persons** within private Households (20%)

**Table 1:** Population of Unattached persons showing Sex variable (3) by Age variable (4) by Year of Immigration variable (4) by Knowledge of Official Languages variable (3) by Visible Minorities variable (6) by Ethnic Origin variable (5) by Income Status variable (3).

(12,960 cells)

### Variable Details

#### Sex (3)

1. Male
2. Female
3. Total

#### Age (4)

1. 0-17 years
2. 18-64 years
3. 65+ years
4. Total

**Year of Immigration (4)**

1. Non-Immigrant
2. Immigrant - Pre 1976
2. Immigrant 1977+
3. Total

**Knowledge of Official Languages (3)**

1. English and/or French
2. Neither
3. Total

**Visible Minority (single response) (6)**

1. Total Population
2. Visible Minority Black
3. Visible Minority South Asian
4. Visible Minority Chinese
5. Visible Minority Filipino
6. Other

**Ethnic Origin (single & multiple response) (5)**

1. Total Population
2. Greek
3. Italian, excluding Greek
4. Portugese, excluding Greek and Italian
5. Other

**Poverty Status (3)**

**FUNCTION CELLS**

1. Above 1996 Low Income Cut Off
2. Below 1996 Low Income Cut Off
3. Total

**APPENDIX 3**  
**INFORMATION LETTERS**  
**&**  
**CONSENT FORMS**



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## **Information Letter For Older Women and Their Families**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

Eldercare has consented to participate in a study called *An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women*. The purpose of this study is to gather information about the experiences of ethnic and racial minority older women in accessing a broad range of health and social services in the community and to examine the role of Eldercare in shaping access to community services.

Health care professionals know very little about the problems older ethnic and racial minority women and their families face in getting to and using health care and social services in the community. The goals of this study are to broaden our understanding of what it is like to access health care services and to make recommendations that will improve how governments, institutions, organizations and professionals make services available to older ethnic and racial minority women.

If you agree to take part in the study, you will participate in a tape recorded interview of approximately two hours, conducted at your convenience. The interview is semi-structured and designed to cover specific aspects of your experience including what services you need, how you go about finding these services, what stops you from getting services, and whether or not services meet your needs.

Participation in the study is entirely voluntary, and consent can be withdrawn at any time. Women and their families who agree to be interviewed will not be identified by name, and information given will not be attributed to individuals either verbally or in writing. In no way will participation in the study affect the services clients receive at the agency. If you choose, you may, at any time, withdraw from the project without penalty of any kind. You will also have the right to speak off the record and/or to have part or all of your taped interview erased.

All recorded interviews will be coded by number to ensure anonymity of participants. Tapes will be transcribed for analytical purposes; any identifying information will be removed from the transcription.

I hope you will choose to participate in the study, since the results may help us better understand the experience of accessing care and contribute to the development of knowledge about health care services. I will regularly be available in the agency during the study period and am available to answer any questions you may have about the research.

This study, which fulfills part of my doctoral requirement at the University of Toronto, is funded by a Social Sciences and Humanities Research Council of Canada Fellowship.

Thank you for your cooperation.

**Shari Brotman, MSW**  
Doctoral Candidate, Faculty of Social Work, University of Toronto



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**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

**Consent Form**

**Interviews with Older Women and Their Families**

I understand the research project and what is involved in participating in it. The research project has been explained to me and any questions that I had, have been answered. I also understand the benefits of joining the research study. The possible risks and discomforts have been explained to me. I know that I can ask any questions I have about the study or the procedures at any time. I have been assured that all information about me will be kept confidential and that no information which could identify me will be released.

As a participant in an interview I have agreed to have the interview audio-taped. I understand that my participation in this study is completely voluntary and that my decision whether or not to participate will not influence the services I receive from the agency. I also understand that I can withdraw my participation at any time and that I have the right to ask to have the tape recorder turned off and/or to have part or all of my taped interview erased.

I hereby consent to participate in an interview.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name (please print): \_\_\_\_\_

I have carefully explained the nature of the research. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and the demands, benefits and risks involved with participating in an interview in this study.

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Researcher (please print): \_\_\_\_\_



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## **Information Letter For Staff of Eldercare**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

Eldercare has consented to participate in a study called *An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women*. The purpose of this study is to gather information on the experiences of ethnic and racial minority older women in getting to and using a broad range of health and social services in the community and the role of Eldercare in shaping access to community services. I will be asking women and their families, Eldercare staff, as well as professionals working in ethno-specific agencies in the community a series of questions regarding what services are needed by older ethnic and racial minority women, how they go about finding these services, what stops them from getting services, and if these services meet their needs. Currently, gerontologists are limited in their understanding of the process of access among older ethnic and racial minority women and their families and the problems faced in accessing care in the community. The goals of this study are to broaden our understanding of what it is like to access health care services and to make recommendations that will improve how governments, institutions, organizations and professionals make services available to older ethnic and racial minority women.

The study will involve observation of agency procedures by the investigator and formal and informal discussions with personnel concerning issues related to older ethnic and racial minority women's access to health care in the community. I will also review agency and government documents concerned with ethno-specific services. Interviews are not for the purpose of evaluating work performance but to elicit information from agency workers about how access is experienced and the process by which ethnic and racial minority seniors get care.

The research requires detailed information about your experience working with ethnic and racial minority elderly women. If you agree to participate, the following expectations will apply:

1) A tape recorded interview of approximately two hours will be conducted, at your convenience. The interview is semi-structured and designed to cover specific aspects of the process and procedures through which older ethnic and racial minority women access care through Eldercare. This is not an evaluative interview. It is descriptive and explanatory, seeking to describe actual work processes and to explain how these processes may affect the way access is experienced by ethnic and racial minority elderly women.

2) You may also be asked to be observed in the process of doing an intake, assessment or case management intervention with a client for the purposes of illuminating the process of working with ethnic and racial minority elderly women. During or directly after this participant observation, notes will be taken on the interaction. No taping will take place during this observation.

**3) A follow-up informal interview of approximately one hour may be conducted to review analysis and in order to ensure authenticity of information recorded and analyzed.**

**Participation in the study by agency personnel is invited but is entirely voluntary, and consent can be withdrawn at any time. Participants also have the right to speak off the record and/or to have part or all of their tape erased. Personnel agreeing to be interviewed will not be identified by name, and information given will not be attributed to individuals either verbally or in writing. All recorded interviews and participant observation notes will be coded by number to ensure anonymity of participants. Tapes will be transcribed for analytical purposes; any identifying information will be removed from the transcription. You may choose to participate only in the interview or participant observation. In no way will participation in the study affect employees' standing in the agency.**

**I hope you will choose to participate in the study, since the results may reveal information about how older ethnic and racial minority women experience health care services and contribute to the development of knowledge about health care access. I will regularly be on site in the agency during the study period and am available to answer any questions you may have about the research.**

**This study, which fulfills part of my doctoral requirement at the University of Toronto, is funded by a Social Sciences and Humanities Research Council of Canada Fellowship.**

**Thank you for your cooperation.**

**Shari Brotman, MSW  
Doctoral Candidate  
Faculty of Social Work  
University of Toronto**



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**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

**Consent Form**

**Key Informant Interviews with Eldercare Staff**

I acknowledge that the research procedures described on the attached "Information Form" of which I have a copy, have been explained to me and that any questions I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I also understand the benefits of joining the research study. The possible risks and discomforts have been explained to me. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that information about me will be kept confidential and that no information about me will be released or printed that would disclose my personal identity.

As a participant in a key informant interview I have agreed to have the interview audio-taped. As a participant in an observation, I understand that notes will be taken during or immediately after this observation. These participant observations will not be tape recorded. I understand that my participation in this study is completely voluntary and that my decision to participate or not will not influence my employment at the agency. I further understand that I am free to withdraw my participation from the study at any time, to speak off the record and/or to have all or part of my taped interview erased.

I \_\_\_\_\_ (please print), agree to participate in:

key informant interview (two hour interview and one hour follow-up interview): \_\_\_\_\_

participant observation: \_\_\_\_\_

(you may check one or both of these items)

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

I have carefully explained the nature of the research. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and the demands, benefits and risks involved with participating in a key informant interview and a participant observation.

Signature of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Researcher (please print): \_\_\_\_\_



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## **Information Letter For Community Workers in Ethno-Specific Agencies**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

Eldercare has consented to participate in a study called *An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women*. The purpose of this study is to gather information on the experiences of ethnic and racial minority older women in getting to and using a broad range of health and social services in the community and the role of Eldercare in shaping access to community services. We will be asking women and their families, Eldercare staff, as well as staff working in ethno-specific agencies in the community a series of questions regarding what services are needed by older ethnic and racial minority women, how they go about finding these services, what stops them from getting services, and if these services meet their needs. Currently, gerontologists are limited in their understanding of the process of access among older ethnic and racial minority women and their families and the problems faced in accessing care in the community. The goals of this study are to broaden our understanding of what it is like to access health care services and to make recommendations that will improve how governments, institutions, organizations and professionals make services available to older ethnic and racial minority women.

The study will involve key informant interviews with agency staff concerning issues related to older ethnic and racial minority women's access to health care in the community. Interviews are conducted for the purpose of eliciting information from community workers about how access is experienced and the process by which ethnic and racial minority seniors get care.

The research requires detailed information about your experience working with ethnic and racial minority elderly women. If you agree to participate, the following expectations will apply:

1) A tape recorded interview of approximately two hours will be conducted, at your convenience. The interview is semi-structured and designed to cover specific aspects of the process and procedures through which older ethnic and racial minority women access care through Eldercare and your agency. This is not an evaluative interview. It is descriptive and explanatory, seeking to describe actual work processes and to explain how these processes may affect the way access is experienced by ethnic and racial minority elderly women.

2) A follow-up informal interview of approximately one hour may be conducted to review analysis and in order to ensure authenticity of information recorded and analyzed.

Participation in the study by community workers is invited but is entirely voluntary, and consent can be withdrawn at any time. Participants also have the right to speak off the record and/or to

have part or all of their tape erased. Workers agreeing to be interviewed will not be identified by name, and information given will not be attributed to individuals either verbally or in writing. All recorded interviews and participant observation notes will be coded by number to ensure anonymity of participants. Tapes will be transcribed for analytical purposes; any identifying information will be removed from the transcription.

I hope you will choose to participate in the study, since the results may reveal information about how older ethnic and racial minority women experience health care services and contribute to the development of knowledge about health care access. I will regularly be on site in the agency during the study period and am available to answer any questions you may have about the research.

This study, which fulfills part of my doctoral requirement at the University of Toronto, is funded by a Social Sciences and Humanities Research Council of Canada Fellowship.

Thank you for your cooperation.

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**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

**Consent Form**

**Key Informant Interviews with Community Workers in Ethno-Specific Agencies**

I acknowledge that the research procedures described on the attached "Information Form" of which I have a copy, have been explained to me and that any questions I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I also understand the benefits of joining the research study. The possible risks and discomforts have been explained to me. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that information about me will be kept confidential and that no information about me will be released or printed that would disclose my personal identity.

As a participant in a key informant interview I have agreed to have the interview audio-taped. I understand that my participation in this study is completely voluntary and that my decision to participate or not will not influence my employment or my relationship to the agency or university. I further understand that I am free to withdraw my participation from the study at any time and that I have the right to speak off the record and/or to have part or all of my tape erased.

I hereby consent to participate in a key informant interview ( two hour interview and one hour follow-up interview).

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name (please print): \_\_\_\_\_

I have carefully explained the nature of the research. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and the demands, benefits and risks involved with participating in a key informant interview in this study.

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Researcher (please print): \_\_\_\_\_

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic and Racial Minority Women**

**Shari Brotman**  
Ph.D. Candidate Faculty of Social Work, University of Toronto

## **The Research Problem**

Over the past several years there has been an increased focus placed on improving seniors' access to elder care by a broad range of professionals in Canada. Recent initiatives have emerged due to concerns regarding the difficulties seniors were having maneuvering through the large and increasingly 'fragmented' array of services available in the community. In specific, elderly ethnic and racial minority women have faced and continue to face the greatest number of problems accessing elder care. This is especially problematic considering that these women suffer from higher rates of chronic illness, disability and disease than any other group. These facts are extremely important to our understanding of access given that the majority of the elderly population is made up of women and that the proportion of ethnic and racial minority persons among them is growing rapidly.

Despite these facts, little information is available on how older ethnic and racial minority women actually experience access. Our understanding has been limited by the ways in which the field of gerontology has conceptualized and carried out research on these women. Problems in the literature include: (1) a failure to define the nature and parameters of access; (2) a lack of focus on the relationship between individual (i.e. client, family and front-line workers), institutional (i.e. transportation, location, language and cultural orientation of the organization, relationship to the community) and structural (i.e. funding, government policies, restructuring of health care) issues and the influence of these on older women's access; (3) little recognition of older women's differential experience of access; (4) a focus on folkloric explanations of differential access experienced by ethnicity and racial minority seniors; and (5) few discussions about the influence of "physical need" on the way access gets constituted. Since older ethnic and racial minority women with disabilities are the ones most profoundly affected by our current emphasis on access and since they have the most to gain or lose by these new efforts to streamline elder care services, it is essential that gerontologists undertake research projects which seek to gain a better understanding of the process of access and the way in which this process is experienced by older ethnic and racial minority women.

## **The Research Questions**

This study is anchored in understanding how things happen the way they do for older ethnic and racial minority women. My research questions are:

1. How do we understand older ethnic and racially diverse women's experiences of access to elder care?
2. What is the relationship between this experience and the work processes of elder care organizations?

This study will attempt to create a deeper, richer understanding of access, one which is based on broader definitions than those currently used by gerontologists in both Canada and the United States and which is more reflective of older women's experience. The goal of this study is to create a "dynamic map" of the process of accessing elder care from the standpoint of ethnic and racial minority women. I hope to explore older women's everyday lived experience of accessing

care and situate these experiences within the working processes of Eldercare. In turn, this research will attempt to situate the work of Eldercare within the larger community and within the workings of health care and governmental institutions. I want to uncover what organizes the experience of access and what maintains it? Emphasis will be placed on exploring the complex of actions which define and shape access to elder care, including those actions which are articulated through the practices and processes of the (i.e. how people know about and get to, assessment and referral practices, case management models and approaches, policies and procedures which govern the treatment of gender, ethnicity and race) and which manifest themselves between clients, their families, front-line workers, managers, ethno-specific communities and state apparatuses (through the articulation of policy and other texts). This will enable me to consider how macro structures impact upon the micro level as well as to document the popular and professional understandings of how it is that access operates at the local level. It is hoped that by illuminating the process of access we will more thoroughly understand the complex and varied issues which play into access as experienced by older ethnic and racial minority women and, as a result, be better prepared to adapt services to meet their needs.

### **Eldercare-Area P as Research Site**

Eldercare of Area P is very well placed as a site for my research for a number of reasons. First, Eldercare is specifically designed to address issues of access and facilitate access to community care services and thus, has an integral role to play in the development of new understandings of how access operates as well as new models aimed at improving access for vulnerable populations across Ontario. Second, since the community of Area P is very ethnically and racially diverse, the issue of access for ethnic and racial minorities takes on increased importance here.

### **Methods**

My study is based on a qualitative research methodology known as "Institutional Ethnography (IE)" (Smith, 1987). The strength of this methodology is that it provides direction for research questions, design, data collection and analysis based on the following premises: (1) women's voices have been largely absent in social science research and in order to address this exclusion, we must develop research designs which are based on women's experience (standpoint); (2) we can only know about the system through our experience of it and thus we must seek to explore how things operate the way they do (process) in particular settings; (3) there are social relations which exist within all interactions between women and 'institutions' or 'systems' such as elder care, but these are not necessarily visible to individual women themselves, thus we must develop research designs which seek to explore how macro structures (i.e. government policies, health care institutions) inform micro practices (i.e. local organizations, relations between front-line workers and clients).

In order to understand these complex processes I will be engaging in the following research activities:

- (1) interviews with older ethnic and racial minority women, both clients of and non-clients.**
- (2) interviews with community professionals working with elders in ethno-specific settings.**

## **An Institutional Ethnography of Elder Care Shari Brotman**

- (3) interviews with front-line workers and managers at Eldercare.**
- (4) participant observation with professionals and clients at Eldercare and/or in the community.**
- (5) analysis of documents of the Ontario Ministry of Health and Eldercare in relation to elder care policies and programs dealing with the issues of diversity.**

**Rather than doing a complete survey of the field, my intent is to develop a map or model of access from the position of ethnic and racial minority elderly women. My focus is on developing direction or theory, not on coming up with definitive answers as to how everyone feels or experiences access. Since we do not yet even know what questions to ask, this research is intended as a beginning attempt to expand the horizons of the discussion. So, although the number of interviews I will do cannot be determined at the outset (this will depend on analyzing data as I go), it will not need to be exhaustive. I estimate a total of 20 interviews overall (clients and professionals included).**

### **Participation and Confidentiality**

**Interviews with agency workers will last approximately 1.5-2 hours and will be recorded and transcribed. The duration of participant observations in specific settings (i.e. home visits, assessments, meetings) will depend entirely on the setting. Interviews are not for the purpose of evaluating work performance but to elicit information from agency workers about how access to elder care is facilitated and organized for ethnic and racial minority women. Participation in the study by any agency personnel is invited but is entirely voluntary and consent can be withdrawn at any time. Personnel agreeing to be interviewed will not be identified by name, and information given will not be attributed to individuals either verbally or in writing. In addition, the organization will be referred to in the final text only by "Eldercare-Area P". All references to specific places and persons will be altered to ensure confidentiality is maintained.**

**I hope to be able to share preliminary analyses/thoughts/observations with research participants and members of Eldercare-Area P in order to ensure accuracy and authenticity. This may require doing shorter follow-up sessions with those involved in the project or with other key informants.**

### **Time Line**

**May 1-June 4 1998 : Proposal goes through the University of Toronto ethics screening process**  
**June 5-October 15 1998: Data Collection and Initial Analysis**  
**October 15- December 31 1998: Continued Data Analysis**  
**January 1-August 31 1999: Write Up**

**Active on-site data collection at Eldercare-Area P will take place during the five month period between May 9 and October 15 1998. At this time I hope to be on- site 3 days per week depending on interview scheduling and community visits. It is expected that I will be out in the community doing interviews with older women and with professionals working in ethno-specific community agencies on a regular basis so that not all data collection time will be spent at the agency.**

**Background Information on Investigator**

I have had a long-standing interest and commitment to working with seniors and ethnic communities both as a social work practitioner and researcher. I received my Bachelor's and Master's degrees in Social Work from McGill University. Upon completing my Master's degree in 1991, I worked for three years at a homecare agency serving the Jewish elderly in Montreal. While there, I ran caregiver support groups, did outreach and assessments and coordinated a research project on the expressed needs of family caregivers of community-residing frail elders. Between 1994 and 1997, I worked at the McGill University School of Social Work Consortium for Ethnic Studies directing large-scale demographic analyses of and with several ethnic and racial communities across Canada including Black, Jewish, Japanese and Chinese communities in cities such as Montreal, Toronto, Halifax and Vancouver. I have presented and published in the area of ethnicity and aging over the past several years. I began my Ph.D. studies in 1995 and have recently accepted a tenure track appointment at the School of Social Work, McGill University beginning in January 1999.

**References**

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**MEMO**

**To: Eldercare Staff**  
**From: Shari Brotman, PhD Candidate-Faculty of Social Work, University of Toronto**  
**Re: Research Project**  
**Date: May 12, 1998**

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic and Racial Minority Women\***

Eldercare has recently consented to participate in a study called *An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic and Racial Minority Women*. The purpose of this study is to gather information on the experiences of ethnic and racial minority older women in getting to and using a broad range of health and social services in the community and the role of Eldercare in shaping access to community services. As the principal investigator of this study, I will be asking women and their families, Eldercare staff, as well as professionals working in ethno-specific agencies in the community a series of questions regarding what services are needed by older ethnic and racial minority women, how they go about finding these services, what stops them from getting services, and if these services meet their needs. I will also be reviewing agency and government documents concerned with access and ethno-specific services. Currently, gerontologists are limited in their understanding of the process of access among older ethnic and racial minority women and their families and the problems faced in accessing care in the community. The goals of this study are to broaden our understanding of what it is like to access health care services and to make recommendations that will improve how governments, institutions, organizations and professionals make services available to older ethnic and racial minority women.

I am writing to you at this time, to ask for your help in conducting this research. In the next few weeks I am hoping to identify a number of people who are willing to participate in the study in a variety of ways:

**(1) Research Advisory Group:**

I am looking for 5-8 people interested in participating in a Research Advisory Group. This Advisory Group will help guide the research process at Eldercare, review research materials (including interview guides and consent forms) and discuss data collection procedures and analysis. The Group will meet on an ongoing basis (approximately once per month) for the duration of the project (May through November). Meetings will last about 1 ½ hours.

Previous research experience is not necessary. Participants in the Research Advisory Group need only have an interest in the research topic and/or experience working with older ethnic and racial minority women. This would be a good opportunity to learn more about the process of doing social science research and to help shape the research project.

If you are interested in joining the Research Advisory Group, please get in touch with me by phone (extension 0000) by May 25<sup>th</sup>. The first meeting to introduce the study and review materials will take place during the week of May 25<sup>th</sup>.

## **(2) Identification of Research Participants:**

### **Older Women and Their Families:**

Between May 19<sup>th</sup> and June 19<sup>th</sup>, I will be looking to interview 4 older women (65+) about their experiences of accessing care in the community. Family members of these women may also be selected for interview. I hope to find participants from those ethnic communities which are highly represented in Area P (these include Black, Chinese, South Asian, Filipino, Greek and Italian persons). Participants need not be current clients of Eldercare. In cases where the participant speaks a language other than English, documents will be translated and a trained interviewer who speaks the language of the participant will obtain informed consent and conduct the interview. If you think you know of someone who would be appropriate and interested in participating, please contact me by phone (extension 0000).

### **Eldercare Staff:**

The research also requires detailed information about staff people's experience working with ethnic and racial minority elderly women. If you agree to participate in the study, a tape recorded interview of approximately two hours will be conducted, at your convenience. The interview is semi-structured and designed to cover specific aspects of the process and procedures through which older ethnic and racial minority women access care through Eldercare. This is not an evaluative interview. It is descriptive and explanatory, seeking to describe actual work processes and to explain how these processes may affect the way access is experienced by ethnic and racial minority elderly women.

You may also be asked to be observed in the process of doing an intake, assessment or case management intervention with a client for the purposes of illuminating the process of working with ethnic and racial minority elderly women. During or directly after this participant observation, notes will be taken on the interaction. No taping will take place during this observation.

Participation in the study by staff is invited but is entirely voluntary, and consent can be withdrawn at any time. Participants also have the right to speak off the record and/or to have part or all of their tape erased. Personnel agreeing to be interviewed will not be identified by name, and information given will not be attributed to individuals either verbally or in writing. All recorded interviews and participant observation notes will be coded by number to ensure anonymity of

## **An Institutional Ethnography of Elder Care Shari Brotman**

participants. Tapes will be transcribed for analytical purposes; any identifying information will be removed from the transcription. You may choose to participate only in the interview or participant observation. In no way will participation in the study affect employees' standing in the agency.

I hope you will choose to participate in the study (either through the Research Advisory Group, as a research participant and/or by identifying older women interested in participating), since the results may reveal information about how older ethnic and racial minority women experience health care services and contribute to the development of knowledge about health care access. I will regularly be on site at Eldercare during the study period and am available to answer any questions you may have about the research. I will post my hours at my desk so that you will know when I will be in the office.

Thank you for your cooperation.

Shari Brotman  
(extension #0000)

• This study, which fulfills part of my doctoral requirement at the University of Toronto, is funded by a Social Sciences and Humanities Research Council of Canada Fellowship.

## **APPENDIX 4 INTERVIEW GUIDES**

**Demographic Information: Older Women and Their Families**

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**Name:** \_\_\_\_\_ **ID Number:** \_\_\_\_\_

**Age:** \_\_\_\_\_

**Ethnic Origin:** \_\_\_\_\_

**Living Arrangement:**      **Alone** \_\_\_\_\_  
   **With Spouse** \_\_\_\_\_  
   **With Child** \_\_\_\_\_  
   **With Other Family Member** \_\_\_\_\_  
   **With Friend** \_\_\_\_\_  
   **Other** \_\_\_\_\_

**Immigration Status:** Immigrant \_\_\_\_ **Year of Arrival in Canada** \_\_\_\_\_  
   **Born in Canada** \_\_\_\_\_

**Mother Tongue:** \_\_\_\_\_

**Knowledge of Official Languages:**      **English and/or French** \_\_\_\_\_  
   **Neither** \_\_\_\_\_

**Health Status:** \_\_\_\_\_

**Interview Conducted in:** \_\_\_\_\_ **Date of Interview:** \_\_\_\_\_

**Name of Interpreter:** \_\_\_\_\_

**Relative:** \_\_\_\_\_

**Name:** \_\_\_\_\_ **ID Number:** \_\_\_\_\_

**Age:** \_\_\_\_\_

**Ethnic Origin:** \_\_\_\_\_

## **Interview Guide: Older Women & Their Families**

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**Here's what we want to know:**

**WHAT DO YOU NEED?  
DID YOU RECEIVE IT?  
HOW DID YOU RECEIVE IT?  
IF YOU RECEIVED IT, HOW WAS IT?  
IF YOU DIDN'T RECEIVE IT, WHY NOT?**

## **Interview Guide: Older Women & Their Families**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

#### **Probing Questions That Can Be Asked For Each Major Section:**

#### **SERVICES NEEDED (What did you need?)**

- What services did/do you need? Use?**
- What were/are your main concerns/feelings at that time?**
- What were/are the main concerns that you had/have to cope with?**
- Was/is your need immediate?**
- Did you know it was a need or did someone tell you?**
- Which services were most important to you? Least important? Why?**

#### **SERVICES AVAILABLE (Did you receive it?)**

- Did you get the service?**
- Who provided it?**
- Was the provider a friend or relative or an agency?**
- How much did you get?**
- Was it enough?**
- How did you hear about the service?**
- Were you referred? By whom?**

#### **SERVICE ACCESS (How did you receive it?)**

- How did you get to the provider agency? What did you do first? Last?**
- Did you need the help of others to use the service? To take you there? To provide follow up?**
- Could getting services be made easier? How? In what ways?**
- If someone you know needed health care or other services, what would you tell them to do? Why?**
- What is it/would it be like to be a [ethnic or racial group] woman using/looking for service?**

## **ACCEPTABILITY (If you received it, how was it?)**

**What was the quality of the service?**

**Would you go there again?**

**What would you change about the service provided?**

**How did the providers treat you? Your family?**

**Did the providers help you find out where to go next?**

**Would you have preferred to have the need met with a different service/person than the one provided?**

**If you had complaints, did you tell anyone? How did the provider respond?**

**Would you know where to go to make a complaint?**

**Describe a typical [visit/activity] related to this service?**

**How does this service compare with others you have received? How does this experience compare with earlier experiences with health care professionals? What about when you gave birth? Did you ever have to deal with the health care system earlier in your life? What happened?**

**Do you think being a [ethnic or racial group] woman makes a difference in getting/receiving help? How? Why or why not?**

## **BARRIERS TO CARE (If you didn't receive it, why not? How do they operate?)**

**Have you ever faced problems in getting to a service? What happened? What did you do?**

**What prevented you from getting the care you needed?**

**Were you able to find out if the service was available?**

**Did you know the service existed?**

**What would it have taken to make the service accessible to you? Change in location?**

**Transport? Help for your family member?**

**Were you unable to use the service because of language or cultural differences?**

**Were you unable to use the service because of personal reasons?**

**What would stop you from using a service? Has this ever happened to you?**

**What would help you use a service? Has this ever been done for you?**

**If you yourself have not used services, do you know an older woman (friend/family member) who has received help? How did that happen? What was it like?**

**Demographic Information: Eldercare Staff**

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**Name:** \_\_\_\_\_ **ID Number:** \_\_\_\_\_

**Position:** \_\_\_\_\_

**Date of Interview:** \_\_\_\_\_

## **Interview Guide: Eldercare Staff - Front-Line Workers**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**I AM INTERESTED IN HOW OLDER ETHNIC AND RACIAL MINORITY WOMEN ACCESS COMMUNITY HEALTH CARE AND THE ROLE OF ELDERCARE IN THIS PROCESS. PLEASE THINK ABOUT THE FOLLOWING STAGES OF INTERVENTION AS I ASK YOU SEVERAL QUESTIONS:**

**INTAKE  
ASSESSMENT  
REFERRALS/TRANSFERS  
CASE MANAGEMENT  
CLOSING CASES**

#### **Probing Questions That Can Be Asked For Each Major Section:**

##### **THE PROCESS OF ACCESS (How do older ethnic and racial minority women get to services?)**

**Please describe for me the process an older woman goes through in accessing community services through Eldercare?**

**What is your role in facilitating access to community care?**

**What forms are used in the various stages of interventions? How are they used?**

**What activities are you engaged in at each stage of the intervention?**

**Are other individuals involved in cases? Under what conditions would others be involved?**

**How is this interaction coordinated?**

**Under what conditions would someone be refused services? Do you feel anyone gets left out? Why? Are there people you are not reaching? Why?**

**Could you tell me about a typical case of an older ethnic or racial minority woman? How was it dealt with?**

**Could you tell me about an atypical case? How was it dealt with?**

### **ESTABLISHING INTERVENTION PLANS (How are services planned and delivered?)**

How do you establish plans for working with various clients? Are alternatives considered?, what would cause you to change the way you developed plans?

What background information do you see as important for case planning? Why? How is it used? Is this information reflected on intake and assessment forms?

How are activities coordinated between volunteers, other professionals, the client and her family?

Is advocacy (individual, group, institutional, governmental) part of your role? How is this played out?

### **RECORDING (How is recording used?)**

How do you use file recording/intake/assessment/intervention forms? What purpose do they serve? How do you use previously filed information?

Are you able to record all the information you see as important about clients? If not, what is left out and why?

Are there changes in work organization or recording format which you believe would lead to better recording/service delivery?

### **ISSUES OF GENDER, ETHNICITY AND RACE (What is the impact of diversity on access?)**

What impacts upon an older ethnic or racial minority woman's access to care? Are these reflected in the intake / assessment / referral process? How?

Is the process of access different/the same for older ethnic and racial minority women?

How? Why is there a difference/no difference in the access process?

Does being from a different ethnic or racial group affect how someone accesses care?

How? Do these women face special problems/issues?

Are these differences reflected in the intake/assessment/referral process? How?

### **MACRO ISSUES (Can you tell me about the impact of organizational issues on your work with older women?)**

What special knowledge, theory and/or experience do you use in carrying out your work with older ethnic and racial minority women?

How does your mandate (legal, professional, agency) affect your work with these women?

How do on-going work issues (caseload size, organization of work, budget restraints) affect the way you work with clients?

Can you identify areas of contradiction in dealing with clients and their families? How do you think about and resolve those contradictions?

**CLIENT AND FAMILY PERCEPTIONS (How are families involved in care?)**

**Are there discrepancies between clients' and families' views of problems and professional views of problems? Internal resources (physical, social, psychological) of the client and family?**

**What do clients and families think about Eldercare?**

**How are clients' family members included in intervention plans?**

**COMMUNITY RELATIONS (How are ethno-specific community organizations involved in facilitating access and in your organization?)**

**What is their role/relationship to Eldercare? To your work specifically?**

**Are there ways in which you think this role should be changed?**

## **Interview Guide: Eldercare Staff - Managers**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**I AM INTERESTED IN HOW OLDER ETHNIC AND RACIAL MINORITY WOMEN  
ACCESS COMMUNITY HEALTH CARE AND THE ROLE OF ELDERCARE IN THIS  
PROCESS.**

#### **Probing Questions That Can Be Asked For Each Major Section:**

##### **THE PROCESS OF ACCESS (How do older ethnic and racial minority women get to services?)**

**Please describe for me the process an older woman might go through in accessing community services through Eldercare?**

**What is Eldercare's role in facilitating access to community care?**

**What impacts upon an older woman's access to care? How? Is the process of access different/the same for all older people? Why do you think that is so? Do minority women face special problems/issues?**

**Are these differences reflected in the intake/assessment/referral process of Eldercare? How?**

**How are relations between the Ministry of Health, Eldercare and clients managed?**

**What role does the Ministry have in guiding the concerns/programs of Eldercare?**

##### **DIVERSITY GUIDELINES/POLICY (Could you tell me about any diversity guidelines Eldercare has implemented/ is planning to implement /would consider important to implementing?)**

**Diversity guidelines might include: staff representation through hiring practices, ethnic matching, board representation, cross-cultural training, support for minority workers.**

**Who determines policy/program guidelines around gender, ethnicity and racial diversity?**

**Are there any provincial guidelines/policy in this area? What are they?**

**How are guidelines (specify) understood in terms of/translated into work practices?**

**What role do boards and committees have in determining or operationalizing guidelines?**

**Is advocacy part of your role? How is this played out?**

**What components do you consider important for improving access among ethnic and racial minority communities? Language, culture, staffing, etc...**

**What do you consider to be important in facilitating access for ethnic and racial minority women?**

**MACRO ISSUES (Can you tell me about the impact of organizational issues on staff's work with older women?)**

What special knowledge, theory and/or experience should be used in carrying out work with older ethnic and racial minority women?

How does your mandate (legal, professional, agency) affect front-line workers efforts with these women?

How do on-going work issues (caseload size, organization of work, budget restraints) affect the way front-line workers work with clients?

Can you identify areas of contradiction in dealing with clients and their families? How should one think about and resolve those contradictions?

**COMMUNITY RELATIONS (How are ethno-specific community organizations involved in facilitating access and in your organization?)**

What is their role/relationship to Eldercare? To your work specifically?

Are there ways in which you think this role should be changed?

**Demographic Information: Community Workers in Ethno-Specific Agencies**

**An Institutional Ethnography of Elder Care:  
Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**Name:** \_\_\_\_\_ **ID Number:** \_\_\_\_\_

**Position:** \_\_\_\_\_

**Organization:** \_\_\_\_\_

**Date of Interview:** \_\_\_\_\_

## **Interview Guide: Community Workers in Ethno-Specific Agencies**

### **An Institutional Ethnography of Elder Care: Understanding Access From the Standpoint of Ethnic & Racial Minority Women**

**I AM INTERESTED IN HOW OLDER ETHNIC AND RACIAL MINORITY WOMEN  
ACCESS COMMUNITY HEALTH CARE AND THE ROLE OF ELDERCARE IN THIS  
PROCESS.**

#### **Probing Questions That Can Be Asked For Each Major Section:**

##### **THE PROCESS OF ACCESS (How do older ethnic and racial minority women get to services?)**

**Please describe for me the process an older [ethnic or racial group] woman might have gone through in accessing community services before the creation of Eldercare?**

**How has this process changed since the creation of Eldercare?**

**What do you feel the role of Eldercare should be in facilitating access to community care for [ethnic or racial group] older women? Is this how it is?**

**What do you think impacts upon an older [ethnic or racial group] woman's ability to access care? How?**

**Is the process of access different/the same for other older people? Why do you think that is so? Do [ethnic or racial group] older women face special problems/issues?**

**Are these differences reflected in the intake/assessment/referral process of Eldercare? How?**

##### **DIVERSITY GUIDELINES/POLICY (Could you tell me about any diversity guidelines that you would consider important to implement in order to help older women access care?)**

**Are you aware of any policy/program guidelines around gender, ethnicity and racial diversity that operate at Eldercare?**

**Are there any provincial guidelines/policy in this area? What are they?**

**What role do boards and committees have in determining or operationalizing diversity guidelines?**

**What about the role of advocacy? Is advocacy part of their role? How is this played out?**

**Are policies and guidelines in the area of representation, ethnic matching, training, support important? Why or Why not?**

**What components do you consider important for improving access to care among [ethnic or racial group] older women in this community?**

**What do you consider to be the central components of facilitating access? What do you see as the role of Eldercare in facilitating access of ethnic and racial minority older women?**

**MACRO ISSUES (Can you tell me about the impact of organizational issues on staff's work with older women?)**

What special knowledge, theory and/or experience should be used in carrying out work with [ethnic or racial group] older women? Do you know if these are in operation at Eldercare?

How do you think Eldercare mandate (legal, professional, agency) affects front-line worker's efforts with these women?

How do you think on-going work issues (caseload size, organization of work, budget restraints) affect the way front-line workers work with clients?

Can you identify areas of contradiction in dealing with clients and their families? How should one think about and resolve those contradictions?

How are relations between the Ministry of Health, Eldercare and ethno-specific community agencies managed?

**COMMUNITY RELATIONS (How are ethno-specific community organizations involved in facilitating access?)**

What is your role/relationship as an ethno-specific agency with Eldercare? Do you have a relationship with Eldercare? Please describe it?

Is it on-going? How often do you meet with workers at Eldercare? Do they call on you for consultation? Translation?

Were you involved in the development/implementation of Eldercare? How?

Are there ways in which you think this role should be altered to improve relations between Eldercare and ethno-specific agencies?

Do you think members of your community use Eldercare? How? Why/why not?

**APPENDIX 5**  
**PARTICIPANT OBSERVATION PROTOCOL**

## **PARTICIPANT OBSERVATION PROTOCOL**

### **STEP 1: RESEARCHER IDENTIFICATION**

1. Identify yourself to participants and explain your presence
2. Ensure confidentiality will be maintained

### **STEP 2: TAKING IN THE ENVIRONMENT**

1. Time of day, place of interaction, length of interaction
2. Purpose of the meeting/interaction (i.e. Assessment, Case Management, Intake: if it is between client and worker/ Staff meeting, Other meeting, Lunch: if it is between workers)
3. Relationship Between Worker and Client/Workers evident in initial encounter (how they interact together, greet each other, where and how they sit, is worker using adult or infantilizing speech...)
4. What role is a family member/friend playing? Who is talking to whom?

### **STEP 3: OBSERVING THE INTERACTION**

Write general notes paying particular attention to the following:

#### **Worker-Client Interaction:**

1. How is the interaction guided by or formed through text (papers, forms, files,...)
2. Do discussions regarding "need" come up? How? Is it mentioned and in what manner?
3. What is the process of the interaction? Is the purpose clearly stated?
4. How much space is given to the client to express her own needs?
5. If the client is cognitively impaired, are efforts made to understand her wishes? Concerns?
6. Is the client's ethnicity or race specifically brought up? How? Are client and worker from different ethnic or racial backgrounds?

#### **Worker-Worker Interaction:**

1. How is the interaction guided by or formed through text (papers, forms, files,...)
2. Do discussions regarding "need" come up? How? Is it mentioned and in what manner?
3. What is the process of the interaction? Is the purpose clearly stated?
4. If the client under discussion is cognitively impaired, are efforts made to understand her wishes? Concerns?
5. Is the issue of gender, ethnicity or race specifically brought up? How?
6. Are workers from different ethnic or racial backgrounds? Does this have an impact on how things are said/what is said? How do you know this?

**APPENDIX 6**  
**DOCUMENT ANALYSIS PROTOCOL**

## **DOCUMENT ANALYSIS PROTOCOL**

**Take notes on each document paying particular attention to the following themes or terms:**

**Need  
Access  
Efficiency  
Streamlining  
Duplication  
Consumer  
Client  
Ethnicity  
Race  
Racism  
Sexism  
Women  
Advocacy  
Families**

- 1. How often do these words come up?**
- 2. In what context do these words come up?**
- 3. What is their specific function in the text?**
- 4. What other words/phrases/concepts are used and how?**
  
- 5. What is the overall purpose of the document?**
- 6. When was it written?**
- 7. By whom was it written?**

**APPENDIX 7**  
**STATISTICS CANADA LOW INCOME CUT-OFFS:**  
**CENSUS 1996**

Measures of low income known as low income cut-offs (LICOs) were first introduced in Canada in 1968 based on 1961 Census income data and 1959 family expenditure patterns. At that time, expenditure patterns indicated that Canadian families spent about 50% of their income on food, shelter and clothing. It was arbitrarily estimated that families spending 70% or more of their income on these basic necessities would be in "straitened" circumstances. With this assumption, low-income cut-off points were set for five different sizes of families.

Subsequent to these initial cut-offs, revised low income cut-offs were established based on national family expenditure data from 1969, 1978, 1986 and 1992. These data indicated that Canadian families spent, on average, 42% in 1969, 38.5% in 1978, 36.2% in 1986 and 34.7% in 1992 of their income on basic necessities. By adding the original difference of 20 percentage points to the basic level of expenditure on necessities, new low income cut-offs were set at income levels differentiated by family size and degree of urbanization. Since then, these cut-offs have been updated yearly by changes in the consumer price index.

The following is the 1995 matrix of low income cut-offs:

Family size	Size of area of residence				
	500,000 or more	100,000 to 499,999	30,000 to 99,999	Small urban regions	Rural (farm and non-farm)
1	16,874	14,473	14,372	13,373	11,661
2	21,092	18,091	17,965	16,716	14,576
3	26,232	22,500	22,343	20,790	18,129
4	31,753	27,235	27,046	25,167	21,944
5	35,494	30,445	30,233	28,132	24,530
6	39,236	33,654	33,420	31,096	27,116
7+	42,978	36,864	36,607	34,061	29,702

Censuses: 1996 (1/5 sample), 1991 (1/5 sample), 1986 (1/5 sample), 1981 (1/5 sample), 1981 (1/5 sample), 1971 (1/3 sample)

Reported for: Economic families and unattached individuals 15 years of age and over in private households

Question Nos.: Not applicable

Responses: Not applicable

Statistics Canada Catalogue Number 92-351-XPE  
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