CARING AT A DISTANCE: WORKING WOMEN, RURAL TO URBAN MIGRATION AND THE COMPASSIONATE CARE CHALLENGE

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ABSTRACT

Migration from rural to urban communities is a life-long process for a family involving complex and shifting decisions about migration, labour market activity, and caregiving/receiving in which gender is a primary factor. Care provider and recipient are part of a cycle of rural in and out-migration that connect social policy, family members, elder caregivers and their workplaces in ways that are not yet fully understood. This preliminary study shifts the conceptualization of rural to urban migration away from one that views it as a single event, to that of a process that takes place and is managed at different stages in the family life of most Canadians, drawing in multiple actors with multiple roles. The study contains new discoveries about how working women who migrate from rural communities manage eldercare for those they leave behind, and how women young and old make associated decisions over a lifetime about if, when and where to move. Employed women caregivers who work in urban areas and provide care to rural elderly must manage to pull together what resources they can to ensure the adequate, appropriate and best possible care for an older person living at home or in a facility. The tensions during decision making processes that families undergo, especially regarding where the care recipient should live, have family repercussions that make visible the connections among the organization of policy, the practices of service organizations, and the effectiveness of urban-to-rural caregivers’ work. These connections are explored in this report. The study conceptualizes and employs a unique policy lens, and explores the intersections of caregivers’ practices and the practices of service organizations to shed light on policy practice in action. Bringing to light the work people do in the multiple sites of the health, home and continuing care systems, this report highlights the practices that directly link clients and their caregivers into policy processes. We argue that an improved understanding of the changing needs of the elderly and their caregivers would benefit from a reconceptualized approach to rural-urban migration that draws on the extensive literature in the area of “transnational families” and puts care relationships at different stages in the lifecycle at its centre. With a better understanding of the spatial and temporal dynamics of caregiving in Canada and the links of policy organization to caregivers’ experiences that are brought to light in this report, though highlighting the unique issues associated with rural eldercare and migrations, a range of areas of policy practice are identified for change.
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EXECUTIVE SUMMARY

Migration from rural to urban communities is a life-long process for a family. This process involves complex and shifting decisions about migration, labour market activity, and care giving/receiving in which gender is a primary factor. Over the life cycle, young people move away from rural parents to urban centres for education and work. As parents age, 2nd generation women are largely responsible for traveling back and forth between rural and urban homes to provide intermittent care and advice and support over long distances, on top of caring for their immediate urban families. This long distance caring intensifies as the first generation’s care needs grow. Sometimes 2nd generation women migrate back to their rural communities of origin for months or even years to care for a parent. In other families, an aged parent migrates to the urban centre to be closer to the family care provider, either moving in or entering a nursing home close by. In all these contexts, care provider and recipient are part of a life-long cycle of rural in and out-migration that connect social policy, family members, elder caregivers and their workplaces in ways that are not yet fully understood.

This preliminary study shifts the conceptualization of rural to urban migration away from one that tends to view it as a single event, to that of a process that takes place and is managed at different stages in the family life of most Canadians, drawing in multiple actors with multiple roles. The study contains new discoveries about how working women who migrate from rural communities manage eldercare for those they leave behind, and how women young and old make associated decisions over a lifetime about if, when and where to move.

Exploring the provision of eldercare across distance in Canada highlights the shortcomings of current policy organization. A focus on the experience of women outside rural communities who provide care to a rural loved one further highlights policy and practice that download care coordination and management to women in caring relationships, and sheds light on the actions of those working at the intersection of family, workplace and service organizations, in the context of urban and rural economic restructuring and institutional (healthcare systems) reforms.

Informal caregivers in Canada provide care to an increasingly aging and fragile population in ways that have dramatic effects on family structures and migrations across provinces. Women who are both employed and coordinate, manage and provide care at a distance to an older person living in a rural residence or facility, face multiple challenges that underscore issues of geographical distance, service and personal costs, and the lack of adequate, consistent or coherent supports for their care management work. Recent trends in rural regional development and the reorganizations of Canada’s healthcare system impinge on the day to day work women are doing to sustain families and family health. In fact, since the 1995 enactment of the Budget Implementation Act and
subsequent healthcare restructuring mechanisms, government support for the community services system, which directly supports caregivers and the frail elderly in Canada, has diminished. At the same time, the reorganization of the formal healthcare system has absorbed the lion’s share of the healthcare budget and shifted the policy focus to reshaping the organization of hospitals’ and physicians’ work. Employed women caregivers comprise the majority of the informal healthcare sector. Women are the majority of those employed in the service sector, in home and continuing care organizations, volunteer associations, and as government policy analysts in healthcare. All of them are working with scarce resources, services that vary across jurisdictions, and in constantly changing working conditions and policy contexts. Employed women caregivers in particular who work in urban areas and provide care to rural elderly, must manage to pull together what resources they can to ensure the adequate, appropriate and best possible care for an older person living at home or in a facility. The tensions during decision making processes that families undergo, especially regarding where the care recipient should live, have family repercussions that make visible the connections among the organization of policy, the practices of service organizations, and the effectiveness of urban-to-rural caregivers’ work.

These connections are explored in this report. Numerous studies report the burden on caregivers, and policy changes have been broached at the federal and provincial and territorial levels to offer ‘respite,’ counseling and ‘family care leave.’ The objective of this study was to expand on previous research, taking the standpoint of those who are triply marginalized – by distance, workplace constraints, and rurality. The study conceptualizes and employs a unique policy lens, and explores the intersections of caregivers’ practices and the practices of service organizations to shed light on policy practice in action.

Based on our study, we argue that the current supports to caregivers and community service organizations are under strain and inadequate to sustain community services, especially urban-to-rural caregivers in doing their jobs of keeping Canada’s elderly and frail in home care and out of hospitals and government subsidized nursing homes. Working women caregivers in this situation must coordinate care using multiple organizations and a patchwork of services while managing their own employment. Social and economic inequities in families’ situations and complex policy contexts emerge starkly under close examination of urban-to-rural care practices. What is revealed is a disconnect between existing policy provision and the actual needs of the elderly and their distant caregivers.

Administrators and staff in service organizations, as well as policy analysts, describe the organization of Canada’s health, home and continuing care systems as hindering their ability to do their job for their clients, and especially for those who are trying to coordinate and compile adequate care at a distance to rural residents and make housing and moving (migration) decisions at the most difficult times of families’ lives. Bringing to light the work people do in the multiple sites of the health, home and continuing care systems, this report highlights the practices that directly link clients and their caregivers into policy processes.
Our findings support an argument that existing conceptions of family caregivers currently at the foundation of policy and policy efforts, fail to take into account the family life cycle and the sequences of ongoing decisions that families must make that involve employment, income, moving and housing and service trade-offs. This unique rural, gender, working caregiver at-a-distance lens brings into view a more complex reality that is fast becoming the norm in Canada with its mobile workforce and aging ‘baby boomer’ families, and contributes to our understandings of both family-care practices and migrations within Canada. Rural-urban migration is made visible here as a gendered and classed process, that while driven by labour market imperatives is also tied to people’s need for care and women’s expected roles as care givers. We argue that an improved understanding of the changing needs of the elderly and their caregivers would benefit from a reconceptualized approach to rural-urban migration that draws on the extensive literature in the area of “transnational families” and puts care relationships at different stages in the lifecycle at its centre.

With a better understanding of the spatial and temporal dynamics of caregiving in Canada and the links of policy organization to caregivers’ experiences that are brought to light in this report though highlighting the unique issues associated with rural eldercare and migrations, a range of areas of policy practice are identified for change.

Recommendations

Conclusions and Recommendations Associated with Section 3

Recommendation 1. Workplaces need to recognize that those who provide eldercare at a distance have unique needs that must be recognized and accommodated in family policies and in practice.

Recommendation 2. Governments need to scrutinize labour policies to ensure that those who provide eldercare do not face barriers to accessing workplace or government benefits and supports.

Recommendation 3. Economic supports for long distance caregivers might include long distance telephone subsidies that could also be claimed by the organizations that they work for. Caregiver travel rates and discounts would also assist those who care at a distance.

Recommendation 4. Temporary EI remuneration initiatives and pension top-ups would assist caregivers of the elderly who must leave their jobs when long distance care is no longer sustainable, particularly for those who provide care to rural seniors who live in resource scarce communities.

Recommendation 5. Interprovincial health authorities should be provided with incentives to develop and maintain detailed information resources that will assist out of
province caregivers to find eldercare assistance quickly, and make it easier for care recipients and their caregivers to be accommodated in different regions.

**Recommendation 6.** Policy analysts need to review national data with a regional lens and consider the impacts of social, economic and political factors in policy and service development that will assist long distance care providers who face greater challenges because of the location of their loved one.

**Recommendation 7.** Government, media and researchers together need to get the message out more clearly that those people who provide care for older Canadians are doing our society an amazing service. The needs of all informal eldercare providers should be recognized, respected, accommodated and rewarded.

**Conclusions and Recommendations Associated with Section 4**

**Work and Income**

**Recommendation 8.** Develop a “drop out” provision in the CPP that allows people who are caring for individuals with disabilities or for the elderly to discount earnings for caregiving. This provision is in place for women who have cared for their child at home for up to seven years.

**Recommendation 9.** Extend Employment Insurance benefits to the self employed and entrepreneurs, in order for women entrepreneurs in Canada to access EI benefits such as maternity and parental leave or the Compassionate Leave for Caregivers.

**Policy Data Gathering on Housing and Informal Caregivers**

**Recommendation 10.** Engage the Canadian Institutes for Health Research (CIHR), Canada Housing and Mortgage Corporation (CMHC); General Social Survey researchers, regional and other associations (e.g. Family Services Association [FSAT] and Social Planning Council [SPC], Toronto) and municipalities, to undertake a collaborative, comprehensive qualitative and quantitative examination of the current data across these areas.

**Recommendation 11.** Commission these groups to assess the potential for government programs to support alternative forms of housing and services where there is most need; ensure the research includes rural and remote areas; ensure the assessments addresses the conjunction of social and economic realities for “mobile families” whose migrations are related to the location of affordable housing, work and services cross provinces and regions.

**Recommendation 12.** While there are proposals to cost the value of caregivers work through the RAI, the criteria for it include that the informal caregiver make formal agreements, be qualified to the same extent as a formal system service provider (now hired by CCACs on contract). This privileges any private orgs that are contracted by CCACs/LHINs to provide services on a lowest cost basis. Mechanisms for equal pay for
equal work in homemaking and personal care, that account for experience, need to be developed.

**Recommendation 13.** The cost of caregiver work needs to be considered. I worked through the on-line questionnaire to see if one of our self-employed would qualify for the tax deduction for her caregiving work which takes up much of her time and caused her to postpone working again after the life event of having a baby. The cut off is approximately $17,000. S’s father’s income, which falls short of covering the cost of his home and care by 200 per month (income is $1800 and cost of home and services is $1900), is $21,600. So S is ineligible. The income cutoff needs to be raised so that more people will be eligible.

**Information, Guides, ‘Talk’ Sheets for Electronic or Face-to-Face Guidance.**

**Recommendation 14.** Engage federal, provincial/territorial representatives and appropriate FPT mechanisms such as the Health Advisory Councils, Ministers responsible for Seniors, Ministers responsible for the Status of Women and Canadian Caregiver Coalition to develop a national program of ‘front line’ of supports to informal caregivers, including ‘state of the art’ fact sheets that support electronic and face-to-face counseling/training on priority diseases and chronic conditions and legal matters such as POA and the implications of being the substitute decision making for another person.

**Recommendation 15.** Develop strategic information ‘briefs’ for caregivers and service organizations, doctors and hospitals.

Short term:
- Develop and implement package of guides for caregivers addressing issues of housing and service choices and explicating:
  1. community service organizations mandates across provinces
  2. forms of housing assistance by province
  3. forms of services assistance by province
  4. legal considerations of being substitute decision maker (POA for personal care)
  5. procedures and processes of working with ‘access’ organizations
  6. the limits of ‘respite’ arrangements

Medium term:
- engage provincial and territorial government representatives and regional health authorities undertake a comprehensive review of the differences between access and community service organizations in every province and territory, paying special attention to issues of rural and remote regions and resources.

**Recommendation 16.** Conduct an evaluation of the Nova Scotia caregiver strategy as it is being built in Nova Scotia. How to build a caregiver strategy within the provincial structures of home and continuing care is essential to the future working of the Canadian system as a whole and would support Canada’s principles of equal access. It would work towards portability and coherence between provinces.
Conclusions and Recommendations Associated with Section 5

**Recommendation 17.** It demands a different approach to the collection of migration data in Canada that records cyclical migrations, especially those taking place between provinces, and especially those related to care for the elderly (whether it is they or their carer who moves).

**Recommendation 18.** There is also a need for more research in this area to complement the growing body of scholarship on transnational migration and transnational social processes.

**Recommendation 19.** Adjustments will need to be made to account for the gender and class implications of existing and new policies. The construction of care as women’s work means that women need better access to flexible work-life policies at work, whether they occupy middle class or working class jobs. Working class women need support in finding ways to meet the demands on them in a context of precarious work where they are vulnerable to firing without notice or explanation.

**Recommendation 20.** Any new migration of racialized minorities into rural regions does not replicate care inequalities that exist in larger cities and in poorer countries.
INTRODUCTION

Population change in Canadian rural areas is related to two major processes: migration and aging. Between 1971 and 1996 all Canadian provinces experienced rural out-migration of youth, the greatest losses occurring in Saskatchewan, Newfoundland and PEI, closely followed by other maritime provinces (Statistics Canada, 2001; Dupuy et al., 2000). Spurred by the restructuring of rural-based industries, including agriculture, and augmented by shifts in government economic and social policy priorities, many rural communities in Canada are aging rapidly as a result. Young people continue to migrate from rural to urban centres, taking with them the labor available for rural social services and the local tax base that supports aging communities (Bryant & Joseph, 2001; Hanlon & Halseth, 2005; Statistics Canada, 1996a; 2005d).

Youth out-migration reduces the chance that adult children will be available locally to provide care when their parents need it (Dupuy et al, 2000; Glasgow 2000). One US study showed that long-distance caregivers of the rural elderly lived an average of 450 miles from the person they were assisting, and took an average of 7.23 hours to reach the care recipient each time they visited (National Alliance for Caregiving 2004). On average, half of the respondents spent 34 hours per week arranging services and another 4 hours per week checking on the person or monitoring care. Three quarters indicated that they provided help with smaller routine tasks, but 40% reported providing more intense personal care such as bathing, dressing, feeding at an average of 12 hours per month. Half reported making significant adjustments to work schedules, missing an average of 20 hours per month. Those who missed work tended to provide care at a greater distance. Those who took time off took unpaid leave, turned down promotion and/or lost work benefits. In a Canadian study, 44% of caregivers reported that they incurred extra expenses providing eldercare and indicated that some form of financial compensation for their unpaid work would help them to continue (MacBride-King 1999).

We situate issues of providing care to the elderly within processes of migration, in order to understand better the broader social and economic processes that affect rural to urban and urban to rural migrations, employment issues, and where workplace and government policy supports might be strategically provided. We find migration processes and family/caregiver decisions to be complex. Government statistics do not explore the complexity or acknowledge some of the migration trends that we hear about informally. Problems with existing concepts of “informal care,” “long distance” and “rural” also arise as actual care giving situations and practices are examined, leading to a re-thinking of these definitions. The complexities and difficulties inherent in these terms and the implications of these for policy are addressed in the analytic chapters of this report.

Linking rural out-migration to eldercare highlights the mutuality of family relationships and emphasizes its more general multigenerational impacts. A life course perspective emphasizes how location, history and culture shape experience (Parker et al, 2002). Exploring the provision of eldercare across distance in Canada highlights the shortcomings of current policy and forewarns its effect on demographic and cultural
change. The migration patterns of seniors in rural communities have been studied by various provincial agencies and by various academic researchers. Significant emphasis has recently been placed upon the diversity of rural communities and their demographic characteristics. Some rural communities have significant in-migration of seniors because they have housing options, such as long term care homes that are targeted toward this aging population. Many rural communities experience an out-migration of young people, leaving seniors to age in place. It has been suggested that seniors in some rural communities enter nursing homes earlier than the national average because of a lack of community or social/family support nearby. Migration rates do not often take into consideration the temporary out-migration of seniors from rural to urban areas and return back again, particularly if they, or their spouse, are ill or need to be closer to a family member for a short period of time. Migration rates also do not capture the movement of caregivers from urban to rural areas on a temporary basis to care for seniors, or the relocation of urban caregivers to rural areas who bring their elderly parents from another location to join them. All of these scenarios highlight the complicated patterns of migration and eldercare between urban and rural locations that consistently fall through the policy lens gap. They make the caregiving challenge that much more difficult.

Our research with rural long-term care workers (Leach, et al 2006), with rural women’s groups, and with working women who leave work because of family related stress, as well as our interpretation of the literature and data generated by Canada’s Rural Secretariat (Binet 2005), lead us to propose that migration from rural to urban communities is a life-long process for a family. This process involves complex and shifting decisions about migration, labour market activity, and care giving/receiving in which gender is a primary factor. Over the life cycle, many young people move away from rural parents to urban centres for education and work. As their parents age, 2nd generation women are largely responsible for traveling back and forth between rural and urban homes to provide intermittent care and advice and support over long distances, on top of caring for their immediate urban families. This long distance caring intensifies as the first generation’s needs grow. Sometimes 2nd generation women migrate back to their rural communities of origin for months or even years to care for a parent. In other families, an aged parent migrates to the urban centre to be closer to the family care provider, either moving in or entering a nursing home close by. In all these contexts, care provider and recipient are part of a life-long cycle of rural in and out-migration that connect social policy, family members, elder caregivers and their workplaces.

As Canada’s population ages rapidly and migration to work emerges as a normative trend (what Michael Corbett (2007) calls the “migration imperative” in Canadian rural communities) associated with economic restructuring and relocation of jobs, few experience these demands more than working women who have migrated from rural communities to (school and) work and now face the challenge of providing care for the elderly relatives they left behind. Rural out-migration leaves rural communities aging at a rate significantly greater than the national average. Moreover, as the Canadian population

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1 Leach and Turner are working with a team of researchers from academia, government and rural communities on a range of issues relating to women in rural communities. The Rural Women Making Change research alliance is funded under the CURA program of SSHRC. See www.rwmc.uoguelph.ca.
ages, policy restructuring increasingly places the burden for providing eldercare disproportionately upon women. Feminists contend that downloading responsibility for care from the state to the ‘family’, in fact means downloading to women in the household. In a patriarchal society, caring for the elderly, rewarding as it is, is undervalued work that women do. Moreover, the sacrifices women elder caregivers are expected to make due to gender-specific expectations and obligations often lead to chronic stress and illness that may be dismissed by those who see caring as a ‘natural’ activity for women (Medjuck et al. 1998). Across most cultures women have felt pressure to uphold traditions underpinned by gender ideologies that construct women as “natural” caregivers (Brewer 2001). Leach (1999), among others, has argued that in rural regions such ideologies are especially powerful.

The often prevalent idea that women choose to provide care or make career sacrifices for family reasons ignores the fact that women engage in paid work for the same economic reasons as men. Instead, such assumptions suggest that biological sex alone determines one’s experiences in the work force, ignoring the relationships between individual choices and the broader structural forces that shape their decisions (Gazso 2004). A focus on the experience of women outside rural communities who provide care to a rural loved one highlights policy and practice that exploits women in caring relationships and sheds light on the actions of those working at the intersection of family and workplace demands, in the context of (both urban and) rural economic restructuring (Winson and Leach 2002, Leach 1999).

In a ‘community care’ model of restructuring that emphasizes private responsibility (Medjuck et al., 1998), families (or more precisely, women in families) struggle to provide assistance to elderly relatives so that they may remain in their homes as long as possible. Long-distance caregivers “…spend their days playing phone tag with social workers, scheduling doctors’ appointments, arranging transportation, paying bills…and holding their breath until the next crisis” (Franklin 2000). The health of rural seniors, particularly with respect to suicide and the access to health services and supports in rural areas, is a noted challenge. If rural seniors are at higher risk for chronic illnesses and suicide, this puts increased demands and significant longer term stress upon employed long distance care providers in their attempts to balance work and family responsibilities. In addition, the loss of colleagues and contacts with other rural women as networks dissolve puts long distance caregivers out of touch with changes in local services and in family health status. The financial demands of eldercare may also cause problems for women caregivers with respect to their own retirement resources, particularly affecting pensions if women are required to take leaves of absence without pay in order to provide care.

Rural-urban migration needs to be seen as a gendered and classed process that, while driven by labour market imperatives, is also intimately tied to peoples’ need for care and women’s expected roles as carer. Our research shifts the conceptualization of rural to urban migration to that of a process that takes place and is managed at different stages in the family life of most Canadians, drawing in multiple actors with multiple roles. Such a perspective is critical if we are to shift the current understanding of rural-urban migration.
as a single, albeit life-altering, event to one that is on-going and potentially life-long in its scope, with serious consequences for policy development and analysis.

There are a growing number of people who are retiring early from employment in order to care for a loved one, and this has important implications in certain key employment sectors in terms of the increasing lack of qualified people and evolving corporate retention initiatives. It also has implications for personal long term retirement resources for employed women who may not have secure pension support or extended health care benefits. Statistical projections show that population aging will accelerate such that by 2031 seniors will account for between 23% to 25% of the total Canadian population – double that at present (Statistics Canada 2005a). Currently, over 20% of Canadian seniors live in rural communities (Eales 2005). In response to this aging trend, adjustment policies have tried to balance this phenomenon by increasing international immigration.

However, the increasingly multicultural richness of the Canadian population has also brought to light both the unique culturally-specific needs of certain aging communities and the associated demands and expectations placed upon their caregivers – two factors that are often overlooked. It is estimated that one in four Canadian seniors was born outside of Canada, and that most immigrated when they were children or young adults. While almost all seniors can speak one or both of Canada’s official languages, in 1996 5.2% of senior women could not speak or understand either French or English (Health Canada 2002). This language barrier adds to the difficulties of the elderly in negotiating the health and social services available to them, and puts further pressure on female family members who need to interpret as well as provide care (Guberman & Maheu 2003/4). At present the number of immigrants who settle in rural communities is relatively small, but there are a number of initiatives intended to attract immigrants beyond the larger cities and out into smaller communities, especially where specific skills are required. This is already taking place in industries that face a labour shortage, such as meatpacking and the oil and gas industry. Thus addressing the needs of the elderly in multicultural societies has not yet been a priority for rural communities, but demographic change in the next couple of decades is almost certain to change that situation.

The multicultural nature of Canada’s population offers important insights overlooked in policy development in this area (Liaw & Mingzhu 2004). Despite the significantly lower than average life expectancy of Aboriginal people, the number of Aboriginal seniors is expected to triple between 1996 and 2016 (Health Canada 2002). Census information shows that Aboriginal people tend to be more mobile than other Canadians (Statistics Canada 1996c; 2005c). Although less than one-half of the total Aboriginal population lived on a reserve in 2001, the majority living in urban centres or in rural off-reserve locations, it is important to note that over half of Aboriginal seniors live on Indian reserves (Statistics Canada 1996b). Compared to other Canadians, Aboriginal seniors report double and triple the rate of chronic health conditions (Durst n.d.; Health Canada 2002). In addition, the survival rate of Aboriginal women over 65 is significantly lower than the national average (Health Canada 2002).
A strong sense of family obligation is considered to be an integral part of aboriginal culture, and women are expected to be the primary informal caregivers (Buchignani & Armstrong-Esther 1999). Resident and non-resident kin have a significant care burden to bear because Native seniors tend not to use formal services available to them in their communities, preferring instead to rely on informal family support. This can translate into higher levels of absenteeism and greater levels of unemployment among younger Aboriginal women who have migrated to larger urban centres, because of the strong pull that family caregiving obligations evoke in this culture.

A static view of culture, which assumes that what works for one culture can be applied to others, and embedded in well-intentioned “neutral” policies, ignores the issues of power and politics and their impact on programs, working against the objectives of achieving a truly multicultural and egalitarian Canadian society (Dorazio-Migliore et al., 2005). Eldercare transcends all socio-economic levels, religions, cultures and occupational status (Gibson 2005; Hanlon & Halseth 2005; Franklin 2000) although each of these shapes the ways it is experienced.

Yet government policy has often imposed ‘blanket’ solutions for rural out-migration without regard for community-specific needs or the special circumstances of rural communities. Federal policies intended to support working caregivers often fail to consider the significance of the social relationships that connect people who migrate from rural to urban communities to their places of origin. They also generally fail to take account of the effects that gender, class, and a person’s stage in the life course have on those social relationships and how they are maintained.

The likelihood of combining employment with assistance to elderly parents varies across Canada by province and even by region, and this draws into question the effectiveness of existing policy that is based upon national data analysis. For example, the assumption that rural and small towns have more informal supports for their aging populations because of the greater likelihood that daughters or daughters-in-law will be nearby is not supported by regional analyses. Also, literature suggests that a greater proportion of rural caregivers are non-spousal and employed. Although out-migration from rural communities is less likely with increasing age, a U.S. study described a process of rural out-migration that suggests a life-long cycle (Longino 1990). However, this type of cyclical migration is rarely captured by census statistics for a number of reasons. One is that the rural homes of the seniors may be maintained despite moves out of the rural community. A second is that the purpose of social statistical reporting is often most concerned with the relationship between migration and labour availability, in other words, the ‘fit’ between the available workers and the demand for labour in specific places. This overlooks the unique circumstances of elderly who migrate from rural communities and the statistical ‘gaps’ that these circumstances create.

Both federal and provincial governments have initiated several programs to enhance seniors’ health in rural/remote areas of Canada and to recognize and support the special caregiving relationship. However research points out that little attention has been paid to the needs of the many employed women who provide care or the programs/policies that
assist working women to balance the demands of work and family. Compassionate care policies initiated by some of the provinces through labour policy, employment standards codes, labour standards acts, etc. can comprise different definitions of need and regulations concerning employers’ responsibilities and employees’ rights. Although new employment based policies have been initiated and revised in the last few years, little attention has been paid to those who are not able to take advantage of government programs because of their employment status (part-time, self-employed etc.).

The Compassionate Care Benefit (CCB) is a new federal policy developed specifically to support working caregivers as their relatives approach death. Funded through the Employment Insurance (EI) program, the benefit has come under considerable scrutiny since its introduction in 2004. Since the federal government announced this policy, most (but not all) provinces have adopted the federal guidelines into their own labour policies. However, uptake on the federal benefit is much lower than expected, and there are several important aspects of the program that create benefit access barriers for many employed caregivers. Critics variously charge that it fails to alleviate the economic stress of those providing care, that basing it upon employee earnings puts women at a disadvantage, that it is restrictive in its definition of eligible “family members”, that its coverage is short (6 weeks for individuals and 8 weeks total for families), that eligibility is restricted to those caring for a relative who must be predicted by a physician to die within 26 weeks, and that self-employed, part-time or unpaid caregivers (predominantly women) already providing care are ineligible for the benefit (Health Council of Canada 2005; Armstrong & O’Grady 2004; Ward 2004; Canadian Auto Workers 2005). Furthermore, for those who drop out of the workforce to care for family members, pensionable time credits are forfeited (Ward 2004), and those who need to draw on EI pools for other reasons (unemployment or maternity leave) during the same year may need to repay some of the benefit at tax time (HRSDC 2005). Although a welcome step in assisting employed eldercaregivers, the CCB policy has far to go in meeting both its objectives and the needs of those it purports to serve.

Our research asks what role social policies, including the federal Compassionate Care Benefit, broader Employment Insurance, and other policies, have for working women who have left rural communities and now provide eldercare there. What are the consequences of these policies for these working women and their families? While the focus was originally to be on the CCB, the rate of take-up of this policy, both within our interview group and in the population more generally, suggested that we needed to turn our attention elsewhere. Thus a cluster of policies and programs and their impacts on rural to urban migrant women caregivers are brought into view. We contend that the CCB policy is inadequate to address the realities of migration as process. Our project therefore addresses two related concerns: (1) it develops a better understanding of the spatial and temporal dynamics of caregiving in Canada and (2) it investigates how these dynamics intersect with policy assumptions and practice in peoples’ lived experiences.

Highlighting the unique issues associated with rural eldercare, long distance caregiving and its associated migration patterns, our research identifies policy reform needs in other social and economic realms. The results of this study have led to concrete policy
recommendations through our new discoveries about how working women who migrate from rural communities manage eldercare for those they leave behind, and how women young and old make associated decisions over a lifetime about if, when and where to move. These recommendations will enhance the effectiveness of policy for those who need to use it, improving the quality of life for women who provide care and those—disproportionately women—who receive it.

Structure of the Report

The next section of the report (II) sets out the methodology used for the study, including strategies for recruiting participants, a description of the participants, and an explanation of the method of analysis. This section also addresses the challenges that arose during the course of the research and considers the limitations of the study. Following that are three separately-authored sections addressing particular aspects of the problem at hand. We decided to structure our report in this way in order to draw on the different and often very particular strengths and areas of expertise of each of us that are related to our very different disciplinary and interdisciplinary backgrounds.

Section III, The Context of Employed Women who Provide Informal Care to Rural Seniors at a Distance: The Disconnect between Reality and Policy, by Gillian Joseph describes the activities that women caregivers engage in when they provide care from a distance, the context of those activities and the effects of managing and providing care on women’s lives. This section argues that many of the assumptions that inform policy and daily practice concerning employed long distance caregivers are inaccurate, and that women’s “choice” to provide long distance care is embedded in social relations and constrained by policy gaps.

Section IV, Reconceptualizing Rural-Urban Migration from a Gender Perspective, by Belinda Leach, addresses the problems inherent in the common understanding of rural to urban migration as a single event. Drawing on scholarship in the area of transnationalism studies, especially as it pertains to transnational families, this section argues for a new approach to rural to urban migration that takes account of the enduring networks between family members across distances and over time. These relationships eventually are called into action when an elderly person requires care, but care is always shaped by ideologies and practices of gender and class.

Section V, Policy Practice, Mobile families and Housing and long term care options, by Susan Turner, explores the working relations of long distance caregivers with home and continuing care and community service organizations. Using an ethnographic approach and drawing heavily on interviews with caregivers, administrators, managers, front line case workers and others working in line processes, this section helps the reader get a good sense of what is happening on the ground. The analysis moves into the institutional arrangements organizing health and support services and to highlight issues of different structures and terminology, the effects of amalgamations on these service organizations, and broader policy issues of housing and care accessibility.
Section VI comprises our conclusions and recommendations for policy.

2. RESEARCH APPROACH

Introduction and Research Questions

Much of the literature and policy discourse dealing with caregivers is organized around the conception of caregivers’ work as a family responsibility. Critical literatures note and measure the stress or issues with ‘work-life-balance.’ The rich data in our interviews with a relatively small sample opens a window onto some of the realities of Canada’s caregivers, service organizations and provincial institutional arrangements. The project used a modified institutional ethnography (IE) to highlight aspects of working women caregivers’ practices that have taken shape within their biographical life courses, family moves and migration, as well as within the institutional contexts of home and continuing care as it currently exists – and as it is being transformed – in Canada. Exploring policy issues has involved starting our research from the experiences of urban-to-rural women caregivers across the country. It meant talking with them about what they do to coordinate care ‘at a distance.’ Using this method of inquiry we were able to identify the effect of out-migration on caregivers, their families and older care recipients, and highlight some of the problems within policy regimes that disadvantage older rural people, women working in care service organizations, and predominantly female caregivers. We engaged informants at the interface where their informal caregiving work and institutional practices joined to produce how policies processes are interacted with, and where their problems become evident. We examined and mapped particular policy processes as they embraced individual caregivers who were negotiating paid employment and other family responsibilities. A cluster of policies relating to labour laws, caregiving benefits, transportation, housing and healthcare, came into view.

Method of Inquiry: Institutional Ethnography

We used institutional ethnography because it treats policy as work processes linking the work that individuals do into particular policy fields of action (Turner, 2003) or policy regimes. The focus is active work in multiple sites that implement policies including application forms and standard textual procedures that directly hook ‘client’ applicants into the policy arena. IE, developed by pioneer Canadian feminist sociologist Dorothy E Smith, emphasizes how people’s everyday practices link them into what she calls ‘ruling’ relations (Smith, 1987, 1990a, 1990b, 2001, 2005). The connections among the situations of everyday life, practice, and policy making are accomplished through “textually-mediated social organization” (Smith, 1984) and the practices unique to particular governing institutions. As a method of inquiry IE begins in the details of women’s lives, and as women describe their activities of managing their everyday lives and engaging resources, they describe their practices linking them into the organization of broader policy, economic and institutional processes. The method is ethnographic in that it assembles expert accounts of diverse practices in multiple sites into a coherent
description of how institutional policies reach down to women in different circumstances. Through its focus on the actual contexts of working relations in which people construct their lives, the ethnography is grounded in the fieldwork study of institutional texts-in-use.

The texts identified within this project include those that respondents use in their practices of making choices, and that position them differently for entitlement to the benefit (‘family’ member, ‘terminally’ ill,) in ways that are inherent in application forms, assessment categories, care plans, and a power of attorney document. Respondents use these texts within institutional procedures and activities that comprise access agencies and service organizations’ work. They are procedures shaped by and accountable to government and intermediary governmental bodies through ‘governing’ policies and procedures for producing accountability and legal and accreditation reliability within the ‘system.’ Those procedures have profound but unanticipated everyday consequences for our respondents arising from policy consideration and design. While IE has not yet been applied to migration, some migration research acknowledges its approach to gathering data that might otherwise be missed (Ralston, 2005). This methodological framework has been applied in studies of policy implementation as people engage in doing the work at various policy stages: in healthcare (Campbell 2001, 1999, 1998; Campbell and Gregor 2000; Rankin 2001; Mykhaylovskiy and McCoy 2002, Smith, G.W., 1995); social work and services (Ridzi 2003; Walker 1995, de Montigny 1995; Ng, 1988); education (Smith 1987; Griffith and Smith, 2005; Andre-Bechely 2005) and policy planning (Turner, 2003, 2001, 1995; Eastwood, 2005). Luken and Vaughan (1997, 2003) investigate urban housing needs of elderly women at the intersection of state housing policy. These studies show the ways policy is delivered, how programs and services are being offered, and just how it is in practice that they do not adequately meet peoples’ needs. Pence (2001) and Pence and Lizdas (2001) demonstrate that ‘the state’ takes up recommendations based on text-based analyses from women’s location in policy processes, to change its operations.

People Interviewed and Data Collection Process

Our study begins in the work and experiences of employed women caregivers and their families (rural to urban migrants) as they make choices to draw upon existing programs and services. We drew our caregiver sample through electronic listservs that engage in discussions about eldercare, through agencies and associations that attract rural women as participants, and through regional health authorities in rural areas that work to support families who need and provide elder care and through the researchers contacts in the Centre for Families, Work & Well-Being at the University of Guelph. We subsequently interviewed front line case managers and managers in access agencies and community service organizations, where their everyday work processes are linked in consultations and intake procedures. One small focus group discussion was held with policy analysts working in different government sites.

Data was collected through 9 in-depth interviews with working women living in urban areas in BC and Ontario who have migrated from rural communities and who now provide eldercare to older parents or a relative in rural areas and rural small towns in
Saskatchewan, Alberta, BC, and Nova Scotia. Turner re-interviewed one caregiver to follow up with her work with the care service plan and power of attorney documents that she raised as central in her complex decision making process regarding her father’s housing and care services. In a second phase, we collected data through formal and informal interviews with 10 women working with access agencies, service organizations and governments in different positions within the health-, home- and continuing care systems in Ontario, BC and Nova Scotia. We asked these participants generally to talk about what is involved in their work, who is involved in doing what, and how it gets done. What was talked about and particular areas of work that were explored depended on the respondent’s location in the process of coordinating care for an older person.

DeVault and McCoy (2006) describe IE interviews as a range of approaches to talk with informants, from planned ‘formal’ interviews to more ‘informal’ types of conversation. We conducted several in-depth interviews, as well as informal conversations with women working as policy planners in a range of institutional sites, to talk about their work and to learn how people’s work is coordinated into a ‘system’ or policy regime. This can be done by tracking and ‘mapping’ graphically (Turner 2006) text-based work processes and it can be done by assembling the ‘expert’ work knowledges of people in different settings that are connected by institutional processes but may be unknown to each other. We have done the latter, assembling the work knowledges of caregivers and access agency and service organization front line workers and administrators whose experiences bring into view the work of the policy regime as it gets put together everyday.

The rich data generated “gives voice” to marginalized groups (Morgan, 2004) and reveals how individuals in these different locations are drawn into, and located in their different positions participate in in-common institutional processes. Formal, in-depth interviews were digitally recorded and transcribed. Analyses highlighted emerging themes from the data that were taken up by the researchers in different ways that fit with their individual expertise and different analytic approaches. Joseph’s analytic overview of the literature raises questions about the disjuncture between policy assumptions and the narratives of employed, long distance women caregivers’ work. Leach turns her analysis to discourses on migration that shape how researchers and policy makers engage in practice with migration issues, and emphasizes how they miss the geographically extended ‘family care networks’ that actively connect people in care work. Turner turns her institutional analysis of the rich ethnographic data to the housing and care services decision processes that emerged as central in the interviews and that involve ‘dispersed family networks’ and workers in home-, health-, continuing- care and community agencies’ procedures in multiple provinces.

Challenges and Limitations of Study

We had difficulty recruiting caregivers to focus groups (see appendix 1 for a list of those organizations and associations that kindly distributed advertisements for us). We had to reconsider how we were going to carry out the research, and proceeded with in-depth interviews. Turner also continued with in-depth interviews and formal and informal interviews with access agency managers, administrators and policy analysts, the latter
also in a small focus group. While we feel this has not limited our research, it was a challenge to our planned schedule, and had to be dealt with along the way. The rich data, visible in the analytic chapters, but particularly in Turner’s chapter which relies heavily on interview data, attests to the complexity and nuances of our findings. The limitation of the study may rather be seen in its truncation by time and resources. Opening up institutional processes and organization that reflect how policy regimes are structured and operate, as is done here, merely opens ‘windows’ onto them. Each author indicates where more work might be done.

The one concrete limitation of the research is that we set out to examine policy issues as they emerge in the everyday work and lives of working, urban-to-rural caregivers and those whose professional and policy work connects to theirs. This must be remembered as the reader moves through the analyses. We had responses from several rural-to-rural caregivers, who did not meet our criteria, and whom we had to turn away. Surprisingly, of even our sample, almost one half had quit paid work, ‘flexed’ work hours if it was possible, or were considering leaving or about to leave their current position. We did not set out to explore ‘access’ to rural services as opposed to urban, which might support notions of ‘place-based’ policy. Nor did we aim to keep the focus on caregivers in a way that would result in a distinct policy for caregivers. Looking with the three-sided lens brings into view several phenomena: the shifting forms of paid work that women organize and manage in a range of circumstances; the complex weaving together of multiple strands of relations in caring for older persons to rural areas with dispersed families; and the actual conditions of moving decision processes/migrations – the family and geographical issues that must be dealt with and institutional arrangements that they must utilize. Canada’s health- and home- care ‘macro’ institutional realities come into view as we see the work of service agencies where their lines of accountability and everyday procedures shape what they do with caregivers.

We have deleted the names of organizations where we felt the information might identify the speaker, but left them in where the terminology is specific to a province, for example, CCACs in Ontario. This holds on to the differences in terminology and structures provinces have developed for delivering services that caregivers try to coordinate. These differences are a striking feature of Canada’s health and home and continuing care systems.

We have tried to identify speakers’ positions, in some cases occupations where the author is interested in highlighting class differences. In other cases institutional positions are identified, and again we have deleted information that might identify individuals.

Sections of the report can be read on their own. The differences in the Joseph, Leach and Turner analytic chapters are described in the Introduction to the report as well.
3. THE CONTEXT OF EMPLOYED WOMEN WHO PROVIDE INFORMAL CARE TO RURAL SENIORS AT A DISTANCE: THE DISCONNECT BETWEEN REALITY AND POLICY

Gillian M. Joseph

Introduction

In the last 50 years there have been social, economic, migration and demographic changes that have had significant impact not only upon those who live in large urban centres across Canada, but also for those in the smallest, most remote areas of the country as well (Keefe, Fancey et al. 2004). For rural areas in particular, these changes have led researchers and policy makers to acknowledge that (a) youth out-migration is resulting in a rapidly aging rural population that may be changing the nature of rurality altogether (Looker 2001; Statistics Canada 2001; Statistics Canada 2006), (b) family economic and social dynamics may be changing in Canada as more women are entering the labour force (Joseph and Hallman 1998; Beaupre and Turcotte 2005; Ferrer and Gagne 2006), and (c) that because few people who leave rural areas return to their place of origin the care that families and friends are able to give to rural elderly is changing and must often be provided from a distance (Keefe 1997). It has been speculated that reduced employment opportunities in rural areas, along with greater restrictions on social benefits could result in increased migration from rural to urban Centres for employment. Considering that rural women are statistically more likely to have elderly parents that live nearby, it is logical to assume that this out-migration will mean a reduction in informal supports for elderly parents. It is therefore not surprising to learn that when it comes to migration, nearly half a million Canadians moved to give or receive care in 1996 (Armstrong and Kits 2001).

In 2002, more than 1.7 million adults between the ages of 45 and 64 provided informal care to 2.3 million seniors, and 7 out of 10 of these caregivers were also employed in the work force (Pyper 2006). In fact, most caregivers are middle-aged women, employed full time, caring for more than one person, caring for a parent, have been caregiving for more than two years, are not living with the person for whom they care and are not the primary caregiver (Fast and Keating 2001).

Although many caregivers would argue that they gain psychological rewards from providing care, the activities associated with caregiving have been found to negatively affect caregivers in many respects, with a significant number having to make adjustments to their employment, incur extra expenses related to their caring responsibilities, and suffer physical, social and psychological health effects (Fast and Keating 2001; Pyper 2006). Furthermore, while work performance, career opportunities and family life of most employed female caregivers is affected, research suggests that those providing care to seniors in isolated rural towns and villages at some distance away may be particularly at risk (Joseph and Hallman 1998).
Yet despite what we know about the context of providing eldercare, there are few workplace or government policies that exist or are accessible to employed caregivers, even though it is estimated that the unpaid care that they provide has a replacement value that saves taxpayers over 5 billion dollars annually (Fast and Frederick 1999). The few policies that are accessible to working caregivers of the elderly, either through government or workplace initiatives, have been shown to be underutilized suggesting that such programs may be based upon generalized assumptions about caregivers’ needs and circumstances that are totally inaccurate and are therefore inappropriately designed for meeting their needs (Medjuck, Keefe et al. 1998).

This section explores the context of employed women who provide long distance informal care to elderly relatives and/or friends who live in rural areas. By integrating quotes as support into the discussion we give voice to those who are often ignored. In the following we show that many of the assumptions about employed long distance caregivers are inaccurate. Illustrating how the behaviour of working women who provide eldercare at a distance to rural seniors is not a true ‘choice’, but is shaped by the social relations in which they are embedded, we show how there is a disconnect between the reality of employed long distance eldercare providers and the current policies that attempt to support them.

The section begins by discussing how the definitions of ‘rural’ and the perceptions of support that arise from them impacts upon the choice to provide care from a distance. The discussion moves on to illustrate some of activities that employed long distance eldercare providers engage in, the context in which these activities are undertaken and the impact of managing and providing those activities from a distance. The activities discussed include using long distance telephone service, traveling long distances, assisting in person and financial assistance. Finally we highlight the disconnect between policy and context to show the policy barriers that prevent employed long distance caregivers from obtaining support, and the accommodations that they are forced to make as a result. These accommodations appear to form a “loop” that continues to reinforce erroneous policy assumptions about caregiver “choice” thus widening the disconnect between context and policy further. The conclusions will highlight the main parts of the argument and provide some policy recommendations.

**The Assumptions about Rurality**

Assumptions about the nature of rural life and the informal care support that seniors within those communities can draw upon play a significant role in the designing of policies and services that meet the needs of rural seniors and their long distance caregivers – in both direct and indirect ways. Indeed such assumptions can both reflect and shape the context of being an employed long distance caregiver. Yet in a study of rural women caregivers, Crosato & Leipert (2006) note that it is important, yet highly difficult, to find a consistent, accurate and relevant definition of what ‘rural’ really means. There are six ways that Statistics Canada defines the term which includes: the countryside outside of larger centres, towns where individuals live outside of urban commuting zones, small populated communities in close proximity where individuals
live in an organized economic and social unit, predominantly rural regions where individuals live in census divisions with more than 50% of the people non-metropolitan regions where people live outside of large metropolitan regions and locations where individuals have rural postal codes. They also point out other research-based definitions of rural that relate to land use, demographic structures, environmental characteristics, homogeneity of population, commuting patterns and access (or lack thereof) to health care services. Yet ‘rural’ is more than just a quantitatively derived term. For those who live there, and for those who have left there, the term ‘rural’ has meaning that distinguishes itself from what is ‘urban’. For some the term “rural” is defined by a perception about a lifestyle that is seen as pleasant and supportive of well-being and which is characterized by a value system of enhanced mutual aid, proximity, conviviality and cooperation (Government of Quebec 2006).

There is a strong relationship between positive perceptions and mental health (Taylor and Brown 1994). So it follows then, that if perceptions about rurality are negative, that this too could negatively affect well-being. In our sample, respondents who had migrated out of rural communities appear to define ‘rural’ not in terms of what it is (or has), but in terms of what it is NOT (or doesn’t have). Two respondents illustrate this point:

**Q: Do you think of [town name] as being rural?**
A: You know, it’s certainly rural still in some ways ...sure, it’s a growing area and there are maybe lots of shopping malls or something like that ...[but] everyone who I hear of over there who’s going through anything is always traveling....So in that way I guess it’s becoming obvious to me that it’s either regressed back into being rural from various health care cuts or it just always was that way. I don’t know. *Post Secondary Institution Manager.*

**Q: What does that mean to you when you think about it as being a rural town?**
A: Probably not the amenities that you would find in a bigger place. The things I guess you’re just used to having. It’s a small grocery store. It’s a small drugstore, so you don’t have the options of going to other places... I guess rural for me, I guess because of living in the city now, it just, there’s not much there to do. There’s not much to take advantage of. If you want to do anything or buy anything major you have to go somewhere else. *Life Skills Trainer.*

When long distance caregivers who have migrated from their communities think about rurality less in terms of positive lifestyle characteristics and more in terms of what is not there, they worry about the kind of supports available to them and the care that their loved one can depend upon.

[My mom has] cancer. And so I was trying to both find out and, well, is this normal, is it normal to be waiting this long?... They don’t even have an oncologist in [town name], so...I had to learn that I probably can’t keep her alive and I, and so I had to stop trying to make sure she did everything and that the only conversations we were having, you know, were about her cancer. And so it was a
really, really difficult process for me…. So trying to do all that stuff from a distance was really, almost impossible. Post Secondary Institution Manager.

I know that I have a tendency to worry a great deal, and if I was living in the same community as my parents then I would probably be spending more time checking in on them and making sure they’re okay. University Researcher

Nevertheless, times are changing for rural Canada. Today, as is the case in urban areas, the social re-structuring in rural communities has resulted in care responsibilities that were previously covered by the formal sector now being downloaded to the informal sector (i.e. families and friends), and this may be even more significant for those who provide care at a distance to rural seniors (Jaffe and Blakley 2000; Creese and Strong-Boag 2005). When hospitals are closed, services discontinued and federal and provincial offices relocated to urban areas, the assumption has been that there will be family members or others close by who can assist seniors to travel to obtain assistance or who will provide care directly as a replacement. Noting that CCAC rural caregivers sometimes do not show up at seniors’ homes on snow days because they are not able to get out, one of our key informants from the Alzheimer Society asserts that when formal service provision in rural communities becomes undependable the responsibility for care again defaults to the family member who may live miles away and is unable to do anything. There has been a great deal written about how downloading responsibilities for care to “families” usually means downloading responsibilities for care to women. Crosato and Leipert (2006) suggest that the proportion of women in rural populations who provide informal care may be even greater due to community pressure upon women to assume traditional roles in line with gender expectations.

However, some researchers have questioned the perception that ‘rural’ means the increased likelihood that seniors and their long distance caregivers can draw upon local informal supports such as family and neighbours to assist with care. For example, one study found that informal care providers in rural areas provided 80-90% of care for elderly people but noted the over-representation of rural caregivers to rural women generally in census analysis (Fast, Keating et al. 2004). In our study, several of the employed long distance caregivers lacked local informal supports to draw upon. Even if potential informal supports are living nearby to the care recipient, they may not be providing care because of strained inter-relationships and/or perceptions and stigma about men as caregivers that may exist to a greater extent in rural communities (Crosato and Leipert, 2006). This suggests that any policy that draws upon the assumption that informal assistance for the elderly is available in rural communities may overlook the impact of social relationships, gender expectations, youth out-migration and shrinking family size. In reality, caregivers may have no choice but to provide care from a distance and may be doing so alone or with little support from their families or the rural community. Our respondents note:

**Q: Are there any other members in your family that assist you in providing care?**
Well, if brothers were sisters they might. But my brother lives five minutes away
from my mom and he’s completely useless. He doesn’t help her at all. My other brother lives in [the U.S.], so he’s way too far away. And my, I have a brother who lives [nearby], but he seemed from the very beginning just to be too afraid of all of this so he just has kept his distance. Post Secondary Institution Manager

It’s come to me because her son lives in [southern U.S.], and her daughter lives in [northern U.S.]. Administrative Clerical Staff

We have family that live there but they haven’t accepted that she’s got [special] health problems, so they don’t deal with her most of the time. My brother does live in the same city as my dad, but he works extremely long hours with his job, and he is not able to provide much support. University Researcher

In a rural/urban study comparing the likelihood that women will combine employment with helping elderly parents, Keefe (1997) challenges the assumptions about the ready availability of rural caregivers that are drawn from national statistical analyses. Showing that there are complex relationships between social, economic and demographic factors that vary among communities, Keefe emphasizes that national policies that only rely on information about the “average Canadian” fail to recognize these regional distinctions, and in particular, those of diverse rural communities. Asserting that the increasing cutbacks in rural formal support systems are an example of policy that is predicated on erroneous assumptions about the availability of informal care supports in some communities, Keefe (1997) emphasizes that there is an urgent need for regional analysis comparisons before policy and services are adjusted or cut. Our findings also suggest that the availability of family and other informal supports in rural communities may not be the reality for all long distance caregivers, putting some at a considerable disadvantage to others.

Our research suggests that common assumptions about the nature of rurality need to be questioned. Proximate informal supports may not be as available to seniors in rural communities as is assumed and where they are available, may be affected by family relationships or more traditional gender-specific roles and expectations. National data sets do not highlight rural regional differences where economic or social circumstances may create greater need. Furthermore, employed women who provide long distance care to rural elderly may have negative perceptions about rurality that may put unique and additional stress on them as caregivers. It could be assumed that caregivers make a “choice” to provide long distance care to seniors in rural areas. However for some long distance caregivers there are complicated social, economic and political factors at play that suggest that employed women who provide care at a distance do so because they have no choice.

The Assumptions about the Activities of Providing Long Distance Care

Exploring the assumptions about the activities that long distance caregivers engage in, and the context in which this is done, helps to understand why this care is so important. Eighteen percent of the Canadian population over 15 years of age provides from one to
more than 10 hours a week of care to a senior, and this does not count traveling time to
and from the recipient’s home (Statistics Canada 2001). Furthermore, it has been
suggested that for caregivers of rural seniors these activities could take up significantly
more time, again, because of the lack of formal health services and the restructuring and
regionalization of services to distant locations (Crosato and Leipert, 2006). It is
interesting to note that men are more likely than women to identify themselves as
caregivers (MetLife Mature Market Institute 2004). It could be speculated then that since
women in general tend to undertake more care-related responsibilities than men, they
may be less likely to recognize when the line between voluntary care and obligation to
care is being crossed. As one of our key informants notes:

Sometimes care-giving – it just creeps up on you. You don’t even realize that
you’re providing care, initially. Caregiver Workshop Facilitator [Key informant]

There is an assumption imbedded in policy and practice that the activities of work and
family are two different aspects of a caregiver’s life that unfold separately and are distinct
from each other. The pervasive academic discourse views work and family as dual or
separate spheres in “work/family balance”, treating women’s responsibilities to family as
something that is separate and usually opposed to responsibilities of employed labour -
while defining men’s responsibility to family in a way that is different to that of women
(Grahame 2003). Much of the research in this area is influenced by the work of industrial
organizational psychologists who tend to place an emphasis on the ways in which
eldercare, and other family responsibilities, affects employee productivity (Medjuck,
Keefe et al. 1998). This emphasis is also reflected in workplace policy. Traditional
definitions of the family, emphasis on care management rather than care provision and
the disregard for women’s private labour within the home ignores the broader social
context in which long distance caregivers of the elderly are immersed (Medjuck, Keefe et
al. 1998).

Unlike these researchers, social feminists view the relationship between work and family
as a bidirectional, interdependent and interrelated social system. They assert that there is
no separating these spheres when, for example, women sometimes purposefully engage
in employment with organizations that offer family-friendly benefits that meet their needs
as caregivers (Ferrer and Gagne 2006). A social feminist perspective re-focuses the lens
on the impact that caring has on the worker rather than on the workplace, analyzing the
underlying reasons and the consequences for women’s lives of which family and work
are part (Medjuck, Keefe et al. 1998; Grahame 2003). In addition, Smith (1993) has
shown that the dual sphere formulation upon which public policies about family are often
based is built on the assumption of a ‘standard middle-class family’; a model which does
not recognize the unique context and needs of the increasing non-traditional or
multicultural families that include the single parent family (predominantly female) and
the gay/lesbian family or those who can not afford to take leave to provide care (Smith
1993). For employed, long distance eldercare providers, the separation between work
and family is not possible.
You know I have a flexible schedule anyway, which I’m very lucky, that way, that the hours of my day are not carved in stone, and also I work a nine-day fortnight, meaning every two weeks I get one day off. So I can flex that day around, and so the days that my mom was coming for chemo…the day she went to the lab I would just come to work late and then work later, and then the days she went to chemo I would take that as my flex day. Post Secondary Institution Manager

When it’s become really difficult I’m able to get some short term counseling through our program at work. University Researcher

It’s extremely tiring, because you’re trying to deal with your working and then on your time off, evenings or weekends, running down and just helping sort out the situation in that house, and then coming back and dealing with whatever has been going on in your own house that needed looking after. And especially since it’s a long distance thing, it just adds to the total stress. Administrative Clerical Staff

As more people live longer and blended families increase, the definition of ‘family members’ who need support is changing. No longer does eldercare mean care for parents alone, but may also include elderly aunts, uncles, in-laws, step-parents, step-in-laws, and close family friends as well as grandparents and great-grandparents (Fast and Keating 2001; Martin-Matthews 2006). Yet Medjuck et al. (1998) note that there are often clauses within workplace policies that restrict the employee’s relationship to the family member to be eligible for the benefit. It is now not unlikely that an elderly parent in need of care will also, in turn, be the caregiver of her own elderly parent or other relative. In two cases noted below, our respondents were caring not only for their elderly mothers, but also for those elderly recipients who were under their mothers’ care as well.

[Ailing father and mother live in different towns]. I would prefer if she [my mother] could live closer and if she could live in something better, but she wants to stay there as long as her mother is alive.

Q: : Does she [your elderly mother] provide care to your grandmother? Yeah, she visits her usually about three times a week and does little chores that the nursing home staff don’t have time to do. She’ll buy her some of her supplies. Yeah, little things like that. University Researcher

Her husband [not my father], who’s also getting pretty old and has health issues as well….so she’s kind of like the caretaker of him, and he has some heart troubles and some diabetes troubles and things like that. So it caused all kinds of upset when the caretaker gets ill. So then I was trying to look after both of them. Post Secondary Institution Manager

For our sample, some of the responsibilities that employed long distance care providers undertook included:

a) Routine long distance telephoning:
- Long distance calling or taking calls from seniors on a regular basis,
- Telephoning the physician, specialist or hospital regarding health status and care plan, often more than several times in order to get hold of them
- Telephoning Social Service agencies to arrange services or to discuss needs,
- Contacting family members for support or getting assistance in emergency
- Being the telephone contact person in emergencies for the First Alert button

A great deal of the care that is provided at a distance needs to be done via the telephone. This changes the nature of the provision of care from a totally ‘hands-on care providing’ model to more of a ‘management’ model (Medjuck, Keefe et al. 1998). It has been suggested that these models of care are gender-specific in nature, since women caregivers who live near to recipients tend to provide more hands-on care and men are more likely to engage in managing care. However, Joseph and Hallman (1998) show that women who provide care at a distance drive further and provide more care than do their male counterparts. This suggests that women who care at a distance are more likely than men to both manage and provide care when needed. Medjuck, Keefe et al., (1998) show that in many organizations, workplace policies make family leave accessible only to employees who manage care and not to those who provide it - thus creating a gender bias in caregiving policy. However, long distance care requires access to costly long distance telephone service, or internet facilities, often during working hours in order to manage care, and this can cause problems in the workplace.

It’s difficult to concentrate at work because you’re wondering when you pick up the phone, is this another call from social services saying she’s done this or that, or … or it’s my aunt calling to say the washing machine’s broken down, she doesn’t know what to do. I phone her almost every day to check up on her, see how she’s doing. *Administrative Clerical Staff.*

I remember being in a situation where my mother had fallen out of bed [and needed nursing home care] … I was on the phone all the time, because you can’t talk to these people after five, and my boss is sitting there glaring at me, and I’m like, “I don’t know what to do!” And, you try to be honest, but you’re in an office where your boss is right there, and it was really, really hard. *Caregiver Workshop Facilitator [Key informant]*

While caregivers who are proximate to recipients may be in a better position to engage in care management or to provide face-to-face care during lunch breaks or after work if needed, those whose loved ones live in another city or in another time zone are at a significant disadvantage. A key informant from the Canadian Alzheimer Society emphasizes that the type of workplace that a caregiver works in, and the job she does, can cause problems for arranging long distance care by telephone. For example, women who are tied to a desk with the internet and a telephone may be more fortunate, while those working in restaurants or on assembly lines are the least fortunate because they would not have access to the resources, or flexible time during working hours, to connect with agencies or other support people. While sometimes agency workers are able to adjust
their hours to accommodate employed caregivers after working hours, many do not provide this flexibility.

Just...just frustration dealing with people. She [the daughter living in the U.S.] would phone...she would look up information on the internet and then she would phone people, and they would refer her to some one else who then referred her to some one else, and that sort of thing. It just seemed to be difficult to find out what your resources are, how to connect with people who can help you figure out how to help your mom, that sort of thing. Administrative Clerical Staff

There are some women that I’ve had the opportunity to meet that work in factories and I cannot call them and they can only call you on their lunch...so that makes it really challenging to try and make sure you’re there to take the call, or if there’s an emergency you have to go through HR to have them paged.

Geriatric Mental Health Professional [Key informant]

b) Traveling:
- For shopping
- To get pharmaceuticals
- To arrange housing for recipients
- To take recipients to medical or other appointments
- Driving recipient to the airport
- Traveling by plane to recipients’ location to provide medical support
- Traveling long distances by car under stress in emergency
- Traveling back and forth to provide respite care

A U.S. study on caregiving reported that 15% of all family caregivers travel an average of 450 miles (up to 8 hours driving) to provide care to family members (Smith 2006). Yet it is interesting to note that distance, in the form of travel time, has a negative effect on the amount and frequency of assistance provided by employed male eldercare providers but not employed female providers - who drive further and provide more care than their male counterparts (Joseph and Hallman 1998). Our respondents support this:

Basically I go down there [to elderly aunt’s house] every couple of weeks [two hour drive]. She needed a line of credit advance...at the bank...if there was nobody available on a Saturday I would have to go down with her on a weekday. I’ve gone down there many times for emergency situations, where I would get a call that she’s fallen and been in the hospital, or she can’t figure something out, or she’s got an issue with the house, that sort of thing. Administrative Clerical Staff.

Typically it’s that kind of thing. If I’m visiting them or if there’s...with my mom if there is a health crisis then I will...I have a couple of times had to travel out there and take some time off of work to get something done. University Researcher
Traveling long distances under stress can also place the caregiver in danger, particularly in rural areas during bad winter weather.

In those times when you get a call and say she’s just fallen and we’ve admitted her to hospital, and you’re wondering …you can’t get through to anybody at the hospital and so you’re wondering what you’re going to find when you get there, so…. you’re not probably as vigilant as you should be when you’re driving.

*Administrative Clerical Staff*

Especially in the wintertime… we always have to check the weather before we’re going to see what it’s going to be like. *Life Skills Trainer*

c) Assistance with Special Activities:

- Cleaning recipient’s house
- Filling in forms on recipient’s behalf
- Packing for recipient’s travel

While research suggests that living arrangements are not associated with emotional support because that can be provided by telephone, e-mail or letter from anywhere, living with someone has been found to be the major determinant of helping seniors with routines of daily living (Armstrong and Kits 2001). Therefore we expected that long distance caregivers would engage in fewer routine and personal activities. While a few of our long distance care providers occasionally provided personal care such as bathing or cooking for the recipient, most of these tasks were undertaken through arrangements with the CCAC or other private services. However providing important assistance with tasks that could not be accommodated by social agencies required significant effort.

I took time off [work] just this week. She’s gone down to [the U.S.] to be with her son for a couple of months, so I took time off to ensure that she packed whatever she would need, and that she got on the plane. *Administrative Clerical Staff*

I took a day off to go to [rural town], to attend the meeting [with healthcare staff] which was a 20 minute meeting. I had to take a whole day off work to do it. *Life Skills Instructor*

Sometimes the daughter is required to sign a plethora of paperwork that is involved – which means she either has to go to where her parent is located, or have the papers faxed to her to sign. *Alzheimer Society Case Worker [Key informant]*

d) Financial:

- Banking
- Giving recipient money
- Paying for items associated with recipient ancillary needs and care
- Paying for medication
The personal economic costs of caregiving are significant and often overlooked. More than half of employed Canadian caregivers made adjustments to their employment to provide care costing them more than $1.2 million in lost current and future income (Fast and Keating 2001). More than 40% incurred extra expenses that were directly related to caregiving, estimated at $30,630 per employed caregiver (Fast and Keating, 2001). Economic restructuring of social services in some cases have downloaded even more costs associated with care and maintenance to families who are already feeling the financial burden of eldercare. Moreover these economic costs can affect caregivers not only throughout their whole careers, but throughout old age as well (Ferrer and Gagne 2006). Our respondents were no different, with the exception that they presumably spent more money on traveling to provide care, and on long distance telephone costs.

Yes, there are things that I have done that are not going to be recovered…Getting groceries when she has no idea. She has no access to her bank account because she can’t remember her PIN number and the bank isn’t open. Taking her out for lunch when she wants to treat. Buying her clothing, because she hasn’t got something that she needs. And then I want to make sure the bill is paid, so I take it home and then pay it through my own bank. Administrative Clerical Staff

He [my father] hasn’t been able to always afford his heart medications or his diabetic medications, and he didn’t tell me this for two years. So I only found out in August that this was occurring, that he was cutting his medications in half or not taking them when he ran out. And that was really upsetting… I think in the last six months I’ve probably given him about $4,000. I do help [my mother] out financially with getting things like clothes and other things that aren’t often considered necessities under welfare plans or disability plans. University Researcher

Yeah. I was hoping to finish paying off my student loan this year, but I don’t think I’ll be able to do that. University Researcher

The Impact of Undertaking Caregiving Activities at a Distance

Like many other caregivers, most of our respondents told us that they were “burned out”. They were distracted at work and they were having difficulty attending to their family responsibilities as thoroughly as they felt they needed to. They were all exhausted, yet almost everyone felt guilty that they could not do more. Over 40% of women who provide over one hour of care per week report significant feelings of guilt, believing that they should, somehow, be doing more to care or should be doing a better job at work. Furthermore as hours of paid work increased these feelings of guilt intensified (Pyper 2006). Some of our respondents had been forced to take time off from work in order to alleviate their stress either for a short period of time, or, because they could not cope with
the frustrations of providing long distance care any more, some had planned to quit working, at least in the short term. It is interesting to note that 6% of Canadians who retired between 1992 and 2002 stated that they would have continued working if suitable arrangements for caregiving had been available to them (Statistics Canada 2004).

Well, earlier this year I found it very difficult. I don’t know how to describe it. I guess I got burned out with all the stress and my responsibilities with work and the balance. I just wasn’t able to balance it all and I had to take a week off and just relax and sort of reevaluate what state I was in and what I was capable of doing. University Researcher

[Sister’s name] has made me feel guilty about being that far away…. and because I work, I feel that I, maybe I would have gone there more often even with the distance, but because I’m working it’s … when you work Monday to Friday, 8-4, you’re tired. Life Skills Trainer

Well, it’s wearing me out, for sure. There was a period a couple of months ago where my daughter just said to me, you can’t do this, you’ve gotta stop. Because I was mentally ready to throw in the towel, you know what I mean? I just can’t handle this anymore. That sort of thing. So she just told me to cut it out, which I did for a bit, but then the emergency calls start coming back and what do you do? Administrative Clerical Staff

The stress and strain of long distance caregiving affects other family members and family relationships as well, resulting, in some cases, in damage to and withdrawal from what could have been a much needed source of support. Being so far away can make a caregiver feel isolated and out of touch. Family conflict may arise over who provides care and what kind of care is actually required(Armstrong and Kits 2001). As policy shifts more and more care from formal to informal sources, long distance caregivers are held accountable to provide care without the adequate resources to do so. Conflict between siblings and other family members adds even more stress to the guilt of providing eldercare at a distance.

I didn’t see as much happening because I wasn’t there all the time and they had, I think, slowly taken things over after Dad died without the rest of us realizing what they were doing either … So, that’s caused some problems in our family. We haven’t always agreed in the last six or so months, on what the best route is for Mom. Life Skills Trainer

Finally, the stress and strain of long distance caregiving is not short-term. It can have significant impact upon a caregiver’s life plan, and on society itself, in the long term. As a respondent notes:

My partner and I have decided not to have children and my parents’ health is one reason why… Especially my mom’s health, ‘cause I just don’t think I could provide them with enough support if I was a parent as well. And as they get older,
Therefore it appears that there are a number of assumptions associated with long distance eldercare that can be drawn into question. Our research finds that for long distance caregivers, work and family are not separate spheres, but are bidirectional and interrelated social systems. We find that aspects of the activities and stresses associated with providing long distance care are different to what research suggests are those experienced by proximate caregivers. Moreover, the effects of providing eldercare at a distance may be long term, with significant impact on the lives of employed caregivers, their families and indeed, society itself.

The Disconnect Between Context and Policy

When the context of providing eldercare at a distance is unrelated to the policies that attempt to support caregivers, a disconnect develops. Researchers have noted that the few policies aimed at supporting workers who provide eldercare are rarely taken up by employees who need them. In fact, it has been shown that family policies are often biased towards those employees who don’t actually need them (Comfort, Johnson et al. 2003; Ferrer and Gagne 2006). In addition, research by Fast, Eales and Keating (2001) shows that the informal caregivers who are least well-served by existing policies are employed women and those who live at a distance from the care receiver.

Critics of existing family-friendly policies have shown that, in spirit at least, the needs of those employees who provide eldercare have been treated as less important than those who provide care for children – leaving caregivers of elderly to their own resources to find ways to manage and provide for the recipient’s needs. For example, Medjuck, Keefe et al. (1998) found in their analysis of family leave policies, that there are significant differences in leave available to care for an ill child versus those available to employees who are caring for an elderly parent. There are also requirements of co-residency, and policies in general allowed for both the provision and management of child care – but only the management of eldercare. Fast and Keating (2001) emphasize that despite the fact that the majority of adult Canadians are in the labour force, few provinces have employment standards legislation with family leave provisions in them and few provincial or national benefits support informal caregivers by reducing their economic burden. Even the Caregiver Tax Credit is available to only one closely related care-giver who also must co-reside with the recipient (Fast, Eales et al. 2001). This means that those who provide eldercare at a distance have no public and few workplace supports for caregiving.

[Respondent is reading from her policy manual] There’s also a family illness [policy], it has to be approved by the administration …No, no, no. The family illness, that was a big thing. I tried to do that once. I went over there when my mom was first diagnosed and I tried to claim the two days back under family illness. But our contract says that the family member must live in the same
household, and that’s why you’re taking the days off to care for them. *Post Secondary Institution Manager*

Mejuck et al. also illustrate that many workplace policies can only be accessed at the discretion of supervisors who can turn down requests for benefits if they perceive that the request does not relate directly to the employee’s job. This means that access to such benefits is not available to all employees equally, and some, but not all, will need to make accommodations and sacrifices to provide care.

**Q – What kind of accommodation does your workplace have for, say, other people who have elder care issues? Is there a special policy or something in your organization?**

Not that I know of, and I’m not really aware of… Well, actually, I shouldn’t say that. My boss did have a situation with his own father, where he had to leave and immediately go look after him. But when you’re in a position, a higher position in a company, I think it’s much easier to do something like that. *Administrative Clerical Staff*

Employee Assistance Programs (EAPs) are designed to assist employees to deal with psychological and social problems. Larger organizations tend to have some provision for employee access to this service. It is less likely that smaller companies would subscribe to these services or that self-employed caregivers would have access at all. However, since the mandate of EAPs rarely focuses on family issues, and since the counseling services are very limited and often short-term, this initiative is not often a reliable support for those who seek assistance for problems related to eldercare over the longer term (Medjuck, Keefe et al. 1998).

We’re talking about caregivers that are care-giving for years… years… and it’s not six weeks. So, I can see that a lot of the caregivers that we work with, they’re in it for the long haul. *Rural Mental Health Resource Worker [Key informant]*

It’s …emergency family assistance program or something like that. And it’s just part of my benefits package, but, you know, you can get just a few sessions. It’s not for anything long term. *University Researcher*

Provincial or national policies concerning access to senior health care resources can differ significantly between provinces or between countries and can result in a long distance care provider having to assume more care or make more complicated arrangements to support a loved one who lives in another district. Yet re-locating a senior in need to be closer to the caregiver may also be difficult. A key informant from the Alzheimer Society points out that provincial health care plans can be problematic for those seniors who do move to join their daughter caregiver from other provinces. In addition, the daughter must register for formal care through the CCAC that is local to the care recipient (parent). This means that the daughter must engage a dialogue between her own CCAC and the CCAC where her parent resides – which again, can be problematic depending upon what type of job and communication resources the caregiver has during
the working day. Either way, someone in the community needs to be on hand to keep an eye out on the situation of the care recipient (in the rural area) in the caregiver’s absence.

Our respondents note:

[Caregiver living in B.C.] Most recently, with my dad, his family doctor is trying to refer him to a cardiologist in Saskatchewan, and I would appreciate it if he would also try to refer him also to one in Alberta … You can usually get into Alberta health care services faster. University Researcher

Q – Is there any thought about her moving down permanently to the U.S. to be with her daughter and son?
I think they have thought about that, but the issue there would be the health insurance, because she has pre-existing conditions, so there’s no point even paying for health insurance, because they’ll turn around and say you’re not covered. So it’s more or less out of the question…. Administrative Clerical Staff

When government sponsored or workplace supports are not accessible for working women to draw upon, they may become ‘conscripted’ into providing eldercare as well as managing it. Particularly for women who are poor and regardless of their culture, there is no choice but that they will be required to provide care to a parent in need – regardless of the distance. By the same token, without support, women reach their breaking point and are forced to “choose” to leave their jobs in order to provide care. As Armstrong and Kits (2001, p. 37) suggest: “Caregiving can be voluntary only if there is access to alternatives and if there are the kinds of supports available that allow choices to be made”. It is interesting to note that women caregivers who relinquish their employment to provide unpaid eldercare full time may give up $15,000 to $26,000 annually in current income (Fast, Eales et al. 2001). Moreover, this calculation does not include employment benefits such as pensions, health and dental benefits or disability and life insurance coverage.

This is not the way I want to connect with my mom and be with my mom, so there’s no choice for me but to move back. And my career, my job, all of that stuff …you know what? It doesn’t matter right now. I don’t have a place to live yet and I don’t have a job [to go to]. How completely inadequate it is to try and care for somebody from a distance. You cannot do it…. this is totally unsustainable ... Post Secondary Institution Manager

You know, you don’t know what to expect, but you know that her mom’s needs are just going to be greater and greater…but still [there is] the need to have to work and make a living. Rural Mental Health Resource Worker [key informant]

When employees can not tap into family friendly policies to assist them in providing eldercare, they have to make accommodations on their own. Benefits such as vacation allowances and sick days are often used to cope with caregiving responsibilities (Medjuck, Keefe et al. 1998). However, when employees tap these resources in order to
provide eldercare, they lose their own opportunities to have access to a day off for sick time or much needed vacation (Medjuck, Keefe et al. 1998). In addition, the impact of having an employee pulled between the responsibilities of work and care is also significant. For example, some employees are encouraged to make up the time that they have taken off which can add to stress when the needs of family are neglected in order to catch-up at work. Yet when other sources of support are not available, strategies used by long distance caregivers require significant planning and are complicated and potentially stress-inducing in their complexity.

If I need to take a couple of hours off, for example to make phone calls, then I can do that. In the past I have usually made up the hours for short things, like dealing with phone calls. I made up those hours. If I have to take a day off then I can take it as a sick day. University Researcher

I sort of switched my day around and I came in to work …I took the six thirty train in, so get to work for seven and I …instead of working nine to five, I work 7 to 1:30, and I took my holidays sort of an hour at a time. So I didn’t have lunch. I was in two hours early. And then I …you know that little bit of extra time in the day I spread out and took sort of a week’s worth of holidays an hour at a time. I can do that here. I know that a lot of people couldn’t do that, so I mean that certainly is one accommodation in the sense that the workplace provides. Another one is, because you asked about our policies, when it comes to sick time, that can also be taken for a family member. So it’s not personally me being sick. We have twelve days a year that we can take. [Maggie ??]

I’ve had a daughter who’s at university who’s been having some health problems, I’ve had to kind of squirrel a couple of holiday days just to keep them available in case I needed to take days off, so I haven’t actually booked my full holiday time. I’ve always left some days available, so if something came up. And I continued that with my [elderly] aunt, because I knew that I would have to have them. Administrative Clerical Staff

I work a nine-day fortnight, meaning every two weeks I get one day off. So I can flex that day around, and so the days that my mom went to the lab I would just come to work late and then work later, and then the days she went to chemo I would take that as my flex day. Post Secondary Institution Manager

When women do not use existing family friendly policies the assumption is that they are not needed. When women are forced to take part-time or in-home work at significantly lower wages because of caregiving responsibilities, this is considered to be their “choice”. When employed women who provide eldercare at a distance are forced to find their own solutions because of a lack of institutional support, behavioural trends are created that reinforce erroneous assumptions. In turn, these assumptions lead to inappropriate policy, or lack of action - thereby augmenting the disconnect between policy and reality.
Most women undertake paid work for the same reasons as do men: to earn a living to support their families. Without acknowledging how such “choices” are influenced by much broader, structural forces such as globalization, restructuring and occupational, social and economic influences, the disconnect between the context of being an employed caregiver of rural elderly at a distance and the policies that attempt to support them grows (Gazso 2004).

**Conclusion**

Although all employed women who provide eldercare to seniors who live in rural areas are affected by the decline in social services, the distances to health care support, the weather and gender role expectations, the challenges for employed women who provide this care to rural seniors from a distance are added to these. For long distance care providers, the economic cost of long distance telephone calls, of car, ferry or airplane travel to provide or arrange care, the costs associated with the care recipient and the salaries, promotions, training and pension contributions lost from taking unpaid leave to travel for care, impacts on the short and long term economic well-being of the long distance caregiver to a greater degree. The significant time sacrificed, distances traveled and context under which employed long distance caregivers must provide emergency and routine care puts them in danger, significantly impacts upon their mental health and their long term life plans and affects how women as caregivers are viewed by others in the workforce. Add these challenges to those that they must also face in arranging and providing care in resource stretched rural communities and it is not difficult to assert that employed women who provide care to elderly seniors at a distance are in “double jeopardy”.

The context of employed women who provide care to rural seniors at a distance is complex. Fundamentally, the assumptions that form the basis for government and workplace eldercare support policies are inaccurate because they reflect the context of providing eldercare as being a “choice” that women make. However, we have shown how perception can define rurality and impact upon the availability of informal support in rural communities – removing the choice about who will provide care. We have shown that the assumptions about eldercare, the type of activities and context in which these activities are undertaken are not covered by formal supports, so caregivers have no choice but to provide this care to seniors themselves… at a distance. We have shown how policies and practices make it very difficult for employed caregivers to work in a stress free environment, confident that their loved one is well cared for. We have illustrated the disconnect between context and policy that leaves those who provide eldercare at a distance without support from government or workplace; having to find complex ways to manage and provide care that can have significant repercussions on their own health. There is much to be done.

The aging of the Canadian workforce will continue throughout the next few decades and discussions around how to encourage older workers to stay in the workforce longer will be paramount to economic stability in many sectors shortly. It will be important to understand and accommodate the needs of older workers, particularly the interrelated
demands of work and family such as eldercare. Furthermore it is important to remember that, without the benefits that employed long distance care providers create for taxpayers, such costs might otherwise be shifted to organizations through increased taxation as has happened in other countries. Cost effective workplace supports for eldercare providers are not beyond an innovative and competitive marketplace. To address the disconnect between context and policy as it relates to long distance eldercare is to benefit the employed caregiver who provides and manages care, the recipient who needs it, the workplace that pays both directly and indirectly and the country who spends scarce financial resources inappropriately because of it. There is no choice.

4. POLICY PRACTICE, MOBILE FAMILIES AND LONG TERM HOUSING AND CARE OPTIONS

Susan Marie Turner

Introduction: Policy Practice Where the Work of Informal Caregivers and Service Providers Intersect

Policy analysts in Canada’s government say they are interested in developing policies for informal caregivers\(^2\), that “rural is on the radar,” but that there are gaps in the data available on informal caregivers. With the attention to the ‘sandwich generation’ who care for both children and aging parents, and the more recent attention to the aging ‘baby boom’ generation who’ll number 9.8 million by 2036 (Statistics Canada 2006) with fewer children to support them, let’s have a fresh look at where policy information gaps exist and what forms of policy action can address the circumstances of seniors and caregivers.

This paper takes up the question of the organization of policy by focusing on the practices of caregivers within the institutional relations that connect the healthcare system through access agencies, community service organizations (CSOs)\(^3\) and families. It

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\(^2\) The term ‘caregivers’ operates generally in the healthcare and social services discourses. The term ‘informal caregivers’ reflects the organization of Canada’s healthcare system such that many family members do unpaid care work and their work has been acknowledged within the discourse. ‘Healthcare’ institutions and practitioners (hospitals, doctors, clinical practitioners) come under the jurisdiction of the Canada Health Act. Home support services to those not in hospitals or nursing homes fall outside the Act and are organized under provincial and territorial legislation. Each sphere is organized through distinct structures, professional, government and non government funding relations and so on. Here I’m exploring work at the interface of these two spheres. Professionals working in service agencies that provide services to care recipient “clients” living at home, in private for-profit and in non profit and other forms of housing, are also called caregivers. I use the term caregivers to refer to women whose work accessing, managing and coordinating care for a family member or friend is unpaid – those in the discourse called ‘informal caregivers.’

\(^3\) I use the term ‘access agencies’ to refer to agencies funded 100 percent by provincial governments. They have direct, in-line accountability to ministries of health and/or long term care and “the Minister” provides program funding through their centres and staff. Community service organizations (CSOs) on the other hand are only partially funded by provincial ministries, may have multiple and insecure funding arrangements. Funding from ministries comes on different terms and conditions.
moves from the experiences and decision processes of caregivers through homecare and community service organizations’ work, to policy. Its initial focus is how informal caregivers’ practices are shaped within working relations with service organizations. The ‘policy lens’ it employs was designed to bring into view different aspects of what we called ‘the compassionate care challenge.’ The aim is to expand the current understanding of caregiving practices – in particular housing moves and employment changes – by taking a standpoint within the decision making processes of caregivers who are dealing with three particular constraints: urban-rural “at-a-distance” caring relations, employment and workplace conditions, and urban/rural service delivery organization. We aimed to highlight a common phenomenon within Canada – working caregivers coordinating and managing care across geographical distance – with a focus on urban-to-rural relations. Doing so addresses intra- and inter-provincial migrations in Canada, a range of paid work scenarios, and pays attention to caregiving practices involving time, travel and housing decisions while focusing on institutional organization. The research begins in the everyday lives of working women caregivers, and then it turns from individual care practices to examine how those practices are linked into and shaped by particular institutional procedures and processes. Tracking through the processes that connect the work of individual caregivers, through ‘front-line’ work into the standardized processes of service organizations, brings into view aspects of a policy regime that affect the practices of those who use and implement it. The aim is not to describe and analyze individuals or groups, but to bring into view aspects of institutional organization and policy practice as it goes on and reaches down into people's everyday lives and work.

Other recent approaches to the experiences and decisions of informal caregivers include government researchers’ analyses of the intersections of work and care situations such as those of self-employed women (Karman and Elleithy 2006), the “intensities” of employment and care work, and retirement decisions (Pyper 2006), workplace ‘adjustments’ due to caregiving requirements (Hunsley 2006) and caregiving consequences for “prime-age” workers including work interruptions and early retirement (Habtu and Popovic 2006). These analyses rely on General Social Survey (GSS) data to bring into view the nuances of ‘work-life balance’ issues for caregivers that arise from that database. Moving and housing decisions for older women have been the focus of work elsewhere (Luken and Vaughan 2003, CMHC 2005 and 2006). In Canada the more general issue of “shelter affordability” for families is recently raised in relation to family income levels, affected by whether there were one or two income earners in the family

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4 The ‘Caring at a distance’ project was designed to bring into view different aspects of what the researchers called ‘the compassionate care challenge.’ The Compassionate Care Benefit is a leave from work with pay in the form of Employment Insurance benefits and is labour legislation administered through HRSDC. The benefit, available to care for a gravely ill family member, included the definition of ‘family member’ as parent, spouse and child. It was much criticized by care advocates as narrowly restrictive, and due to a lack of use of the program, recently underwent formal evaluation. There has been to date no follow up by the government to the evaluation process, although in Ontario the Employment Standards Act was amended in 2006 so that ‘Family Medical Leave’ now includes siblings, aunts, uncles and close friends who are employed and leave work to care for a dying person. We are using a much more generous notion of ‘work’ and ‘working’ here. While the challenge to the government to commission a national task force on a broader range of supports for eldercare is outstanding, the fact is that this kind of policy is irrelevant to the situations of all of our interviewed caregivers.
(Luffman 2006). Housing and affordability policies are not the focus here, but concerns, assessments and negotiations about costs, time, travel and service availability in different housing situations and geographical locations for both senior care recipient and caregivers’ families, emerge within, and are found to be at the core of, ongoing decision making processes that entire family ‘networks’ engage in when dealing with decisions about their aging parents care. Policies that aim to address contemporary issues of home-, long term- and health-care in Canada must address directly the issues of affordable housing in conjunction with support services and their routes of accessibility.

Informal caregivers in Canada provide care and coordinate services to an increasingly aging population in ways that have dramatic effects on family structures and migrations within and across provinces. Women who are both employed and who coordinate, manage and provide care at a distance to an older person living in a rural setting at home or in a facility, face multiple challenges that underscore issues of geographical distance, service and personal costs, and the lack of consistent or coherent supports for them in doing their care management work. Recent trends in rural regional development and the reorganizations of Canada’s healthcare system impinge on the day to day work that women – as caregivers, service providers and policy analysts – are doing to sustain families and family health. In fact, since the 1995 enactment of the Budget Implementation Act and subsequent healthcare restructuring mechanisms, government support for the community services system, which directly supports caregivers and the frail elderly in Canada, has diminished. At the same time, the reorganization of the formal healthcare system has absorbed the lion’s share of the healthcare budget and shifted the policy focus to reshaping the organization of hospitals’ and physicians’ work. Employed women caregivers comprise the majority of the informal healthcare sector. Women are the majority of those employed in the service sector, in home and continuing care organizations, volunteer associations, and as government policy analysts in healthcare. All of them are working with scarce resources, services that vary across jurisdictions, and in constantly changing working conditions and policy contexts. Employed women caregivers in particular who work in urban areas and provide care to rural elderly, must pull together what resources they can to ensure the adequate, appropriate and best possible care for an older person living at home or in a facility. It is their situated spatial and temporal everyday realities that help us see where the delivery system’s inequities and service needs emerge. The events that precipitate protracted decision making processes and the tensions that families undergo in them, especially regarding where the care recipient should live, have multiple family repercussions that are situated and embedded in extended family and community relations. Those repercussions make visible the links between the organization of the healthcare system, access agencies’ homecare services, workplace policies and service organizations’ and urban-to-rural caregivers’ work.

**a) Beginning in Caregivers’ Practices**

Negotiating and coordinating a range of support services to older care recipients living in rural settings involve women caregivers and service providers in ongoing working

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5 The Canadian Institute of Health Research separates ‘home health care’ and ‘home care’ (meaning support services). Thanks to Timothy Diamond for this clarification.
relations. The focus on these working relations and on the ways that caregivers are drawn into particular agency and organization processes is a distinct approach. Current Canadian research that has previously informed policy development, analysis and evaluation (Fast, Keating et al, 2004, Keefe and Fancey 2004) gives us a picture of informal caregivers who shoulder the burden of much of the eldercare provided in Canada (Keefe 1997, Pyper 2006) and supports a range of sound policy recommendations including a national family policy, a national eldercare policy, workplace and labour practices and comprehensive provincial strategies (Keefe 2005). The analysis that follows emerges from a rather different line of inquiry.

Developed by feminist sociologist Dorothy E. Smith (Smith 2001), institutional ethnography approaches have been widely used by researchers to expand the understanding of knowledge and practices of institutions such as education, healthcare, social work, land use planning and skills training. In the field of health and medicine, Mykhalovskiy and McCoy (2002) begin in the standpoint of people with disabilities, people in nursing homes, people living with HIV/AIDS, and nurses respectively, to examine the textual managerial processes operating to organize and change healthcare practices. I begin in the standpoint of informal caregivers. We interviewed and in some cases did follow up interviews with a small sample of caregivers. Interviews were unstructured. We asked how the caregiving work got done, expanding into the areas of concern for them into the institutional processes in which they were participating. Rather than treating them as informants on their own circumstances and practices alone, their experiential accounts are examined and analyzed with a view to identifying specific sites where their activities connect with the work of service providers and policies that shape their work. Caregivers meet ‘the system’ where they are drawn in by, and learn to activate, specific procedures for accessing services. Here the dynamics of workplace, policy and care giving practices come into view sharply.

b) Turning to the Intersection to Service Organizations’ Work Processes

Multiple service organizations operate at the interface of policy, organizational requirements and informal caregivers’ work to negotiate a ‘package’ of supports for care recipients. To grasp just how policies come down into people’s everyday lives and work, I explore how ‘informal’ and professional caregivers coordinate their work to produce the ongoing processes of service organizations. I thus shift from the intersection of their work, into the front line managers’ work, locating service organizations within a changing policy field of action. I’m shifting the view to actual institutionally organized processes that connect families, case workers, managers and policy makers in the provision of home- and long term- care. The method is to assemble their different ‘work knowledges’ of these processes, to discover and show how their work within these relations is organized by a complex of policies that operate as standardized text-based sequences. The aim is a better picture of the actual institutional processes –shaped by policies – that are the everyday context for agencies’ and caregivers’ work.

Urban-to-Rural Caregivers and Dispersed Family Networks: Making Paid Work, Housing, Move and Care Decisions
Working caregivers in any circumstances must coordinate care using multiple organizations and a patchwork of services while managing their own paid work. Working ‘long-distance’ caregivers of an older person in a rural area told us about the day to day situations that shape their work and decisions about paid and caring work and housing arrangements for themselves, their families and the care recipient. Social and economic inequities in families’ situations and complex policy contexts emerge starkly under close examination of urban-to-rural care practices. These are described in slightly different ways in the analyses by Joseph (2007 in this report) and Leach (2007 in this report). While the literature on informal caregivers mainly focuses on the burden on caregivers, the stress, the lack of consistency or security of workplace and government supports, my focus in this section is their work with service delivery systems. What is little known, especially of those who coordinate and manage care across geographical distance, are these dimensions that we have found associated with the geographical distance, dispersed family networks, and housing and relocation decisions, and that present special challenges for policy.

Doing long distance care work involves caregivers in complex decision processes. The caregivers we spoke to are not always the ‘primary’ informal caregiver nor always the one who has legal authority for personal care. In all situations, however, what is visible is that they are planning, negotiating and coordinating across multiple geographical terrains, weighing different care services in different locations and different housing options. They deal with doctors, clinics, hospitals, and multiple service agencies and organizations. Some of their care recipients have multiple chronic health problems and require continual trips to care providers in different locations. Not only is ‘one-stop shopping’ impossible, each ‘stop’ for access to a service has text-based work associated with it. Negotiating a division of labour among family members to do this work, and finding a ‘fit’ with existing services and living arrangements is complex work. It requires specific skills that are glossed by the current term ‘navigating’ used in the healthcare discourse. Rather than taking up the institutional terminology, I begin with a close look at urban caregivers’ work with rural service delivery agencies and available housing options. These are the actual conditions for dispersed families making housing and move decisions for themselves and for and with the aging senior.

The caregiver speaking lives an hour drive from her aunt’s home, stands in for her cousin who lives in the US.

My cousin has a son who actually was supposed to come out and …he lives in [a large city in] B.C., and he and his wife were going to move back to this area [Ontario] and were apparently going to move into her house and help look after her. But then issues came up where he didn’t come. Now he’s supposed to come in the spring, which still leaves a gap of a couple of months, because she’s coming back in January. He’s going to be looking for work here in the [metropolitan] area…. Now my cousin in [USA city] feels that this is all going to happen, that he’s going to move back and look after my aunt, but her house is so small I can’t really understand how that’s going to work. He has a teenager in high school [and] his
wife is pregnant with another child. So to me there’s no room, plus the fact that my aunt is … it’s getting more and more difficult just to be with her on a 24-hour basis.

There’s a few [nursing homes around the small town area] but I don’t know if there are any that have any vacancies. Now they managed to get her into the one home that she did go into [temporarily] because she volunteered there while her husband was in, when he had Alzheimer’s. They gave her a discount as well as giving her a place immediately, but I don’t know if that’s going to be possible down the road. Financial is a big concern. Now she does have this little house… so possibly that could look after her care for a number of years… if they did sell it.

I’ve talked to [access agency]. I’ve left the other stuff for my cousin to organize, to find out what actually is available for her and so on. And some of those things you can do over the phone, and they have a plan in [US city] that she can make unlimited long distance calls, so I didn’t feel that I wanted to get involved in that. [The agency] have called me when they’ve had issues, when neighbours have complained about what’s been going on or my when aunt has phoned them in the middle of the night leaving messages, and different things… they started calling her daughter in [US city] and emailing her after that, with some of their concerns… you have to remember that I don’t really have any let’s say authority in the situation.

The speaker above, who works full time, lives an hour’s drive from her aunt living in a rural Ontario area and sees an urgent need for change in her aunt’s housing. Her thinking through the housing and care options for her aunt involves numerous family members in the US and across Canada, their family situations and paid work and moving plans. Not responsible for housing or decision making regarding personal care, she is nevertheless caught up in working relations with the agency that coordinates home-care for seniors.

The speaker below gives us a closer look at issues particular to those caregivers in urban areas who don’t own their own vehicles and to those in rural areas and small towns for whom needing a specialist means driving to a city. Her caregiving work is shaped directly by the organization of medical care into diversified specialties and procedures of referral. Referral leads inevitably to taking the time and the cost to travel to another town or city. A mid-level college administrator without transportation, she’ll fly in order to manage in person the textual work of her father’s application for social housing.

I live in [large BC city] and we don’t have a car, so I take the bus everywhere, and I usually spend about two to two hours and fifteen minutes a day on the bus going back and forth to work, and I rent an apartment with my partner. [My father] lives in [small town] in Saskatchewan. It’s got a number of services, but it’s got one hospital that sort of serves the region, and not a lot of specialists. And in the last couple of years he’s started to develop a lot of heart problems, so trying to get him the care that he needs, he always has to go out of town for that. He’s no longer able to work, and he’s applying for disability pension through CPP (Canada Pension Plan) and he lives in a bedroom. That’s all he can afford. It’s a bedroom with a little kitchenette. And trying to get him affordable housing is very difficult. He’s on
a waiting list for what little social housing there is in [small town] but because it is a boom town with the oil and gas industry, it’s very expensive to rent there.

I keep in touch with their doctors [parents live apart in small towns in Saskatchewan and Alberta]. Both of my parents have a difficult time advocating for themselves with their doctors or with any kind of person in authority. And they get confused easily by, for example, all the different bureaucratic requirements of applying for disability or whatever it may be. And so I will, in my dad’s case recently I’ve been basically nagging his GP to try and speed up the referral process to a cardiologist and other specialists to get him help, and helping him out with applying for his disability benefits and his housing …social housing application.

Municipal affordable housing policies come into play in the above situation, and intersect with policies on subsidies and geographical differences in housing costs, regional economic development strategies and local housing markets.

The situation described below became “impossible” and resulted in the caregiver making a decision to leave secure paid work and move. Again referral means traveling a distance to the specialist, in this case by ferry and bus over an hour away. Here the intersection of health care referral procedures with the provincially drawn regional boundaries of service or “catchment” areas means that her mother cannot access specialists in a nearby island city that is within a half hour drive. This shapes her decision to quit her job and move.

[My mom lives at home, has cancer and cares for her husband. I’m in the same province but have to travel by ferry and bus]. It’s a growing area, lots of shopping malls because there are a lot of seniors that live there now. But the more I hear about things like medical services, it still seems to be quite rural, because everyone I hear of over there who’s going through anything is always traveling. They’re either traveling to [large mainland city] or they’re traveling to [mid sized island city] to get a test or to be seen by an actual “–ologist,” as opposed to a practitioner.

If I thought there was a good naturopath over there that has the up to date knowledge about cancer I’d see if she would go. But no. They’re not there. I had to coordinate the free travel for medical appointments arrangement between the government and BC Ferries. Arranging for all those over a telephone access line and getting doctors’ numbers and forms and all that kind of stuff, I was doing. [I have to travel off the island because] for some reason there are different health authorities, or whatever, and so [small island town] people cannot go to [mid size island city a half hour away] for [disease] service. They’re either …it’s kind of like [small town] and North Island or something, and then if they want to do something they come to [mainland city by ferry]. I’ve already applied for a year’s leave of absence. I’m just moving over there. You know, this is impossible to do.

The account below reveals the ongoing housing and move decision process of a dispersed family for their mother in a rural small town where the lack of personal care and housekeeping services ultimately forces the sudden costly move to a nursing home. The
account reveals extended processes in which care decisions change in the context of (a lack of) care services and type of housing available. Issues of staffing for rural access agencies (CCAC in Ontario), the kinds of services required in home-care and affordability for rural-based dispersed families become visible in the process.

My mom [who was living on her own in Ontario rural small town] was becoming more dependent on [speaker’s brother and sister-in-law] without the rest of us realizing. So they called a meeting. They gave us two days notice and said, “we’re having this meeting, you better be there.” So we came. This is my family, it’s not CCAC, and so we went and at that point it was clear that [they] wanted Mom in the nursing home and wanted her in right away and at that point. My sister[s] and I … there are other siblings, I have a sister in New Brunswick and a brother in Alberta, but they obviously weren’t involved because they’re farther distant. The three [Ontario] girls decided that Mom didn’t need to go to the nursing home yet as long as she had other care. [Sister] contacted CCAC and we were able to get more care. She had something going on or was getting meals every day of the week except for the weekend and was doing not too badly. The reason she has gone to the nursing home is because her memory is not good enough. She doesn’t remember if she’s taken her pills. She doesn’t remember even sometimes what she’s had for meals.

[Months later, after taking turns spending a week each with her, coordinating vacations and taking leaves from work] the four siblings that are in Ontario had a little get together and decided that we needed to bump Mom’s name up on the nursing home list. She was at the lowest priority. There’s always a waiting list and the reason we bumped her from the ward to the semi-private was because the semi-privates come up more often because more people want ward so you get moved up on the list because most people don’t want to pay for semi-private, they prefer to have a ward. [We had] made some phone calls and it wasn’t going to be easy to get someone to come in. We were hoping that we could get someone to come in sort of in the mornings, just for an hour to make sure that she took her pills and sort of get her going for the day, and then someone to come in around supper time, not necessarily to make supper for her, but to sort of oversee, because actually she wasn’t cooking anymore because she was getting enough meals. Apparently they don’t do cooking, but just to sit with her because she eats better with other people’s company. That was home care, but there wasn’t anyone available for those types of hours. So that wasn’t going to work, so we ended up bumping her up to semi-private at the nursing home [because] there was no person available who was willing to work those particular hours.

Families want to keep aging parents in independent types of housing, but a lack of services and affordable supports means they are unable to do so. The account below shows how a family keeps mom with kin and out of the nursing home, and further highlights the difficulties of families who share care and housing across provinces. While there isn’t the same urgency to make a decision to move out of a family home, sisters reorganize their own lives and homes to provide adequate care and housing for their mother. One quits a full time job and the other relies on her ability to coordinate flexible
hours at her workplace with a regional train schedule and route. Both are dealing with the problems of accessing adequate services while living in different provinces and moving the mother from one to the other. One sister deals with service and transportation issues in the rural area; the other with transportation and service affordability issues where she lives in a mid size city and commutes daily by train to her rural small town workplace. Single and in a small apartment, she sleeps on the couch when a relative comes to visit her mom during the several months of the year her mom is with her.

My sister [with whom mom lives in a town of 200] in Nova Scotia actually quit her job. It was partly her children, but also my mom that she wanted to be more at home. And so she quit her job that was an hour away – an eight to four thirty job. She left early in the morning. She traveled with my brother-in-law, so she would be leaving home at six and coming home at five or six o’clock at night. She quit work and started volunteering in the school …I think about four years ago.

Everybody sort of shuffled around ….her house originally, when my mom moved down there, the basement was set up with an apartment. My mom sort of had that for a while. And then my mom fell and broke her foot, and so they changed the house all around, because my mom couldn’t go up and down the stairs so at that point my sister and brother-in-law moved down and took her bedroom. Initially when my mom moved there it was like a separate apartment. There’s still a little kitchen area there, but it’s not a separate area now. …actually, I didn’t even think about that, but that is a whole change of how they lived.

Here the same caregiver gives an account of her own ways of reorganizing housing and dealing with a lack of personal support and other kinds of services for her mom.

Originally she’d come and visit for a couple of weeks. And then it just started more and more. Last year from May well into September. I was also home and off work for close to two months…I was deathly ill for a part of it [in hospital]. When she’s with me, she’s just at home alone … when she’s in Ontario she’s not entitled to any services, so any of those things she would have to pay for, because she’s not in the right province … that piece I have checked out… anything that’s sort of a free service, or subsidized [she’s not entitled to].

[My] niece, this isn’t the first year, she came up last summer and stayed with my mom for a week. I know my mom gave her some money. And then another week I had my aunt come up and she stayed for a week. I’m in a very little apartment, so it means that in both cases I gave both of them my bed, so I slept on the couch.

Diabetics have to on a very regular basis have their feet checked, so this little mall in [Ontario city] has a wellness centre, and VON (Victorian Order of Nurses) work out of there. She has to have her feet soaked before she goes in. They’ll check her feet and trim her toenails and things like that. In Nova Scotia it’s not part of that home visit. She can go and have it done or somebody in her town that will come
around and do that. There is a more of a fee to do that. Here I think it’s seven or eight dollars to have the VON do that. In [NS town] it costs twenty dollars.

I don’t have a vehicle or drive, so [I take cabs with my mom]. And then I learned there’s a whole thing around that. At one point I called one and he basically looked at me and says I don’t take wheelchairs. I said, well, fine, I’ll call the other cab company. I know they do… When I said that, then he sort of said, oh, well does it sort of fold up, and I said yes. And I said I have no problem putting it in.

The speaker works back and forth from caregiving situations and workplaces and compares her own circumstances (favourably) to her sister’s.

I know my sister does a lot more of the going back and forth to the doctors than I do. There’s her own doctor, but in the last year there’s a lot of things, because she had a bit of a health crisis and there was a whole other series of doctors that had to be seen. She had to go back and forth to the health clinic, and because of her heart there was some kidney problems, so kidney specialists and getting her eyes checked, and the dentist. The specialists tend to be more in [large NS city]. It’s about fifty minutes. [mid size city] is a little bit further on, fifty minutes to an hour depending on where they have to go in town. [Other city], they’re sort of comparable as far as distances. For my sister when she’s doing that, because usually specialists you take what times they give you, either she would be taking time off work or my brother-in-law would be. Usually my sister.

I feel that it is easier for me, because I have a flexible workplace. If I didn’t have that it would be really difficult. …it was just this year that the train started stopping earlier. I used to take the train in at quarter to seven. Now I can get one at quarter to six. It makes a huge difference in the time being home and things like that. It always went through. It just never stopped in [rural small town] before.

You know if I worked in retail or I worked in a factory, probably ninety per cent of places you don’t have that kind of flexibility around your work. So that’s definitely a plus for me. I just flew down east. Being able to do that is another thing, too. If I was working a minimum wage job, I wouldn’t be able to do that.

Here she considers housing and moving options for the mom and sister’s family, and other moves that have affected the way they are all able to provide care.

And we have these little conversations. My sister in [Ontario city an hour and a half from speaker] thinks all ‘round it would be much easier [for her to be in a home]. She goes back and forth… I think when we have to, you know, we’ll move but I’m not certain where. [It] certainly wouldn’t be in their [NS] town. There’s a little, tiny seniors apartment type of thing. But there’s no sort of care facilities in the town they’re in. I honestly don’t know where. My mom has some money but not a lot of money, and some of the medications aren’t covered, glasses and walker and those type of things. That’s a piece that …she worked outside of the home very little.
There was a little bit and some times that she did. After we left, she did home care. That wasn’t formal. You know, she worked for a family so there was no CPP and things like that. Yeah, she did caregiving herself after all of us had left home.

I don’t think that they would move. My brother-in-law thinks that that would be a lot easier on my sister [for my mom to go into a home] but she said, then I would be traveling. So there would be still that traveling back and forth, and it wouldn’t be …in essence right now, if she’s not home one of my nieces might be home, or …this year it’s got a little bit more … I’m just going to go a little bit back. My sister that passed away, my brother-in-law up until last Christmas lived next door. And he had kids and had a partner. So there was also somebody next door. Now there isn’t, you know, somebody next door who was family. He moved to Ottawa this year, so that has made a bit of a difference too.

What looms here is the fact that the parent herself did not work much outside the home, and is entitled to less in her old age for having done so. The full time worker speaking, has a ‘flexible workplace’, but it would be of no help to her if the train route and schedule didn’t also match up with her flexible hours. Trains, buses, taxi company policies figure largely in the care work. This mobile family draws on the resource of at-home teenagers who also learn to provide care at a distance and become part of a traveling cross generational network. But it is a family support network that is rather different from that assumed in the discourse on ‘self care’ which draws on a concept of young people as internet savvy researchers (Decter and Grossos 2007). It operates in order to sustain an affordable and family centered housing arrangement that, in the face of mobile workers and families and inadequate rural region housing options, is increasingly fragile.

Finding appropriate and affordable housing for seniors is central to caregivers work, and not easy to put into practice for many. Below we see a young married caregiver who is, by necessity, managing and negotiating among dispersed relatives, researching and coordinating among service agencies, dealing with a series of healthcare and housing changes – some planned and some forced upon her – while caring for her two year old. She postpones her return to even part-time paid work and to her own self-employment. The difficulties in her decision process reflect the divergent lines of accountability and text-based procedures of community service agencies and the organization of distinct, exclusive ‘long term care’ housing options. Determining what could possibly come to be ‘suitable, adequate and affordable’ housing for her father is not simple. Her efforts to construct a rational process out of it all are not successful.

When we were looking for him to find a place, my brother and I… I wanted him to be in an apartment setting on his own, with attendant care present in the building, and I had gone through the Ontario March of Dimes in [ON city], and I actually did find him a place that was subsidized. The rent would have been much, much lower. It would have been about $700 a month, and all the other services would have been included, and we were really lucky that we found this place and that it would have worked out, but my father didn’t want it. He changed his mind. He didn’t like it. I think it was overwhelming for him to go from being with … his brother and his
family for about a year...My brother did not want my father going to live [with uncle]. He wanted him to be in more of a setting where there’d be nurses and a certain schedule and a routine and my main priority at that time was the transition and I thought it would be healthier for my dad, given that they were saying they would take him and try it, and see ... and then, once there was the meltdown and my dad left, my other uncle ...another uncle came and took my dad out.

...it was a very difficult situation after that happened, but it really sped things up. It really forced my brother and me to communicate and figure out ...a more long term place for my dad. Because my brother and I ...I think we were both sort of in a way immobilized. We didn’t know what to do. We’d never confronted a problem like this before, where we had to make these decisions, and suddenly ...And I was seven months-new mom when my father had the stroke, and my brother was in the middle of planning his wedding. So the timing of it was so challenging.

And what I liked about this particular apartment is that it was a two bedroom, so that if a family member needed to stay there, they could. The option would have been there. And I wanted to get [community organization] involved so my dad would have that, and I was also going to get the Community Care Access Centre in, and they have different centres like that all over Ontario.

In the next four paragraphs the caregiver is laying out a kind of tally of costs and services associated with two different housing options for her father.

I talked to them, I talked to [community service organization] and because the cost was a lot lower, we had more flexibility, like housekeeping. Of course my father couldn’t have cleaned his own place, but we would have been able to hire some one and that would have been another support person, another person I could have talked to. Because being in [large city over a two hour drive away] I needed as much there going on as possible. So that didn’t work out. And now my dad is in this place in [rural small town] after looking at a number of places with my brother.

Right now the cost of him being in this [private] retirement residence in [small rural town] is approximately 1800-plus a month. And his disability is basically about 1900 a month, so it’s barely covering it. ... a lot of these places ...they’re privately run but they’re standardized, so there’s not a lot of fluctuation in the cost, but it depends on the level of care you get, on if you want extra then you pay for extra, and it depends on whether or not you’re sharing a room ... he has his own room, and he was able to bring his own furniture, which was a big factor in this being a place that he agreed to go to, even though he’s not happy there now.

The CCAC assess the person based on where they are, and the reason why he is getting the extra support is because his income is totally absorbed now with the nursing home that he’s in ...at the nursing home that he’s in, and... So what they’re doing now is they assess him and they, I talked to them there, I said, this is my dad, he’s fifty-four, he’s in this old age home, can you please ...he’s only getting one
bath a week. Can you …can we do something about that. And they said, okay, we’re going to go, it might take a little longer because he is getting support there. But it was actually fairly quick. The benefit of being in a rural area is the waiting list isn’t as long, so they were pretty quick to act, and now there is a woman from the CCAC going to see him three times a week. She’s also doing extra housekeeping in his room, which …I’ve noticed his room is cleaner now. And he’s getting an extra bath a week, which is a huge improvement, because my father, because of his weakness, it’s harder for him to get to the bathroom on time sometimes, things like that. So that’s helped. Now I’ve also got [community organization]. I’m very lucky. They just opened up a new branch of [organization] extended into the [region] area, and so as soon as their program got rolling there.

The same caregiver speaks about her paid work and the challenges of returning to it.

I was working here in [large city at retail shop], and I stopped working there when I was about eight months’ pregnant. I was working part-time near the end. And then I had received a grant for my [home-based business], so during my pregnancy, mostly, I worked a little bit at the [shop], but mostly I was working on my last [business product] ‘cause I was lucky enough to get a grant just before… I think I was three months’ pregnant when I got the grant from [funding agency]. …once my dad left my one uncle’s place and was with another uncle for just about a week, they said, you have to do something. He can’t stay here. My dad didn’t want to go into another facility… he really wanted to be with family, but he wasn’t able to recognize how hard it is for him to be somewhere where, you know, the level of care that he needed. And so … he was with [my brother], then he was with my uncle, and then he was with [us] for about four days.

I’m actually starting to [work at home] again, a little bit, but barely. Again, ‘cause that’s what happens with …something like [my work] really easily gets a back burner. Like a lot of my free time is absorbed with dealing with stuff with my dad. And mental energy, too. Hard to focus on trying to…if I could get paid a little more I might go back [to work in shop] part time, but it’s really not worth it, because coordinating child care …and I was also teaching in schools, going into schools… and I’m supposed to be doing a job like that in a couple of weeks, where I go into a school. I visit the school three times, work with two classes for three weeks. So I’m still doing a little bit of that. …But the challenge is, definitely figuring out, when it’s part time …and have to be able to justify the work, like getting paid and then paying for [childcare] that’s the challenge.

All of the speakers above are situated in ongoing relations with a number of workplaces and paid work scenarios (their own, their siblings, and indirectly, the former workplaces of the older person being cared for that determine a level of pension and benefit income), as well as service organizations and transportation systems that set the conditions for and shape their decision making. Within those relations they are considering what could be adequate care services and housing. Options for them are also shaped by federal, provincial/territorial and municipal policies and regulations. All of the women we talked
to have entered into relationships with service organizations and the health care system in some way, whether or not they had authority (legal power of attorney) over personal care. All were negotiating with a wide ranging and dispersed family kin network, managing or leaving their paid work, and all were embroiled in housing and move decisions for themselves, their families and the care recipient.

We can see that the complexity of caregivers’ practices emerges as they engage with service organizations in doing their unpaid caregiving work. They each acquire a ‘working knowledge’ of caregiving tasks, resources, options within ‘the system’ that is shaped within the institutional relations they must engage in. This ‘working knowledge’ of the system includes what they actually have to do: practices such as monitoring and assessing the care recipient’s needs and matching that with what agencies provide and income affords. Doing research, financial accounting, decision making, mediating and conciliation among family members, contacting, negotiating, advocating and sometimes contracting with public and private service providers with different mandates and procedures – the actual practices glossed by the term “navigating” that has currency in healthcare discourse – managing and organizing housing moves, assessing their own workplace situations, costs of staying or leaving, and ultimately making those decisions about leaving and or reducing paid work – these are among the skills required to work at the intersection with home and community service organizations and healthcare.

Learning How to be a Caregiver: Work Forms That ‘Navigating’ Takes

The ‘working knowledge’ of the system that caregivers coordinating long distance care have, is extensive and complex. The caregiver speaking below had been working in ‘the system’ over two years. Yet she is still learning, and feels overwhelmed by the responsibilities of ‘being the primary’ in the context of distinct and divergent lines of care and accountability work that go with different housing options associated with the publicly funded access agency and community service organization. The working knowledge she has leads us to see how strategically locating specifically targeted information for caregiving families – guides on lines of procedures, on mandates, paperwork and power of attorney (POA), might assist services organizations and dispersed families, in doing this work, and that how access agencies and community service organizations do their work and how they are differentially funded, needs deeper consideration in policy decisions regarding public funding.

a) Language and Mandates of Access Agencies and Community Service Organizations

In the section of her talk below, she reveals how she has learned, the resources she draws on, and what she knows about the language and mandates of agencies and institutional processes. She weaves these into her account that leads to her primary topic of concern, which is finding appropriate housing for her father.

I did a lot of research on the internet. I talked to my mother a lot because she worked for [service agency] for 12 years. She basically directed us to the agencies, and she basically gave us, both my brother and I, a sense of the kind of language
we needed to use in order for things to move more quickly. Because of the waiting lists, my mother was concerned, if we couldn’t find my father a place, what would we have to say to get things …we’d have to say that this was an emergency situation... We had to use that word, emergency…we couldn’t hum and haw about it …we couldn’t just say, oh, we need to find a place. We had to use very particular language and learning the language has been a big part of it, because of a lot of the paperwork that you’re doing you have to be able to say what he can do, what he can’t do …just describe certain aspects of… what he was like before the stroke and after. All of that stuff, and how the [condition] affects his ability on top…. compounded with the stroke.

Initially they [community organization] want to know his history, they want to know what I think he needs or what the family would like for him and so those sorts of things are really important. And whatever you’re stressing is what they will try to help focus on, and then based on their meeting with my father, too, and …I think if you understand what they do, and you understand their mandate as an agency then it’s a lot easier for them to work with you.

Looking at a lot of the literature and talking to them, I learned this idea of independence and what it means, and what it means for some one who is disabled to live with a certain amount of risk in order that they have a more dignified and more … just existence. So those kinds of things, and when I talked to the woman at [agency] I remember one of the things that’s important for me, being [at a distance in large city] is that I can’t be there for my dad all the time. I can’t be there for him at the drop of a hat. I can’t be the main … he wanted to be in the country. My brother’s a teacher. My brother can’t see him every day, even though my brother is closer…about a fifteen minute drive. There’s a lot of things with my dad that you just have to explain over and over and over again, and I think that’s the big challenge for me being in [city] is that I’m two and a half hours away when the traffic’s bad. I want to be there more, but I also have a family and [two year old] gets carsick and it’s just very hard to get there. I can’t go every weekend. Now my brother and I try coordinate when I can go, when he goes. I have another uncle that …we’re on email and we coordinate who’s going, who’s going to be there.

The biggest thing for me is…learning how to be a caregiver. It involved so many things. It involves navigating the documents and the language, taking in, sort of, multiple opinions and assessments, both professional and from other members of my family regarding my Father and what is best for him …in terms of the short term and the long term, all of those things, in terms of his mental health and his financial situation … taking all of those things into account and, right now, what’s happening is that my Father has had an opportunity, possibly to be moved from where he is now in [rural small town] … to an apartment setting where he would be assessed for two months and it’s a TLP, which is a, what’s it called, oh my goodness… Transitional Living Program it’s called.

b) Paperwork and POA
The same caregiver has dealt with consent forms and manages extended decision making for housing and services. Here she is reading the POA and she works back and forth between the document in hand and the situation that she is in the midst of – trying to sort out what she should do to choose the better of two imperfect housing options, figuring out how to assess her father’s capabilities, eligibility, likelihood of success and quality of life – in the terms of the legal text in her hand. This is the document that authorizes her to be the substitute decision maker (“sdm” in agency internal documents). While she is the primary’ given her limited financial resources and geographical distance, she must negotiate with and persuade male family members without whom she “can’t make anything really happen.”

As soon as I got all the forms and all the paperwork done and all the consent forms they had some one out to visit my dad quite quickly, and then within that week calling me and telling me how it went, what they want to do, and I’m really happy about that, because their expertise is [chronic condition] and they also have … a number of different kinds of programs.

My brother mainly looked after a lot of my father’s financial stuff, put a lot of his banking online so he could help him with that. I did all the other kinds of paperwork …all the medical stuff…anything related to anything in terms of where he’s going to be, and getting my father to sign things. I was able to really explain things to my dad in a way that I think made him more comfortable with it. And so now I have power of attorney for his medical stuff. His financial things …he’s still in full control of that at this stage…there’s no substitute decision maker or anything like that. …I explained to my dad that I needed that power of attorney for his medical stuff so that I could talk to people, so that I could get everything in motion, because there are just things that he couldn’t initiate on his own. So with that it meant that I could get a lot of things going, and that I could do a lot on my own.

But for me the complication, and this is partly where some of the language things come in, is that because I have power of attorney for his personal care… I’m primary person involved in making these decisions, so … in helping my Dad make these decisions, it’s been challenging because my Dad being [chronic condition] and also suffering with some of the complications of the stroke, it means that … sometimes it’s hard to figure out how much to decide for him, how much to let him decide, all of that and recognizing that I do need, any decision that I make, even if I am the one making a decision with my Dad without the support of my family, some of my family members, especially my brother and one of my uncles, because they would be the ones involved with physically moving him and then moving him again or whatever would happen, that if I don’t have that support then whatever decision I make, is just, it’s not … it won’t … I can’t make anything really happen.

In the following, she attempts to bring the text to bear on a possible move for her father.

I was looking at the power of attorney documents and trying to understand better for myself what it means to be the person who is the substitute decision maker, how I determine it, in terms of just the language … how to make the decision. So that’s
what I was looking at and I saw … I marked it… the key … is determining whether or not he is capable of making certain decisions, like how do you judge that. My brother doesn’t think my Dad is capable of making some of these bigger decisions and … it’s such a complicated thing to figure out.

There’s this distinction which says here, (reading the text): “the power of attorney for personal care may only be used during a time that you are mentally incapable of making your own personal care decisions, yet it is up to your attorney to decide whether you are mentally incapable with a few exceptions. If the decision is about medical treatment or admission to a long term care facility a health professional must determine whether you are incapable of such decisions before you attorney may act.” And this, to me was important too, it says: “you might, for example, be incapable of making a serious healthcare decision, but still be able to make your own choices about routine day to day matters. In other words, your attorney will only be allowed to make those decisions that you can’t make yourself.”

So this is complicated in terms of housing because to my mind, my Father is in many ways capable of making a lot of day to day … the routine decisions, but in terms of a big decision like where to go, where to move, what is best … can he learn to take his medication with regularity, with just reminders or will he every so often say, “I’m not talking my medication”, and is that okay or is that not okay? So, navigating that and that affects directly how I determine what my role is and the other part was this phrase – because they outline the things with a question, you know, in a question format – so … (reading the text):

“What does ‘incapable of making personal care decisions’ mean?” Okay, what does that mean? And according to this power of attorney booklet, it means that …Number 55, “It means that a person …” and again there’s two parts and, the second part being “It means that a person can’t understand the information that is relevant to the particular personal care decision or can’t appreciate what could happen as a result of making a certain decision or not making a decision about the matter.” So, to me this is really … this is … what I’m dealing with right now.

It’s difficult because, you know, these factors are coming up again. If he moves out of this place that he’s at now, it means he’s, you know, he’s got to move with the upheaval, he’s got to be moved again …and that was the other thing that I’ve been involved with doing now, re-reading the contract … for the [private] centre that he’s in…and the package.

Here she describes what would happen if a move took place and the future possible process of working with a new agency and service organizations and sees that she would know how to “put the puzzle together again.”

The way it works is, once he’s in whatever new place he’s in, he gets moved to an apartment setting and [community organization] is facilitating that and helping with that. Once he’s established, his account, his file would be closed for [rural area] and I would have to call the CCAC in [city] and say, “my Father is now in [city.] He’s
in this apartment. He is getting this, this and this from [service organization]. I want him to be assessed for attendant care support from the CCAC. I would have to probably be fairly specific about what I thought my Dad needed.

Before I didn’t know how to do it, I didn’t know who to call first, but now that’s what I would do as soon as my Dad had been moved I would look at okay, what’s [agency] giving him, where are the gaps, can the CCAC fill some of these in, maybe I also need to privately hire a cleaning lady or see if I can find a volunteer from some other place or maybe contact now the Ontario March of Dimes and see … I have to kind of put the puzzle together again and see … get as much as I can in there for him because it’s all sort of separate and you have to call all these people.

Being the primary means signing the POA and care plan and working with the case manager who physically sees her father. That working with is complex.

I’m the primary, in a way, but having [community case manager] now participating means that because I’m here in [large city] and I have my life here and my two year old and everything, it’s been wonderful because she will call me and say, “… I’ve seen your Dad and I want to find out about this, this and this …” … there’s a whole bunch of things that she follows up on and if I don’t know the answer then I can phone my brother or I can figure it out and I call her back and say, “yes, I’ve given [brother] all the information about the assistive devices program (ADP) and I’ve given him a list of where he has to go and [brother] is going to be taking him for an appointment, but he hasn’t made the appointment yet. He’s going to be making it this week, when I know if my Dad’s gone or not then I’ll … so she can answer my Dad’s questions too … because she’s seeing him. The main thing that she needs from me is she needed me to sign this [care service plan] so that I’m clear about what they’re doing … which I sent back to her. The other thing is the copy of the Power of Attorney for personal care.

c) Reading the Care Service Plan: Hooking Into the Organization’s Work Processes

Here the interviewer and caregiver (A) are reading the care service plan together. A is working back and forth between the document, what she’s been doing with the case manager, and what she knows about how the system works and what options are available. She assesses different categories of the assessment of her father and matches what is in the text with past and future activities she and the case manager will do.

I: This is quite a big document compared to the other one.

A: It is. The other one was one sheet that was from CCAC and this is … and I’m still waiting from the [new] one from them… this one says their service goal number one is the housing. (Reading text) “To stabilize Mr. B’s economic activity and enhance his independent functioning, he will secure suitable housing.” (reading further): “Mr. B will explore and view options for suitable housing.” … “staff will
assist Mr. B to follow up with [city Housing Authority] when a subsidized unit becomes available or if further information is required.”

It could be several years in the making, in terms of waiting lists and everything. The waiting list for service in a rural area is shorter, but I’m not sure about housing. Because there isn’t a lot of housing that’s set up for people like my father in rural areas. There’s more in cities but the waiting lists are quite long, anywhere from 2 to 8 years is what I’ve read and there’s other sorts of settings that encourage independence, but that are congregate living settings, for example, where the waiting lists are really high as well. So, for apartments and for group home settings, there’s a lot of demand, because in those settings, there’s usually men and women mixed and different ages and that’s where the staff are trained to work specifically with [people with specific conditions] …

There’s another thing…I put a star beside it … the adaptive behaviour scale… this will explain how they came to understand certain things about his level of … the way he was assessed.

I: I see, “not entirely uniform and consistent.”
A: Yeah.
I: “Economic activity” … these look like they’re categories.
A: Yeah, what the document looks like… I’m curious, because that …that comes from some other text.
I: The economic activity score …
A: Yeah.
I: The physical development score.
A: Yeah.
I: So there are … there are probably lines under these areas that add up …
A: Mhmm, yeah. (reading text) … “Daily living skills, Mr. B completed the majority of his personal care needs such as daily cleansing, shaving and dressing. Homecare visit him … visited him twice per week to assist him with showering.” homecare is CCAC… but I noticed that the physical stuff … like in terms of his physio, in terms of communication, in terms of behaviour, those things … the [community organization] will kind of …intervene in and be involved with, A behaviour example would be here …

“Mr. B refused to pay his nursing home bill one month. Outreach staff discussed the reasoning behind his non-compliance and explained the consequences of his actions and he was able to resolve the issue. [daughter] reported that his agitation increased at the end of each month when his payment was due.” So, we talked about it and then … I talked to her about it and then she said, “I will talk to your Dad too. I will talk to him when I see him, about it, to help kind of explain it … this sort of stuff to him.”

And then, I guess, I was looking for the physical stuff …

“To improve his physical development, Mr. B will participate in physical reactivation exercises.” So then …she was the one who said she would follow up on that for me, on my behalf, to make sure that that … and that’s something too. I
have a whole list of things that I have to talk to her about when I … for my next e-mail. Last week was a different issue. It had to do with a walker. So, I e-mailed her about that and this time I have to ask her about whether or not the physiotherapy is happening again or not or who I have to talk to.

d) Entering a Different Service Organization’s Text-Based Process
Here A describes an entirely different multi-step process she must learn, activate textually and engage in, in order to access the hearing device her father needs.

He is eligible for some funding for the hearing aids and this is why it’s taken us so long because hearing aids are expensive. It’s a program, it’s a … it’s through … I can’t remember the name of the program now. I do have it. I have it right here. Oh no, this is a different program, oh god. I didn’t actually fill out the forms. My brother did that part because he had to have the forms filled out at the actual clinic where the hearing is tested.

…So, this is another thing that [case manager] was asking me about … what’s happening with this because I get all the information for my brother and sent it to him and said, these are the clinics in [nearby rural town] where you can go, where you can get funding and you have to ask them for the application. You fill the application out with them and then it goes from there. So my brother did make the appointment and then they did go and then my Dad says that he needs his ears cleaned and, so now I have to talk to the doctor, get hold of him somehow and make sure that my Dad’s getting his ears cleaned. He’s got a new doctor that he got after a few months in [rural town residence]. He’s the sort of in-house doctor that sees the patients there and comes into the building to see them.

And my Dad doesn’t like him apparently, but my Dad didn’t have anything good to say about his old doctor either, so I don’t know if he’s just … if he is abrupt and doesn’t stay very long and I don’t … all the complaints that my Dad makes against him he made about his old doctor too, so, and maybe that’s the nature of being a busy doctor dealing with a lot of old people, I don’t know.

e) Setting up the Log
So now, that’s what I have had to do … I’ve set up a schedule for myself so that on this day … I have a schedule when I make those phone calls related to my Dad and related to … because before I wasn’t doing it and I was forgetting and I’d e-mail [case manager] and then I’d remember three days later that I was suppose to call.

The difficult challenge with figuring all of this out is that there is not … the idea of resolution is so elusive. You want that, but that just is not part of how it really works. But I am learning a lot and everything that we’re doing and talking about really is helping me. It’s helping me navigate it a little better and ask more questions and differentiate the roles. I think the system needs the caregivers in the system. And the people in the system have to work together very closely in order for things to keep moving because I think that the same kinds of things happen on
their end. If I don’t follow up with [case manager], if I don’t update her, then she
doesn’t know things … there’s those gaps that we’ve talked about. There has to be
things going back and forth and if I don’t consistently stay in touch with her, then I
don’t know what’s happening and I can’t talk to my father because I don’t know
how to answer some of his questions and, so it’s very important. And I feel like for
them too, they need to be reminded that, okay, he’s in [this residence] but he
doesn’t have unlimited resources. His money will run out if we don’t, in the next
few years, find an alternative for him. You know, that’s a reality.

The caregiver we’ve spent time with (a through e) is putting together a working
knowledge of how healthcare, homecare and community services are organized. She is
learning how her work gets results in care for her father. Front line workers ‘help’ and
community service front line workers have to intervene to ensure that the care promised,
actually happens. She has to keep up the connections among family, to the community
service agency, the information, research, inquiry required. This work tells how she uses
the services available to her, to the community organization and to the access agency and
private home where her father is. She talks about – as her mother advised – what her
father can and can’t do (assessment) and matches up her descriptions with the services
she knows are available from each agency and then within the legal framework of the
POA document she is reading. How the sources of services are organized is what she has
been learning. That learning process has been going on for more than two years. She is
learning how services are organized by disease, by body function, and the division of
labour accordingly among agencies in ‘the system’. Financial coverage is similarly
divided, among Workers Compensation, provincial coverage, and so on. And she learns
the equally complex work of community and ‘access’ agencies in doing this same work.

Caregivers’ work is comprised of complex sequences of ongoing negotiations,
management and decision making work ranging across different geographical
jurisdictions. Work in Nova Scotia (Keefe 2005) notes regional-provincial differences in
Canada, but this work assumes the caregiver and recipient are in proximity and that
decision points are primarily two: placement in a facility or home, and provision of
services. In Navigating Canada’s Health Care (Decter and Grosso, 2006) the underlying
hidden assumption in the section on advice for navigating seniors’ care is of a caregiver
family or network that manages, coordinates and provides care to the elder person. But,
more significantly, the assumed characteristics of this network of family caregivers are
that it is multi generational, literate, computer literate, has flexible work arrangements,
communicates well, is able to readily access information, provide the first level of
‘primary’ care and, should there be any lack of these abilities and competencies, whose
gaps are then filled in by the services available in the region (or by distance – national
Lifeline, telehealth, internet, etc). This is the self-care discourse in action. A political
construct that has been put into operation in the system, it discriminates against families
and individuals who are poor, not hooked up to the internet, and with few resources.

Beginning in the work of caregivers, as has been done here, situates caregiving practices
within a larger institutional complex. Caregivers are visibly coordinating among
dispersed family members, working with multiple organizations, sometimes using the
internet, flexing their paid work, leaving paid work, always relying on multiple forms of transportation, in order to both be with the aging parent or relative and manage housing and care decisions and situations from a distance. Long-distance caregivers are not absent. They are not equally able to ‘navigate’ and facilitate access to suitable housing and care services. Working with the terms of legal power of attorney for personal care for her father, this caregiver reveals the continual character of the ongoing working relations with case managers that hook her into the text-based work processes of the CSO and CCAC. In the next section, CSO and CCAC work processes are explored.

**Home and Community Service Organizations and Caregiver Relations: Coordinating Care Within Institutional Processes**

_The hardest thing to understand is that there is a system, and the system is complicated, so you’re constantly trying to educate them about what the system is, and where they can go to get help. “Navigating the System” used to be called “Where to Get Help in Your Community”...the workshop won’t necessarily roll out the same way each time we do it. It depends on the group – why they’re there, what they’re looking at in terms of navigation. But, you know, all the research shows that there’s this big vacuum of information and, there’s just so much [to navigate]. (Programmer, CSO)_

_The long distance caregiver [is] more of a coordinator, facilitator. They coordinate the hands on. They’re still present. It’s just done in a different model ...and we see some families very successful with that. We have seen other families that aren’t. (geriatric professional)_

_Some organizations are very regimented to time breaks, so that makes it challenging to make sure [they’re] there to take the call or if there’s an emergency, you have to go through HR to have them paged. We’ve designed our model to family needs, but other places are very strict “we work 9 to 5, it’s too bad.” (geriatric mental health professional)_

_Knowing the system, it was still difficult to coordinate [care for parent]. (geriatric professional)_

Women working in service organizations talk about many aspects of their work as ‘navigating the system’ and coordinating services. “Help coordinating” is the term used in government discourse on ministry line agencies (Government of Ontario, 2005) to describe access agencies’ work. The term ‘navigating’ is part of the professional healthcare discourse and must be deconstructed if we are to understand how policy comes down into the everyday work of the health and home-care system. The notion of ‘navigating’ has organized the creation of ‘navigator’ positions in cancer care in Nova Scotia. Women service managers and caregivers we talked to spoke specifically about having to learn, and teach, the essential skills of “navigating” and “the language of the system.” There is more to this, when one looks closely and with the lens focused on migration and distance. In the preceding section, caregivers illustrate what it takes in
practice to coordinate services and housing for a senior. What we see when we also make visible what it takes for home and community service organizations to do their work, will be useful for policy workers in government, agencies, hospitals and doctors offices, and in community based organizations. These are the institutional work processes at the ground of a policy-built system that requires all this ‘navigating’ and coordinating work.

Caregivers and service providers are connected in ongoing work. How they do the work and how successful they can be is shaped by family circumstances and, more significantly, by and within institutional forms of action. The procedures that agencies implement, with which caregivers must engage, give us a view of a policy regime where it ‘hits the ground.’ We’ve seen how policies affect urban-to-rural long distance caregivers managing ‘informal’ care work within a range of paid work, housing and affordability, and urban-to-rural travel and communications scenarios. They include:

**paid work:**
- has ‘flexible work’
- postpones return to work after having child, no EI as self employed
- quits paid work
- reduces work to part time
- in full time work not flexible
- community service organization programmer flexes her working hours, schedules evening meetings, phone calls and workshops etc

**housing and affordability:**
- shares with sister and multiple family members across provinces
- gets other family members to live in when ill herself
- family moves to basement, renovations
- sleeps on the couch
- Worry about moving mother to a nursing home, few choices in region
- dilemma regarding decision on rural long term private or assessment in urban assisted housing, wait lists, affordability and suitability issues emerge
- senior in own home
- in one daughter’s home 2/3 year and 1/3 year in other daughter’s apartment in different provinces
- in retirement home
- nursing home after shifting around 4 children’s homes
- in brother’s home
- in son’s home
- grandson and family from another province to move in and be caregivers in small home

**urban to rural travel/communications**
- travel is huge issue for all
- train allows caregiver to flex work, flying ON to NS expensive, email counseling of sister
learns to drive in order to coordinate care and visit father in rural retirement home where wait lists were shorter
• takes ferry and bus – finds cancer agency will reimburse
• community service organization incurs costs, not covered in their funding, for long distance phone bills (required at prime time due to different time zones) and translation
• Lifeline crosses provinces
• cell phone, email with case manager is continual, proactive necessary

In the background of these scenarios, seemingly individual and unique, is the general context of diverse service organizations’ mandates, structure, funding and staffing levels. Services are organized within healthcare to correspond with a particular disease of the care recipient. For example, those with diabetes will be served by the diabetes society agency, those with cancer by a cancer agency, and so on. Several of our interviewees were trying to sort out the trade-offs among services since their parent has two or more types of disease and ‘needs,’ and needs included not only ‘personal support’ but also ‘homemaking’ to an extent beyond what contracted agencies can or will provide in different housing situations. Who would be the ‘lead’ agency was sometimes a question that had to be sorted out and caused delays in getting services to the patient.

With different services available within each organization, different regional health authorities, and different services with different access routes in each province, caregivers must engage in a service ‘seek-and-find’ and juggling act. The search and juggling act is time consuming, but the added dimension of urban to rural geographic realities make this striking. These added dimensions include the following:

• ‘at a distance’ often means across provinces and other jurisdictions where there is no continuance or consistency of policies, housing and services across these boundaries.

• The ‘working’ caregiver of the existing literature is often assumed to be someone in a full time (sometimes part time) job who has a simple dual choice about what their workplace will be and whether to make changes to ‘balance’ ‘work and life.’ While the critical literature takes into account socio-economic differences in relation to access to adequate care, both conceptions are being eclipsed by a new ‘patient-centred’ ‘self-care’ healthcare discourse.

• The elderly person in rural areas, upon closer look, resides in a range of “rural settings” and these rural areas in Canada are shifting rapidly. In some instances formerly urban-centred service organizations are relocating to regional centres, relocations that may themselves be creating new geographic realities that influence migration patterns, and hence have consequences for policy.

Shaping housing access and affordability issues in the different situations cited above is the context of diverse, yet few, housing and service mix choices, in any province. What comprises ‘adequate, suitable, and affordable’ housing? The issue for inter-provincial family caregivers is finding an adequate mix of services from different sources in conjunction with an elusive ‘appropriate’ housing situation. Others researchers have struggled with the issue of affordable housing (CMHC 2006), and attention needs to turn...
to ‘house and home’ versus public/private ‘housing’ for old people as it exists. In interviews and conversations, service organization managers reveal a policy direction that rolls out from federal through provincial legislation in the name of ‘integrating’ health services for efficiency and accountability. How integration ‘hits the ground’ is the ‘building’ of ‘beds’ and facilities. At the same time, what happens is the undermining the webs and work of community service organizations. The institutional language of coordinating services operates in the long term care and government policy discourse. It stands counter posed here with the language of caregiving illustrated in section one, and with the language we see in this section, in the work of home and community service organization managers and front line workers.

Homecare and community service organizations are doing their work within the context of the planned reorganization of healthcare delivery systems. In BC, the policy direction is public-private partnerships. The government is going out of the business of nursing homes. They’ve built assisted living residences – essentially retirement homes with ‘packages’ of care services. The management discourse says this is a matter of getting the proper services in the proper place. At the same time, home support workers and how they are supplied is being consolidated. Home support agencies are being eliminated. In BC, the reorganization into regional health authorities resulted in the loss of numerous home support agencies. Agencies numbered seventeen, were reduced to eight, and now there are three. The policy language and implementation of integration needs to be examined carefully in light of the realities of the mobile family situations we describe, increasingly that of aging ‘baby boom’ families. Aging people are not able to manage in their homes, but they are not ready for these kinds of public/private nursing homes. Home and community service organizations are visibly the front line and the ‘human capital’ of this system. In the integrations they are losing out. Our respondents report they are losing their staff, workers are forced out of their jobs, and the provincial systems are weakening at the front lines, despite the discourse of doing things better. These factors must be taken into account quickly for Canada to be able to effectively deal with the exponential growth of its aging population. While this area is recognized as a priority among policy researchers, it is not yet recognized among governments and realized in policy action. What is happening on the ground for people falls out of view. Meanwhile, community service organizations are experiencing acutely the effects of amalgamations in healthcare. The policy issues they are dealing with remain, as this manager says “under the radar.”

All the research shows that there’s this big vacuum of information and now we’re entering into a new era of local health integration networks, and we’re not sure yet how we fit into those, and how all of that is going to unroll. We [community service organization] will be dealing with five of fourteen. We could conceivably deal with a few more so, just trying to sort that out. We’re not even introducing that to clients. But for us that’s a huge potential change. I think we’re going to be under the radar for some time. It’s a broken system – it’s not necessarily a system that works all the time for all people. And one of the things that I’ve always been struck by when you do caregiver work is that we do have people that stay with us for very long periods of time. [Community Services Organization manager]
Policy Issues Under the Radar

Access agency managers in expanding regions, service providers in large urban and mid-sized cities, and managers and staff in rural community service organizations raised issues that are affecting their day to day practice. In particular, there is a striking disjuncture between implementing the policies – providing the services they are funded to provide – and dealing with “what comes in the door” in the context of service integration into regional authorities. Inequities and access issues are emerging in Ontario as it is being reorganized currently. Below are sections of talk from Ontario CCAC and community service organization managers that open up windows onto what is happening.

a) CCACs

Housing policies, regional health authorities, beds and efficiencies

Housing policies in CCACs and regional health authorities emerge in talk about beds and efficiencies. Here a CCAC administrator describes how amalgamations and efficiencies come down to individual families in two different provinces and how moves are shaped within the nursing home system. What is strikingly absent are other options. She works within the institutional discourse, identifying that a ‘crisis mechanism’ for moving people into beds is the institutional mode, and how it is not working for people.

[They have] targets (in BC) in terms of [system efficiencies], specifically the placement process [into] long term care homes. Their expectation is that offers will be received and the person will be moved in within 48 hours, and they’re trying to move that down to 24. If [you’re a facility manager it might make sense] but if you’re telling your mother that, well, we got the call today, and this is the last night you’re going to spend in your own home, and we’re going to get the moving van here tomorrow. We don’t support people through, and I think those are some of the most traumatic, difficult decisions that we have to make and there really isn’t any support for caregivers [in relation to that process].

When SARS was in Ontario they created a new kind of priority designation, and it was purely used at that point as a crisis mechanism …that meant that if you were in a hospital you had to take the first available bed that came up, anywhere within your community. It was purely used to get people out of hospital quickly. Some areas where they have bed shortages have continued to use that mechanism when

6 Aboriginal housing issues are even more critical. While this is not the focus of this study, policy analysts know that type II diabetes is a major chronic health issues among aboriginals as is heart disease. First Nations care managers cited by one of our agency informants say they’ve got a problem with accommodations; that there are few places where an aboriginal senior can live that’s near their own community and within their own culture, so they have a huge issue with that. A lot of young people are leaving reserves, and when you leave reserve you leave your family, and the family loses caregivers.
their [ALC] numbers get very high, and, we have people from Sudbury going to long term care beds in Parry Sound, which is just ... if you’re the 84-year-old wife of the ninety year old guy who’s moved to the bed in Parry Sound then you may never get to see the poor guy again. ... and with consolidation now, we’re moving from 42 CCACs to 14 so that we’ll match the LHIN boundaries.

Provincial structures, funding models, personal support service limits and staffing

Structured differently in every province, home and continuing care units are in-line units funded by either health or social services departments. Where these units are situated and who funds them is another layer of organization that will affect service. The departments will have different criteria for funding services. In the discourse called ‘community’ organizations, Ontario CCACs’ mandate and funding is 100% Ministry of Health and Long Term Care. As one professional describes it, “we’re a health service driven by a health number.” This creates a fundamentally different service agency from community-based organizations that have partial government funding and must fundraise, charge fees for some services and compete with ‘sister’ agencies. The administrator below constructs a view of a ‘two-compartment’ system, one tightly structured, with formal eligibility criteria and assessment and the other loosely organized and volunteer based.

We [CCAC] serve cradle to grave. People assume that the vast majority of our clientele is senior, elderly, but in fact about half of them are under 65, and 20 per cent are children with high needs. And we don’t have in Ontario some of the direct funding models that are available in other countries and in other parts of Canada, that basically allow caregivers either to receive direct compensation for the care that they provide, or to hire their own staff and structure the care in a way that better suits their needs.

Part of the problem is the way our service limits are configured. Most provinces set a maximum dollar limit that’s roughly equivalent to the kind of bed that you’d be occupying. What we have are separate number of units of each service that you can receive. So we have separate limits for nursing and personal support. The nursing one is so much richer than the personal support limits. You can put eight hours of nursing in compared to two hours of personal support. If you’re dealing with somebody like a medically fragile child who requires that professional assistance then they may be able to get that eight hours a day. If you’re dealing with a frail senior whose care can be managed by a personal support worker just being available [with them] throughout the day, two hours is all that you get.

The way home care developed in Ontario, it started as an acute program, and homemaking was only offered to support professional services [going into the home]. The ability to provide homemaking personal support as a stand alone service was the last [increase of service] to come into play. And it was introduced in such a way that it was very carefully rationed. It was never designed in recognition of the working caregiver.
We don’t have the ability within our system to bring the caregiver into [our service to receive the respite in the home]. The client for us is the person who receives the care. Community support system may identify it the opposite way, probably the correct way, in terms of looking at who the service is for, but we’re a health service driven by health number.

We don’t have a really well structured community support system. We’ve basically got a system that’s set up in two compartments. One, which is the CCAC system, which is a highly formal system driven by eligibility and formal assessment and service allocation and that really focuses on specific kinds of intervention with clients; and then a community support system that’s driven primarily by volunteers with some structure around it, home support, home maintenance and other respite services that are associated with those things, but there isn’t any kind of standard basket for those services, and depending on what community you live in, you may have three of the five on the list, but not the full spectrum of services.

The view above is not what we found on the ground. Managers told us what is commonly known – that eligibility criteria are narrowing in the ‘formal’ system as are structures. CCACs Ontario are being funded to go into hospitals, which puts the focus on post-acute. This is taking place as funds are allocated to new accountability bodies and mechanisms. For community organizations, eligibility, which, because they are only partially government funded, requires ‘third party payment,’ is widening as the formal system excludes people and redraws boundaries. These organizations have strong structures, professional assessments and mechanisms for monitoring, with less funding.

Cross country service portability

The challenge that comes up consistently is the lack of portability of particularly home care services across the country. An access agency administrator describes the issue:

So if you are a daughter living in BC and you decide that your mom in Ontario isn’t doing all that well, maybe she should come live with you, or live closer to you, she has to wait a three month waiting period in BC before her health number becomes active to access services. And the same would be true for coming to Ontario. We field a number of calls [where] somebody has brought a parent here and then realized that they couldn’t get access to services [for three months].

[we’d] really hoped after the Romanow and Kirby reports to develop a national basket of services that would at least be a basic expectation regardless of where in the country. And that might be the opportunity to deal with some of the portability aspects, but it’s not a service that’s dealt with under the Canada Health Act. [The provinces are] not that far apart in terms of how we provide services.

b) Community Service Organizations

Technology, tenuous funding, and labour issues
How policy issues emerge for CCACs and community services organizations is grounded in their different locations in funding structures and processes that are being reorganized. A critical issue that arises is technology use and the consequences for different user groups. Inequities are created among clients given access to and affordability for internet use varies by place and by household income. Households and individuals within households, as service providers note, have differential access. The caregiver who works in a call centre or factory and tries to get counseling from a service organization during her break, uses the phone. The caregiver who works in a professional position has skills of internet use and has a home computer can do this in and outside work hours.

Technology use is, however, an issue for service providers themselves. They report that more of their clients are trying to coordinate and manage care at a distance, and in their own work they experience a tremendous increase in the need to make long distance phone calls for which they have no budget. Their work practices have shifted increasingly to coordinate with other agencies located in other jurisdictions and across provinces. The need for service organization workers to use the phone to negotiate care between what I’ll call the “caregiver service organization” and “care recipient service organizations” emerges from the circumstances of their client caregivers ‘at a distance’ from care recipients. This is a result of broader rural-urban-urban adjacent migrations also based on the labour shifts within specific forms of restructuring and reorganizing of economic development strategies in such areas a healthcare, education, as well as specific shifts across Canada from resource based industries to service industries and as a consequence a mobilized work force. That everyday requirement of communication by phone across the country is further organized and shaped within the healthcare and counseling/social work professions, by such factors as the federal and provincial legislation and regulations on privacy. Where the legislation exists to protect patients and clients, it is having consequences that add extra burdens onto the work of community service providers. Further, while technology issues appear to be solvable by broadband initiatives such as those by Canada Futures and The Ontario Rural Council, here managers in government community service organization highlight deeper problems for their work.

Professionally what I have found significant, more so in the last four years, is a number of family caregivers are living away from their parent and a few things relate to technology. Computers would be ideal and we have a number of families e-mailing us, but with the Privacy Personal Information Act and the privacy regulations, we’re not able to e-mail out with them, unless we use a disclosure [form signed] …the [government] hasn’t got themselves together yet [on the policies]. The other issue is directly [our work with] the caregiver, via e-mail, it’s an issue, there’s a liability there … so you can’t give them any information back.

And when one person is contacting you say from BC, what other agencies want sometimes is the families to call themselves, but it’s hard when they’re long distance and you’re going to make several phone calls for the time difference.

Inequalities and access issues are emerging in Ontario within the healthcare system’s amalgamations. In the illustrations below, managers speak about inequities that existed
between access agencies and community organizations previously, and how they are escalating within boundary reallocations, new provincial accountability mechanisms, CCAC contracting out, referral and service limit policies, and policies that affect staffing, language translation and community organizations’ ability to carry on.

About 55 percent of our budget comes from the government, from the Ministry of Health and Long-term Care. Just before 1997, there was some enhancement dollars for caregivers support work. It was very minimal, it wasn’t huge amount of money and to this day, just over 50 percent of out budget is being funded externally. And we’re making the decision internally to fund the three programs and the senior too.

Over time the Ministry of Health and Long-term Care has developed funding for caregiver support and counseling programs and caregiver education programs – they’re not funded at the same dollar amount across [the city] or across [the province]. Some [organizations], you apply for the funding and you might get it, you might not get it. So there isn’t a necessary equity.

There are a number of organizations now in [city] that are funded to provide caregiver support and counseling and caregiver education. Not all of them are catchment specific. So I had another call this morning from the cultural counseling agency, working with Chinese elders in [area of city] “but you serve [this area] right?” “Yep. We don’t necessarily have the [resources, staff, translator].” “But you serve [this area] right?” She had called the major provider agencies in the Chinese community - don’t serve [that area] so they have these agencies and the funding, but that catchment isn’t [these two areas that are ours].

We do provide services too, because of the United Way funding, to people who live or work in Toronto. So you can commute from a 905 and the way we interpret it in the seniors unit too, is if you have a senior relate here in Toronto and you’re out-of-province, then we will provide service to you out-of-province, if we can’t get you hooked-up somewhere else. We have done that on occasion. We now have a very extensive waiting list, so we are not able to be that flexible, but in days gone by we didn’t have as much of a waiting list, we would try and, I mean, we still do try … We have four bodies. About 2.75 full-time equivalent….well they’re not full-time. It’s one full-time person. …for us, quite frankly…we don’t have the staff.

CSO funding policies on translation services
The speaker, a manager in a city providing service to metro-adjacent and further distant caregivers, outlines the issues on contract labour wages and minimum rates that emerge in the context of Canada’s immigrant population and policies to attract families and caregivers to rural regions.

There’s this whole thing that goes on, that makes it very difficult to deal with. [That’s] the diversity of people who are calling us and the Ministry of Health and Long-term Care has not seen to it to fund translation services. It makes it extremely difficult for us to work with people where English is not their first
language. But we don’t receiving funding for translation services. Where I manage a violence-against-women program and I get funding for translation services for anyone who doesn’t speak the language of our team. For that, the funder is usually the Ministry of the Attorney General or the Ministry of Canadian Social Services and there are agreements where we phone up an interpretation agency who makes a match with an interpreter and we phone three-way or face-to-face or someone that needs legal counsel or needs to review legal things, the interpreter travels to meet the person. That is not happening in another part of this government of Ontario.

The CCAC may make referrals to us and we make referrals to them because they do a lot of hands on work and social work and may go in and do an assessment and so on [but it’s time limited service]. They’re not designed to be the long-term.

Contracts and referrals
Two managers describe some effects of CCAC contracting, competitive bidding and referrals on community service organizations and front line personal support workers:

What’s the difference between a community support agency, community care access centre, and a private agency that you get out of the Yellow pages? I always spend at least ten minutes or more in a workshop on that, because people don’t get it. They’ll go to their parent’s home and the fridge will be full of carbs. There’s a coordinator from the CCAC, there’s a worker from the CCAC, there’s a coordinator from the community agency, there’s a worker from the community agency. It’s figuring out who all the players are. Because we moved to the competitive bidding process through the CCAC, it created another layer of bureaucracy, and the CCAC are coordinating, they’re not providing, and they’re coordinating within their approved list of providers.

It’s kind of like, in this box it’s community care access centre, if you need help getting into a bath and you need help getting out of the bath, you may get some service. Especially, if you’re acute, you’re post-acute. If you’re chronic, we’re going to have to work hard and this is where advocating for yourself comes in.

I think we have to be much more flexible in these things. Cutting people off, after they’ve been receiving it – you’re hurting the most vulnerable. And indirectly you’re hurting the caregiver because the one thing I emphasize to everybody, “Hello, the women are not at home!”

There’s going to be a rude awakening for the politicians of the future, with the baby boomers coming online and the big cohort of sixty year olds hitting at the moment. We have so many different layers going on. Homecare in the community, contracted or not contracted, the personal support workers that are doing this work are not paid on an equity basis to the long-term care facilities, they’re not paid on par to hospitals, they’re at the bottom of the heap, surprisingly, or not, they don’t stay in the business. They are almost exclusively women of colour who are new immigrants to the country. They are people with, who may have tremendous
amounts of education, but can’t use it in the country. That’s a big issue, but – and they’re working under these very – because of this contracting situation, they’re getting paid by the hour and they don’t have a lot of constancy in their jobs. So not surprisingly the good ones get out of the business very quickly. They go to the local long-term care facility that’s opening and so there’s no valuing of the provision of care in the community, to support it. So politically there isn’t a value being placed on care in the home.

**CCAC time limited services policies and CSOs pick up chronic care with fees**

Here managers describe divergent mandates of CCACs funding structures and how those affect the ground level work.

A [CCAC worker] told me, “well, there’s always a discharge plan on the homecare”, which is true. It’s designed to the idea that, when I had a fracture, “okay, you’ve got a fracture, you’re going to get better”, so we know that the service is going to be time limited. But for some of our clients, if they have a chronic disease like osteoporosis or severe arthritis that impact their mobility. If they’re in a wheelchair and they need help with various things, they aren’t going to get discharged; they are not time limited. So how do we accommodate them? Can we give them consistent people? Can we make that work for them? Can we give them the appropriate number of hours that they need? That’s what I think is important, that our community services matches the need of the client’s community and that they aren’t on some revolving door process. I mean, what are we doing, saying to some frail, vulnerable, 83 year old senior, “well, you know you can get six hours a week, but we think that you don’t need it anymore.” Or alternatively, your needs have increased beyond what we’re prepared to provide for you, so now your only choice is to move out of home of 50 years.

There has been increased funding to the access centres, but there’s not increased acuity. So the access centres have actually been put in this rather interesting predicament of kind of looking for acute clients because they’re being funded to provide to acute. So that the chronic clients, they’re just dropping off the map. And those of us in the community are the ones that are here to pick up. And for years and years and years, the community has picked up, but the community sector can’t do it and we’re not 100 percent funded. Any service that someone receives in the community sector, that isn’t CCAC authorized, the client has to co-pay for. So there is a payment involved and it can range.

Exclusive of counseling, if you wanted to get services on par from community care access fund, or say you needed top-up or needed, or you were deemed ineligible for access centre services, but you needed it, then you have to pay, you have to pay per hour for the services and that can be $8-16 an hour in [major city] probably by now. And it will vary from neighborhood to neighborhood based on the funding available to that community support agency because none of them get 100 percent funding from the ministry. Some have United Way dollars, some don’t, some have city some don’t, you know, some have good or better, deeper pockets in their
community to access for fundraising, some don’t have that ability because of where they’re situated. So there’s all of these layers going on. No wonder why we have to have a workshop going on called “Navigating the System.”

With ‘one stop shopping’ or the hotline, we run the risk of going the other way. I really don’t know how you would put together a database that would be inclusive enough of all the variations in the community. So then becomes the question of – there have been lots of questions raised about, well, what are absolute necessary services in the community that need to be everywhere in Ontario? This of part of what the LHINS are asking and trying to deal with, but what’s necessary for one isn’t necessary for another.7

7 The concept of one stop shopping combined with e-government means governments organize on-line services. Ethnographic research also involved working through on-line services and government information. How does government communicate who does what and how services are available to caregivers or to seniors? The issue has been raised in other studies and by professional organizations. Ontario’s government “bundles information and services around key life events” (Gov of Ontario 2006 p.189), On their website, “Being a caregiver” is a “life event” like “having a baby” and “losing a wallet.”

I worked through their on-line questionnaire to see if our self-employed caregiver A would qualify for the tax deduction for her caregiving which takes up much of her time and caused her to postpone working after the life event of having a baby. The approximately $17,000 per year cut off is based on the income of the care recipient. Caregiver A’s father’s income, which falls short of covering the cost of his home and services by $200 per month is $21,600. So our caregiver is ineligible. Proposals to cost the value of caregiver work through the new assessment survey tools called “RAI” (website Q&A) involve criteria that the informal caregiver make formal agreements and be qualified to the same extent as a formal system service provider.

The government website also houses and features an invitation to ‘caregivers’ from other countries to immigrate to Canada to do caregiving work. The site provides detailed information on processes, forms and so on. It warns that Canadian labour standards do not protect them, and that they must negotiate acceptable legal contracts with private employers. Here is another ‘system’ in place that structures women’s work to fall outside the legal framework Canada has yet to protect workers who do this work.

On the Government of Canada HRSDC website information on the CCB is next to impossible to find. One has to first be told to search through a gc site and then it is difficult to find even if one has reached the HRSDC website. The gc’s “on-live services” are then onerous. An EI application must be done on-line or through a Service Canada Centre in person. The first step is to get a Request for Record of Employment form (ROE). The on-line service requires the potential applicant to submit the following documents: the ROE, SIN, ID, bank information, ill family member information, medical certificate and a narrative of the circumstances. The CCB itself does not address chronic long term caregivers situations, and a crisis situation usually precipitates an intense moving and employment decision making process that could last weeks and months. While Health Canada, as part of a broad strategy for policy development, instituted a research focus that included Centres of Excellence for research to inform the policy process (Health Canada 1999 p.23) and part of that research focus was the impact of health restructuring on women, the Canadian Institute of Health Research funding was cut in March 2007 to 37 million. It requested 300 million. Many of its links on its website are now ‘dead.’

Pyper’s (2006) otherwise excellent paper – a Canadian government in house analysis of caregivers – excludes however ‘quitting job’ from the employment changes index. Half of our small sample of interviewed caregivers themselves or the primary caregiver in their family network, reported having either quit or postponed a return to paid work after a leave, and were seeking or hoping to eventually find,
Here managers underscore inequities.

CCACs are a creature of legislation established by the province of Ontario. Community support agencies are governed under the Long-term Care Act, but they grew up based on local community needs. These community service agencies are very rooted in their local communities and they’re – they’ve grown up based on needs in the community and then slowly as government funding comes available, some of them got more than others.

The implications that [contracting] has had for our clients and for our companion agencies … one agency took a 32 percent hit, so they lost 32 percent of their business when they lost their contract. It’s very hard to keep an organization alive when that happens. And they’re non-profit, so how do they pay severance?

The Integrated Service System Discourse

Both CCAC and community service organization managers talked about major issues for them emerging out of amalgamations. CCAC administrators talk from a standpoint within the discourse of the integrated service system. There are integrated service models across Canada and internationally that focus on homecare and community support services. However the government policy focus here is accountability. That comes down through the provinces and is mainly without new resources for organizations that directly provide services to caregivers and people with long term needs. Here, a CCAC administrator talks about an ideal system and how it is supposed to work. She speculates that the solution to support for caregivers may be found in the self care model, talk that emerges from within the governing, managerial discourse and constructs issues and solutions in its terms – disease management, self-care model, information about services, lifestyle support, a system in which primary healthcare is the central actor and agent.

The Minister is starting to talk about the strategic plan that the government will be introducing this spring. And one of the things that he’s starting to talk about …are seniors, care for the frail elderly, and chronic disease management, and I think chronic disease management particularly is an area that we’re likely to see some more focus, and one of the components of that is the self care model, and education, and really focusing on helping people to take care of themselves, which doesn’t translate into support for caregivers necessarily, but may help in terms of helping people take care of themselves.

From a system perspective there’s always been that sort of tension between knowing that part of the job that needs to be done is to make sure people know the service is there and available for them. But the concern on the other hand is [we] know there’s all kinds of untapped demand out there. [We] know there are people
who need the services and haven’t accessed them because they don’t know that they’re there. And I think the fear, particularly on the government’s part, is you could overwhelm the system overnight if people knew what was technically to be there for them.

Ideally, in a well-developed model what you have is the moment the physician identifies that you’re pre-diabetic or diabetic, you get off to the education program, you get the lifestyle support, the things that prevent you from getting to the point where you actually need more intense services. The key to it really is the organization of the primary care system. As the primary care system starts to organize into family health teams or other kinds of groups [with the] capacity to provide that seven day a week 24-hour access to service, and they’re linked to the rest of the community system in a way that works, so that person shows up at their office they know who to contact at least to get the person hooked up with the other kinds of services [that they need].

We’re working very actively to try to work with the family health teams as they develop. We actually assign case managers to work with the family health team so that there is that linkage. So we’re connected to the hospitals, we’re connected to the family doctors, and also linked to the other community agencies, so that there is at least the beginning of a system. It’s a challenge for everybody. I think everybody’s big fear is that the hospitals are just going to suck up all of the money.

The CCAC administrator here anticipates no change at the front line, except ‘transparency.’ She speaks within the institutional relations that a) see CCACs as the community system and b) now contiguous with the new bodies given authority to act on behalf of The Minister.8

With our consolidation, we’re moving from 42 CCACs to 14 so that we’ll match the LHIN boundaries. They’re being chopped and combined, because the LHIN boundaries don’t follow municipal boundaries. It’ll be smoo.. be one administration …basically be the same care. There won’t be any changes in front line service delivery. It just means there will be one executive director and one senior leadership team for those organizations. …They haven’t closed any of our local offices and we’re not anticipating that they would and we tend to have offices located across our regions. So at the front line level it should be fairly transparent. I don’t even think clients will know that it’s happened. But what it means is that we’ll be able to plan border to border within the LHIN, so the potential’s there for a much more integrated approach to delivery right across the system. And what it does for the first time is create a community system just by virtue of budget size that starts to look something like the equal of a hospital. That’s part of the challenge in the big health care tables, is that the hospitals are so much bigger than everybody else. So what this does is sort of raise the community system to a more peer level,

8 Of the 30 or so amendments to the provincial legislation, the 2004 Commitment to Medicare Act, more than half amend wordings and clauses in order to authorize Local Health Integration Networks to act as ‘the Minister.’ The 2006 legislation, the Local Health Integration Act, constructs the bodies and their mandates.
which will have some interesting implications in terms of planning. But it will also mean that I think the CCACs and the LHINs will have a somewhat unique relationship, because they’ll be the only organizations that will both have that will be border to border within that geographic area.

Here the speaker engages with the managerial business of budgets and planning.

[The function of the LHIN is] planning and funding. The budget size won’t change. It will still be the same provincial budget. The province is thinking that by streamlining the administration they’re going to free up dollars to move to the front line, but I don’t think in the grand scheme of things [that there will be] any great savings at that level...The ministry is still working on funding formulas so I think they’re still anticipating that from a centralized perspective they would still have some ability to determine what’s going into different pots.

The legislation specifically acknowledges some permeability of services across borders, so I think the potential is there for LHINs to come to some kind of [agreement] …it wouldn’t make sense to dismantle systems. There may be some things you need to do in a transitional period that are different than what you planned for in the long term, but there’s nothing to say that one LHIN couldn’t transfer money, potentially, to another LHIN to fund a service provider to serve a particular part of their area. I think they’ll have to be kind of creative in the early years just because of the nature of their boundaries and their historic boundaries.

Well, again, our governance structures are intact here, so that creates a whole different dynamic when you’re one organization [under] one board.

Indeed, on the other hand community service organizations – which are only partially funded and autonomous in their operations – experience amalgamations differently. Below, their managers and administrators talked about their work with caregivers and the work of their organizations that has developed over years of working with a network of ‘sister agencies’ at the managerial level and developed ‘best practices’ through a network of organization directors. One manager reported a model of continuous improvement of organizational operations that involves monthly internal training of managers and case managers at meetings where professional and ‘on the ground’ knowledge is shared. Built-in organizational processes orient to and continually monitor clients for ‘quality of life’ and improvements in their clients’ physical and psychological states. Adequate and appropriate housing and services together are continually monitored. These networks are being undermined in the amalgamations due to loss of agencies and the shift to LHIN initiated ‘networks’ which are in the process of being constructed in Ontario. Managers and front line workers indicate that there are negative outcomes, also reported in BC and Manitoba (informants, Leach, Hallman et al, 2006):

The manager speaking below describes how their work, once part of broader ‘sister agency’ networks and networks of community organizations’ directors, is being restructured in the terms of local integrations. What becomes visible is that routes of
delivery and access are being narrowed and redefined with the participation of large hospitals and private companies.

We’re not part of the [executive directors] network now. With the development of the LHINS, there’s a [disease based] network that’s developed in this area, in our LHIN four. They’ve put a proposal together for the LHINs that say these are the resources. They’ve looked at three different pathways – the LHINS are interested in Pathways. How do we serve people? How do we share resources? What is everybody doing? How could we be better? They’ve looked at three different scenarios of how typically do you provide rehab services with people within the community, how do you get them readmitted to a hospital setting when things don’t go well and there was another way. They’re trying to [determine] how to get the system to work most efficiently. They’re putting together a proposal for the LHIN of this is what we see as the need and how we see it working best. Also on this network are people like [hospital] and private providers of [disease] services. I have the impression that that’s unique to have private providers at the table as well.

We looked at how people get funding and people are given funding based on the kind of people they serve and there seems to be a disjoint between the funding and [reality]. The funding tool they use is outdated is the feeling at the table. They might be serving the same population, but because they are seen by the Ministry of Health as serving different populations, their funding structure is different. So, they’re struggling. There’s a (reads text) OCSA: Standards and Indicators for Community Support Services, the Guide to Quality Care, an orange book. You get a designation of kind of service C1 and a B2. And they talk about something called GAIN that seems to influence their funding too. We’re trying to squeak out from the pie from hospitals which have huge budgets. LHINs are not going to have huge budgets so what do you do? And in the LHIN there will only be one provider of [our] services. Now we have four. That’s the whole direction of the LHIN.

Amalgamations have already reduced the numbers of CCAC agencies. We heard the ways that community agencies will also disappear. Lines of reporting and what is to be reported will change. Community organizations may have excellent reporting mechanisms, indicators, strong professional and community boards, and business ‘best practices.’ They are being sidelined in the narrowly focused integration process.

What they want us to report on is very different than what the Ministry wants reports on. I think that’s why we’re at the table so that we can determine what we should be reporting on. What are indicators of best practice and service? What we report on (and how) could change for sure. We’re big enough and have a very strong leader, and we’ve developed good indicators of quality of service and we can quickly change, whereas a hospital is a huge organization and to change a mindset or a direction of a hospital can take years, whereas we’ve always had to adapt in order to change, meet the needs and be responsive to our funders. We are accredited and report to the Canadian Council on Health Services Accreditation as
...they’re [LHINs] asking the wrong [questions]. When people are not involved in the business, they ask the wrong questions.

The manager above gives a glimpse of the business practices of her organization’s work processes that build in quality of service, quality assessment, quality of life indicators and quality operations. This is all changing and for service organizations in both urban and rural areas. For agencies that operate in rural regions, the changes are exacerbated. The case manager below tells us how:

Most of them are rural and small towns, but there’s no cities out here. We find, especially me coming from [city] where you know what kind of services are available, when you’re out here, you don’t have just the services, community centres, and the number one barrier here is transportation. It’s huge. How do you get people where they want to go? We don’t transport clients, so even to say, “hey, let’s go check out this housing” is a big … they can’t just hop on a bus. You have to secure transportation if you want to develop a support group. How’re you going to get them there? They’re coming from an hour and a half away and a lot of our participants don’t have transportation to get there. Services in their area are few and far between. They may not have any support groups. They may not have community centres and if they want doctors or specialists, they go to [city.] You have to gear these things to the area. It takes a little more thinking and creativity. In the city you’ve got one spot and that’s where it’ll be. That doesn’t work out here. You never know what’s going to come in the future. Whatever services are needed out here, the sky’s the limit on what they would benefit from out here. We are talking about a traveling support group. Again, it all depends on two of us out here. And again, it depends on funding.

Conclusions

In the context of the actual working relations of caregivers and service organizations, we can see just how issues of policy and institutional organization emerge. “Falling outside the Canada Health Act” is how one policy analyst stated the main problem for developing policies for caregivers. Federal policy analysts understand home care to be provincial and territorial responsibility entirely and that the government takes a “hands off” approach to home and continuing care. The issue remains however, that this organization of policy and interventions does not smoothly match the realities of care work that is not contained within provinces and the everyday realities of a system that relies heavily on community based organizations with tenuous funding. The dispersed family networks that are coordinating care to seniors and are in ongoing relations with community and homecare organizations across the country, highlight broader policy issues and principles of adequate service to our aging population. While we realize the framework for CSOs is provincially based, the broader issues are: 1) how homecare and continuing care is structured across Canada, and 2) how the policy gap presents issues of where services and housing are located and whether they are located equally and are equally accessible. The final issue 3) is that of portability of services and housing between provinces.
Highlighting housing within the framework of home and continuing care speaks to how government departments might take a broader look and see what is happening on the ground with regard to Canada’s health and health determinants. Housing is not treated as a determinant of health, and it emerges in this study as a major factor in the outcome of caregivers’ contact with home and continuing care services for the well being of seniors. If it were treated as a determinant, it might fall under ‘social and economic factors.’ But housing policy research could be undertaken with a view to developing publicly funded pilot projects on alternative housing forms that allow ‘aging in place.’ Previous initiatives have been for-profit, so do not fall under public health. There is not a well developed literature, but research on the economic viability to the health system of aging in place housing has been established in terms of keeping people out of hospitals. Studies have also found the cost benefits of alternative forms of housing (CMAJ 2006).

A subset of move and housing decisions caregivers’ talk above reveals is home renovation and the forms of housing arrangements that accommodate extended families. While these may be municipal building codes and standards, governments fear to tread where developers are rushing in (Gadd 2007). The development industry is building for a projected healthy and wealthy market. The onus is therefore on the governments to build in equitable access to housing for seniors, and could take a lesson from the trend the same baby boom created as they moved through public and high schools and when they had passed through, these public buildings were converted to community centres, residential and office buildings. How housing and labour markets influence migration patterns and location choices of immigrants is a question that the Metropolis project of Citizenship and Immigration Canada is looking at (http://canada.metropolis.net/). Their gender sensitive approach could well be extended to eldercare.

A striking finding within the inquiry into the organization home and continuing care is the different terminology and structures in each province. This is not simply a matter of language. It reflects the fundamental differences in organization, funding and operations that add layers of difficulty in ‘navigating’ not just within but between provinces. While it will have been said elsewhere, a federal task force to work with representatives from the provinces to establish consistent language that recognizes the community based organizations as well as the different ‘access centres’ in each province, would go a long way towards a national ‘best practice.’

One of the key things learned in this study for the author is the range of flexibility that community service organizations put in place internally in order to match their work with the needs of caregiver families, including long distance family care networks that reach across provinces and into other countries. Their flexible operation is central to how CSOs are able to work, and that is being affected by the integrations and amalgamations taking place. Some community service organizations are losing referrals and losing staff and in some cases cannot continue. Others have impossibly long waiting lists and are badly understaffed. We have examples in Canada of negative impacts of health authority integrations in BC and in Manitoba, and the managers and administrators located in different kinds of organizations in Ontario are telling us – and we can see when we get
down to where services are being delivered – that Ontario will likely be added to those provinces being negatively affected by amalgamations.

Policy analysts in health and social services identified issues of rural and remote regions and the ‘expert knowledge’ gaps between federal units dealing with health/home care and units dealing with rural (aafc, rural secretariat, aboriginal and inuit health and so on). While policy analysts in different departments themselves try to communicate and connect their work, there is no formal coordination of their lines of policy work. Hence we get a sharper focus on the conception of ‘rural’ and ‘distance’ when we hear of a family living on a remote Northern Ontario reserve whose aging uncle has diabetes and heart problems. The location of discrete services for medical care is striking. “For diabetes treatment you have to go to Sudbury, for heart treatment/surgery you have to go to Toronto. For the niece living in Ottawa, this means that she gets a phone call from the family telling her to visit and care for the uncle who is in the hospital in Toronto. Of course Toronto is not ‘close’ to Ottawa but it is close compared to where the rest of the family lives on the reserve and with fewer and more expensive options for transportation.

A fair national system would address working women and informal family care networks that need a range of supports to continue providing the in home and at a distance care to the aging population. While there is little doubt women, and women in paid work, still do the lion’s share of caregiver work as professionals and as family members, the challenge for policy and research is to extend the view to capture Canada’s reality of dispersed extended families within the conditions of an increasingly streamlined, if accountable, healthcare system that does not comprehend these contemporary realities under the current Canada Health Act. But further, a national policy framework and strong provincial policies and funding to support CSOs will be crucial for a Canadian system that addresses health and home care needs.

An evaluation of the Nova Scotia strategy for caregivers being developed with a view to standards and within the continuing care policy might be useful at this crucial period in the development of integrated service models across the country. Policy analysts look for best practices and Canada just might have one that fits with our systems and that could be transferable to other provinces.

The “Caring at a Distance” project conceptualized and developed a new understanding of the complexities of care giving in a large country such as Canada, emphasizing how care giving work done in the contemporary context of geographical distance, economic and labour force restructuring, and institutional reorganization. What is called ‘informal care giving’ is a complex contemporary phenomenon in Canada and emergent in the ongoing transformations of Canadian regional economic development and restructuring of public institutions. This context must come into view as the actual conditions of service providers’ work and intersection with caregivers. The realities of an increasingly mobile workforce, shifting geographical land development and housing trends, and an aging ‘baby boom’ generation also come into play in the shaping of the development and organization of public policy priorities and restructuring of public institutions. Our focus has been on a segment of this large mobile labour force that is dealing with seniors and
their care decisions and who are working across jurisdictions and requiring fresh attention, support and better supported service organizations and labour practices. In the context of current attention to seniors, the policy issues highlighted here that emerge from the ground level work of participants in the system, need not remain under the radar.

5. RECONCEPTUALIZING RURAL-URBAN MIGRATION FROM A GENDER PERSPECTIVE

Belinda Leach

Introduction

Rural to urban migration has long been addressed as a concomitant of processes of economic development, industrialization, the commercialization of agriculture, and urbanization, and has been observed worldwide. Yet for decades most scholars and policymakers have viewed it as a fairly straightforward phenomenon. Individuals buy their one-way tickets to the economic opportunities of the city, perhaps sad to be leaving the homes of their childhoods, but conscious of the limitations imposed by the rural, confident that in a new urban setting, life will improve. They are simply responding to the geography of opportunity. This perspective certainly simplifies analysis and policy development, narrowing the focus to declining rural populations and increasing urban ones, but it flies in the face of observed realities.

As we have already established, one of the most pressing issues that face many mid-life women is that of caring for elderly relatives from which one is physically far away. This issue brings into focus a serious problem with the conventional approach to migration. It presents an opportunity and a requirement for thinking about rural-urban migration differently, as a life-long process for a family. Considered in this way, migration involves shifting and complex decisions about migration, labour market activity and caregiving and receiving, in which gender is a primary factor. Moreover migration decisions and related ones, such as those pertaining to labour market participation and withdrawal or even non-participation, and who gives care and how, all have gender effects and simultaneously are gender determined.

This rather different view requires that rural to urban migration be seen as a process that while largely driven by labour market imperatives (as standard, modernization and development related migration theory supposes), is also intimately tied to peoples’ needs for care and women’s expected role as carer. Both labour market concerns and caring needs change and are responded to over the life course of extended families, and are immensely complicated when family relationships are stretched out across long distances. Thinking about rural-urban migration this way shifts its understanding from the prevailing one that it is a single - if life-altering - event, to understanding it as on-going and potentially life-long in its scope. In the process, women and men actively make
decisions that involve multiple, sometimes competing, factors. This has serious implications for policy development and analysis.

Seeing rural to urban migration as a more intricate process of ongoing connection and negotiation among family members requires a new analytical approach. The “transnational turn” in international migration studies (Sorensen 2005), and especially the attention to the “transnational family” is helpful for reconceptualizing rural-urban migration as process rather than event. It is especially useful for trying to think through issues of family and care relationships “at a distance”.

The pathbreaking work that signaled a paradigm shift in scholarly attention to international migration was *Nations Unbound*, by Linda Basch, Nina Glick Schiller and Cristina Szanton Blanc (1994). Rejecting the idea of the immigrant as experiencing “permanent rupture, of the abandonment of old patterns of life and the painful learning of a new culture…. “, these authors drew attention to the “networks, activities, patterns of living and ideologies that span their home and the host society” (Basch et al. 3-4). They define transnationalism as “the processes by which immigrants forge and sustain multi-stranded social relations that link together their societies of origin and settlement” (p. 5). Importantly, these processes involve actions, decisions and subjectivities embedded in networks of relationships that connect them simultaneously to more than one region of the world. Close ethnographic attention to these sustained human processes has contributed to the development of a new transnational analytical framework for examining migration. Those working with this framework have been especially interested in issues of care across long distances. Transnational families are “families that live some or most of the time separate from each other, but yet hold together and create a feeling of collective welfare and unity” (Bryceson and Vuerela 2002: 4).

There are of course limitations to the application of this idea to internal migration. The most notable is that rural-urban migration does not take place across national borders, as the term “transnational” denotes. Consequently, negotiating citizenship regimes, and physically crossing a national border – often a traumatic experience for those whose right of residency on one side or the other could be called into question - is not there. Yet, given the high frequency of migration practices, international borders may figure in peoples’ care options, even if their own migration has been internal. Furthermore, the nationalist political connections that transnationalism scholars have observed that people often maintain in both sending and receiving locations (Basch et al. chapter 1), and the consequences of those for national identity, are absent when the migration route is inside a particular country. But it may be argued that questions of identity do surface for rural migrants, only to be submerged and made invisible by alternative dominant discourses of regional identity, such as Quebec nationhood, western representation, Toronto-centrism, and Maritime underdevelopment. Interestingly, one facet of rural identity is a “migration imperative”, as Michael Corbett calls it, wherein “[t]he alleged necessity of leaving rural places is not simply an innocent reflection of social conditions, it also contains an aura of obligation and compulsion for the individual youth who experience them” (Corbett 2007: 2). This idea contributes to a rural identity that people take with them when they leave or that remains an unfulfilled aspect of it if they don’t.
Conventional migration studies have been accused of adhering to a kind of methodological nationalism, where the bounded national state is taken to be the natural and logical arena within which social life takes place, making it difficult for transnational ties to be accounted for (Wimmer and Glick Schiller 2002). The corollary to this is an implicit assumption about rural-urban migration that whatever happens inside a national boundary is not subject to an analysis that takes into consideration differences in region and mobility, for example. Of course, for a large country like Canada attention to region has loomed large in scholarship and policy circles, yet there continue to be blindspots to the effects of size and distance, and family caregiving, I argue, is one of those.

In this chapter I modify Sorenson’s framework of “transnational family life” (Sorenson 2005) to apply it to the gendered process of rural to urban migration. I argue that this approach is helpful for shifting our view of rural out-migration as a one-way, single event, towards seeing it as an ongoing process in which family members engage, but on very different, gendered terms, as relationships are nurtured and maintained, care given and received, and financial and other resources allocated in both places. The purpose of this chapter is to begin to develop an approach to rural-urban migration in Canada that has the capacity to incorporate the sustained connections that migrants and their families maintain across distance and through time. Transnationalism scholars have made central to their analysis issues of gender, class and racialization as crucial to understanding transnational processes within the context of the global economy and its constant restructuring. A new approach to rural-urban migration that incorporates these features will allow us a far more nuanced understanding of rural-urban migration, family care networks connected across distances, and the practical exigencies of maintaining these, especially during periods when family demands are high. Using this framework allows certain key issues and patterns emerging from our data, which are rarely the focus of attention in the rural-urban migration literature, to be considered. This will have positive consequences for the capacity to understand the policy needs of long distance carers.

The paper is in three sections. I begin with a discussion of rural-urban migration in terms of three particular issues: its relationship to demographic change and economic change, as a gendered process, which necessarily requires attention to class, ethnicity and “race” as well. The terms “rural” and “urban” as they appear in the “rural-urban migration” idea erase factors that stratify and divide rural and urban residents, such as gender and class, as well as race and ethnicity (inter alia). These have serious implications for policy take-up.

The second part sets a brief discussion of how rural to urban migration is characterized in much of the literature against the realities of migration that emerge from empirical materials collected as part of this project. This section sets out the contours of a processual, life course approach to rural-urban migration to make the point that rural out-migration can take place at different stages in the life cycle of a family, for reasons not always or only determined by labour market and economy, but always shaped by those. This part then argues that whereas rural-urban migration is typically seen as a single event, it requires a life-course approach. When viewed as part of a family’s life course,
migration and care decisions are clearly gendered, and simultaneously affected by class as well.

In the third part, I consider the implications of an approach to rural-urban migration that considers seriously the gendered nature of care work, drawing on the idea of “global care chains” that emerges from the transnationalism literature. I address the question of the racialization of carework that has frequently characterized research that focuses on global cities. I consider how social class affects the provision of care by adult children to their parents. Finally I conclude with some future research and policy directions to address the gaps in our knowledge of rural-urban migration processes from a gender perspective.

**A Gender Lens on Rural-Urban Migration**

Social science research has tended to take rural out-migration as a “natural” concomitant of the historical modernization process (Berry 2000), warranting attention mainly in two ways: first, and most centrally, in terms of its impact on city infrastructures and social relations, and second and with less urgency, in terms of its impact on the predominantly agricultural regions that people leave. In certain ways, rural places have been viewed from a modernization perspective as little more than labour pools for growing cities. Recently, increased attention has been paid to the sheer numbers of people who have left, and continue to leave, rural communities worldwide, prompting concern about the continued viability of many rural areas worldwide. More recently for Canada, new interest has been shown for the types of people who leave, in terms of gender, age and education levels. But the point of this exercise has been mainly to demonstrate the effect of the loss of such people, especially the better educated, on rural communities, such as the decline of rural services and commercial decline, and the concomitant gain to urban labour markets (Audas and McDonald 2004; Bryant and Joseph 2001). In recent years much has been made of the reverse flow of urbanites into rural communities, or counterurbanization. This trend has been identified primarily in Europe, and to some extent in the United States, where it has practically steadied the net loss of population from communities closer to metropolitan areas. But in the Canadian context it is significant that while this phenomenon has been observed in some metro-adjacent areas in Ontario and British Columbia, this has not been the trend in Atlantic Canada and the Prairie provinces, which continue to experience net out-migration (Audas and McDonald 2004:17). In-migration comprises both young families seeking the benefits of a rural lifestyle and older people seeking a new environment for their retirement years. The aging of rural populations – whether associated with people leaving or arriving – is repeatedly pointed out (Moore and Rosenberg 2001).

The consequences of youth out-migration and the aging of rural communities are significant, and both have a major impact on care relationships within those communities. The gradual diminution of the tax base, associated with both demographic trends and with aspects of economic restructuring has implications for rural social services, especially those delivered through municipalities (Bryant and Joseph 2001). The lack of skilled workers for positions in the caring professions means that the elderly have limited access to specialized care they may need locally, and that they are likely to have to travel
to find it (Leach et al. 2006). Furthermore, and most significant for our present purposes, the rural elderly are less likely to have their own adult children around to take care of them when the need arises.

These factors combine with well-established elements of rural economic restructuring such as the crisis in agriculture that leads people to abandon farms or turn them over to developers, the loss of traditional industries and employment, and the amalgamation of municipal and social services which have led to hospital closures and the consolidation of government services in larger centres (Winson and Leach 2002)

Traditionally men have been assumed to be the “lead migrant”, bringing their wives and children behind them. The primary motivation for migration was typically identified as the search for better employment and income potential. More recently migration scholars have viewed those decisions as the result of multiple factors, of which improved economic standing is only one. Male migration for work in some contexts, for example, has been analyzed as an important element of their training for work back in their home areas (Wright 1995).

It is only fairly recently that particular attention has been paid to women migrants. This is partly because historically women’s migration rates were much lower than men’s, a feature that used to be attributed to women’s “natural” desire to stay close to home. Newer scholarship invokes the role of (colonial) policies that made it difficult for women to migrate, ensuring that men would return home and ensuring “the rural subsidy of labour-force migration” (Wright 1995:784).

With some exceptions (such as women’s migration from the Caribbean as early as the 1930s to take up nursing positions), women’s international migration on a larger scale is a more recent phenomenon associated with planned development efforts (and sometimes with their failure). Feminist scholars have turned their attention to this, and analyzed it in terms of a wide range of issues (see Bock 2006 for a review). These include constraints on women’s mobility that arise from gendered ideologies and cultural norms, such as limitations on women traveling alone, or leaving their father’s home, especially in the absence of a husband. They incorporate practical factors such as access to the economic resources that migration requires (purchasing tickets and mandatory travel documents, as well as money for immediate needs in the new location), as well as the gendered nature of the labour markets that they hope to penetrate. They also take account of the gendered impacts of government policy (some of which articulate well with cultural and ideological factors) that make it easier for some groups than others to consider migration.

Motivations in favour of migration are also gendered. Recent accounts point to women’s desire to escape male control over their lives. Irish scholars have noted that an intolerant climate for women and their subordinate place in Irish society has been a prime motivator for women’s outmigration (Ni Laoire 1999:226). In other parts of Europe the idea of the ‘male periphery’ has been used to signify the way rural communities are dominated by male-centred economic and leisure activities, such as fishing, hunting and cruising in cars (Dahlstrom 1996). In this context, aspirations for economic independence are also a
driving force. Economic security for women in rural areas may be increasingly compromised by changes in the structure of agriculture which often favour men, leading women to believe they will find better opportunities in cities. This factor applies to rural areas of high wage countries as much as to low wage countries. As many have argued (Corbett 2007; Leach 1999; Ni Laoire 1999; Sachs 1996:6-8) ideological constructions of masculinity and femininity are deeply embedded in the patriarchal roots of agrarian and resource extraction histories, in places like Canada, the United States and Europe, and are often resistant to change. The corollary to this is that urban areas are often more conducive to supporting women’s everyday lives (Halfacree and Boyle 1998:5) as empowered individuals in very practical ways, such as providing public transportation for access to work and to services, and accessible childcare.

All these motivating factors suggest that women are agents of their migration trajectories, despite push and pull factors that facilitate or constrain their actions.

These gendered motivation factors clearly intersect with class. It is usually easier to uphold ideological expectations around the work of men and of women where the resources exist to allow it. In poorer families, economic demands may of necessity take precedence over ideological and cultural expectations. In rural areas property ownership, especially with regard to farm property, but also woodlots and fishing boats, remains a factor in family decision making, as it did historically. Land and other forms of property continue to be commonly destined for male successors, at times precipitating women’s migration to seek other forms of income, in other situations allowing rural women to seek propertied husbands.

The historical constraints on women as migrants have to some extent been turned around in recent years, resulting in what has been termed the “feminization of migration” (Ehrenreich and Hochschild 2003:5), associated with two broad and interrelated trends, the labour market for transnational care work and the reunification of families through immigration programs. Family unification policies have the effect of recruiting immigrants for low paid work, of which carework is one.

In rural Canada the out-migration of women has been higher than that of men in recent decades (Dasgupta 1988), although since little attention has been paid to gender differences in this form of migration, details remain fairly sketchy. From his qualitative study, Corbett (2001) concluded that young women have a greater propensity to leave home communities, whereas, a decade earlier, Day (1990) found rural women’s desire to leave their communities to be less than that of men. The 1996 census indicates a slightly greater propensity among young women to leave rural communities than among men (24.4% and 21.8% respectively). The only province where men are more likely to leave is Newfoundland, and the widest gap between men’s and women’s leaving patterns, with more women leaving, are in Manitoba and Saskatchewan (Dupuy et al. 2000:95, 101 and 102).

**A Biographical Approach to Rural-Urban Migration: Process Not Event**
A striking element of most of the literature on rural-urban migration, in Canada as elsewhere, is the focus on migration as a single event. Dasgupta (1988), for example, writing about change in rural Canada treats “migration” and “family” as entirely separate sociological domains, failing to investigate how each interacts with the other. Sorely missing from this and most analyses of rural outmigration has been attention to the social processes that accompany it, notably the continued connections between those who leave and those who stay, and the many implications of those enduring but complex social relationships.

A closer reading of the stories of those who leave rural communities and of those they leave behind suggests an alternative approach, in which decisions about work connect with the family life cycle. Our research suggests that commonly young people move away from their rural parents and the communities of their birth, to seek out education and work opportunities in urban centres, a finding confirmed by statistical analysis (Dupuy et al. 2000). Although they may wish to return home (and sometimes not), for most of these, continued opportunities for work in their professional fields, or at desirable pay levels, do not exist “back home”, so with some exceptions most stay in the urban centres. Recent statistics indicate that as many as 25% of rural out-migrants do return to their original communities (Dupuy et al. 2000), but data on their gender has not been made available, and the motivation behind such decisions has not been investigated.

It could be argued that caring at a distance actually begins when young adults move away. At first, parents provide long distance care, but over decades the direction of care gradually tips the other way.

Interestingly, attention to a migration cycle has been implicitly noted for men. They have been seen as leaving their rural homes for specialized education or to gain skills or experience that they can bring back and add to the social and human capital of the rural area (Wright 1995). Short-term migration of men, to work in more prosperous labour markets such as Ontario and more recently Alberta, for weeks or months at a time, has been a taken for granted phenomenon in impoverished rural regions, such as Atlantic Canada. Similarly, occupational absences associated with work in the fishery or ocean-based oil and gas installations have all been viewed as characteristic of particular economic regions. Yet these forms of migration have rarely been treated explicitly as gendered, and having gendered effects. Moreover, these forms of migration are quite clearly cyclical, closely associated with individual biographies.

Although outmigration is less likely as people age, a US study suggests a life long interest in migration, as the number of over 60 migrants increases (Longino and Bradley 2001). Moreover, the motivations for moving change quite dramatically among the elderly. The “young-old” often move to particular destinations, on the grounds of climate and landscape while the “old-old” tend to move for reasons associated with care, either to be closer to relatives for care, or into institutional settings (Grundy and Glaser 1999). Migrations for care reasons at other stages in the life cycle also take place. Alston (2006) discusses the migration of married women and their children from drought-stricken rural areas of Australia to cities, sometimes hundreds of miles away, so that the mother can...
take paid employment while the husband attempts to maintain the farm until rainfall makes it productive (and financially viable) again. In this context, as Alston points out, women’s care for their families includes income generating activities that permit children to continue to be educated, received health care, etc.

Our research data, combined with some brief mentions in the literature on care, as well as our conversations with many individuals who have moved from Canadian rural communities to cities, suggests a relatively common pattern. As their parents age, women who have moved away from them, take on the responsibility for ensuring that adequate care is provided. Sometimes this involves coordinating with siblings who stayed behind, through regular phone calls to them and to the parents. It involves increasingly frequent visits to monitor the parents’ situation and set up new arrangements. Gradually this means traveling back and forth to provide intermittent care (sometimes as respite for other relatives) and support. This is all carried out at the same time as taking care of their urban families. In these stories daughters play a different role from sons. Although men accept responsibility for their parents’ wellbeing, this plays out in different ways than for women, as I discuss below. Our research also indicates that caring relations may span more than two generations, as the next generation of young adults gets caught up in arrangements for their grandparents’ care. The ongoing connections between rural and urban residents following migration point to the usefulness of an approach that modifies the transnational families framework.

In some circumstances women move back to rural communities to take care of parents in a more intense fashion for months or even years, and sometimes permanently. This decision is clearly the outcome of an individual’s particular circumstances, taking into account especially immediate family demands and the presence or absence of a job and its relative pay and other conditions, as well as the availability of other forms of care for the relative, including other family members. In an alternative scenario, an elderly parent may move to the urban centre to be closer to his or her daughter/caregiver. And frequently women continue to travel back and forth, intensifying their contributions to parent care both in person and in absentia, until the last parent dies. In all of these cases negotiations of different kinds among people of different generations are clearly taking place over a long period of time. Following Halfacree and Boyle (1993), I argue that migrations have to be contextualized biographically, in terms of the life course of the family and often, a family livelihood strategy.

This type of cyclical migration is difficult to capture through the census or other surveys for a number of reasons. For example, people may maintain a rural family home, despite moving out of it themselves, renting it or sometimes allowing family members to live there. As well, social statistical reporting is mainly concerned with the relationship between migration and labour availability. Consequently, migration of the elderly, for example if they move to be closer to a caregiving daughter, is of little interest because it is not labour market behaviour. Of course, it could be argued that this is closely connected to the labour market behaviour of the adult child.
The story we heard from a post secondary institution manager exemplifies the kinds of mobility decision-making that people engage in. Her family moved from Vancouver to a rural area of British Columbia when she was 10. Like many young rural people, she moved back to Vancouver to go to university, and then stayed “because the work was here”. Later her mother moved again to a larger community on Vancouver Island. Here the mother lived with her second husband for whom she was primary caregiver until her own diagnosis with cancer. At that point the daughter began to coordinate care for both of them. For her mother, this involved coordinating her visits to Vancouver for specialized cancer care, including immediate post-chemotherapy care. As her health condition improved, the mother has been able to use local health services, but the daughter continues to monitor both those services and her mother’s general health. In addition, she has organized services provided to her mother’s husband, because this alleviates the burden on her mother. She has taken on these responsibilities despite having two brothers who live closer than she does to their mother. She relies on one of her mother’s neighbours, “across the street”, who she phones, or who phones or e-mails her, “if I’m needing to know something or if anything happens that she thinks I don’t know about”.

This woman is divorced, and the kind of job she holds has permitted her considerable flexibility in taking time off to assist her mother. Recently she made the decision to take a leave of absence from her job to move closer to her mother, “to go there and be there”, for the final period of her mother’s life. She says she plans to look for work, but she doesn’t know if she will find any, and she doesn’t know whether she will stay.

Other women’s stories tell of journeys that are not captured by the dominant narrative of a single rural to urban move. The life skills trainer tells of her sister who moved with her husband back to the rural community where they grew up to be able to care for their widowed mother. The community service organization manager’s mother had followed her other daughter who had moved with her family to another province. The university researcher told us that her mother had moved to be close to her own mother. Now, she wants to move her mother to be closer to her and her husband, but she doesn’t think this will be possible until her grandmother no longer needs her mothers support. The administrative clerk reported that the grandson and his wife of the aunt she provides care for are considering moving from BC to Ontario to care for her as her needs intensify.

International borders also figure in internal caregiving practices. The administrative clerk reported that the woman she cared for was not able to move closer to her own children, both of whom are now living in the US, because her pre-existing medical conditions would preclude her from getting medical insurance there.

One Canadian government publication draws attention to this issue, though not in terms of rural-urban migration processes. Cranswick (1999) reports that in 1996, almost half a million Canadians moved for the purpose of giving or receiving care. While most of these simply moved closer to the other person, 130,000 actually moved in with the person. Half of these moves entailed an adult child caring for a parent, but almost 20% involved helping unrelated friends. Most of the caregivers who moved were married and over a third had children under 15. Almost 70% of the caregivers were women. While attention
to moves for this reason is welcome, it again focuses on the move as a single event, missing the difficult years of long distance care that precede such a decision.

That the relationships between parents and their adult children who have left rural communities is cyclical, continuous and complex suggests a number of things. First, it indicates that the rural-urban move is not a single event, but rather a lifelong process involving decisions about care, labour and mobility. Second, it suggests that the process is both gendered and classed. Constructions of femininity, especially, but masculinity as well, figure a great deal in the decisions being made; and class position, especially in terms of the relative flexibility often associated with more middle-class jobs, constrains or allows particular courses of action regarding both migration and care.

**Gender, Race and Class in the Provision of Care at a Distance**

One of the strengths of the transnationalism literature for my purposes here is its focus on transnational relationships. Much of this has paid attention to care relationships across distance. The relationships between women who leave and the children left behind have been a particular focus here, and there is an enormous literature that continues to grow on this topic (see for example, Parrenas 2002). Consequently, it takes an approach to transnational family life, “in which family relations and functions are carried out across rather than within specific geo-political spaces” (Sorensen 2005: 1). In the transnationalism literature most attention to the elderly is in their role as grandparents, but there is just beginning to be notice made to the care of the elderly when the next generation has moved away. This is especially an issue in China where extremely rapid urbanization is responsible for massive rural-urban migration, and this combines with the results of the one-child policy such that there is no other sibling available for care.

In areas of the developing world where women’s migration is dominant, such as the Philippines, especially, but also the Caribbean and Mexico, women often leave to take caregiver jobs of various kinds, as informal caregivers to children and the elderly in private homes, in hospitals and nursing homes, and in a host of service jobs closely connected to care). The irony of this situation – where women leave their own children and other family members and travel long distances to care for other women’s families – has not been lost on scholars or activists. Hochschild, for example, has described this situation as a “care drain” in the areas of origin. This connects to the rural brain drain idea, which as pointed out earlier, has created a gap in professional services in rural Canada.

In the international context, this process is associated with both race and class. In the high wage countries women’s labour is increasingly in demand to substitute for the domestic labour of middle-class women, or to fill less desirable working-class jobs for which there is a labour shortage. This work has also become racialized in different ways. In the US “Mexican” women are often associated with employment in private homes as cleaners, housekeepers and for childcare. In Canada and in many other countries the Filipina nanny epitomizes the ideal for child care among middle class working women. In contrast to the major cities, rural Canada remains predominantly white. Policy efforts to encourage
immigration beyond the major cities, as well as the expansion of programs permitting short-term migration to areas with particular labour needs (such as agriculture and the meatpacking industry, and more recently the oil and gas industry), are changing this to an extent. These programs could eventually create a female labour force that is available and “appropriate” in gender terms to care for the rural elderly.

This exodus of women from their home countries has led to what have been called “global care chains”, wherein women in developing countries migrate to work as carers in richer countries, leaving their own children and other dependents in the care of other relatives. An important empirical finding within this work is the intention of women to return to care for their families once they have accumulated the financial means to be able to do so. In the meantime remittances substitute for the direct care of children and other dependents.

Parrenas (2005:14) points out that migrant careworkers are an effect of the political-economy of care inequities in the high wage countries and the depletion of care resources in developing countries as a result of structural adjustment programs. Litt and Zimmerman (2000:157) argue that poor women’s carework is structured through immigration, as the infrastructure upon which the expansion of the high wage economies depend. In their analysis, women’s subjugation in the gender hierarchy comes into play whether they are providing or paying for care. Furthermore, this is connected to a generalized instability in international systems of care, which is rapidly and potentially disastrously affected by processes like economic change, migration and societal crises, such as natural disasters or disease epidemics. The large literature that analyses the restructuring of health care in rural Canada (Cloutier-Fisher and Joseph 2000; Gregor 1997) reveals a system that has been pared back to such minimal levels that it can barely meet regional needs. Predicted infectious disease epidemics, during which general mobility is likely to be restricted will have dire consequences for the care of the rural elderly who depend on their distant relatives.

Care chains between rural and urban regions of Canada appear to be emerging as a product of rural health care restructuring. Women from rural communities who trained as health care professionals are less and less likely to be able to find employment in rural communities, as smaller hospitals and clinics close. These women seek out care for their elderly relatives who remain, using the work of other women to substitute for their labour. If, as is often the case, the care of the elderly is informal and privatized, rather than formal and publicly funded, those carrying out the care are likely to be low paid because women’s own resources are limited.

The phenomenon of migrant carework results from the ideological construction of carework as women’s work, in high wage countries and those of the global south, which allow women to be exploited in providing care. Spitzer et al.(2003) argue that often women’s caregiving is constructed as something to be freely given rather than bought. But this has classed and gendered effects. Economic resources greatly determine care options, not just for those requiring care, but for those expected to provide it as well. Women’s career success may bring with it added flexibility, but it may also have the
effect of limiting the care they can provide. For men it usually means that they can care “better”, because they can travel and/or provide remittances. Men can provide care from a distance because they tend to have greater resources whereas women who are likely to have fewer resources have to provide “in person” care. In our interviews, even when brothers lived closer to a parent in need of care, women were still expected, and expected themselves, to take major care responsibilities. Frequently brothers were characterized as “useless” in this respect. Baldock’s (2000:216) research with migrant academics in Australia providing care to parents in other countries showed a distinct gendered division of care, with men providing financial advice and housing repairs, while women took care of medical issues and organized family celebrations.

Providing care within a family always generates tension and conflicts; managing these from a distance takes an even greater toll on the caregiver. Disagreements over priorities and the management of resources (Landolt and Wei Wei Da 2005) combine with structural and ideological constraints on facilitating care.

The class position of women is also a major factor in the form their care takes. It is instructive that all the caregivers we interviewed held middle class jobs. This provided them, as they were quick to point out, flexibility to organize their work days that would not be available to them in working class jobs. This meant that they were able to negotiate with their managers to take time off at short notice and to organize their work weeks to provide themselves with time to visit their relative. The life skills trainer, for example, had arranged to have Mondays off so that she could visit her mother on Saturdays, and still have two full days at home to do the domestic responsibilities expected of her there. The sister of the community service organization manager had quit a 9-5 job to which she had to commute and taken a much lower paid part-time job to be able to carry out her care responsibilities. Doing this meant that she was more dependent on her husband’s income that she had been before, and removed some of her own independence. These findings resonate with Baldock’s (2000) research with migrant academics who had the flexibility to organize aspects of their work lives (sabbatical affiliations, conference participation) around the care needs of their distant parents.

Most interviewees identified high costs associated with caring at a distance that cut into their disposable income. These were costs associated with travel (especially as gas prices climb ever higher and airfare include a fuel supplement), often steady remittances to help their relative with day to day expenses, and as well occasional expenses during visits, including food and clothing, and medical expenses.

The transnational care literature has focused on the role of technologies of communication in carrying out care from a distance. Telephones have figured largely in this, but increasingly cell phones (for voice calls and text messages) and e-mail have become more important. Our interviews show a similar trend among urban caregivers who use various technologies to stay in touch with those they care for. Access to these devices in Canada is fairly costly and often entails long term commitments. Furthermore, these various forms of instant communication keep women on call as carers 24 hours a day, no matter how far away from the recipient of care they may be (see also Gardiner
Barber 2006). These technologies therefore allow women to keep doing the carework, and eliminate a need to challenge the structures within which they do it.

Class also figures in the problem of negotiating policy regimes between provinces. For one thing, women frequently need to be able to do this during the typical work day, to be able to speak with the professionals responsible for their relative’s care. Work flexibility is essential to be able to do this; it cannot be done on 5 or 10 minute breaks from an assembly line or fast food counter. Furthermore developing an understanding of different policies and practices may be easier and faster for those with higher levels of education.

**Conclusion**

This chapter has argued for a new approach to rural-urban migration in Canada that draws from the approach used by transnationalism scholars to analyze and understand migration across long distances. This approach takes migration as a process based on long term and enduring relationships, especially within families, that require ongoing attention and that shift in terms of demands over time. It effectively calls for an approach to migration that sees it as part of the biographies of individuals and families.

Our interviews indicate that urban-to-rural caregiving at a distance incorporates many of the characteristics associated with transnational care. These include:

- enduring relationships between family members across the rural-urban divide and over long periods of time following migration,
- the persistence of gendered constructions of care that mean that even when they are far away, daughters and other female relatives are viewed as the most appropriate (“natural”) caregivers, by themselves and others;
- the emergence of care chains between regions,
- the growing use of communication technologies to facilitate care and the monitoring of care.
- Class position affects rural-urban networks but does not alter women’s ongoing responsibility for care

The proposed approach will require policy changes as well as suggesting new areas for research. It demands a different approach to the collection of migration data in Canada that records cyclical migrations, especially those taking place between provinces, and especially those related to care for the elderly (whether it is they or their carer who moves). There is also a need for more research in this area to complement the growing body of scholarship on transnational migration and transnational social processes.

In policy terms, adjustments will need to be made to consider the gender and class implications of existing and new policies. The construction of care as women’s work means that women need better access to flexible work-life policies at work, whether they occupy middle class or working class jobs. Working class women need support in finding ways to meet the demands on them in a context of precarious work where they are vulnerable to firing without notice or explanation.
Finally, policymakers need to ensure that any new migration of racialized minorities into rural regions do not replicate care inequalities that exist in larger cities and in poorer countries.

6. CONCLUSIONS AND RECOMMENDATIONS

This report has been structured to reflect the authors’ foci on different aspects of the issues and policy arenas that overlap in the lives and work of long distance urban to rural caregivers, dispersed family networks connected in caring relations to multiple service agencies and community service organizations. The chapters have each delved into the workings of these different arenas and the everyday work at the ground where issues of policy emerge. Reflecting that approach, our conclusions and recommendations arise out of the arenas explored in each chapter. Joseph pulls from the professional literature and the interviews with caregivers and key informants to suggest a range of policy actions to be taken by employers, governments and interprovincial health authorities. Leach recommends new areas for data gathering and analysis for government and academic research in the area of migration, and that take into account gender and socio economic inequalities. Turner’s recommendations emerge from the intersections where care and housing decisions involve caregivers in ongoing work with homecare and community service organizations. The recommendations acknowledge existing policy information gaps and lack of coherence, particularly the conjunction of housing and continuing care policy research. They note the emerging problems for service organizations only partially funded by provincial ministries of health or social services, and aim to expand the work of policy research to economically viable and fruitful collaborations in these areas.

Conclusions and Recommendations Associated with Section 3

Recommendation 1. Workplaces need to recognize that those who provide eldercare at a distance have unique needs that must be recognized and accommodated in family policies and in practice. The impact of work and family conflict can not be separated into two distinct spheres. It must be recognized that by assisting employees to meet the demands of providing and managing long distance eldercare, workplaces reduce employee stress, increase their well-being and thereby potentially increase the long term loyalty and productivity of their employees.

Recommendation 2. Governments need to scrutinize labour policies to ensure that those who provide eldercare do not face barriers to accessing workplace or government benefits and supports. Policies and initiatives must reflect the same respect for the needs of seniors and their caregivers as there is for caregivers of other family members.

Recommendation 3. Economic supports for long distance caregivers might include long distance telephone subsidies that could also be claimed by the organizations that they work for. Caregiver travel rates and discounts would also assist those who care at a distance.
Recommendation 4. Temporary EI remuneration initiatives and pension top-ups would assist caregivers of the elderly who must leave their jobs when long distance care is no longer sustainable, particularly for those who provide care to rural seniors who live in resource scarce communities.

Recommendation 5. Interprovincial health authorities should be provided with incentives to develop and maintain detailed information resources that will assist out of province caregivers to find eldercare assistance quickly, and make it easier for care recipients and their caregivers to be accommodated in different regions.

Recommendation 6. Policy analysts need to review national data with a regional lens and consider the impacts of social, economic and political factors in policy and service development that will assist long distance care providers who face greater challenges because of the location of their loved one.

Recommendation 7. Government, media and researchers together need to get the message out more clearly that those people who provide care for older Canadians are doing our society an amazing service. The needs of all informal eldercare providers should be recognized, respected, accommodated and rewarded.

Conclusions and Recommendations Associated with Section 4

Work and Income

Financial issues predominated in the housing and care services decision processes of women we interviewed. We talked to caregivers who were self-employed, quit paid work to care give, reduced their working hours, and incurred traveling and other expenses to do care work. The poverty rate for senior women in Canada is almost double that of men – 19.1% in 2003 compared to 10.2% for senior men. (Statistics Canada Table 202-0802 – Cat. No. 75-202-XIE. “Persons in low income before tax, by prevalence in percent.”) Women comprise 60% of the Canadian population over 65 and in 2003 40% of those women were living alone and in poverty.

Recommendation 8. Develop a “drop out” provision in the CPP that allows people who are caring for individuals with disabilities or for the elderly to discount earnings for caregiving. This provision is in place for women who have cared for their child at home for up to seven years.

Recommendation 9. Extend Employment Insurance benefits to the self employed and entrepreneurs, in order for women entrepreneurs in Canada to access EI benefits such as maternity and parental leave or the Compassionate Leave for Caregivers.

Policy Data Gathering on Housing and Informal Caregivers
Two data gaps have been noted by federal and provincial government researchers. Housing and the diverse situations of caregiving families have not been adequately surveyed or examined, and policy development consequently is lacking. In the labour market discourse the phenomenon of “mobile workers” is generally understood. This study has identified that some portion of this mobile workforce is, in fact, “mobile families” whose mobility is often shaped by considerations of housing and care for an aging parent. The data gaps coincide with our increasing aging population and institutional restructuring trends that download care of the aging to families. Studies have been done that link existing institutional arrangements for housing to migration patterns that in turn reinforce cultural biases as well as issues of access and equity (Baha Abu-Laban www.international.metropolis.net.) This focus can be applied to housing for seniors and highlight the differences in municipal capabilities to provide housing options.

**Recommendation 10.** Engage the Canadian Institutes for Health Research (CIHR), Canada Housing and Mortgage Corporation (CMHC); General Social Survey researchers, regional and other associations (e.g. Family Services Association [FSAT] and Social Planning Council [SPC], Toronto) and municipalities, to undertake a collaborative, comprehensive qualitative and quantitative examination of the current data across these areas.

**Recommendation 11.** Commission these groups to assess the potential for government programs to support alternative forms of housing and services where there is most need; ensure the research includes rural and remote areas; ensure the assessments addresses the conjunction of social and economic realities for “mobile families” whose migrations are related to the location of affordable housing, work and services cross provinces and regions.

**Recommendation 12.** While there are proposals to cost the value of caregivers work through the RAI, the criteria for it include that the informal caregiver make formal agreements, be qualified to the same extent as a formal system service provider (now hired by CCACs on contract). This privileges any private orgs that are contracted by CCACs/LHINs to provide services on a lowest cost basis. Mechanisms for equal pay for equal work in homemaking and personal care, that account for experience, need to be developed.

**Recommendation 13.** The cost of caregiver work. I worked through the on-line questionnaire to see if one of our self-employed would qualify for the tax deduction for her caregiving work which takes up much of her time and caused her to postpone working again after the life event of having a baby. The cut off is approximately $17,000. S’s father’s income, which falls short of covering the cost of his home and care by 200 per month (income is $1800 and cost of home and services is $1900), is $21,600. So S is ineligible. The income cutoff needs to be raised so that more people will be eligible.

**Information, Guides, ‘Talk’ Sheets for Electronic or Face-to-Face Guidance**
Canada’s provincial and territorial governments are recognizing the utility of home care services in reducing hospital and other institutional stays and thus reducing costs to the healthcare system. The demand on home care and community based care services will increase as the Canadian population ages.

**Recommendation 14.** Engage federal, provincial/territorial representatives and appropriate FPT mechanisms such as the Health Advisory Councils, Ministers responsible for Seniors, Ministers responsible for the Status of Women and Canadian Caregiver Coalition to develop a national program of ‘front line’ of supports to informal caregivers, including ‘state of the art’ fact sheets that support electronic and face-to-face counseling/training on priority diseases and chronic conditions and legal matters such as POA and the implications of being the substitute decision making for another person.

Informal caregivers are faced with taking on personal care as well as homemaking and medical assistance to loved ones and to provide services that in formal settings are the work of professional nurses, doctors and other professionals. They may be making critical decisions as a substitute decision maker. While recommendations have been addressed by organizations focusing on palliative and end of life situations, it will be necessary to broaden such strategies to dispersed families grappling with identifying and securing the appropriate housing situation and care services for an aging relative/friend.

**Recommendation 15.** Develop strategic information ‘briefs’ for caregivers and service organizations, doctors and hospitals.

Short term:
- Develop and implement package of guides for caregivers addressing issues of housing and service choices and explicating:
  1. community service organizations mandates across provinces
  2. forms of housing assistance by province
  3. forms of services assistance by province
  4. legal considerations of being substitute decision maker (POA for personal care)
  5. procedures and processes of working with ‘access’ organizations
  6. the limits of ‘respite’ arrangements

Medium term:
- engage provincial and territorial government representatives and regional health authorities undertake a comprehensive review of the differences between access and community service organizations in every province and territory, paying special attention to issues of rural and remote regions and resources.

**Recommendation 16.** Conduct an evaluation of the Nova Scotia caregiver strategy as it is being built in Nova Scotia. How to build a caregiver strategy within the provincial structures of home and continuing care is essential to the future working of the Canadian system as a whole and would support Canada’s principles of equal access. It would work towards portability and coherence between provinces.
Conclusions and Recommendations Associated with Section 5

We have argued for a new approach to rural-urban migration in Canada that draws from the approach used by transnationalism scholars to analyze and understand migration across long distances. This approach takes migration as a process based on long term and enduring relationships, especially within families, that require ongoing attention and that shift in terms of demands over time. It effectively calls for an approach to migration that sees it as part of the biographies of individuals and families. Such an approach will require policy changes as well as suggesting new areas for research.

**Recommendation 17.** It demands a different approach to the collection of migration data in Canada that records cyclical migrations, especially those taking place between provinces, and especially those related to care for the elderly (whether it is they or their carer who moves).

**Recommendation 18.** There is also a need for more research in this area to complement the growing body of scholarship on transnational migration and transnational social processes.

**Recommendation 19.** Adjustments will need to be made to account for the gender and class implications of existing and new policies. The construction of care as women’s work means that women need better access to flexible work-life policies at work, whether they occupy middle class or working class jobs. Working class women need support in finding ways to meet the demands on them in a context of precarious work where they are vulnerable to firing without notice or explanation.

**Recommendation 20.** Any new migration of racialized minorities into rural regions does not replicate care inequalities that exist in larger cities and in poorer countries.
APPENDIX 1: ORGANIZATIONS CONTACTED TO ASSIST IN CONTACTING CAREGIVERS

Alzheimer Society of Guelph
Alzheimer’s Society of Hamilton and Halton
Anchors and Sails
Bay St. George Status of Women
Canadian Caregiver Coalition
CANES
Community Care Access Centres (in various communities)
Caregiver line of Newfoundland
CMHC
Family Caregivers Network Society
Family Caregiver Newsmagazine
Guelph Public Library
Homewood Health Centre
Kingston Public Library
Network of Caregiver Projects (care renewal)
Par-L e-mail list
Reaching Out to Caregivers Program (VON)
Social Planning Council of Sudbury
Social Planning Council of Toronto
Solutions Magazine
Sprint – Toronto
Status of Women Canada
St. Joseph’s Outreach Program
Toronto Alzheimer Society
Toronto Family Services
United Steelworkers – Women of Steel
University of Guelph
VON Canada
Women Today of Huron
Zonta International
APPENDIX 2: LIST OF INSTITUTIONAL LOCATIONS OF INTERVIEWEES

Interviews were conducted with the following participants. The list is constructed to indicate the institutional locations of our interviewees. We are interested in where in institutional processes people’s work is located and how it is connected so that the issues for policy emerge from their locations. This is what is of interest in institutional ethnography, rather than actual organization names or position titles of individuals. Consequently issues of confidentiality and anonymity are avoided.

Caregivers across the country

Provincial access agency managers and case managers

Community service organization managers, program coordinators, administrators and case managers

Hospital professionals

Regional health authority consultants

Policy researchers in governments and service associations


Campbell, M.L. 1999. Home support: What we’ve learned about continuity and client choice. Discussion paper, Project Inter-Seed: Learning from the health care experiences of people with disabilities. University of Victoria and South Vancouver Island Resource Centre for Independent Living, Victoria, BC.


Canada, Statistics Canada. 2001. *Population 15 years and over by hours spent providing unpaid care or assistance to seniors, by provinces and territories.*
http://www40.statcan.ca/l01/cst01/famil57a.htm?si=population%20years%20assistance%20seniors%20province.


www.bradonu.ca/rdi/Publications/Thinktankfinalreport.pdf


**Ralston, H. 2005. Identity Construction of Immigrant Mothers and Daughters in**

*Multiracial Local, National and Global Diaspora Space*


