

**Developing new strategies to support future caregivers
of the aged in Canada:
Projections of need and their policy implications**

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Paper Presentation
International Union for the Scientific Study of Population
Tours, France
July 18-23, 2005

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Financial contribution from the Health Policy Research Program, Health Canada is gratefully acknowledged.

Developing new strategies to support future caregivers of the aged in Canada: Projections of need and their policy implications¹

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The aging of the baby boomers and the 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 important, if not more, than the provision of medical services (Carrière & Légaré, 2000). Meeting the required needs of elderly people in assistance to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) should be a major concern of public policy over the next few decades. In Canada, there has been significant discussion of the increasing age of the population and other demographic characteristics which affect the availability of informal support. 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 divorce and reconstituted families, assumptions of continued assistance at a high level from informal support networks are often critiqued.

This paper has two objectives: First, to project annual growth rates in need for informal 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 informal 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. 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

¹ Financial contribution from the Health Policy Research Program, Health Canada is gratefully acknowledged.

arrangement of the elderly population, gender), are important to consider when projecting formal services.

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.² In order to recognize the complexity of assessing the need for future home care services, 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 see Statistics Canada, 2004). The model incorporated three disability scenarios to project trends: (1) Probabilities of disability levels held constant at 1996 levels; (2) Probabilities of disability levels gradually decreasing (compression scenario); and (3) Probabilities of disability levels gradually increasing (expansion scenario). For the compression scenario we 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.

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 (allowing us to look at individuals living alone) and the number of surviving children. These two trends point in different directions.

First, the proportion of elderly persons living alone will be relatively stable from 2001 to 2031. There is a small increase among men while the trend is fairly stable for women (see Figures 1a and 1b). 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

² At the time of the study, these were the available data sets. Since then, data from the 2002 General Social Survey has been released and will be used in further studies.

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 favoring females. Mainly between the 2031-2051 period, we also observed that among females there is a projected decrease in the proportion living alone. Based strictly on this first factor, the period 2031-2051 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 informal 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 65+ with no surviving children will increase over the next 50 years (see Figure 2). For females aged 65 years and over the proportion without any surviving children increases from 16% in 2001 to a high of 24% in 2031 (and 30% in 2051). Close to 1 out of 4 elderly women may be without a surviving child by 2031. However, among those who typically require services (85+) this trend will 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%) as the parents of the baby boomers constitute most of this age group. For the following period (2021-2051) 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% in 2031 (and to 28% 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.

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 we looked at the presence of a surviving child, we have not looked at the geographic proximity of those children. 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, we know very little about the assistance provided by stepchildren and children of divorced parents, especially assistance toward fathers (De Jong Gierveld, & 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 Caregivers will Increase

In terms of future demand for formal and informal support, three scenarios (constant, compression, and expansion) were produced to analyze future trends in disability among the elderly Canadian population. Results of the constant scenario (where disability is held constant at 1996 levels) show that there is about a ten percentage point difference between males and females (see Figures 3a and 3b). For males, the percentage of those aged 65 and over with a disability varies from a high of 38% to a low of 34%, while for females the percentage varies from 47% to 43%. When examining persons aged 65 and over who need assistance with everyday activities (shopping, personal care, housework, and meal preparation), microsimulations show that the proportion needing assistance is relatively constant throughout 2001-2031, varying between 15% and 18%, the lowest point being attained in 2021-2026 (see Figure 4). The *proportion* of elderly persons needing assistance remains relatively constant because of a more favorable age structure of the elderly population (i.e. baby boomers). The number of elderly persons in need of assistance, however, could more than double between 2001 and 2031. The *number* and *proportion* of elderly persons needing assistance will increase steadily between 2026 and 2051.

Source of Assistance

Using three scenarios of disability (constant, compression, and expansion) projections of the use of informal support, institutionalization, and formal support are presented (see Figure 5). 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 informal support, will 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% (see Table 1). The projected grow rate is highest for institutional care at 2.9% followed by formal support at 2.7% and informal support at 2.2% (see Keefe, Légaré, & Carrière, 2004a for details).

Policy Implications

Implications of Increased Demand

The number of elderly persons who have a disability and who require assistance will double in 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 fewer children, increases in the number of older persons with a disability and changes in characteristics such as educational levels, marital status, living arrangements; factors that at least in the past have been predictors of home care service use. As the results of projecting disability demonstrate (see Keefe, Légaré, & Carrière, 2004a) the ability of society to become healthier (to have the probability of having a disability equal to someone five years younger – compression scenario) will reduce the rate of growth for the population in need of support from 2.5 to 1.9%. 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 informal and formal support system.

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 informal 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 informal caregivers in the delivery of care in the following discussion, we recognize the fundamental need to support population health strategies, policies, and initiatives aimed at decreasing disability and/or their consequences on daily living. These improvements are under the larger rubric of population health.

Factors Affecting Availability of Family Caregivers

Given the increasing demands for support from the increased number and proportion of elderly persons with disabilities, there will be a gradual but significant increased demand for informal support. Research suggests that spouses, followed by children, if available, are the most frequent caregivers to elderly persons with a disability. Other caregivers including siblings and other relatives, neighbours, and friends are less likely to help and the help they do provide tends to be with transportation, grocery shopping, etc. and not personal care; they are not included in our analysis (Chappell, 1992; Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Our findings suggest two trends in the availability of informal 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 is a critical variable related to understanding availability of informal 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, Martel, Légaré, & Martin, 2001). The narrowing of the life expectancy gap between men and women is the key explanation to our research finding of the decline in women and men living alone. This is significant in terms of availability of informal support, as spouses, regardless of gender, are the primary source of support for an elder 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 so they both do not end up as residents of a long term care facility.

Our findings demonstrate that over the next 20 years (2001-2021) the likelihood of having a surviving child will increase among the population aged 85 and older. This is an unique time in our history when only 16% 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 older 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 generation differences will have less 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 & 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 person 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, counseling, 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. We know that the increased labour 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. Secondly, 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 & 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 have caregiver-related policies. These include employment insurance (federal level) and tax credits (both federal and provincial levels). Employment leave policy “Compassionate Care Benefit” allows eligible employees up to 55% 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.

A synthesis of national-level policies for caregivers of elderly persons with needs for assistance in Canada and nine other countries is available from our website www.msvu.ca/mdcaging/policyprofiles.asp. Alternative or augmented policies are the focus of our discussion in the next section.

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:

- 1) Home care policies: Include Caregiver Assessment as part of home care policy; Increase available caregiver services such as respite care; and Expand eligibility criteria (or caregiver definition) to include friends and neighbours.
- 2) Workplace policies: Expand the Canadian Compassionate Care benefit³ (Government of Canada, 2005) in terms of expanding eligible employees and length of leave; Include family leave days in the federal labour code; and Provide incentives to private workplaces to expand their policies on family leave to include eldercare responsibilities.
- 3) Income security policies: Compensate caregivers financially through a non-taxable allowance; Implement a refundable tax credit for caregivers; and Expand the Canada Pension Plan to include a drop-out clause for eldercare and pension credits for cumulative caregiving work.

Internationally, some of the 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. 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 \$90 CAD biweekly) for all caregivers providing 20 or more hours per week and an additional means-tested carer payment for low income caregivers (\$459 CAD biweekly). For more information on international financial compensation policies for caregivers, please see our website: www.msvu.ca/mdcaging/policyprofiles.asp.

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.⁴ To this end we have chosen to cost out two policy proposals, one which increases services for caregivers and one which introduces a modest financial support for caregivers. These two proposals were investigated using two scenarios of establishing the

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

⁴ All dollars in this paper are presented in Canadian dollars. One Canadian dollar is roughly equivalent to .66 Euro and .80 USD.

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 compensate caregivers by providing them with a set stipend in recognition of their work. Assumptions of cost include respite services costing \$25 per hour; a caregiver stipend costing \$50 per week; and long term care facility bed 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 2001-2051 (see Keefe, Légaré & Carrière, 2004b for details). In attempting to project utilization rates of policy proposals and their projected cost in the future, we recognize that there may be a number of caregivers for each elderly person requiring assistance. However, it is likely that government-sponsored policy will be directed towards the primary caregiver or one caregiver per person in need.⁵ For the purposes of this policy discussion we limit our caregivers to be 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 one of four types of activities of daily living. In Scenario 1 the number of caregivers was limited to the proportion of elderly persons receiving informal support (ranging from 61-65% over the 50 year period) and in Scenario 2, it was assumed that each care receiver has a caregiver (e.g. 100% of moderate and severely disabled elderly living in the community would have a family/friend caregiver providing support). These scenarios give the range of potential costs from minimum to maximum to assist policy makers in their analysis.

The cost of delivering the monthly stipend 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 compensation in 2001 to 2.2 billion in 2031. Scenario 1 is based on projected use of informal support by elderly persons with moderate and severe disabilities and ranges from a high of 65% in 2001 to a low of 61% in 2051. The cost to other parts of the health care system of not supporting caregivers needs to be calculated. Here we have introduced the possibility that without caregiver support the care receiver may enter a long term care facility three months earlier than if the caregiver had received support. For example one month in a long term

⁵ Or at least support one caregiver at a time as per the Canadian Compassionate Care Benefit.

care facility costs the government, depending on the jurisdiction, an average of \$3000 per month.⁶ If such policies would delay institutionalization by three months, the cost savings of introducing a respite care policy would be three times that of the institutional costs. The cost savings of the caregiver stipend option is six times that of the institutional projections (e.g. in 2001 an additional three months of long term care would cost 6.5 billion compared to the 2.1 billion in respite care and 1.1 billion invested through a caregiver stipend).

Scenario 2 assumes that should policies of respite or caregiver stipends be introduced, there would be more informal support available⁷ and that *all* elderly persons with moderate and severe disabilities would have an eligible caregiver. 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 2.1 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 three 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 and Keating et al., 1999).

⁶ 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 born by the resident (may vary by province).

⁷ 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 a stipend (in other words they would “come out of the woodwork”).

Recent Developments and Policy Directions

Disability has a significant impact on the need and use of home care services in the future. Understanding its impact must be viewed in the context of home care in Canada. During the time frame of our study The Commission on the Future of Health Care in Canada released its 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 the informal support network. 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 the informal support system. 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: (a) there are no infrastructure costs as the person is in his/her home, (b) the level of professional services required may be reduced and para-professional staff are less expensive, and (c) 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 (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 our results which suggest the informal support network will decline slightly over the next 30 years.

This shift towards 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. Moreover such policies are 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). Recent debate in Canada about the most appropriate ways to support family and friend caregivers has been fuelled by the announcement of the federal government of a Minister of State for Families and Caregivers.

The main distinction of our project 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 informal 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 our health care system.

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Figures & Tables

Figure 1. a. Proportion of Males 65+ Living Alone Among those Living in the Community; b. Proportion of Females 65+ Living Alone Among those Living in the Community.

Figure 1a

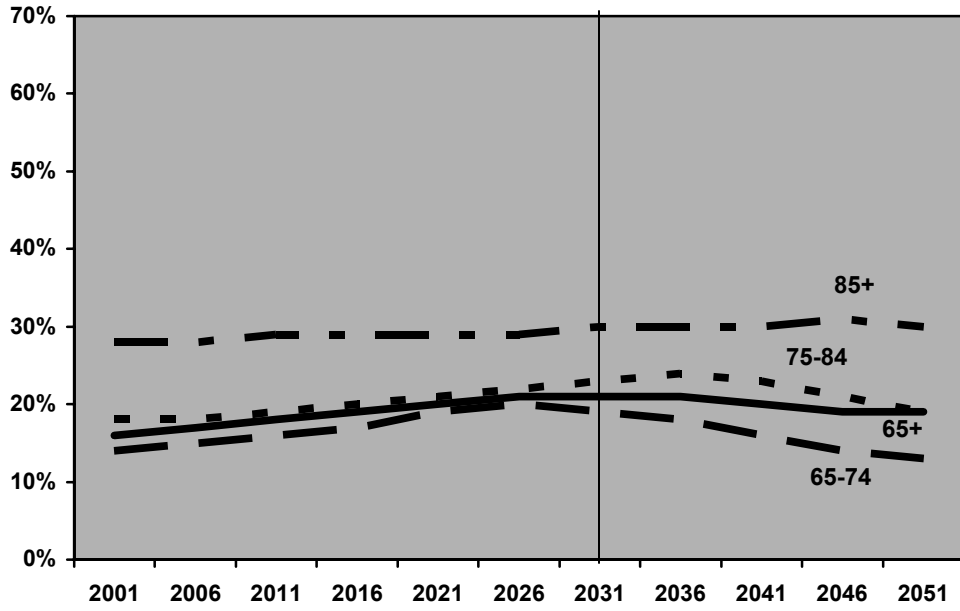


Figure 1b

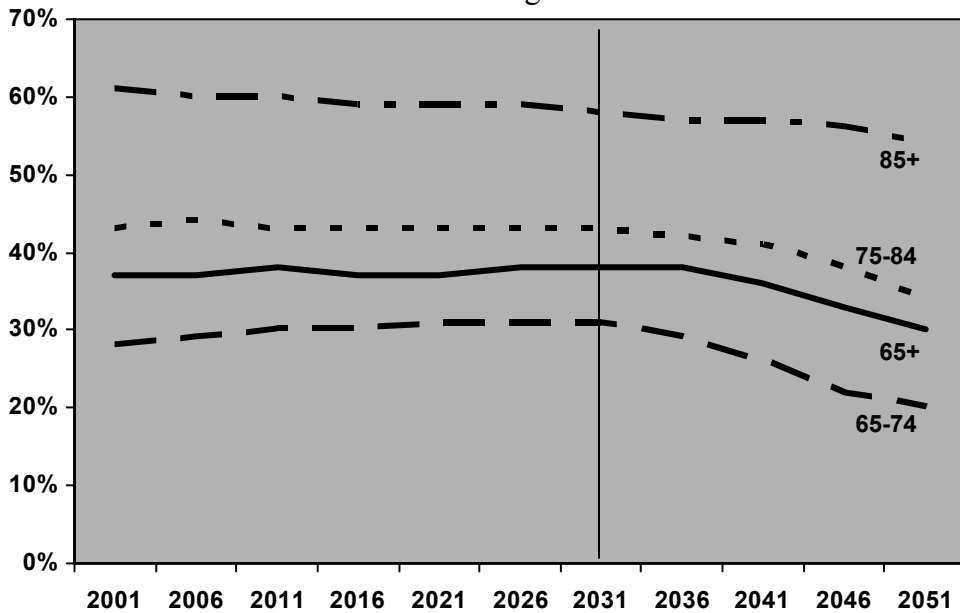


Figure 2. Proportion of Females 65+ Living in the Community with No Surviving Children.

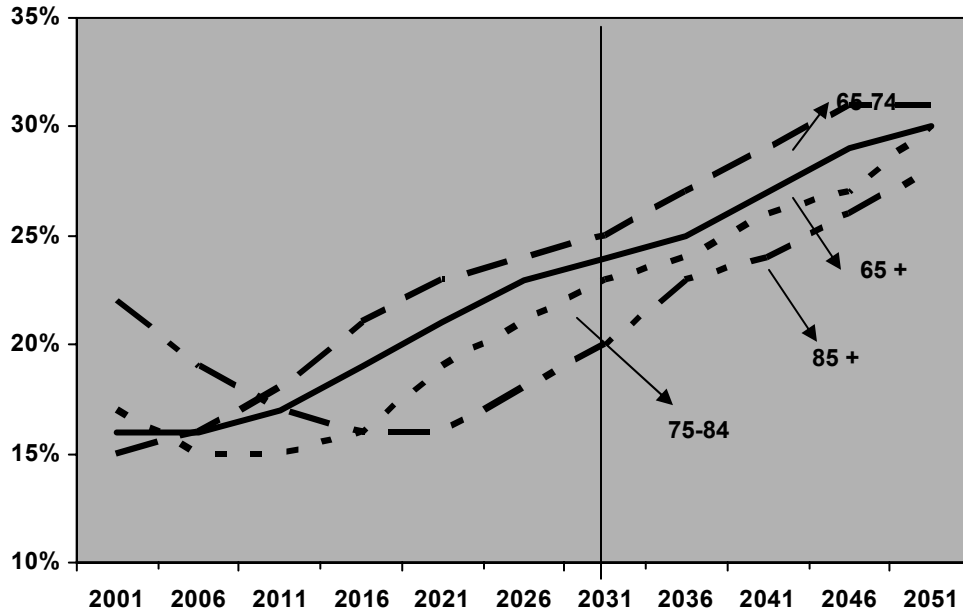


Figure 3. a. Proportion of Disabled Males Aged 65+ among those Living in Private Households, Canada, 2001-2031; b. Proportion of Disabled Females Aged 65+ among those Living in Private Households, Canada, 2001-2031.

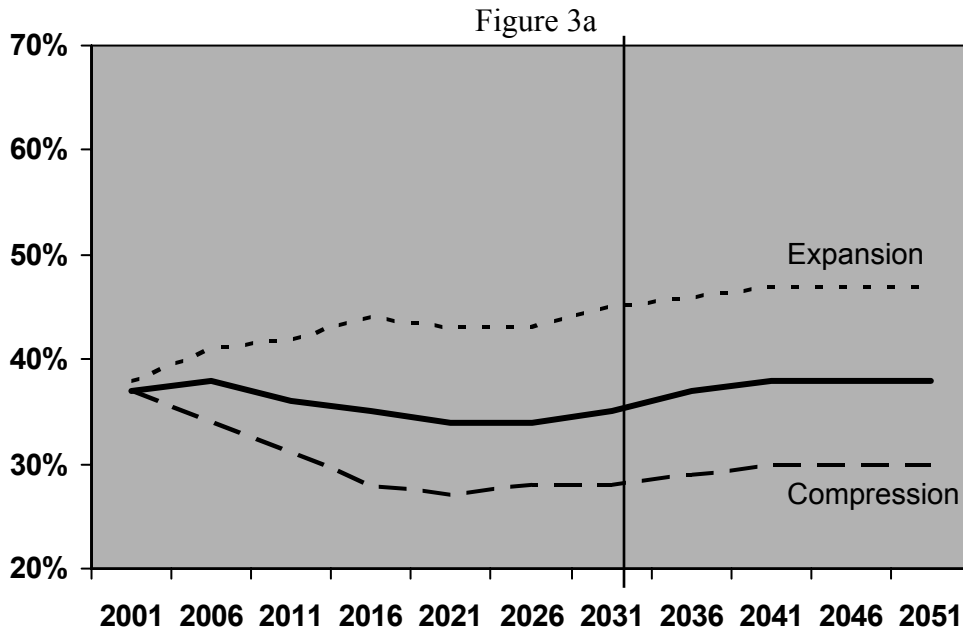


Figure 3b

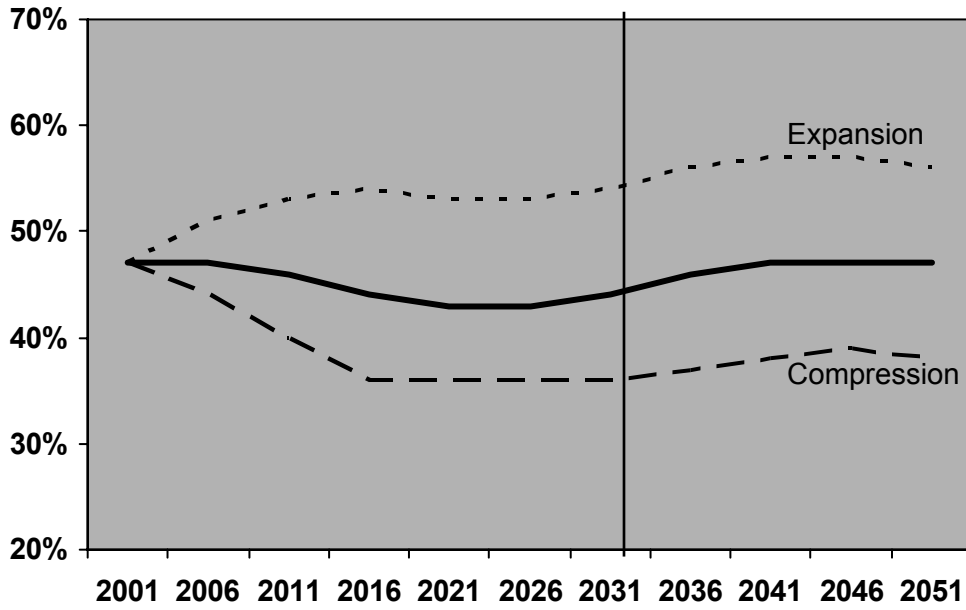


Figure 4. Proportion and Number of Elderly Persons Needing Assistance Using the Baseline Scenario, Canada, 2001-2051.

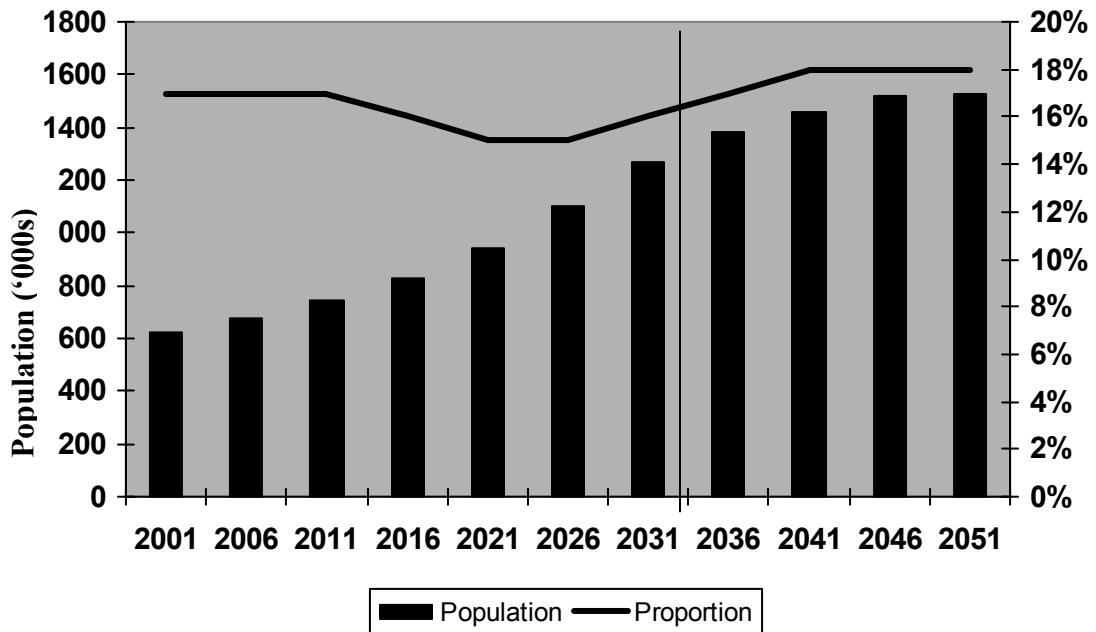


Figure 5. Distribution (in %) of Disabled Elderly Living in Private Households Needing Assistance by Source of Assistance, Canada, 2001-2031.

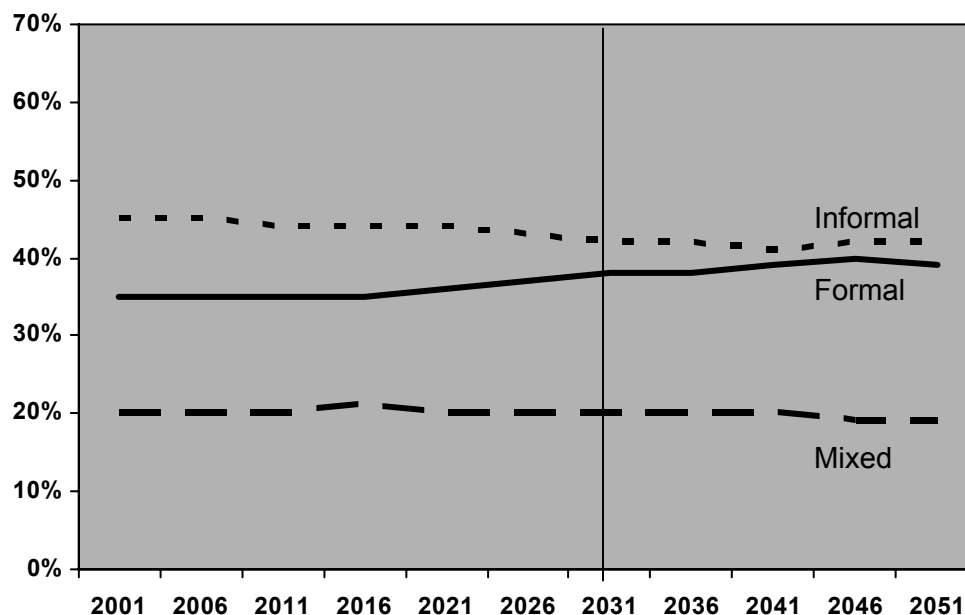


Table 1. Annual growth rate (2001-2031) of the Population Aged 65+ Receiving Assistance by Source of Assistance and Disability Scenario (Base, Compression, Expansion), Canada.

	Baseline scenario	Compression scenario	Expansion scenario
Population 65 +	2.6	2.7	2.5
Population in need	2.5	1.9	3.1
Formal	2.7	2.1	3.4
Institution	2.9	2.6	3.3
Informal	2.2	1.5	2.8

Figure 6. Scenario 1: Cost of Supporting Persons 65+ with Moderate or Severe Disability who Receives Informal Support (Compensation=\$2400 per year/per person; Services= \$5200 (4 hrs/week/year) additional respite; Institution= additional 3 months (\$3,000/month)^{8,9}).

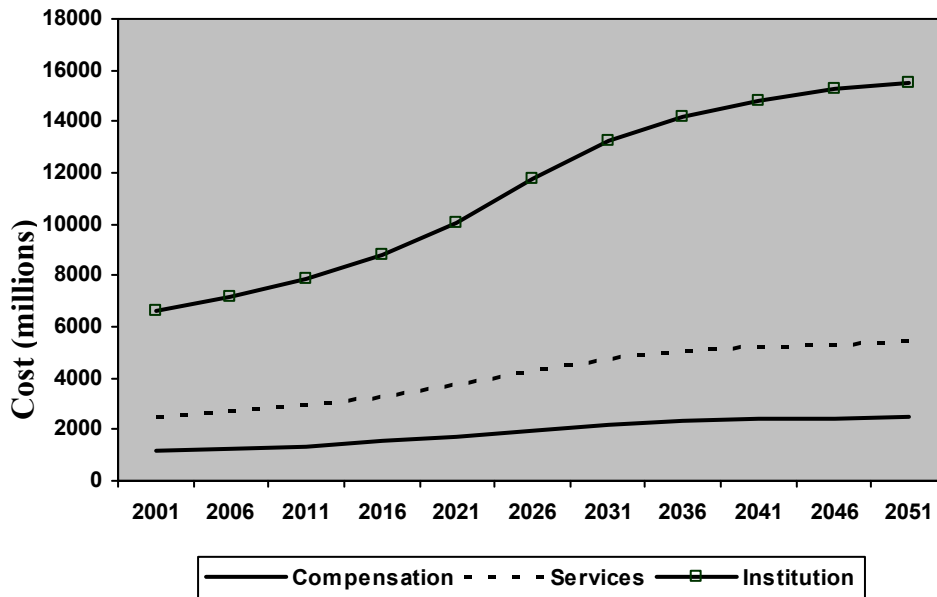
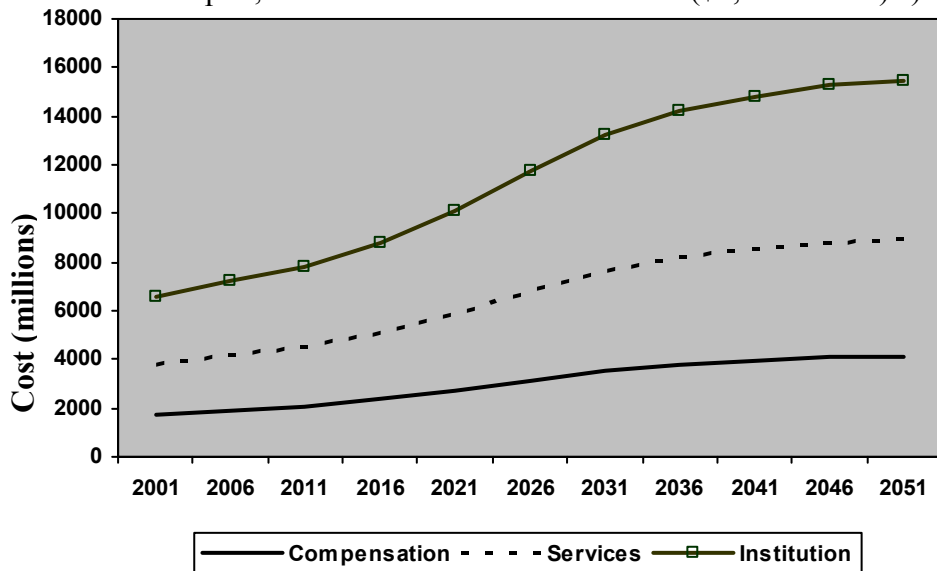


Figure 7. Scenario 2: Cost of Supporting Persons 65+ with Moderate or Severe Disability (Compensation=\$2400 per year/per person; Services= \$5200 (4 hrs/week/year) additional respite; Institution= additional 3 months (\$3,000/month)¹⁰).



⁸ All dollars in this paper are presented in Canadian dollars. One Canadian dollar is roughly equivalent to .66 Euro and .80 USD.

⁹ 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 born by the resident (may vary by province).

¹⁰ Ibid.