

# Developing New Strategies to Support Future Caregivers of Older Canadians with Disabilities: Projections of Need and their Policy Implications

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Dans cet article, grâce à des projections, nous évaluons la croissance annuelle au Canada, de 2001 à 2031, du soutien structuré et bénévole dont auront besoin les personnes âgées vivant avec des incapacités. Nous y analysons également les implications, sur le plan des politiques publiques, du besoin croissant d'aidants naturels. Basées sur le modèle de microsimulation *LifePaths*, de Statistique Canada, ces projections intègrent les taux d'incapacité et la disponibilité potentielle d'aidants naturels à l'intérieur des familles. Nous en concluons que continuer à trop compter sur les familles pour répondre aux besoins des personnes âgées ne constitue pas une approche durable. Enfin, nous proposons la mise en place de politiques publiques pour offrir du soutien financier et du répit aux aidants naturels, et nous évaluons la faisabilité économique de ces politiques.

This paper projects annual growth rates between 2001 and 2031 in the need for informal and formal support among elderly Canadians with disabilities. The paper also discusses the policy implications of the increasing demand for informal caregivers. Using Statistics Canada's *LifePaths* microsimulation model, these projections incorporate disability rates and the potential availability of family caregivers. The authors conclude that

continued focus on family to meet the needs of elderly Canadians is not sustainable. New public policies involving financial support and respite for family caregivers are proposed and their economic feasibility is evaluated.

## INTRODUCTION

The aging of the baby boomers and increasing life expectancy will accelerate the growth in the number of elderly people over the next three decades. As a result, the prevalence of chronic diseases will increase and the need for social services will become just as great, if not greater, than that for medical services (Carrière and Légaré 2000). Assisting elderly people in performing daily activities should be a major concern of public policy over the next few decades.

The formal network consisting of both public and private initiatives may be integral to the total support system of elderly people in need, but in comparison to the informal network it provides significantly less amounts of care. When examining the total number of hours of services being provided in 1996, Lafrenière *et al.* (2003) found that for four activities mostly linked to chronic home-care support (housework, shopping, meal preparation, personal care), more than 70 percent of hours had been provided by members of the informal network. Also, in 2002, 39 percent of senior women and 46 percent of senior men received all of their care from informal sources (no change from 1996). At the same time, the proportion of older adults who received care from formal sources alone fell from 31 percent of women to 25 percent of women, with no change for men (Cranswick 2003).

In Canada, there has been significant discussion of the increasing age of the population and other demographic characteristics that affect the availability of support of family and friends. Noting the lower fertility rates of baby boomers, the increased participation of women in the labour force and the changing family structure in terms of increased di-

vorce and reconstituted families, assumptions of continued assistance at a high level from family and friend support networks are often critiqued.

Currently, there is no national policy addressing family members caring for disabled elderly in Canada; all community care policies governing home-care programs are under provincial jurisdiction (Canadian Home Care Association 2003). Services provided by the formal network to assist elderly persons to remain in the community are provided through government-sponsored home-care programs or through private enterprises. Publicly funded home-care programs exist in every province and territory in Canada and their expenditures have increased over 100 percent in the past seven years (Health Canada 1998).

Today, community care policy looks like a good way of limiting the increasing expenditures related to an aging population. However, Hébert *et al.* (2001) are more cautious when looking at the lower cost argument in favour of home care. They agree that generally, care at home and in intermediate facilities is less expensive than care in nursing homes. However, the argument does not seem to hold when looking at severely disabled people. There would seem to be a limit to the efficiency of home care, especially for those severely disabled people. Nor does the argument hold when informal costs are factored in. "When a societal approach which included both formal and informal costs was used, families were found to contribute one half or more of the overall care costs of home and community care" (Hollander *et al.* 2002, v). Moreover, within the post-acute home-care model, evaluation of the total system costs have not provided definitive cost savings — particularly if costs such as the impact

on the informal support system are factored in (Hollander and Chappell 2002).

There are a number of issues related to the increased pressure to shift care from institutions to the community as a way to cut costs. Central to this policy discussion is having adequate human resources to carry out front-line services. This labour force is often described as having limited training, low wages, few benefits, and limited supervision (Government of Canada 2003). Until recently there has been only limited attention to researching Canadian home-care workers. A recent sector study on home care was the first nation-wide approach to understanding human resource issues, both paid and unpaid, in the delivery of home-care services (*ibid.*).

The demographic changes in the Canadian population in tandem with changes in the composition of informal network will likely have a significant impact on the need for formal support in Canada. There is not necessarily a demographic crisis in Canada because of the aging of the population, but the arrival of the baby boomers raises new challenges. It is critical that more attention be given to understanding the impact of these changes and for what type of policy changes we need to prepare.

This paper has two objectives: first, to project annual growth rates in need for family and formal support among the elderly Canadians with disabilities between 2001 and 2031; second, to assess the policy implications of the projected increased need for assistance and the changing nature and extent of the family support network. More specifically, the cost factors related to introducing public policy to support family caregivers will be analyzed.

## DEMOGRAPHIC PROJECTIONS

Projections of the need for future continuing care services typically are based on current utilization patterns and population aging (Government of Canada 2003). However, because continuing care

services are more social than medical and can be provided by family and friends, factors affecting the availability of family and friend caregivers, along with other factors (living arrangement of the elderly population, gender), are important to consider when projecting formal services. Pickard *et al.* (2000) used a similar approach when projecting the demand for long-term care for elderly persons in England to 2031. Their model incorporates both demand (as measured through dependency) and supply of informal support (as measured through probability of receiving help with instrumental activities of daily living).

Data from the 1996 National Population Health Survey and the 1996 General Social Survey were used to identify factors associated with disability and source of assistance among the elderly, respectively.<sup>1</sup> In order to recognize the complexity of assessing the need for future home-care services (in particular, everyday housework, shopping for groceries, meal preparation, and personal care), these results, along with changes in disability among older persons, and changes in family structure were incorporated into Statistics Canada's *LifePaths* microsimulation model (for more details on *LifePaths*, see Statistics Canada 2004). The model incorporated three disability scenarios to project trends: (i) probabilities of disability levels held constant at 1996 levels (constant scenario); (ii) probabilities of disability levels gradually decreasing (compression scenario); and (iii) probabilities of disability levels gradually increasing (expansion scenario). For the compression scenario it was assumed that the probability of having a given level of disability according to specific individual characteristics would gradually (over a period of 15 years) decrease. This is done by giving to an individual of a certain age the probability of having a specific level of disability of someone five years younger. In the case of the expansion scenario, the approach was exactly the same except that this probability is increased to someone five years older instead of five years younger.

### Potential Supply of Caregivers

When trying to assess the effect of the changing nature and extent of the family network over the next few decades on the demand for formal home-care services, many factors should be considered. The microsimulation model provides a look at two of these factors: living arrangement (i.e., individuals living alone) and the number of surviving children. These two trends point in different directions.

Findings from previous research using Statistics Canada *LifePaths* microsimulation indicate that first, the proportion of elderly persons living alone should be relatively stable from 2001 to 2031 (Carrière, Keefe and Légaré forthcoming). There is a small increase among men while the trend is fairly stable for women. Since today's older males rely more on their spouse than do older females for assistance with everyday activities, there might be, all other things being equal, a small increase in the pressure for formal home-care services. The proportion of elderly females living alone is significantly higher than the proportion observed among males. This is not surprising considering the age differential at marriage and the differential in life expectancy favouring females. Mainly between the 2031–51 period, a projected decrease in the proportion of females living alone is observed. Since the 1990s, the proportion of women living alone in some international countries has stabilized, while for others it has declined (Italy, Germany, Austria) (Tomassini *et al.* 2004). Based strictly on this first factor, the 2031–51 period seems to indicate a downward pressure on formal home-care services, as the proportion living alone should slightly decrease.

Second, the effect of number of children on the probability of using formal and/or family networks is mainly determined by having no surviving children at all compared to having at least one. Projections using Statistics Canada's *LifePaths* microsimulation model indicate that the proportion of females aged 65 and over with no surviving children should increase over the next 50 years (Carrière, Keefe and Légaré forthcoming). For fe-

males aged 65 years and over the proportion without any surviving children increases from 16 percent in 2001 to a high of 24 percent in 2031 (and 30 percent in 2051). Close to one out of four elderly women may be without a surviving child by 2031. However, among those who typically require services (85 and over) this trend should not begin until 2021. Females aged 85 and over (the most vulnerable) initially have the greatest proportion without any surviving children. However, between 2001 and 2021, this proportion decreases significantly (from 22 to 16 percent) as the parents of the baby boomers constitute most of this age group. For the following period (2021–51) the pressure on formal home-care services should increase as the baby boomers gradually join the oldest old, causing the proportion without surviving children to increase to 20 percent in 2031 (and to 28 percent in 2051). In 2036, however, the proportion of females aged 85 and over without any surviving children will roughly be the same as observed at the beginning of the projected period. Contrarily, in England, the proportion of 80-year-olds with at least one surviving child over the next two decades should increase, as fertility rates were higher and mortality rates lower, for this generation (Murphy and Grundy 2003).

Of course, other important factors will affect the supply of home-care services provided by family members. For example, expectations from older parents toward their children may be very different from what has been observed in the recent past. Also, even though the presence of a surviving child was examined, the geographic proximity of those children was not examined. This is an issue that would need to be looked at in the future. The family network of tomorrow's elderly population will also be affected by an increased proportion of divorced individuals. Although the microsimulation takes into account the trend in divorce, very little is known about the assistance provided by stepchildren and children of divorced parents, especially assistance toward fathers (De Jong Gierveld and Dykstra 1997). More research is needed in this area to better understand the effect of the changing nature and extent

of the family network on the demand for formal home-care services.

### Demand for Support

In terms of future demand for family and formal support, three scenarios (constant, compression, and expansion) were produced to analyze future trends in disability among the elderly Canadian population. Results from previous research, as shown in Fig-

ures 1a and 1b, indicate that there is about a ten-percentage point difference between males and females using the constant scenario (where disability is held constant at 1996 levels) (Carrière, Keefe and Légaré forthcoming). For males, the percentage of those aged 65 and over with a disability varies from a high of 38 percent to a low of 34 percent, while for females the percentage varies from 47 percent to 43 percent.

FIGURE 1a  
Proportion of Disabled Males Aged 65 and Over among Those Living in Private Households, Canada, 2001–2051

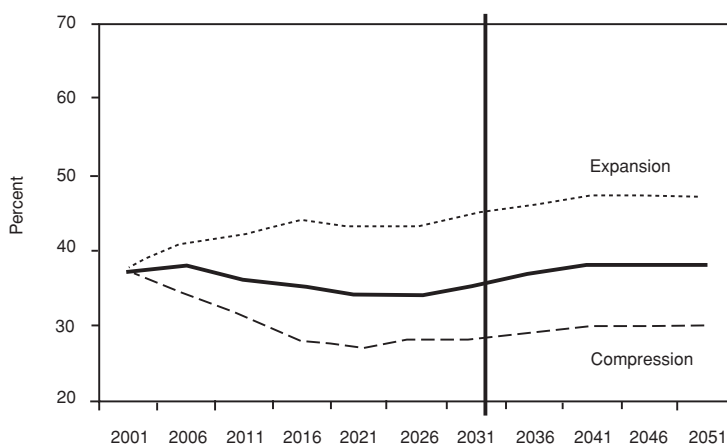
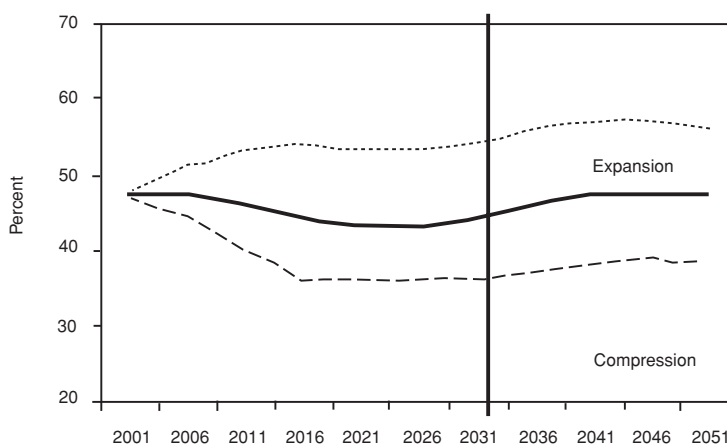


FIGURE 1b  
Proportion of Disabled Females Aged 65 and Over among Those Living in Private Households, Canada, 2001–2051



Source: Carrière, Keefe and Légaré (forthcoming).

When examining persons aged 65 and over who need assistance with everyday activities (shopping, personal care, housework, and meal preparation), in Figure 2 microsimulations, based on the constant scenario of disability, show that the proportion needing assistance should be relatively constant throughout 2001 to 2031, varying between 15 percent and 18 percent, the lowest point being attained in 2021–26 (Carrière, Keefe and Légaré forthcoming). Although the *proportion* of elderly persons needing assistance remains relatively stable, the number of elderly persons in need of assistance could more than double between 2001 and 2031. The number and proportion of elderly persons needing assistance should increase steadily between 2026 and 2051.

**Source of Assistance**

Using the constant scenario of disability, projections of the use of family support, formal, and mixed (both family and formal) support are presented in Figure

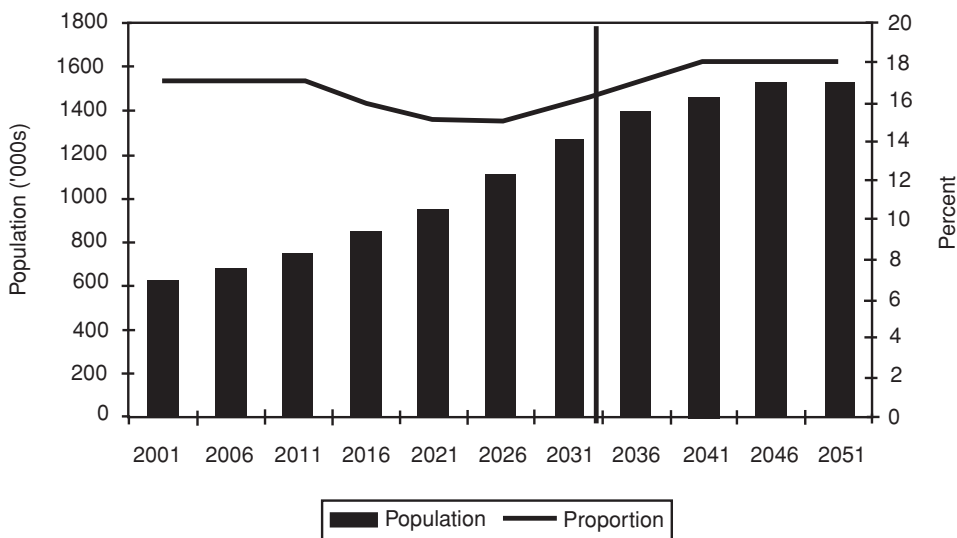
3. For example, if disability remains constant at the 1996 levels, data suggest that the projected need, combined with a relative decrease in the use of family support, should result in a relative and absolute increase in the use of formal support. Specifically, the annual growth rate of the population aged 65 and over with a disability receiving assistance is 2.5 percent. The projected growth rate is highest for institutional care at 2.9 percent, followed by formal support at 2.7 percent, and informal support at 2.2 percent (Carrière, Keefe and Légaré forthcoming).

**POLICY IMPLICATIONS**

**Implications of Increased Demand**

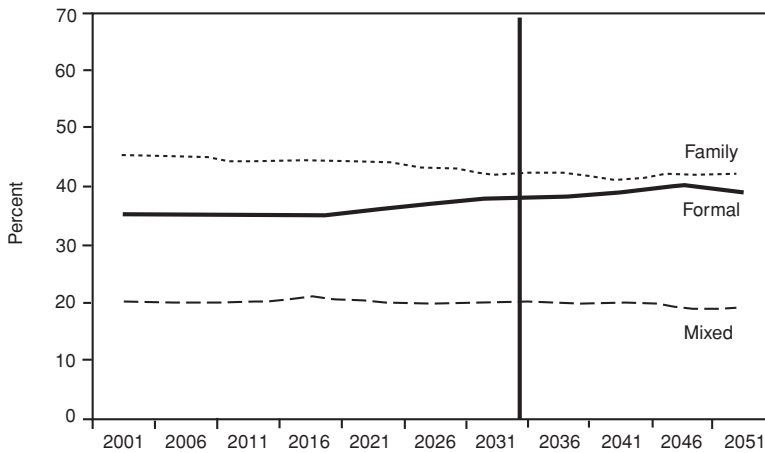
The number of elderly persons who have a disability and who require assistance could double within the next 30 years. This projected shift results from the intersection of numerous forces that include, but are not limited to, future cohorts of seniors having

FIGURE 2  
Proportion and Number of Elderly Persons Needing Assistance Using the Constant Scenario, Canada, 2001–2051



Source: Carrière, Keefe and Légaré (forthcoming).

**FIGURE 3**  
 Distribution (in %) of Disabled Elderly Living in Private Households Needing Assistance by Source of Assistance, Canada, 2001–2051



Source: Carrière, Keefe and Légaré (forthcoming).

fewer children, increases in the number of older persons with a disability and changes in characteristics such as educational levels, marital status, and living arrangements; factors that at least in the past have been predictors of home-care service use. Findings from our previous research using Statistics Canada *LifePaths* microsimulation show that changes in disability (compression or expansion) can have a significant impact on the rate of growth for the population in need of assistance. For example, an increase in the health of Canadians (compression scenario) should reduce the rate of growth for the population in need of support from 2.5 to 1.9 percent (see Carrière, Keefe and Légaré forthcoming). Consequently, recognition of the fundamental importance of policies whose outcome will be to improve health is imperative. If policy changes improve the overall health of the population, this will have a profound effect on the projected need for services. The compression scenario is likely an exaggeration of actual changes in disability; however, these data reinforce the proposition that prevention

or delay of disability is the most effective in reducing the demands of population aging on the formal support system and family caregiver.

Figures 4 and 5 present the percentage increase in the population aged 65 and over compared to the percentage increase of those aged 65 and over in need of assistance assuming that disability will remain constant and if disability is compressed. Three scenarios were produced to analyze future trends in disability among the elderly population. The first scenario (constant scenario) simply applies the probability of having a given level of disability (none, mild, moderate or severe) according to a given set of socio-demographic characteristics as observed in 1996. These probabilities were computed after running a multinomial ordered logistic regression using data from the cross-sectional sample of the 1996 National Population Health Survey. Assuming no change in disability, the population in need of support will double between 2001 and 2026 (Figure 4). In comparison, if disability is compressed by five

FIGURE 4

Population Aged 65 and Over, the Proportion with a Disability Using the Constant Scenario and Gross Domestic Product (based on 2.5 percent annual growth rate)

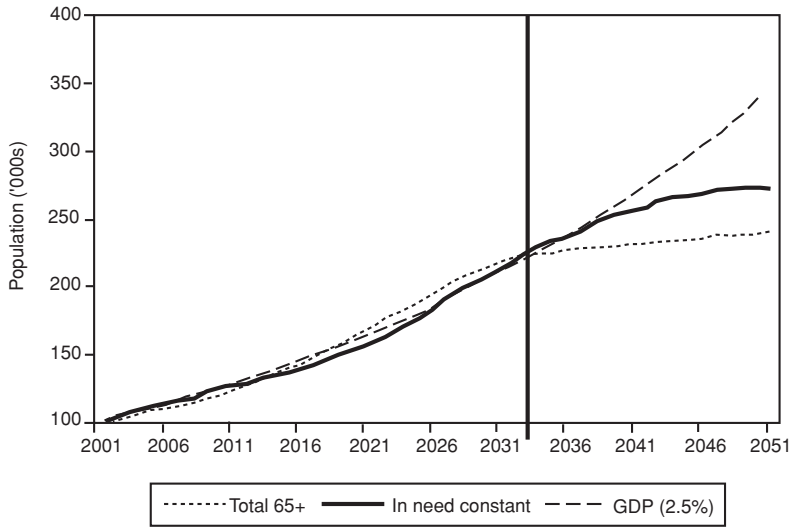
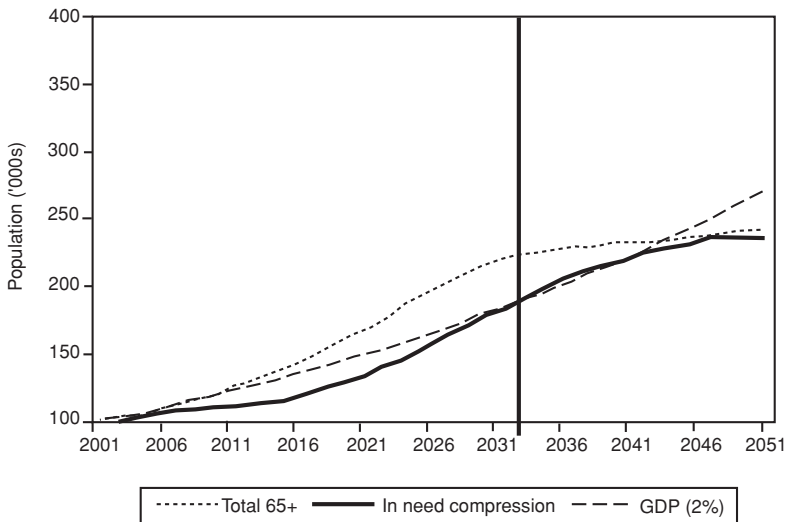


FIGURE 5

Population Aged 65 and Over, the Proportion of Disabled Elderly in Need of Assistance Using the Compression Scenario and Gross Domestic Product (based on 2.0 percent annual growth rate)





years, the doubling of the population in need would be delayed by a decade, doubling by 2036 (Figure 5). The annual rate of growth of the gross domestic product (GDP) would need to be about 2.5 percent to maintain the productivity necessary to keep up with changes in the rate of increase for the constant scenario of disability. In contrast, if disability is compressed by five years, the GDP would need to increase by an average of 2 percent in order to keep up with the increased demand of disability needs (Figure 5).

In fact, if improvement in health was achieved, this change would have a greater effect on the projected use of formal services than the availability of family support. Simply not requiring assistance (or delaying the probability of needing support) for a period of five years reduces the need for formal services. Despite the focus on family caregivers in the delivery of care in the following discussion, we acknowledge that the need to support population health strategies, policies, and initiatives aimed at decreasing disability and/or their consequences on daily living is fundamental.

### **Factors Affecting Availability of Family Caregivers**

Given the potential for an increase in the number of elderly persons with a disability over the next 30 to 50 years, there should be a gradual but significant increase in the demand for family and friend caregivers. Research suggests that spouses, followed by children, if available, are the most frequent caregivers to elderly persons with a disability. Excluded from this analysis were other caregivers, including siblings and other relatives, neighbours, and friends because they were not a significant predictor of use in 1996. These caregivers are less likely to help and the help they do provide tends to be with instrumental activities of daily living (e.g., transportation, grocery shopping, etc.) and not activities of daily living (e.g., personal care) (Chappell 1992; Keating *et al.* 1999). The findings suggest two trends in the availability of family support — one suggesting that spouses may be more available in the future

due to the reduction in the mortality gap between men and women and the other demonstrating a long-term reduction in the availability of children.

The living arrangements of the elderly are a critical variable related to understanding availability of family support. In particular, among the elderly, living with at least one other person is a strong predictor of having an informal source of support (Carrière *et al.* 2007). The narrowing of the life-expectancy gap between men and women is the key explanation to research findings of the decline in women and men living alone. This is significant in terms of availability of family support, as spouses, regardless of gender, are the primary source of support for an elderly person in need. At the same time, there are significant policy implications about facilitating both elderly spouses to remain as independent as possible in the community. Specifically, policy needs to be able to support both the care receiver and the caregiver in order that they both do not end up as residents of a long-term care facility.

The findings demonstrate that over the next 20 years (2001–21) the likelihood of having a surviving child should increase among the population aged 85 and over. This is a unique time in our history when only 16 percent of women aged 85 and over will have no surviving children. These are the parents of the baby boomers. While there are more children available to potentially provide assistance, other social changes may affect children's availability to assist elderly parents. For example, the increased participation of women in the labour force is an important factor in the potential availability of caregivers. Consequently, labour market policies facilitating the caregiver to combine work and eldercare should be considered as an important policy direction. From 2021 onward the proportion of women aged 85 and over with no surviving children will rise significantly as the cohort of baby boomers have fewer children.

The presence of siblings was not a significant predictor of assistance using the 1996 General Social

Survey, but it is cautioned that the importance of siblings may be elevated when the availability of children is reduced. This is especially the case for baby boomers, who due to generational differences will have fewer children, but more siblings and friends, as these networks are considered more important. The sibling relationship should be included in the definition of family in workplace policies to support eldercare. The projected availability of friends and neighbours is not possible, but it is certain that with the decreased availability of children the importance of friends as potential caregivers will increase.

Another variable affecting the availability of caregivers in the future is potential shifts in the gender specificity of caregiving. Well-documented in the research is the significant role of women as the predominant caregivers to the elderly. Recent analysis of 2001 census data suggests that men are becoming increasingly involved in childcare and unpaid household work (Keefe and Side 2003). While this same trend is not yet evident for eldercare, increased participation by men in domestic work may be a precursor for increased assistance to the elderly in the future.

### **Policy Strategies for Improving Support to Family/Friend Caregivers**

Continuing care programs involve care to persons in their home as well as residential long-term care and comprise non-insured services within the *Canada Health Act*. These programs are under provincial/territorial jurisdiction in Canada but often funded and/or delivered through district or regional health authorities. Consequently, eligibility criteria, service components, models of service delivery and funding policies vary significantly across jurisdictions. Home care, in particular, is promoted as a cost-effective alternative to long hospital stays and long-term facility placement. These home-care programs are only cost-effective because of their implicit (and in some provinces, explicit) assumption that family and friends are available and willing

to assist in the provision of care. Policies related specifically to family caregivers usually come in the form of education, counselling, and respite services, but services are very limited and often provided through voluntary agencies.

Recent policy shifts emphasizing reduced stays in hospitals and increased post-acute home care have had two negative impacts on family and friend caregivers. First, they assume that such caregivers are available and able to provide care to the hospital patient who has moved home “sicker and quicker” than in the past. The increased labour force participation of women and the increased mobility among families means that the family member may not be available. Moreover, increasingly frail spouses are being called upon to care for their partner — in this case they may be available but not able. Second, the increased emphasis on post-acute home care has deflected resources and the importance of the preventative-maintenance model of home care — one in which support for persons living with chronic illnesses facilitates their ability to remain in the community and decreases their use of hospital services (Hollander and Chappell 2002). Chronic home care includes such fundamental support to caregivers as respite care to enable caregivers to have a break from their caring situation.

In addition to health-care policy, other policy domains in Canada have caregiver-related policies. These include employment insurance (federal level) and tax credits (both federal and provincial levels). In addition, employment leave policy, entitled “Compassionate Care Benefit” allows eligible employees up to 55 percent of their salary for six weeks to care for a terminally ill spouse, child, or parent. Most of the federal taxation credits are non-refundable and limited. Alternative or augmented policies are the focus of the discussion in the next section.<sup>2</sup>

In the short term, children will be available as potential caregivers of the elderly population;

however, their availability is questionable given increased labour force participation and increased mobility patterns. In the long term, there is a need to address policies that support caregivers. Potential policy directions to support caregivers include home-care policies, workplace policies, and income/security policies:

- *Home-care policies.* Suggested changes include making caregiver assessment part of home-care policy; increasing available caregiver services such as respite care; and expanding eligibility criteria (or caregiver definition) to include friends and neighbours.
- *Workplace policies.* Suggested changes include expanding the Canadian Compassionate Care Benefit<sup>3</sup> (Government of Canada 2005) in terms of broadening eligibility criteria and extending the length of leave; adding family leave days to the federal labour code; and providing incentives to private workplaces to expand their policies on family leave to include eldercare responsibilities.
- *Income security policies.* Suggested changes include financially supporting caregivers through a non-taxable allowance; implementing a refundable tax credit for caregivers so that all caregivers will benefit from the tax credit; and expanding the Canada Pension Plan to include a drop-out clause for eldercare and pension credits for cumulative caregiving work.

Internationally, some of these initiatives are in place. For example, Germany, France, Norway, Sweden, and the United Kingdom have pension security policies for caregivers. The United States has a tax credit for caregivers; however, it is not refundable, meaning that the credit is deducted from taxes owing and therefore the caregiver must be paying taxes in order to benefit. Furthermore, both Australia and the United Kingdom have programs in place where caregivers are compensated. Australia, in particular, provides a small non-taxable allowance

(about C\$90 biweekly) for all caregivers providing 20 or more hours per week and an additional means-tested carer payment for low-income caregivers (C\$459 biweekly).<sup>4</sup>

### Costing Policy Proposals

Understanding the costs of these proposed policies will be an essential component to having such proposals seriously considered by government and/or private industry.<sup>5</sup> To this end two policy proposals were chosen to be costed out, one that increases services for caregivers and one that introduces a modest financial support for caregivers. These two proposals were investigated using two scenarios of establishing the projected number of caregivers. The first proposal is to increase services by providing the caregiver with four additional hours of respite services per week. The second proposal is to directly support caregivers financially by providing them with a set allowance in recognition of their work. Assumptions of cost include respite services costing \$25 per hour; a caregiver allowance costing \$200 per month; and a long-term care-bed facility costing \$130 per diem. All costs are assumed to remain constant over time.

Two scenarios were created based on projected numbers of elderly persons in the community needing assistance between 2001 and 2051. In attempting to project utilization rates of policy proposals and their projected cost in the future, it is recognized that there may be a number of caregivers for each elderly person requiring assistance. However, it is likely that a government-sponsored policy will be directed toward the primary caregiver or one caregiver per person in need.<sup>6</sup> For the purposes of this policy discussion caregivers will be limited to one person eligible to receive support because they care for an elderly person (aged 65 and older) who has a moderate or severe disability and who needs assistance with activities commonly associated with home-care services (i.e., everyday housework, shopping for groceries, meal preparation, and personal care). In Scenario 1 the number of caregivers was

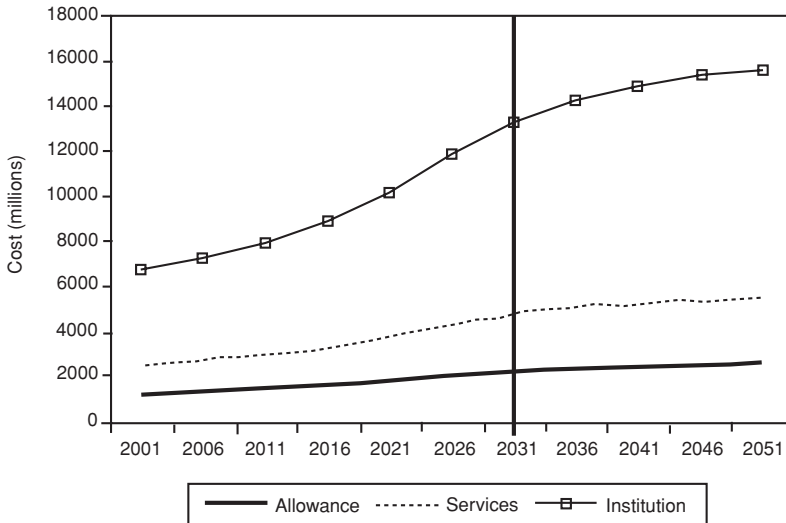
limited to the proportion of elderly persons receiving family support (ranging from 61 to 65 percent over the 50-year period) and in Scenario 2, it was assumed that each care receiver has a caregiver (e.g., 100 percent of moderate and severely disabled elderly living in the community would have a family/friend caregiver providing support). These scenarios give a range of potential costs to assist policymakers in their analysis.

The cost of delivering the monthly allowance for caregivers is about half that of delivering an additional four hours of respite services per week (see Figure 6). These costs would double over time from a projected \$1.1 billion for caregiver allowance in 2001 to \$2.2 billion in 2031. Scenario 1 is based on projected use of family support by elderly persons with moderate and severe disabilities and ranges from a high of 65 percent in 2001 to a low of 61 percent in 2051. The cost to other parts of the health-

care system of not supporting caregivers needs to be calculated. The possibility that without caregiver support the care receiver may enter a long-term care facility four months earlier than if the caregiver had received support was introduced into the scenarios. For example, one month in a long-term care facility costs the government, depending on the jurisdiction, an average of \$3,000 per month.<sup>7</sup> If such policies would delay institutionalization by four months, the cost savings of introducing a respite-care policy would be three times that of the institutional costs. The cost savings of the direct caregiver allowance option is six times that of the institutional projections (e.g., in 2001 an additional four months of long-term care would cost \$6.5 billion compared to the \$2.4 billion in respite care and \$1.1 billion invested through caregiver allowance).

Scenario 2 assumes that should policies of respite or caregiver allowances be introduced, there

FIGURE 6  
Scenario 1: Cost of Supporting Persons Aged 65 and Over with a Moderate or Severe Disability Receiving Support from Family



Notes: Caregiver Allowance = \$2,400 per year/per person; Services = \$5,200 (4 hrs/week/year) additional respite; Institution = additional 4 months (\$3,000/month).

would be more informal support available and that all elderly persons with moderate or severe disabilities would have an eligible caregiver.<sup>8</sup> The cost associated with this assumption is represented in Figure 7. Because more caregivers will be assisted in this scenario the cost of these policies is significantly higher. Additional respite services of four hours per week for all elderly persons with moderate or severe disabilities would cost \$3.8 billion in 2001 (compared to \$2.4 billion in the previous scenario) and double to \$7.6 billion by 2031.

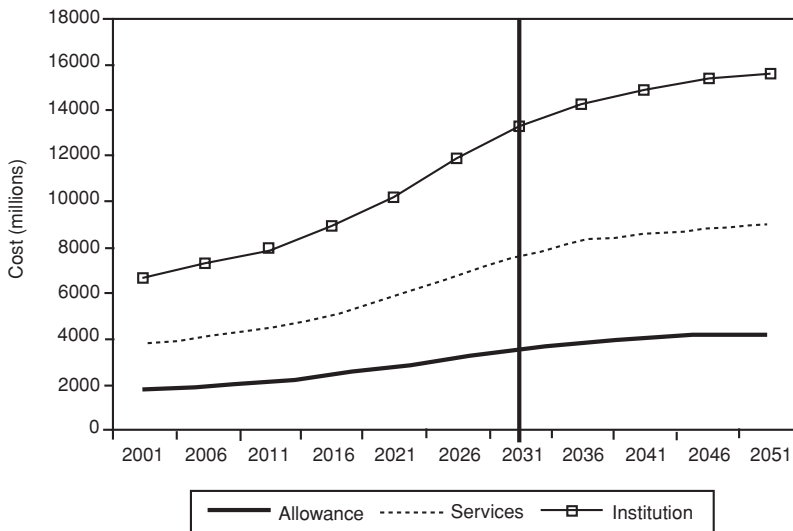
These proposed policy changes need further development to project what the cost would be to the health-care system of not introducing such policies. An average of four months additional institutionalization is a crude measure of the cost of not supporting caregivers. There will be situations where the care receiver will refuse placement in a long-term care facility. Continued involvement of

caregivers in these situations will have other direct and indirect costs to the health-care system resulting from their potentially decreased quality of health. These costs include the caregiver's increased use of pharmaceuticals, visits to physician and other medical services, and increased risk for depression and other chronic illnesses or injuries (see Cranswick 2003 for description of health consequences affecting caregivers). For employed caregivers, other costs range from short-term costs of reduced productivity, to long-term consequences of reduced career options and retirement savings (see Cranswick 2003; Keating *et al.* 1999).

### RECENT DEVELOPMENTS AND POLICY DIRECTIONS

Disability has a significant impact on the need and use of home-care services in the future. Understanding its

FIGURE 7  
Scenario 2: Cost of Supporting Persons Aged 65 and Over with a Moderate or Severe Disability



Notes: Caregiver Allowance = \$2,400 per year/per person; Services = \$5,200 (4 hrs/week/year additional respite); Institution = additional 4 months (\$3,000/month).

impact must be viewed in the context of home care in Canada. During the time frame of our research, the Commission on the Future of Health Care in Canada released its final report (Government of Canada 2002). The Commission recommended that the federal government broaden their funding role for home care and provide first-dollar coverage for post-acute home care, mental health home care, and end-of-life care. These recommendations were supported by the federal, provincial, and territorial government ministers and are admirable in their goal to reduce hospital-based care, but may be detrimental because of their continued reliance on family and friend caregivers. This emphasis on post-acute home care does not address the increasing demands in the population because of chronic health-care needs. Indeed, in some regards, expanding home care only in terms of post-acute replacement will place increased pressure on family and friend caregivers. Reduced hospital stays increase complexity of care and expectations/burden on family/friend caregivers.

The underlying assumption of post-acute home care suggests that care can be delivered in the home more cost-effectively than in the hospital, based on three factors: (i) there are no infrastructure costs as the person is in his/her home; (ii) the level of professional services required may be reduced and para-professional staff are less expensive; and (iii) the most challenging given the changing nature and extent of the informal support network, that family/friend caregivers are available to provide supervision, manage formal services, and provide hands-on support on a 24-hour basis. Reports from the Standing Senate Committee on Social Affairs, Science and Technology (2002) and the Commission on the Future of Health Care in Canada (Government of Canada 2002) emphasized post-acute home care — a program reliant on an increased level of availability and involvement of the informal support network. This assumption contradicts earlier results which suggest the family network will decline slightly over the next 30 years.

This shift toward post-acute home care and away from chronic home care will result in changes to the way in which home-care services are organized, who is eligible, and what is the responsibility of the state versus the individual. Analysis of health-care structuring and community-based care in British Columbia revealed that declines in resources and access to hospital and institutional care are not being accompanied by increases in home care and some support services (Penning *et al.* 2002). Such policies continue to be predicated on assumptions that family and friends are available to provide such care. At present there is no national policy to provide direct support to family members caring for elderly kin in Canada. Continuing care policy lacks recognition of the needs of family and friend caregivers. The recognition that there are costs, both financial and health-related, involved in being a caregiver is important. More than one-third of caregivers incur extra expenses. One in ten caregivers report health problems stemming from caregiving work (Cranswick 2003). Caregiver advocates in Canada were initially encouraged by the federal government's establishment of a Minister of State for Families and Caregivers in 2004; however, such hope was deflated by the downsizing of this position to a parliamentary secretary in 2006. Nevertheless, discussions about the most appropriate ways to support family and friend caregivers continue.

## CONCLUSION

The main distinction of this research is to take into consideration the dynamic process involved in population aging. The projections, by accounting for the changing characteristics of the elderly population, the changing probabilities of disability and physical dependence, and the changing nature and extent of the family and friend support network will lead to a more realistic picture of the future need of formal home-care services. There is opportunity to develop comprehensive policy to address these

issues. Failure to do so will result in even greater costs to the health-care system.

## NOTES

Revised version of this paper was presented at the IUSSP conference, 25<sup>th</sup> International Population Conference, Tours, France, July 2005. Conference paper received International Novartis Award.

<sup>1</sup>At the time of the study, these were the available datasets. Since then, data from the 2002 General Social Survey have been released and will be used in further studies.

<sup>2</sup>A synthesis of national level policies for caregivers of elderly persons with needs for assistance in Canada and nine other countries is available from [www.msvu.ca/mdcaging/policyprofiles.asp](http://www.msvu.ca/mdcaging/policyprofiles.asp).

<sup>3</sup>An Employee Insurance benefit for persons providing end-of-life care or support.

<sup>4</sup>For more information on international financial compensation policies for caregivers, see [www.msvu.ca/mdcaging/policyprofiles.asp](http://www.msvu.ca/mdcaging/policyprofiles.asp).

<sup>5</sup>All money amounts in this paper are presented in Canadian dollars. One Canadian dollar is roughly equivalent to 0.66 Euro and US\$0.80.

<sup>6</sup>Or at least support one caregiver at a time as per the Canadian Compassionate Care Benefit.

<sup>7</sup>Assume that the government cost is based on average per diem costs of long-term care of \$130 by 30 days per month and allowing for \$900 in shelter costs to be borne by the resident (may vary by province). Also based on the assumption that 75 percent of Canadians with moderate and severe disabilities will delay institutionalization by four months.

<sup>8</sup>Based on the idea of the woodwork effect — that caregivers would be more likely to be involved if there was a benefit to them such as an allowance (in other words they would “come out of the woodwork”). For Scenario 2: assume that the government cost is based on average per diem cost of long-term care of \$130 by 30 days per month and allowing for \$900 in shelter costs to be borne by the resident (may vary by province). Also assume all

elderly persons with moderate or severe disability have a caregiver and that institutional cost is based on 75 percent of Canadians with moderate and severe disabilities requiring an additional four months of institutionalization.

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