One Hundred Years of Caregiving

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April 2001

This paper was prepared for the Law Commission of Canada under the title *One Hundred Years of Caregiving.* The views expressed are those of the authors and do not necessarily reflect the views of the Commission. The accuracy of the information contained in the paper is the sole responsibility of the authors.

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EXECUTIVE SUMMARY

Unpaid caregiving today is both the same, and fundamentally different from, such caregiving at the beginning of the twentieth century. The context for care has changed enormously, and along with it, the nature of care.

Canada entered the twentieth century as a producer of raw materials and goods. It ended the century as a producer of services. Rapid urbanization accompanied this transformation, a transformation made possible in part by the development of a welfare state. Especially in the years immediately following the Second World War, the welfare state helped reduce inequality in income, in access to services and in employment as well as in human rights protections. So did unionization and the entry of many more married women into the labour force to do this new service work. At the same time, less discriminatory immigration regulations fundamentally altered the racial and ethnic composition of the country. Smaller, more mobile families, with fewer children and more often involving a divorce, reflected changes in the economy, in access to birth control and divorce, and rising female labour force participation. Common-law relationships and openly gay or lesbian relationships became much more common.

Formal health care services expanded rapidly and became widely accessible through public intervention. Along with improved nutrition, housing, income, sanitary and employment conditions, these developments meant both that more people survived with a disability and that more people lived into old age. Some new diseases, such as Alzheimer’s and HIV/AIDS, emerged just as many infectious diseases disappeared. New technologies, combined with health care reforms focused on deinstitutionalization and cost-cutting, not only increased enormously the number of people cared for in households but also transformed the nature of the care provided. Although most women and men are in the labour force (and for the same reasons) and most children are in school, the care demands on households have both grown significantly and taken on new dimensions as highly complex care is transferred to the home. There is much more diversity in the demands for unpaid care and in the household resources available to meet these demands. At the same time, cutbacks in the welfare state are now reducing or eliminating other supports such as public housing, transportation and employment protections. This, in turn, increases the inequality in access to services and supports. In spite of these massive changes, some things have remained much the same. Unpaid care is still primarily women's work, especially in terms of the most personal and time-consuming aspects. And families and friends are still willing to provide all the support they can, even to the detriment of their own health and personal relationships. Laws still require children to support their parents and spouses to support each other, although it is not clear if this extends to health care services and the laws are seldom invoked. Then, like now, the great diversity in family forms and resources meant very different capacities for care. Volunteers and private-non profit organizations continue to work in partnership with governments to provide supports. But they, too, are increasingly overwhelmed by the work, just as they were at the beginning of the last century. And once again, much like a hundred years ago, governments are raising concerns about an aging population straining public resources and blaming families for failing to take responsibility for their care.

Throughout the century, families and friends, volunteers and strangers have participated in unpaid caregiving, often finding this a rewarding experience. But the rewards are few if the relationship is one of coercion or without supports and relief. Indeed, caregiver burden may mean poor health for the caregiver, poor care for the care recipient and highly strained personal relationships.

What is necessary is the creation of the conditions for voluntary and skilled care. This means asking the following questions of all policy, legislation and regulations:

1. Is caregiving and care receiving voluntary?
2. Can caregiving be equally shared among women and men?

3. Can caregiving be culturally sensitive without making inappropriate assumptions about cultural groups and without contravening other equity principles?

4. Can the assumptions made about personal relationships related to caregiving be justified?

5. Is there recognition of the different interests that need to be balanced in caregiving?

6. Is need defined in ways that exclude some groups while privileging or stigmatizing others?

7. What are the long term consequences?

8. Are the objectives reinforced or undermined by other legislation, regulations or policy?

9. Are the contributions of care recipients recognized and the skills required for giving care acknowledged?

10. Are current patterns themselves constructs of policy or does policy reflect actual preferences and practices?

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I. INTRODUCTION

Caregiving is not a simple act but rather a complex social relationship -- one embedded in personal histories and located within specific conditions. These relationships can be found throughout our society and in a multitude of forms. Caregiving exists within health care institutions and in hostels, in households and on the street. Where it happens, and with whom, changes over time and with place, even for the same individuals. Partners and friends, mothers and fathers, daughters and sons, relatives and strangers, old and young participate in caregiving, although there are clear patterns linked to gender, age, and social circumstance.

This paper focuses on what is often called informal caregiving. Such care is usually unpaid, done with little formal training and based on an existing relationship. Yet even the distinction between formal and informal care is far from simple. Some relatives are paid for such informal care; some begin as strangers; many have become quite skilled at caregiving and share the job with those who are part of the formal system.

To help sort through this complexity, the paper begins with a discussion of the diversity in caregiving relationships. It then moves on to consider what changed and did not change significantly in these relationships throughout the twentieth century. On the basis of this exploration of history and diversity, the final sections set out a framework for assessing legislation, regulations and policy that influence caregiving among adults.

II. RECOGNIZING CAREGIVING IN ALL ITS DIVERSITY

A. What Is Involved in Caregiving?

Caregiving among adults comes in an incredible variety of forms. The following stories, based on actual personal histories, convey only some of the variety in caregiving relationships, only some of the complexity and only some of the forms caregiving takes.

Marie and her partner Louise live with Louise's mother Monique. Monique has severe bronchial problems that require considerable medical attention and treatments she cannot manage on her own. She cannot be left alone either. Working for the government and covered by a union contract, Marie does have the right to some care time and she would be happy to use it to stay with Monique, a woman whose company she thoroughly enjoys. It is not entirely clear, however, that this right extends to her partner's mother. Marie has already told her employer that she must leave at 5 each day so Louise can go to her job. This is her right under the contract, but she may well be jeopardizing her chances for promotion by doing so. She would very much like to be able to transfer some of her benefits to Louise, who has no such rights at her workplace and who has to work odd hours in order to accommodate her care work and meet her economic needs. As the primary caregivers, Marie and Louise recognize that they need a break from their double days and do this by ensuring that each year they take a two week vacation away. Their incomes allow this, but not paid replacements. To go away means arranging with some 7 friends and relatives to replace them while they are gone.

Himani and Wassem had twenty years of satisfying marriage before their son Paresh started acting in disturbing ways. In the three years it took to get a diagnosis of schizophrenia, their marriage fell apart. Himani was left to care for their adult son alone and with little income. Many days with Paresh are fine, even fun. But now when Himani sees the signs she has learned indicate a bad period ahead, she often cannot get the help she needs from the formal system. For her, this means facing a sometimes violent episode without assistance.

Once a week, Katherine picks up her friend Laura and goes with her to the breast cancer support group. Laura's husband is away during the week, and in any case does not see what use he would be in such a place. Unlike Laura's professional colleagues, Katherine is an actress who has time during the day to spend with her friend. On the way into the clinic, Katherine often meets another actor taking someone to the HIV/AIDS clinic across the road. Organized by the gay community, the volunteers not only offer transport but also provide the kind of information necessary to access services and manage care.

Roberto had turned 84 the day he had to struggle up the stairs with his wife Maria. Maria's surgery had failed to solve her problem and she had come home to die. Frail himself, he was determined to provide her with the kind of care she had so often provided for him. With most of his relatives back in Italy, he had to do as much as he could himself, especially with the boys so far away and caring for their own families. Homecare helped, but not for many long hours in the day and Maria did not like the food they cooked. He still had to bath, feed, dress and toilet her when they were gone.

Sam and Marcia learned quite soon after their baby was born that she had severe disabilities which would undermine her development. Sarah required total, and specialized care, 24 hours a day. Both parents need their paid jobs in order to survive economically, especially with the extra costs created by their daughter's care needs. They manage because they found an excellent residential care facility that provides skilled and comforting care during the week. They visit Sarah regularly during the week and bring her home on the weekends. But the government is constantly threatening their funding; so much of their time is taken up with pleading for public support. This precarious support is a constant strain, one that puts enormous stress on their relationship.

The forms of care can be thought of as falling into four broad, overlapping categories. The most pervasive form is the management of care.[1] Almost all caregivers are involved in care management, but some caregivers are primarily managers. They find out about, and arrange for, formal services as well as ensure that the formal services are received. They act like case managers, determining hours of service and eligibility, making appointments and convincing care recipients to participate. They mediate between care recipients and paid care providers, and advocate on behalf of recipients for care inside or outside the home. This organization of care not only involves negotiation among paid providers and with the care recipient; it also involves negotiations among informal providers. Managing money, providing financial assistance, completing forms, assembling documents and organizing test results are all part of care management. Equally important, care management usually requires decision-making, often without the active participation of the person needing care. Each aspect of organizing care may involve conflicts; conflicts among formal and informal providers, conflicts between the groups and conflicts among any of the providers and the care recipient. This organization also requires cooperation among all of these participants and needs to be done even for people living in institutional settings. The need for such "orchestration of care", bureaucratic management and financial assistance[2] varies over time, with illness and in relation to the availability of public support and services.

Another common form of caregiving involves what are in the literature on caregiving called Instrumental Activities of Daily Living (IADL). When people become ill, have day surgery, are released early from hospital, have more long-term disabilities or simply become frailer with old age, they require assistance with cooking, shopping, cleaning, laundry, and home maintenance tasks. They may also need help getting around, within and outside the house. People may require assistance with only some of these tasks, or with all of them. Residential care reduces the need for most, but not all, of this support.

Some people require more than assistance with figuring out which services to use or with daily survival in their homes. They need direct help with much more personal and more medical aspects of care. This third form of care is referred to as assistance with the Activities of Daily Living (ADL), and includes dressing, bathing, eating, using the toilet, brushing their teeth and combing their hair. It also includes taking medications, inserting needles and using a variety of equipment such as catheters, oxygen masks and feeding tubes. Here, too, residential care fills much of the need but still must be supplemented by informal caregivers in many cases.

Finally, there is the form of care that should pervade all the others but may also exist on its own. Everyone requires social and emotional support. But those who have undergone surgery, live with disabilities or live into frail old age have particular needs for companionship, for touch, for listeners and talkers and for comfort of all sorts, especially if they are not able to leave their home or institution. The need is particularly great in the case of palliative care. Caregivers may be engaged in only one of these forms, but many provide all four forms of care.

B. What Care is Provided?

What care is provided depends on a range, and mix, of factors. Government policies play a critical role in what care is provided, especially in terms of formal services. The *Canada Health Act* requires that all medically necessary care provided by a doctor or hospital be offered to Canadian residents without charge and in an accessible manner. As care moves outside these boundaries, however, there is no national standard for formal, public care. This is why the National Forum on Health, a group appointed by Prime Minister Chretien to advise on health policy, recommended national homecare and pharmacare programs.[3] The Forum had little to say about long-term care facilities, although they too are largely outside the *Canada Health Act.*

Given that health care is primarily a provincial responsibility and that many of the services required in relation to informal caregiving are not included in the *Canada Health Act*, there are significant provincial variations in the supports available to informal caregivers and recipients. In terms of homecare, provinces provide professional services such as nursing and physiotherapy without charge but many provinces charge user fees for homemaking, personal care, housecleaning or transportation. Some provide supplies and equipment without cost while others charge; some cover required medications while others do not. Some have extensive provisions for respite care while others provide very limited access. There is also considerable variation in eligibility rules and in the limits placed on services, creating even greater differences in supports available.[4]

Ontario, for example, has established maximums of “80 hours of homemaking services per month for the first month; and 60 hours thereafter” and 4 nursing visits per day as maximums regardless of need[5], and has introduced user fees for drugs purchased under the public plans for the elderly, the disabled and those on welfare. By contrast, B.C.’s policy is to make community nursing “available 7 days a week, 24 hours a day” and home support services have a maximum of 120 hours per month, although more can be provided if a supervisor approves the additional hours.[6] Moreover, B.C. has a universal pharmacare program and no or low user fees for particular groups.[7] Access to institutional facilities also differs somewhat across provinces. While only 1% of Canadians live in such facilities[8], the eligibility requirements, the location, the number of beds available, the nature of the services provided and the fees charged vary in ways that limit options for those care givers and care recipients who need such services.

Government policies on direct and indirect financial support also influence the care provided. Direct financial support for care providers is quite limited and equally varied. For the decade between 1984 and 1994, Nova Scotia provided compensation to caregivers, most of whom were young females in rural areas. This means-tested program paid considerably less than minimum wage for quite heavy workloads, and primarily served to reinforce caregiving as undervalued women's work.[9] Quebec now provides up to $600 to caregivers to purchase respite care, again based on a means-tested system. Most provincial financial support, however, comes indirectly through the tax system for deductions related to medical expenses, attendant allowances, and disability. Since 1998, the Federal Government has offered the Caregiver Tax Credit. This allows those who live with, and care for an elderly relative to claim up to $400, if the claimant's annual income is less than $13,853.[10] These deductions and credits mean little to the many low income women who provide care, given that they have little income from which to deduct the taxes and that they may have "to absorb the cost of additional caregiving services before being eligible for reimbursements".[11] There is, however, little research on the impact of direct financial compensation programmes on care givers or recipients.[12]

Access to formal services and other government financial supports for caregivers are clearly important to both care providers and care recipients. Yet, contrary to much popular discussion, the availability of care does not automatically mean less informal care is provided. Indeed, study after study demonstrates that between 85% and 90% of care is provided informally.[13] Even these figures may understate the amount of informal care provided, given that "it is probably also the case that a lot more help is exchanged in families than is ever reported in surveys because people do not consciously think about what they are doing in providing help."[14] This is particularly the case for women who may see their caregiving work as a simple extension of usual practices. As a variety of researchers explain, for women, caring about someone very often is equated with caring for them and the work as well as the skill of care becomes invisible in the process.[15]

Informal and formal care are complementary rather than alternative forms of support.[16] Instead of replacing informal caregivers, formal services are more likely to fill in when there are no informal caregivers or to provide some services that are supplemental to informal care.[17] As a study conducted for Statistics Canada concludes, "the informal network operates in concert with the formal delivery system"[18] and the availability of formal services does not mean families and friends shirk their responsibilities. Nor does access to formal services mean people rush to use them. The overwhelming majority of health problems are managed through self-care. And "most people who consult a physician have tried treating themselves before seeking medical advice".[19] This is especially the case for women.

In addition to providing formal services, governments also influence the care provided through employment regulations. No jurisdiction requires employers to provide 'caregiver leave'. However some employment or labour standards legislation allow short-term and unpaid leave.[20] While most collective agreements simply reflect the statutory emphasis on parental, sick and bereavement leave, some include additional leave provisions for those with disabilities and for personal reasons. The Public Service Alliance of Canada, for example, has negotiated leave with pay for family related responsibilities. In this case, family is broadly defined to include not only spouses and common-law partners but also any of the children dependent on them. Parents as well as stepparents or foster parents are considered family and so are any relatives permanently residing in the employee's household or with whom the employee resides. The paid leave is only for a maximum of 5 days, although leave without pay is allowed for long term care of a parent for up to 5 years.[21]

Physical location also influences what care is provided, in part because formal services vary within provinces. Urban populations often have better access to care supports than do rural ones. "Poor quality housing and insufficient health and social services characterize many rural communities. Distance makes access to services more difficult and adversely affects rural women's ability to provide care."[22] Declining employment opportunities in rural areas, combined with health care reforms, mean fewer resources for increasing needs. This, in turn, means greater inequality in coping ability.[23] Native communities in particular frequently lack formal, community based services.[24]

Similarly, those living in large urban centers are more likely to find services that respond to their particular cultural or religious practices. For example, concentrated populations mean urban Japanese Canadians can access some culturally sensitive programs. Such access can affect whether or not they use formal services at all, regardless of need, and may matter as much as quality and location in seeking care.[25]

Physical location also matters in terms of informal caregiving. The further away friends, relatives and volunteers are, the more difficult it is to provide direct personal care. Children move away for education or employment; people immigrate, leaving their relatives behind. Nevertheless, many people do provide care-at-a-distance, especially care that is of the management sort.[26] Or they move themselves or others in order to give care. In 1996, nearly half a million Canadians moved to give or receive care. The majority of those who moved were married, more than a third had children under the age of 15 and had paid work. Those who move, then, have a range of caregiving responsibilities. While daughters are the most likely to make such moves, a significant proportion are friends (18%) or other relatives.[27] Living arrangements do not play a central role in emotional support, and may be provided in person, by telephone, e-mail or letter from anywhere. But living with someone may be the major determinant of help with activities of daily living; even more important than a marital or blood relationship.[28]

Social location matters at least as much as physical location in terms of what care is provided. Being a mother, a daughter or a spouse is critical, because daughters and mothers are the most common primary caregivers, followed by spouses, friends and volunteers.[29] We have little Canadian information on caregiving among same-sex couples or singles, but we do know that the gay and lesbian communities have formed support organizations and care services, especially for those suffering from HIV/AIDS.[30]

Gender and income also have a profound influence on what care is provided. According to a recent study, “Women family members were expected to supplement home care services without pay and at great personal expense in terms of their own health, incomes, benefits, career development and pension accumulation, while men were not under as much pressure to do so.”[31] Financial costs were picked up by recipients and families; those without money do without and those who were poor or isolated fare worst of all. Deinstitutionalization, early discharge, day surgery and cutbacks in public health services all shift more care work and care costs onto individuals and families, and especially onto women. The more care is privatized, the more poor cannot afford care. Those without homes or relatives are particularly at risk of not receiving care.[32]

Finally, the needs of the person receiving care are a critical component in what care is provided. Those who are expected to recover after day surgery or early discharge from a hospital place high, immediate demands on caregivers for assistance in the full range of caregiving activities. Patients recovering from cardiac surgery, for example, require monitoring for their heart rate, for infection and for wound healing; they need reassurance and comfort, as well as help in eating, bathing, going to the toilet, keeping the house in order and in managing their diet and exercise program.[33] However, these demands are expected to diminish over time until eventually care is no longer required. The situation is quite different for someone suffering from Alzheimer’s or Multiple Sclerosis. Care needs can only increase with time and last until death.

Care varies as well with the stage of an illness. Initially cancer care may mainly involve management and emotional support. During and after treatment it may require the full range of care forms. If the cancer is successfully treated, the need for all but emotional and social support may disappear. But if the treatment fails, then care needs gradually, or perhaps quite quickly, increase, ending over a relatively short term in death.

Chronic diseases too have stages that create varying needs for care. Multiple Sclerosis, for instance, may go into remission, allowing a person to live relatively independently for long periods. Arthritis and rheumatism may mean that only heavy housework and house maintenance are a problem for a long time, with more needs appearing over time. Stroke patients may fully recover after temporary severe disability, or become quite dependent for the rest of their lives.[34]

Some chronic diseases and disabilities, however, exist from birth and mean that life is only possible with the provision of the full range of care, or with one form of care throughout life.[35] Others may become paraplegic suddenly as a result of an accident. Care throughout life, or for most of it, is not uncommon. Of the 53 women interviewed for a study of rural caregivers, 5 had been caregiving for more than 20 years and one had been doing so for 35 years. Such caregivers provide care "all the time", often with little support from the formal system.[36]

In short, what unpaid care is provided depends on government policies and on the health issue, as well as on physical and social location. Formal care does not substitute for informal care. Rather, most care is informal or self-care and formal services supplement them.

C. Who Needs Care?

The short answer to the "Who needs care?" question is "Everyone" at some time in their lives. The surprising answer is not necessarily seniors. According to a recent study based on Statistics Canada data, "when it comes to receiving assistance from others, similar proportions of seniors and non-seniors received assistance. And across age groups, only a minority reported that they received no assistance."[37] Another Statistics Canada report describes seniors as a diverse group that is aging well.[38] More than nine out of ten seniors live in a private household, and although over half say they get some help with household chores and personal tasks, half also say that they provide care to others.[39] In other words, care is for many seniors an exchange of services. Nevertheless, a significant number of seniors do need care. Of the 30% who required health-related personal assistance, three out of four needed assistance with daily living activities and a quarter required extensive personal care. Women were not only more likely to need care but also more likely to have those needs go unmet. The lower the income and education, the greater the unmet need. And living alone also meant that the necessary care was less likely to be provided.[40] While most of this care is provided by informal caregivers, losing a partner is a major factor in entry into the use of formal homecare services.[41]

The number of people with long-term disabilities is also growing. Like seniors, they are a diverse group. Their disabilities may be physical, mental or intellectual, or a combination of these. These disabilities may be life long, result from a particular event or develop with age. The disability may mean only one form of care is required or it may mean the entire array of supports is necessary, during one period or throughout life.[42] Take those with an intellectual disability, for example. Better care and better conditions for health mean that only now are many people with intellectual disabilities living to grow old. Many were placed in institutions, but in recent years have moved into communities where they may no longer have family connections, or their families feel hesitation about taking on their care and guilt about placing them in an institution.[43]

Shorter term, but often more intense care is required by those with terminal illnesses and by those released early from hospital or undergoing day surgery. The increased demand for care after early release from hospital or day surgery strains existing community resources, often leaving the frail elderly who have been receiving care without much formal assistance.[44] Palliative care services are beginning to appear both as formal residential services and as support for informal caregivers in the home.

D. Who Provides Care?

The clear answer to the "Who provides" question is women. As daughters, mothers, partners, friends, or as volunteers, women are the overwhelming majority of unpaid primary caregivers and spend more time than men in providing care. Women are much more likely than men to do personal care and offer emotional support. Men's contributions are more likely to be concentrated in care management or household maintenance, shopping or transportation.[45] In other words, women are more likely to provide the care that is daily and inflexible while men provide care that can be more easily planned and organized around paid work.[46] And men are more likely than women to get formal help when they do provide care, on the assumptions that they must have paid jobs and that they lack the skills necessary to provide care.[47] Yet women provide personal care even when they have paid jobs, although higher income women may be able to become more care managers than care providers.[48] The little research that has been done about differences among women caregivers suggests that income and education matter at least as much as culture in terms of the kinds and amounts of care provided.[49] While most women want to provide various kinds of informal care, they do not want to be "conscripted" into this relationship.[50] And the poorer women are, regardless of their culture, the more likely they are to have little choice about providing care.[51]

Some men have, and continue, to provide the full range of care forms. Like women, they care for their spouses. However, fewer men are called on for such care because their wives usually outlive them, given women's greater longevity and the pattern of men marrying women significantly younger than themselves. Men care for their parents too, providing up to a quarter of the care.[52] Men also care for their same sex partners, and serve as volunteers who manage care, provide transport and support, deliver meals and do household chores.[53] And like women, men may provide care to siblings, in-laws or other relatives.[54]

Friends also provide considerable caregiving, although we know less about them than we do about the spouses, mothers and children who are caregivers. A Statistics Canada study found that nearly one in five of those who had moved in order to provide care were friends, rather than relatives, suggesting that friends do much more than offer the occasional visit.[55]

We know even less about differences among caregivers related to culture. The research that does exist does not indicate major differences in the provision of care but some in the stated commitment to care. For example, Japanese Canadians express a high commitment to filial obligation. This is reflected in the provision of emotional support but not in support through financial or other services.[56] Some cultural groups are also much more likely than others to live in households that hold several generations, suggesting cross-generational caregiving. But this is not necessarily the case. While for example East Indian immigrants tend to live in multi-generational households, it is important not to assume that this, like the lower use of formal services, simply indicates cultural choices. This pattern may be as much about immigration regulations requiring support for sponsored relatives and limited economic resources as it is about preference.[57] That Chinese, Greek and Italian elderly are less likely to live alone than are other Canadians may reflect low incomes, lack of pensions and immigration rules as much as cultural values.[58] Similarly, the fact that Native seniors are much more likely to live with relatives than are other Canadians may reflect poverty as much as choice or values.[59]

Like sponsored immigrants, spouses face rules governing support. The rules are fairly clear in terms of financial support, but less clear when it comes to providing direct care services. It is not evident that spousal support means you could take your partner to court to demand they change your diapers, insert your catheter or attach your oxygen mask. Certainly many of the policies and regulations in health care assume such support, especially from women, and enforce it through a failure to provide alternatives or through regulations. In Ontario, for example, government guidelines for in-home services say that people are not eligible for services until they have exhausted the support capacities of their family and friends and without regard to whether the caregivers are employed or not.[60] Who constitutes a family for the purposes of providing such care, however, is not clear even in the regulations.

Children also can face legal obligations for support of their parents. These filial responsibility laws require children to provide support if parents need support, have supported the children in the past and if the children can afford to provide support.[61] Sons are more likely, given higher work wages, to be able to afford financial assistance. It is perhaps not surprising that these laws are seldom used, in part, because many sons do support their parents when they can, just as spouses and same-sex couples and friends do. When they cannot or when they reject their responsibility, the enforcement of these filial laws can undermine family relationships.[62]

Employees also have legal obligations; ones that may prevent rather than promote caregiving. One in four employees provide care, and a large proportion of care providers is employed.[63] Not surprisingly, those with both eldercare and childcare responsibilities, most of whom are women, are the most likely to lose time at work as a result of caregiving.[64] The very limited leave allowed for such care, combined with very few protections from being fired when caregiver stress leads to missed time at their paid jobs, mean that caregivers are very vulnerable at work. Those who care for people unrelated by blood or marriage may be particularly at risk.

III. CARE AND CONSEQUENCES

Although caregiving and care receiving are about relationships, much of the research on the impact of caregiving has focused on the negative consequences for providers and viewed care recipients as objects rather than as participatory subjects. Not surprisingly, caregiver burden is a common theme in the literature.

There are many, and varied, aspects to this burden. Rural women who provide care describe feeling frustrated, especially with the repetitiveness of the tasks, and the problem of dealing with the frustration of the care recipient.65 They have to convince their husbands to allow them to bathe them and, like others who care for younger adults with severe physical disabilities, describe the "difficult and potentially hazardous situations resulting from a combination of the weight of the person being bathed and the lack of strength of both parties."[66] Lack of training for what is highly skilled caregiving also creates additional stress on relationships. For many caregivers, the most emotionally upsetting activities are those related to bladder and bowel management, in part because they are such intimate tasks. Male caregivers found bathing their wives disturbing for similar reasons.[67] Rural caregivers feel ineffective in dealing with mood swings of the care recipient and with their own guilt, guilt about being healthy, guilt about not understanding the illness and guilt about not making the right choices for the care recipient.[68] Such guilt is widely shared among caregivers, especially by the women who provide most of the care. This guilt may be compounded by their role as sole confidante and decision-maker and by cultural pressures.[69] Caregivers who move to provide care, like those who live-in or close-by, report changes in their sleep patterns, a decline in overall health, depression, a reduction in their social activities and holidays, and extra expenses.[70] A study of caregivers for those with Parkinson's suggests that the strain is greater the closer the caregiver is to the recipient.[71] In other words, loving the recipient may make it harder to care.

Stress of all sorts is a recurring theme, as is family conflicts over who provides care and what kind of care is required. Conflicts may also arise between informal and formal caregivers, over what care should be provided and how it should be provided. Moreover, shifting care to homes means that formal services invade the household and "boundaries separating these domains" are continually crossed, creating greater strain on the entire household.[72] New policy initiatives urge partnerships between families and paid providers, but this may well be more an exploitative relationship than a partnership one, especially if the primary purpose is the reduction of public expenditure. In the partnership, "most family caregivers were left socially isolated without adequate resources to provide care. Intentionally or not, holding family caregivers accountable for the provision of care without adequate resources is completely unacceptable."[73] Indeed, these researchers, on nurse/family relationships warn that "failure to provide resources to help family members provide care could risk even further increases in health costs, as injuries or illness" result for caregivers.[74] Moreover, "failure to provide resources to help family members provide care could risk even further increases in health care costs, as injuries or illnesses of the elder and/or family caregiver ensue."[75] Privacy is reduced for the entire household and for their relationships. Even before the most recent cutbacks in services, research indicated that caregivers have higher rates of affective and anxiety disorders that noncaregivers and use mental health services twice as much.[76] Caregivers for people with dementia are particularly at risk, and among those, people whose first language is neither English nor French are especially fragile.[77] Immigrants may feel particularly isolated and limited in their access to services that meet their needs.[78] This may contribute to depression, with those who have no outside help suffering the most.[79]

Caregiving can mean career interruption, time lost from work, financial loss and, especially for women, even job loss.[80] Indeed, women feel much greater tension than men, between their caregiving and their paid work, and between their caregiving and other family responsibilities. This is not surprising, given that women do more of the personal care and domestic work.[81] For both women and men, the consequences of such interruptions can be felt far into the future in terms of low pensions and benefits in their own old age.

Although friends and volunteers provide considerable caregiving, virtually all of this caregiving burden research has been done on relatives, especially on the mothers, wives and daughters who do the majority of the care. This lack of research may not simply reflect a failure to recognize their contribution, however. It may also reflect the fact that friends and volunteers have more choice about where and when they provide care, as well as about what care they provide. There is also a lack of research on same-sex partners, but there is little reason to believe the burden would be lighter for them.

There is considerable discussion in the literature about the subjective factors, such as negative attitudes and cultural values towards caregiving that influence the impact on the caregiver. However, "a belief one is ill-equipped to meet the demands of caregiving may not be unrealistic. Economic factors, a lack of instrumental support or caregiver illness may greatly impede one's ability to cope and may thus be a realistic, objective perception."[82] In other words, caregivers may perceive a burden because there is one. This is especially the case for those who must provide long-term and constant care.[83]

It should be emphasized, however, that caregiving also has rewards. Caregivers experience warmth and satisfaction; they get joy from helping others and often feel rewarded through the personal interaction and the very real support they often receive in return.[84] Yet, like most human relationships, caregivers' experiences are contradictory.[85] Resentment, stress, frustration and ill health too often occur along with the good parts, and are most likely to occur in the absence of support, relief and choice. The strain is too often manifested as abuse[86], not only of the elderly but also of the disabled whatever their age. Older people with intellectual disabilities may be doubly disadvantaged by prejudice against both the elderly and the disabled. Support groups, while often offered as an inexpensive way to relieve the burden of caregiving, have little impact, especially in the absence of other, more material supports.[87]

What about the burden on care recipients? We know less about this burden or about their views on the relationship. What we do know suggests they too have burdens in addition to those caused by their physical or mental problems or both, especially when their low incomes and cutbacks in services eliminate choices about care. Care receivers may be placed in a position of “compulsory acquiescence”; not primarily by their informal care providers but rather by the public system’s failure to offer them choices.[88] Elderly women experience conflicts between their need for support and the expectation of self-sufficiency, as well as between the media panic over the costs of an aging population and the system’s failure to recognize the specificity of their individual needs.[89] Seeking to maintain reciprocity and their pride, these women feel the strain of limiting their demands and the strain within their relationships.[90] Like caregivers, they experience guilt and frustration.[91] On the other hand, having a partner can make a significant difference, even in ill health. Indeed, “married seniors in poor health enjoy a high level of emotional support and are just as socially engaged as those in good health”.[92] It seems likely this is the case with couples or others who are not married but who have enjoyed a long life together. As is the case with caregivers, there appear to be significant differences in the burdens felt by women and men. “Female respondents described feeling guilty when their husbands did laundry and prepared meals if they had never been involved in these tasks before.” At the same time, these women with osteoarthritis or osteoporosis defined help from spouses with mobility, at home or in the community, as simply part of the relationship. Men, on the other hand, did not usually see help from a spouse with such household tasks or with personal care as dependence.[93]

In sum, caring is about complex relationships that take a wide variety of forms. These relationships are shaped not simply by individuals, their culture and their personal histories but also by the services, supports and alternatives available to them. The focus in recent research has been on the caregiver in part because the conditions for caregiving are changing significantly, and changing in ways that make caregiving more difficult and varied. “Those with more resources, by virtue of class, race or age, will be better able to offset the costs of caring, whether by purchasing private help or by being able to negotiate public resources from a more privileged position”.94 And those in stable relationships supported by adequate income and services are in the best position to give and receive care.

IV. THE CONTEXT FOR CAREGIVING: ONE HUNDRED YEARS

Context matters. The context shapes the possibilities for caregiving, setting the stage for patterns in care. Much of the discussion about caregiving, however, is based on myths about the past and present. Such myths often distort our assessment of legislative, regulatory and policy options, so it is important to look at what has changed and what has not changed much over the last hundred years.

A. What Has Not Changed Significantly Over the Last Hundred Years

Neither government fears that families will shirk their responsibilities for care nor fears of an aging population are new, although neither fear has much justification. One hundred years ago the majority of elderly lived in private households and were listed as family heads or spouses of family heads, indicating relative economic and social self-sufficiency.[95] This is still the case today, with most of the aged living with spouses and only a minority listed as dependent on others. Over 90% of seniors now live in a private household, most with their immediate family.[96] At the same time, living in extended families is not uncommon today. Indeed, the number of three generation households increased in the last decade of the twentieth century, with half of them headed by immigrants and 40% including someone with some disability.[97]

Like today, many adult children continued to live with their parents because they could not find paid work that would support them in living independent lives.[98] It was in rural areas that the old were most likely to live with their children while overcrowding and poverty in urban areas made co-residency much less likely.[99] Although this co-residence may well mean that adult children are providing some care for their elderly parents, it also often means they themselves receive support. In both periods, women without spouses were more likely than men to live with their children because they did not have enough income to live on their own.[100] Such women were likely to be contributing members of the household, especially in rural areas, and not simply dependent care recipients.[101]

Even though the elderly were and are mainly self-sufficient, concern about the costs of an aging population are recurring themes throughout the century. The end of the nineteenth century, like the end of the twentieth, saw the “rapid increase in demand for institutional accommodation for the province’s aged population during a period of fiscal restraint"[102] while governments blamed families for shirking responsibilities. A century ago, 3% of the elderly and of those with disabilities lived in institutions while about 1% does so today.[103]

The government response then, like today, was to restrict admission to institutions and argue that care was a family obligation. Then, like now, some families were not able or willing to provide support and providing support often caused conflicts within families. The recognition of such conflicts can be found historically in the “elaborate provisions in wills and maintenance agreements” obliging support.[104] Similarly, filial laws first introduced in Quebec in 1866 indicate that children did not always support their parents in their old age, although the limited cases of actual enforcement of these laws suggest either that most children provided support or that parents were unwilling to force the case.[105] Governments also began, as early as 1906, to discuss pensions for the elderly and other forms of support for the disabled because many of the elderly and disabled did not have families providing care.[106]

Although there is considerable evidence that support for those needing care has long been recognized as a collective and public responsibility,[107] there is even stronger evidence indicating state commitment to and enforcement of family responsibility.[108] Yet in both periods, there is little evidence to support the claim that many families abandon their responsibilities for the elderly and the younger disabled or that age alone creates dependency. Most families then and now care for their kin. Marriage vows once involved spouses promising to love, honour and obey in sickness and in health, and this is still the expectation today whether or not such vows are involved. Equally important, concerns about an aging population are not new and such concerns persist even in the face of evidence indicating that the overwhelming majority of the elderly do not rely on the state for care. Indeed, many of the elderly themselves provide care in ways that relieve the state of care costs.

Charities and volunteers have not abandoned their responsibilities during the twentieth century either. At the end of the nineteenth century, governments like the one in Ontario “came to accept a great deal of responsibility for the care of the ill, the insane, the destitute, and the dependent aged”.[109] At the same time, much of this care was provided through the funding of charitable or lay organizations. This is still the case today. Canadians also continue to volunteer in large numbers, through both formal and informal networks to deliver food and to transport people to care services, to provide information, to visit, to offer personal support and care.[110] “One-fifth of caregivers were neighbours and friends, evidence that the caring society also reaches beyond family obligations”.[111] Moreover, volunteers are now doing a considerable amount of caregiving that would otherwise be done by paid workers, “transformed into wageless workers with less control over their caring work”.[112]

The notion that families and charities provided all the care desired, and did so well, is often linked to the notion of everyone living in large, rural households based on a heterosexual couple still with the same partner they married in their teens. Yet households were much more diverse than that. Women and men often waited until they had the economic resources to marry and a significant number never married at all. Death from childbirth, from injury, from infectious diseases and other illnesses meant that many heterosexual couples found themselves widowed early. Remarriage, and along with it the blending of households, was common. While the law made divorce difficult to get, desertion was not uncommon and there is every reason to believe that the deserters and deserted later took up residence with others, usually without the benefit of marriage. Nor was it unknown for friends to live together. What is unknown is how many of these friends were also sexual partners. Urban households, especially those that were not affluent, tended to be quite small.[113] Urban household were also much more likely to contain recent immigrants who usually occupied areas of the city recently abandoned by other immigrants only to be replaced themselves by the next wave of immigration.[114] In some areas, such as British Columbia, there were far more men than women and the men often looked after and lived with each other.[115] In other areas, like Paris Ontario, women formed the primary labour force and provided important support networks for each other.[116]

Nor can it be assumed that all families were based on a mother at home, with time to care for others while father earned the bread needed by the entire household. In rural areas, most women worked hard in production on the farm and had little spare time for caregiving. In urban areas, many men did not earn enough to support the family and the entire household entered the labour force. For those who were not married, paid work was often the only option. However, that paid work frequently involved providing care in someone else's home. In fact, the household with a male breadwinner earning enough income to support the family and with a woman who had enough time to provide care was a dominant family form only for a brief period following the Second World War. It was a form made possible both by high, secure and well-paid male employment and by a welfare state that offered not only considerable support but also a redistribution of economic resources.[117]

B. What has Changed Significantly over the Last Hundred Years?

While there are very similar patterns in some areas over the last century, there are also some quite radical differences that create different conditions and demands for care.

One of the most obvious changes is health. Better nutrition, transportation, working and housing conditions, along with more formal education, have all contributed to better health. At the beginning of the twentieth century, Canadians were not generally in good health and even the Sickness Survey of 1950-51 showed that "Canadians were not a healthy people".[118] Relatively secure employment and decent wages for many men and some women made an important difference to the health not only of the men but also of those who were largely dependent on them. So did the welfare state. Much of the planning in the aftermath of World War Two was based on the assumption that "organized provision will be made in the post-war world for the risks and contingencies of family life that are beyond the capacity of most of them to finance adequately from their own resources".[119]

Under the welfare state, income tax was changed to make those with higher incomes pay a greater share. This progressive taxation strategy contributed to redistribution of resources. Labour standards legislation and worker's compensation protected many workers, as did unemployment insurance, maternity leave and both public and private job-related pension schemes. Unionization became easier and more effective in gaining rights for workers. Human Rights legislation supported equity in a variety of situations and allowed affirmative action in others. The universal pension for elderly people reduced poverty and dependence in old age, while the Canada Assistance Plan, the means-tested Guaranteed Income Supplement linked to the Old Age Pension and various plans for those with disabilities all helped reduce inequality and improve health.[120] More public transport made more people mobile and public housing gave some a home. Innovations in housing strategies for the elderly and the disabled helped many live with dignity without depending on their families.[121] Universal public education from kindergarten to high school also contributed to greater equality and thus to health.[122] Unlike most of the support in the nineteenth century, many of these programs were defined as rights of citizenship rather than as charity schemes targeted at the deserving.[123]

Together, and combined with the move from primary resources and goods production to services and the accompanying urbanization, these welfare state measures contributed to a significant decline in the time men spent in the labour force. At the beginning of the century, men began paid work at an early age, worked long hours, had few or no vacations and stayed working until they were no longer physically able, often gradually reducing paid work and dying shortly after they finally quit.[124] Now full-time paid employment cannot begin at least until age 16, and for most it begins far later, after years of formal education. And for many it ends at least at age 65, where compulsory retirement is legal, and pensions or early retirement packages mean some people leave even before then. Most men can then expect to live well beyond retirement from their paid work. This development may have contradictory effects on men, and the extent to which they enjoy being out of the labour force will depend in part on both what kind of job they leave and what kind of income they have.

Public health measures such as immunization, food inspection, drug regulation and water treatment reduced the spread of infectious and other diseases. Universal health care coverage for hospitals and doctors were part of this welfare state development, as were the expansion of residential care facilities and public home care services. Universal coverage, combined with new developments in drugs and techniques, were major factors in falling infant and maternal mortality rates, as well as in the successful treatment of many illnesses.[125] By the 1990s, the overwhelming majority of Canadians rated their health as good to excellent -- even among those over age 75 -- and Canada was near the top on most health indicators.[126] Many more people survived with significant or severe disabilities and with chronic diseases. Those with intellectual disabilities, for example, are finally getting to live into old age.[127] Old age also became older, as longevity increased. Nearly 12% of the population was over 65 in 1999 and those over 85 are the fastest growing segment. Women are the overwhelming majority of the old old.[128]

Of course, the welfare state was far from perfect and far from successful in eliminating inequality. Many more women than men were able to benefit from the employment-related schemes and few with long-term disabilities had access to these rights based schemes.[129] Welfare programs often served to reinforce dependency without alleviating poverty and offered support as charity. Nevertheless, contributions of the welfare state to reducing inequality have become increasingly clear as its demise coincides with growing inequality among both individuals and families.[130] Virtually all of these programs are under threat, have been reduced, or transformed into targeted programs. Meanwhile new problems are emerging. The most obvious are HIV/AIDS and Alzheimer’s.

One program under threat is the health care system. Enormous changes have taken place in this system throughout the last one hundred years but the last decade has seen some of the most important for caregiving. New techniques, drugs and technologies have made it possible to do day surgery and provide many other interventions on an outpatient basis or with shorter patient stays. Moreover, many of the sophisticated treatments once available only within hospitals can now be done at home, thanks in part to new equipment. Combined with an emphasis on cost-cutting, these developments mean that many people are sent out of the hospital while still requiring complex and skilled care. The obvious consequence is more informal caregiving and unpaid caregivers providing much more complex care. The less obvious consequence is the entry into the home of strangers to assess the need for, and to provide, care. This can mean both less privacy and more conflict over what care is provided by whom.[131] And perhaps least obvious is the shifting of care costs onto the caregiver or recipient and their often shared concern about the quality of care provided by informal carers. It must be emphasized that this is not care being sent back home, where it was once done by mothers and daughters. Our grandmothers never cleaned catheters or checked intravenous tubes; they did not examine incisions or do much wound care.

Little research has been done on this new form of care but what is available indicates that the caregiving is done primarily by women. For elderly patients discharged early from hospital, access to formal in-home services were significant in boosting morale perhaps in part because they had confidence in the skills of the provider.[132] In the case of patients recovering from cardiac surgery, 84% of the women caregivers were employed outside the home. Their jobs in “lower status positions” meant that leaves are difficult to obtain and caregiving, even for a short period, could threaten their jobs.[133]

The other, relatively recent development in health care is the move of people from institutions into the community. Deinstitutionalization began with psychiatric patients in the late 1960s[134] and now applies to all those previously cared for in large facilities. Then, like now, the move has been made often without appropriate alternatives available and the community too often means a poorly-equipped home or the street.[135] Those at home are expected to provide care, and the expectations are higher for women. Moreover, such care often means giving up paid employment, and women are more likely to leave the labour force than men to provide care in part because they have the lower paying jobs.[136] It may simply make sense, at least in the short term, for the lowest paid member to leave the labour force in order to provide necessary care and few jobs allow women to take paid leave to provide care.

This leads directly to another major change in women’s labour force participation. Today, unlike a century ago, most women are in the labour force for most of their adult years.[137] They have jobs for many reasons, including the fact that jobs grew in traditional female work with the expansion of the welfare state. However, the single most important reason for taking paid work is the same for women and men: they need the income.[138] Although women have made significant progress within the labour force, they are still segregated into the lowest paid occupations. They are also over-represented in part-time and temporary work. Those who are self-employed seldom have people working for them and many hold multiple jobs.[139] Moreover, women's steady improvement since the 1950s seems to have halted or even reversed. "In 1999, 41% of employed women aged 15-64 had a non-standard employment arrangement, compared to 35% in 1989" and women's labour force participation rates have stayed virtually the same for the last decade.[140] In that same year, 3% of women, compared to 1% of men in full-time jobs lost time at work because of family responsibilities.[141] The increases in women's non-standard work may in part be explained by their increasing caregiving activities. Instead of losing time at work, they may have to take jobs that require less time or that can be done at home. Women's full-time work is less likely than men's to come with a private pension and non-standard work is even less likely to have any benefits at all. As a result, many of the women who account for the majority of the elderly have only public pensions. And for many, the lack of a pension is a direct result of their caregiving.[142]

At the same time, many of the employment protections have been removed in a deregulated market, leaving fewer and fewer households with even one secure, decently paid job to support the household. Partly in response to these changes, more men and women are working longer hours often at two jobs.[143] As a result, fewer and fewer families have the time or resources to provide much care just as care demands are increasing. This seems like a volatile mix.

There have also been changes in family patterns. There are fewer marriages and fewer children, born closer together in terms of age, within marriages. Openly common-law relationships have become much more common, as have openly gay and lesbian relationships. More marriages end in divorce and more blended families have children who still have other living parents outside the current marriage.[144] More families have only one parent, most of them headed by women. Housing and job shortages, as well as inadequate incomes, are forcing more people to live with relatives and friends. And new patterns of immigration mean that households are much more culturally and racially diverse.[145] What these developments mean for caregiving is difficult to determine but it is clear that the changes in relationships will influence where, when and how care can or will be provided. And it seems likely that there are fewer and fewer family members, and thus fewer people, to provide care.

C. The Changes That Matter For Care

What this summary indicates is that people have provided, and continue to provide, care for friends, relatives and strangers. For the most part, they do it willingly and with care.[146] Moreover, those who receive care now or in the past themselves provide care, and caregiving is often part of rewarding relationships. However, the demands on caregivers are expanding enormously with the increasing acuity and disability levels of those receiving informal care. Longevity is also contributing to the workload, although not as much as public discourse would suggest. Moreover, there are more people needing this complex care at the same time as the welfare state is reducing services provided in the formal system and increasing pressures on families in general and women in particular to fill the gaps. Yet more and more women have little choice but to work in the labour force, few of their labour force jobs allow them to provide care and, if they do give up full-time paid work in order to care, they are jeopardizing not only their future employment but also their money for old age as well.[147] More and more research is suggesting that this caregiving is often a burden under current conditions, placing strains not only on the health of the providers and recipients but also on their relationships and on both their current and future finances.

V. FRAMEWORK FOR ASSESSING LEGISLATION, REGULATION AND POLICY

This summary of 100 years of caregiving provides a basis for developing a framework for assessing government intervention. Legislation, regulation and social policy should seek to facilitate caregiving among adults, and do so in ways that allow both care providers and care recipients to retain their dignity and their relationships. This means asking the following questions;

1. **Is caregiving and care receiving voluntary?** Caregiving can be voluntary only if there is access to alternatives and if there are the kinds of supports available that allow choices to be made. This, in turn, can mean the most effective and efficient care. The Hall Commission[148] which provided the basis for public health care recommended that a full range of services, including homecare, long-term care and pharmacare, be publicly provided on the grounds that this would help ensure that services were delivered not only appropriately and in an accessible manner but also in the least expensive manner because choice would be based more on need than simply on what was available.

2. **Can caregiving be equally shared among women and men?** Women told the National Forum on Health, a body established by Prime Minister Chretien to advise on the future of health care, that they did not want to be "conscripted"[149] into unpaid caregiving. The research clearly shows that such caregiving is, and has been, primarily women's work. This is the case regardless of their age, income, labour force participation, cultural, physical or legal locations. While the values of the women who provide care play some role in this workload, there is significant evidence to demonstrate that legislation, regulations and policy constructs women as caregivers.

3. **Can caregiving be culturally sensitive without making inappropriate assumptions about cultural groups and without contravening other equity principles?** Equity, if defined as exactly the same services provided to everyone, can mean services that do not respond to many people's

specific needs. Experience with both the *Canada Health Act* and the *Canadian Human Rights Act* has shown that it is possible to establish principles that allow for considerable variety in how these principles are met. There is considerable diversity in the needs, in the resources and desires of caregivers and recipients that should be, when appropriate, accommodated in legislation.

4. **Can the assumptions made about personal relationships related to caregiving be justified?** Legislation, regulations and policy often assume the heterosexual nuclear family. They also often assume that especially the women in such families have the skills, resources, time and desire to provide care. Yet many people do not live in such relationships, and those that do may not see their families as the best place to find or give care. Equally important, caregiving often involves many people with no blood or marital ties who nevertheless need supports in order to provide care

5. **Is there recognition of the different interests that need to be balanced in caregiving?** In searching for ways to facilitate caregiving, it is necessary to recognize that there are tensions and differences that can never be resolved but rather need to be balanced and understood in their particular contexts. Perhaps the most critical of these is the tension between care providers and care recipient. Each has different, and often contradictory, needs. Paid and unpaid providers also frequently have conflicting practices and agendas. So too do governments and institutions focused on costs savings when they encounter caregivers seeking supports. There are also tensions between the desire for privacy and the need for caregivers to share information; between the transfer of care to the private home and the regular entry into that home of care providers. All these, and more, tensions exist within the larger one between individual and collective responsibility for care.

6. **Is need defined in ways that exclude some groups while privileging or stigmatizing others?** Programs and supports defined as welfare rather than as universal rights can serve to create inequalities. As the discussions and research that led to many social programs in Canada make

clear, we are all at risk of illness and disability, and thus in need of care. Illness is usually not the fault of the individual and frail old age is seldom attributable to individual actions. Canadians have agreed that we have a collective responsibility for care and that care is a right, not a privilege. It is important for legislation, regulations and policy to reflect this right.

7. **What are the long term consequences?** Although some services and supports and obligations may seem to make sense today, they may have negative consequences in the future. So, for example, a woman who provides care for her partner may benefit immediately from a caregiver allowance but this allowance may mean she drops out of the labour force and finds herself in poverty when she is old. Moreover, the care she provides today may cut her off from friends who will provide her with support tomorrow. In thinking about consequences, we need to think beyond the provider and recipients to their network of relationships and to the larger society.

8. **Are the objectives reinforced or undermined by other legislation, regulations or policy?** Strategies in one sector may enable caregiving while those in another may mean caregiving is a burden. For example flexible hours in paid work may allow women to be caregivers at home or in their community but they may also serve to reinforce women’s responsibility for this caregiving, limiting their capacity to do their paid work or threatening their health. Or respite services available for caregivers may be out of reach because there is no accessible public transit to the care. Or housing policies may mean that people who need some care cannot afford to live in their own homes or independently.

9. **Are the contributions of care recipients recognized and the skills required for giving care acknowledged?** While the research shows that care recipients are often the most vulnerable and in need of complex services, it also shows that many care recipients are themselves contributors in forms of caregiving. It is important to recognize their participation and facilitate it. It is just as

important to recognize that care is skilled work, especially as more and more complex care needs are sent home.

10. **Are current patterns themselves constructs of policy or does policy reflect actual preferences and practices?** It is important to ask if policies have created patterns that then get replicated in ways that exclude alternatives. For example, current immigrant laws on family unification mean that those families that want to live with relatives are the most likely to apply and, in any case, the regulations require these families to continue supporting the relatives brought into Canada under these provisions. It cannot be assumed that families who immigrate under such conditions reflect all families from these cultures, however, or that these families have the resources necessary to provide such care.

A. Concluding Remarks

The research on unpaid caregiving suggests "the need to refocus attention away from the creation of partnerships and protecting against unnecessary substitution towards broader concerns with supporting the partnerships that already exists."[150] The risk is not that families will not provide care but rather that they will not be able to provide care without risking their health and their relationships if formal services fail to support them. Indeed, "more generous social programs reinforce both family and social responsibility."[151] Under conditions of declining public support, broader definitions of family may simply mean more people are conscripted into care rather than better caregiving or better relationships. Unless there are formal supports for unpaid caregiving, both the caregivers and their relationships are increasingly likely to fall apart. And such supports need to recognize the diversity in needs and the diversity in networks, networks that extend beyond kin to create the most satisfying care.[152]

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