

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 caregivers², 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

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.'⁴ 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

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.⁵

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

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 had 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 taking 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.⁶ 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 our 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 wheel chair 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 of 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 *hotlin*, 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 there 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*

employment that gave them the flexibility and income to support themselves, their families, and their compassionate care work over a long distance with their older family member.

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 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

well. But...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 (aaaf, 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