

Caring-About-Caregivers: Caregiving for the future of Ontario

Long-Range Scenario Planning Supporting Caregiving into 2033

November 27, 2009

Ministry of Health and Long-Term Care

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Caring-About-Caregivers: Caregiving for the future of Ontario

One in five Ontarians is a family caregiver, contributing to more than 70% of total caregiving needs¹. In 2011, there will be 1.4 million women in Ontario aged 25-44 of whom 4 in 10 will become caregivers at an age when they have to juggle work, family and social life². These caregivers are our invisible healthcare partners. They are tired and hurting. Without family caregivers and other informal caregivers, Ontario's health care system will not be sustainable.

In September 2008, the Caring-About-Caregivers Long-Range Scenario Planning (LRSP) project began to explore ideas that would better support family caregivers and other informal caregivers. Working with 300 participants, 8 long-range themes and 23 robust ideas were identified that can begin today to support caregivers into the future. After consulting with project participants, partners and stakeholders, four strategic themes are recommended for further strategy and policy development:

- *Adapting the Definition of Caregivers to Changing Families and Communities*
- *Competing and Caring in Shifting Economies and Demographics*
- *System Navigation and Education*
- *Building on Social Networks*

In Baroness Pitkeathley's address to the UK government, she said, "If the carers (caregivers) movement in the UK has had any success – and it has had a great deal – that success has principally been about what I always call – Turning a private trouble into a public issue."³ Similar to the UK, the voice of the caregiver in Ontario is becoming louder and so too "a private trouble" is turning "into a public issue." Other Canadian jurisdictions such as British Columbia, Alberta, Manitoba, Quebec and Nova Scotia have begun to respond to the same "private trouble" with different approaches. The Government of Canada's Special Senate Committee Report on Aging also identified the need for a National Caregiver Strategy. The government of Ontario needs to "step up to the plate" now and position itself to respond to the call for a comprehensive caregiver strategy.

In Canada, the traditional support networks for informal caregiving are disappearing. For example, nuclear families have decreased by 18%. There are three times as many single person households, as households of 5 persons or more. 51.5% of the population was not married in 2006, outnumbering the married population for the first time since the census began. 42.7% of households had no children. 1.5

million single parent families, i.e. 1 in 4 families with children is headed by a single parent, up 8%. Single parent families headed by men increased by 14.6%, more than 3 times the rate of single parent families headed by women⁴.

In addition, the burden of Canadian caregivers is high. 10% of Canadians report having a family member who requires constant care from a family caregiver. 27% of Ontario families have been providing constant care for over 2 years. 1 in 6 Ontarians report that constant care requirements have a major impact on the ability to earn family income. 1 in 4 caregivers has no help; 1 in 4 have paid help; 61% need more help. The average caregiver has spent twenty hours per week caring for four years; one quarter have spent forty hours per week. 32% also have children under 18 living at home. 15% of caregivers describe their quality of life as poor⁵.

Canadian research estimates informal care represents over \$80 billion dollars in economic value: an “industry” comparable to the manufacturing sector in labour income and more than twice as large as the combined labour incomes for the financial, insurance and real estate industries⁶. According to the Hollander, Liu and Chappell report⁷, the cost of caregiving for Canadian seniors 65+ extrapolated to 2007 is as follows: the annual cost at hourly market rates for homemakers is \$24,155,528,240. The annual cost at hourly market rates by type of provider is \$31,298,054,777.

In light of the above information, it seems relevant that, in 2006, the Ministry of Health and Long-Term Care (MOHLTC), in support of the development of the 10-Year Plan For Health, conducted a long-range scenario planning (LRSP) project on the sustainability of Ontario's health system into 2026⁸.

Support for family caregivers and other types of informal caregivers was identified as one of two critical emerging domains that required further investigation because there were insufficient existing policies, development and research work available. The importance of this domain was validated by health leaders and researchers across Canada, as well as senior government decision-makers in Ontario.

In September 2008, the MOHLTC began the Caring-About-Caregivers initiative to explore the importance of caregivers in the sustainability of the health system and how to support caregivers into the future. Using LRSP, over 300 participant stakeholders and experts collaborated in identifying caregiving challenges and promising ideas for the future that we can begin exploring today.

From these challenges, 8 themes and 23 strategic options evolved. These gave direction to four final themes and recommendations. These thematic areas are: Adapting to the Definition to Changing Families and Communities; Competing and Caring in Shifting Economies and Demographics; System Navigation and Education; and Building Social Networks. Government now has an opportunity to move forward with a caregiver strategy that will not only meet the needs of informal caregivers and recipients of care but also do so in a responsive and accountable manner.

Introduction

Looking ahead three decades from now, the future of informal caregiving is a fundamental challenge for Ontario. Ontario adopted social, educational and economic structures to accommodate the baby boom surge. This trend and other emerging demographic shifts (e.g. increasing immigrants, decreasing birth rates, diminishing numbers of traditional nuclear families) will pose many challenges to the health system. Thinking about the future and acting today to plan for it are facilitated by long range scenario planning – a planning mindset that is optimistic, opportunistic, and that builds on the belief that choices made individually and collectively can make a difference.

A discussion on the future of informal caregiving is based on the roles and relationships between individuals and families, government, community and market, and how these components interact and change over time. The dynamics within and between these groups reflect changes in demographics such as: an aging population, fluctuations in the economy, technological advancements, shifts in individual preferences and social norms, and decisions on public policy. “Effective partnerships between caregiver organizations, researchers and practitioners are driving policy advances and leading to a growing recognition globally of the role of caregivers in economic and social development.”⁹

Current research indicates that declines in informal caregiving contributions result in either heightened spending on formal community care services or in costly and unnecessary institutionalization.¹⁰ Yet, besides these known costs, there are other social and economic considerations. These considerations include the direct implications on the social, health and economic status of caregivers themselves, all of which are potentially affected by the caregiving role. For example, informal caregiving also affects the right to participate in the workforce. Without protection and support, informal caregiving may represent a significant leakage of skills and talent from the labour market — a labour pool which is projected to decrease in the coming decades.¹¹

Looking forward to 2033, it is essential to ensure a new breadth in the approach to informal caregiving. The 2033 picture of informal caregiving does not reflect caregiving as an isolated family responsibility within which all losses and costs are expected to be contained and absorbed. As the global population ages, it is certain to have a significant impact on each social component. Some factors, such as the aging of baby boomers or the smaller size of their families cannot be changed. These are demographic trends which are fixed and relatively immune to intervention. However, other factors are uncertain and unpredictable such as the political, economic, cultural, social and technological trends. Changes in each present both risks and opportunities. But waiting until after change has occurred is often too late. By becoming open to action now, we can anticipate and respond to changes-to-come, and avoid significant expenditures and opportunity costs in other components of our social fabric. Strategies for informal caregiving, as presented in this report, are inter-connected and inter-dependent, thus all needing to be addressed to some degree in any subsequent provincial policy response.

Valuing informal caregiving suggests that it complements and completes the continuum of care and support for residents/clients and patients. Despite the challenges, there continue to be many optimistic predictions that many, if not most families, will continue to try to provide social support and personal care, even in the face of escalating economic pressures. How we anticipate and exploit future changes in social norms, economic activity and technological advancement are seen as essential to the task of managing the intersection of family with community, government and business.

Not everyone is equipped to be a good family caregiver and even though a family member may wish to provide care, they may not be the most appropriate person to provide that care because of a history of abuse, neglect or not having the mental/emotional/physical capacity. Baroness Jill Pitkeathley, the former director of Carers UK, has unequivocally stated that “there are some relationships into which caring should never be imposed,” and “it cannot be assumed that family members are equally suited to provide care for an older person ... this would indicate that those individuals and families who are thinking about taking on the caregiving role need to be assessed with respect to their relevant capabilities before such a responsibility is considered”¹²

Caring for a family member has long been viewed as the primary responsibility of the family in Ontario. Yet isolating this role overlooks the many intersections between family and informal caregiving in our social architecture. The responsibility for caregiving is a social one, with deep connections and dependencies with community, government and business. Does this vision of informal caregiving, within the context of a significant shifting demographic, reflect reality? Why does the previous and traditional vision of informal caregiving need a paradigm shift? A review of significant milestones helps to position both the need for a new vision of informal caregiving and the changes needed in the existing health system design.

Context

In 2004, the Ontario government indicated that "Instead of short-term fixes, we're working to transform health care delivering effective care in the community... Ontarians will have access to around the clock family health teams... We will enhance home care so that patients have the choice of receiving care at home"¹³. Miriam Hirschfeld also comments on the same need and challenge¹⁴, "Changing demography, epidemiology and social realities - such as urbanization, growing poverty, migration, changes in family structures, and growing participation of women in the labour force - make the search for long-term policies one of the most pressing challenges facing modern society".

Concepts such as informal caregiving and the caregiver continue to be used to refer to health care in the broader community. These are not new. However, some historical milestones show how central, important yet changing these concepts become to health care across all age groups as they are impacted by ongoing changes in social, economic, technological, environmental, legal, political, and shifts in demographics.

Noteworthy is the fact that home care lacks national standards of care resulting in a diversity of service responses involving public and commercial/business sectors. Despite the responses, responsibility for

providing care for persons in their communities has remained, in large part, with the family, neighbours and volunteers. As care from informal caregivers is eroded, or threatened, a variety of stakeholders and community groups have mobilized to express their concerns.

The supportive care recommendation in the Romanow Commission Report¹⁵ lacked focus and priority for informal caregivers – provinces were urged to expand supportive home care but only ‘as resources permit’¹⁶. Supportive care became the responsibility of provincial governments but only as their discretion might dictate. So, by example, what did Ontario do?

The government took on the role of contracting out to nonprofit and for-profit homecare providers, the services required to support the home care sector, including the screening of patients/clients to assess service needs. Thus, 43 CCACs (14 today) were established across Ontario. However CCACs struggled to accommodate a growing demand for supportive care. Priority was given to ‘medically necessary’ services to accommodate the earlier hospital discharge of acute and sub-acute patients and their needs for care.

The reality is that informal caregiving is not easily defined or described as a simple act or skill. It is rooted in a complex social relationship. Uniquely, informal caregiving is needed not only in homes, hospitals and long-term care facilities, but also in hostels and ‘on the street’ where the homeless live¹⁷.

Noteworthy is the fact that traditional support networks are disappearing. Nuclear families have decreased by 18%. There are three times as many single person households, as households of 5 persons or more. 51.5% of the population was not married in 2006, outnumbering the married population for the first time since the census began. 42.7% of households had no children. For the first time, there were more households without children than with children. 1.5 million families, 1 in 4 families with children, is headed by a single parent, up 8%. Single parent families headed by men increased by 14.6%, more than 3 times the rate of single parent families headed by women¹⁸.

The 2006 Census enumerated 8,896,800 census families in Canada. Married couples constituted the largest group (68.6%), although their proportion has been steadily decreasing for the past 20 years. Common-law and same-sex couples are on the rise. In addition, Canadian adults are not marrying – just over 51% of adults (15 and over) were unmarried – up from 49.9% in 2001. Two-thirds (65.7%) of Canada's total of 5.6 million children aged 14 and under lived with married parents in 2006, a decline from 81.2% in 1986¹⁹.

According to the 2006 Census²⁰, Ontario had the highest proportion of married-couple families in Canada (73.9%). Common-law families represented only 10.3% of all census families, the lowest proportion in Canada. Lone parent families account for 15.8% of families. In 2006, 17,500 same-sex couples in Ontario were counted, representing 0.6% of all couples in the province. Over one fifth of same-sex couples in Ontario were married.

The context within which caregivers and care recipients interact matters. Context impacts and determines the parameters within which informal caregiving occurs and the quality and outcomes of the care given. To date, informal care is "unpaid, done with little formal training and based on an existing relationship"²¹. The question arises: How prepared and confident are informal caregivers in accepting and executing the requirements demanded in increasingly complex care settings in the home? Aronson has remarked that "Just as family, marketplace and voluntary solutions to home care users' unmet needs are inequitably distributed so, too, are their capacities to engage in the physical, cognitive and political work of receiving and accommodating themselves to insufficient care"²².

Impacting the complexities and challenges of informal caregiving are: efforts to de-institutionalize care; changes in family patterns and lifestyles such as one-parent, common-law and gay/lesbian families; and the decreasing numbers of volunteers who traditionally have contributed many hours of care in a variety of programs and services throughout communities. In the context of these changes, is there a need to re-examine the services needed by informal caregivers?

The need to integrate informal caregiving in communities is not without substantial and complex challenges that must be addressed through careful and long-term planning. Common issues that remain include caregiver burden and frustration; lack of training/education and information for what is called 'skilled caregiving'; the degree of stress experienced in relationships in the caregiving environment; a general decline in overall caregiver satisfaction and health; depression; reduced opportunities for social interaction outside the caregiving environment; and extra expenses and significant financial losses as caregivers give up employment to care for loved ones²³.

The issues are substantiated by evidence from research. For example, 10% of Canadians report having a family member who requires constant care from a family caregiver. 27% of Ontario families have been providing constant care for over 2 years. One in six Ontarians report that constant care requirements have a major impact on the ability to earn family income. One in four caregivers has no help; one in four have paid help; sixty-one percent need more help. The average caregiver has spent twenty hours per week caring for four years; one quarter have spent forty hours per week. Thirty two percent also have children under 18 living at home. Fifteen percent of caregivers describe their quality of life as poor²⁴.

"Intentionally, or not, holding family caregivers accountable for the provision of care without adequate resources is completely unacceptable"²⁵.

The foregoing challenges suggest direction for the types of supports needed by informal caregivers and those receiving care. "These include recognition of the value and importance of caregiving by families, communities, governments and businesses; information about supports that are available; training for caregivers to increase skills and sensitivity and for employers to foster managerial expertise; respite care; help with daily caregiving activities such as routine chores; and financial support to ensure family income security"²⁶. Also, "governments can take a leadership role in leveraging supports from all sectors in society, thereby creating a more sustainable and equitable approach to caregiving in Canada"²⁷.

Caregiver Cost

How much should caregiving cost us today?

Cost of caregiving for Canadian seniors 65+ extrapolated to 2007. The annual cost at hourly market rates for homemakers is \$24,155,528,240. The annual cost at hourly market rates by type of provider is \$31,298,054,777²⁸.

The Caregiver in Ontario – A Portrait

Annual Costs of Caregiving for Seniors Aged 65+ v.s. Population of Potential Caregivers Aged 15-64 Extrapolated to 2030

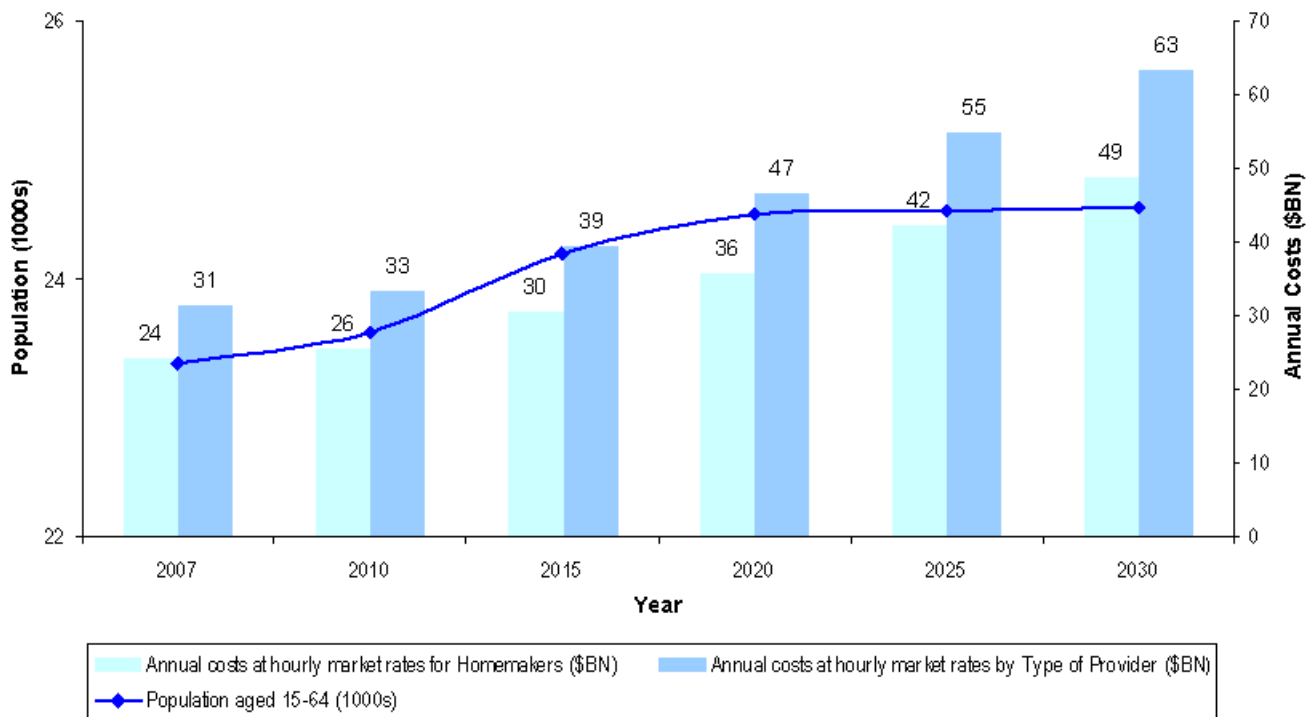


Figure 1 Using 2007 extrapolated costs from “Hollander (2009) Endnote (7)” and population projection from “United Nations World Population Prospects 2008”

What do our stakeholders say about Ontario’s informal caregiver?

It has been stated that the role of informal caregivers requires recognition and support through evidence-based policies and programs. Policies and programs need to be applied fairly to informal caregivers in

both community and institutional settings. Informal caregiving, in its current state, leads to a high level of physical and mental stress. 46% of caregivers experience stress. 14% experience physical discomfort or physical pain. 15% report that people for whom they care are verbally or physically abusive. 19% were frail, disabled, or needed care themselves.²⁹

In light of the above, collaborative and consultative sessions and strategic conversations were undertaken by the Ministry of Health and Long-Term Care (MOHLTC) to address the contextual issues, heighten the quality of the care experience for informal caregivers and care recipients, and help create informal caregiver supports that would sustain home care within the parameters of quality and economic realities.

In September 2008, the MOHLTC initiated the “Caring-About-Caregivers” project to explore long-range ideas to respond to the emerging challenges faced by caregivers. The initiative was undertaken by the Long-Range Scenario Planning Unit of the Health System Strategy Branch (HSSB) of the MOHLTC through the ‘Caring-About-Caregivers’ initiative, and was structured around three purposes. These were to:

- implement the LRSP methodology to identify and address gaps and issues faced by informal caregivers;
- identify robust strategies that support informal caregivers and that are relevant despite the unpredictability of the future; and
- identify areas for informal caregiver policy development based on recommendations drawn from evidence.

This report is the tangible outcome of an Long-Range Scenario Planning (LRSP) initiative that is unlike some earlier study initiatives that often lacked consultation with providers, recipients of care, advocates and academics within a collaborative and consultative environment.

It helps to position further research and action to advance caregiving within a newly visioned context that carries informal caregiving in Ontario to 2033.

Methodology

About Long-Range Scenario Planning (LRSP)

Long-Range Scenario Planning recognizes that the future cannot be predicted. However, we need to make long-term choices informed by strategies that are robust enough to succeed in the face of unpredictable change.

The LRSP process is a collaborative effort which engages opinion leaders, practice leaders, planners and decision-makers across the system, informed by subject matter experts and available data. It involves the identification of expected major trends, drivers and challenges over the next 25 years. It blends those elements into extreme but plausible scenarios. Those scenarios are then tested against strategic responses, to identify critical future turning points.

About Scenario Integrity

An important element in long-range scenario planning is testing the plausibility and integrity of future scenarios, and robust strategy themes that are common across scenarios.

There is a risk of unintentionally excluding some demographic cohorts when looking for robust themes, or those themes with the broadest effects. Marginalized groups run the risk of becoming even more marginalized if the effort is not made to incorporate their perspective.

To address this, the Caring-About-Caregivers project tested the scenarios, themes, and strategies with key expert informants from a selection of cohorts which are often underrepresented in policy decisions. As an example of this process, leaders and experts from the Lesbian, Gay, Bisexual and Transgendered (LGBT) community and from First Nations communities were consulted in a separate process, which supplemented the LRSP exercise. These and other experts' feedback on the robustness of stratagems is reflected in this document. While this is not a comprehensive exploration of how these stratagems will affect these communities, it is hoped that this additional consideration will improve the inclusiveness of resulting policy decisions.

About the Caring-About-Caregivers Initiative

The expectations our society holds of caregivers tend to be framed in dated scenarios: intact nuclear families; discretionary time; sufficient workplace benefits with coverage and flexibility; extensive community networks; and accessible, responsive and healthy non-profit agency networks. The care burden is also changing as we move costs away from a formal and publicly funded system and towards the individual. Where are the long-term opportunities to redress this growing imbalance?

Long-range scenario planning enables an exploration of plausible futures over the next 25 years. LRSP was used to determine areas of promise as identified by over 300 participant stakeholders and experts. These areas of challenges and promise include:

- how we manage and share information;
- how we leverage technology as an enabler;
- how we consider the social and economic importance of care and caring; and
- how we enable a tri-sectoral (government, business and non-profit) wraparound model of supports for the individual caregiver, and for those who receive care.

This report builds on the robust common themes from the scenarios, the policy implications of these themes, and the policy and societal actions that can be taken in the short- and long-term.

LRSP in Action - Consultation Process

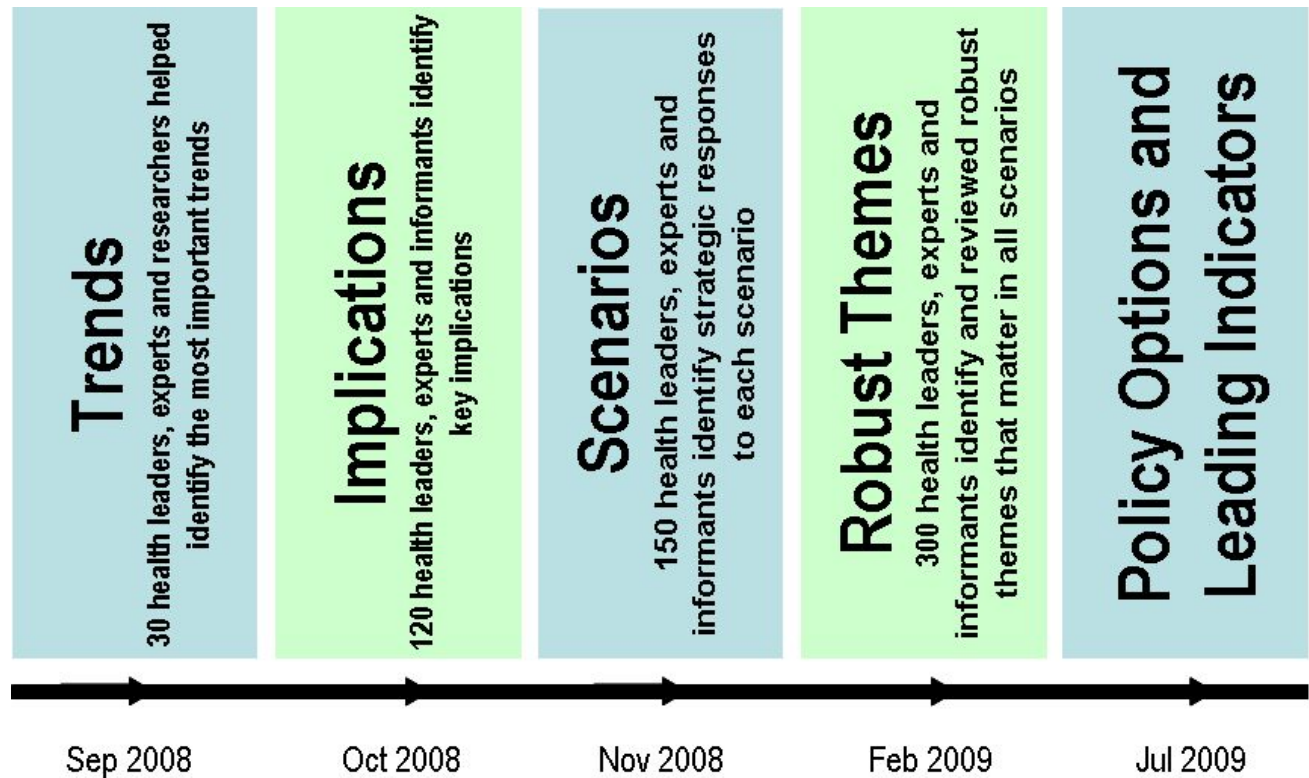


Figure 2 Caring-About-Caregivers Process Timeline

Trends

The Caring-About-Caregivers (CAC) Project began in September 2008 with three streams of work to identify major caregiver themes and trends with unpredictable impact on caregivers:

- Literature scan on caregivers to identify dominant themes and existing research (MOHLTC Research and Planning Unit)
- Environmental scan for major trends with unpredictable impact on caregivers (CAC team)
- Interviews with 30 health leaders, experts and researchers to validate the themes, the trends and their potential impact on caregivers (CAC team)



Figure 3 Trends and Drivers Impacting Caregivers

Results of the three work stream was compiled into a PESTEL (Political, Economical, Social/Demographic, Technological, Environmental, Legal) Primer on major trends and their potential impact on caregivers into the future (See Appendix – Project Phase 1 - 2 Products: PESTEL Primer).

Implications

In October 2008, 100 health leaders, experts, researchers and caregivers participated in two three-hour workshops to identify major trends and their implications for caregivers. The PESTEL Primer was circulated in advance. Participants were asked to review the primer and identify what they felt were the top trends and implications for caregivers. At the workshops, participants were first presented with a video presentation, "In 1983" showing what Ontario and the world looked like 25 years ago. They were then given an overview of the PESTEL Primer, and asked to participate in a "Wicked Questions" session to identify inherent paradoxes and contradictions in the system and their work. They were also asked to identify the top trends and implications for caregivers. Facilitators recorded the workshop sessions. The participants were also given workbooks to record their thoughts. Twenty key informants and experts were also interviewed on the same questions.

Scenarios

The transcripts from the Implications Workshops and the workbooks, as well as the interviews, were consolidated and thematically coded by the project team in 3 passes. The top trends and their respective implications were analyzed and clustered into 4 groups of plotlines. Four narrative scenarios about caregiving 25 years in the future were developed (See Appendix – Project Phase 3 Products: Future Scenarios of Caregiving). These scenarios were tested by the team and selected participants for plausibility and relevance to the topic of caregivers.

In November 2008, 120 health leaders, experts, researchers and caregivers participated in two three-hour workshops to identify strategic responses to the future scenarios. The scenarios were circulated in advance.

Participants were then asked the following for each of the four scenarios:

1. What is desirable, and what is not?
2. What strategy, policy, program or public infrastructure is needed in the scenario to make it viable for caregivers?
3. What strategy, policy, program or public infrastructure is needed today so that the features described in (2) are viable?
4. Promising examples or ideas?

Facilitators recorded the workshop sessions. The participants were also given workbooks to record their thoughts. Thirty key informants and experts were also interviewed about the same questions.

Robust Themes and Options

The transcripts from the Implications Workshops and the workbooks as well as the interviews were consolidated and thematically coded by the project team in 3 passes. The top strategy themes were identified together with their respective promising examples or ideas. A further literature scan was conducted to validate the strategic themes, examples and to identify additional options. The results were summarized in the Policy Implications discussion paper (See Appendix – Project Phase 4 Products: Robust Themes and Ideas).

8 strategic themes 23 strategic options were identified in the discussion paper:

Adapting to the Changing Demographics of Family

1. Reconstructing the Policy Definition of “Caregiver”
2. Ensuring a System of Protection for Care Recipients

The Importance of Social Networks: Changing Forms of Social Connection

3. Strategic Investment in Neighbourhood “Hubs”
4. Strategic Investment in Social Cooperatives
5. Building a System for Social Networking
6. Implementing “Good Neighbours” Legislation

Valuing Caregiving

7. A Public and Political ‘Voice’ for Informal Caregivers
8. Strengthening Ontario’s Awareness of the Informal Caregiving Role
9. Expanding the Meaning of “Best Employer”
10. Reanimating Volunteerism for the 21st Century

Improving the Scope and Efficiency of Informal Caregiving through Technology

11. Stimulating the Development of Technology-Enabled Systems

12. Using Virtual Technology to Reduce Information Deficit

Timely Access to Reliable Information

13. A Structure to Enable System Navigation

14. A Provincial System of Caregiver Education

Promoting Opportunity and Choice for Support

15. Creating a Formal Process for Caregiver Assessment

16. Empowering the Choices of Informal Caregivers through Self-Directed Care

17. Building a System of Support through Stable and Efficient Investments

18. Adopting a “Triple Bottom Line” (Social, Environmental, Economical)

19. Building a System of Support through Flexible and Portable Hubs

Flexible Benefits and Supports: Competing and Caring in the Context of Shifting Demographics

20. Initiating a Government – Business Dialogue for Informal Caregivers

21. Building Benefits and Employment Protection for Informal Caregivers

Promoting Equity and Enabling Vulnerable Populations

22. A Provincial Program with ‘Universal’ Benefits and Protections

23. Strengthening Outreach and ‘Wraparound’ Services for Informal Care Needs of the Vulnerable

Based on an analysis of the themes and options, the project team designed a questionnaire to survey internal and external stakeholders in order to validate and prioritize the strategic options as presented in the discussion paper.

Questions for the questionnaire were developed in February 2009 in order to prioritize the strategic options based on both internal and external stakeholder feedback. Each respondent was asked to reply to the following questions:

1. Which of the strategic options do you believe are compelling and also hold the greatest potential for significant change?
2. Are you currently engaged in initiatives; developing initiatives; or aware of the initiatives of others that support the strategic options in the report? Please provide contact names for follow up.

3. Are you currently engaged in initiatives; developing initiatives; or aware of the initiatives of others that invalidate the strategic options outlined in the report?
4. Which strategic options would benefit most from public policy development work now?
5. Are there other long-range or catalytic options that you would like to recommend?

The brief open-ended questionnaire was distributed to participants via email and in person through discussion groups. A copy of the strategic option draft discussion paper was distributed with the questionnaire.

Questionnaire Sample: Respondents were participants in earlier discussion groups, key informants in the field and representatives from the Local Health Integrated Networks (LHINs) and Community Care Access Centres (CCACs). The consultation process was held over a two month period. 310 questionnaires were distributed with 76 returned. This represents a response rate of 25%.

Questionnaire Data Extraction: Numerical Responses for recommended and priority options were recorded if the strategic option number was listed. If the strategic option was described, it was classified and coded.

Text explaining the reason for preferences or alternate suggestions was categorized and marked for extraction. Similarly, text identified as offering a new option or additional comment was marked, coded and extracted.

Questionnaire Coding Frameworks: Coding frameworks were developed for the following content areas in order to identify whether respondents shared the same opinion with regard to:

- The reasons why Strategic Options were preferred
- The content for: a) Variations of the Strategic Options; b) New Options; and c) Other Comments

Plan for Analysis of Questionnaire Responses: Frequency tables were developed for both recommended and preferred strategic options. The 8 themes from the discussion paper were ranked by average frequency of the endorsements of the individual Strategic Options for each theme. Themes were then ranked by average frequency.

Feedback related to each option was integrated into the text. Strategic Options which were ranked above the median of 11.5 were revised based on this input and from research and program examples provided by respondents to the questionnaire. Options with similar themes which were ranked above the median were

merged for further clarity. Feedback received on redundancies in the options was also taken into account (See Appendix – Project Phase 5 Products: Prioritization results).

Follow-up discussions with project participants and partners were then conducted to help finalize priorities. Four final major themes emerged as priority public policy development areas.

1. Adapting the Definition of Caregivers to Changing Families and Communities
2. Competing and Caring in Shifting Economics and Demographics
3. System Navigation and Education
4. Building on Social Networks

These are detailed as recommendations in the following sections of the report.

Recommendations

Theme 1 – Adapting the Definition of Caregivers to Changing Families and Communities

The recognition of informal caregivers is identified across all scenarios and by many interviewees and questionnaire respondents. By recognition, it is meant that the social status of the informal caregiving role needs to be acknowledged as a valuable contribution to society, as well as having significant economic value. Such formal recognition has the potential to increase the likelihood of persons taking on a caregiver role and safeguards against a perceived diminished social position. At present, most people are unaware of the economic and social value of informal caregiving. While information exists about the economic value of informal caregiving, this value is neither regularly monitored nor reported for public understanding. There is also no systematic method of trying to accurately capture the less tangible “social value” of informal caregiving.

Recognizing the value of informal caregiving and enhancing political and economic responsiveness to the caregiving role is viewed as vital to the well-being of the caregivers themselves, and their family and friends. One way to increase the value of caregiving is to clearly define the role of caregiver.

An important determinant of the future supply of informal caregivers is the reconstruction of legislation, rules, and eligibility criteria to an open definition of ‘informal caregiver’: one that includes non-family members and support networks, to include friends, neighbourhood and community. Two assumptions currently prevail in policy: 1) the caregiver(s) is a biological child or spouse; 2) the caregiver of preference is female. Neither of these assumptions is accurate or sufficient for caregiving policy in 2009, and will be radically outdated by 2033. The definition must be gender neutral and support both women and men in the role of caregiver. This is reinforced by a comment from one of our stakeholders who indicated that “*Women are (way) ahead when providing personal care and homemaking. But we still need to look at what men are doing now, so we can focus on what they can (be encouraged to) contribute in the future. But, right now, where we start from is that men are taking their mothers shopping and shoveling snow.*”

Public legislation, regulation and business policy on who is or can be a caregiver significantly determines the forms of eligible sources of informal caregiving. Public policies can expand or constrain the size of informal caregiving supply. Moving toward a definition of caregiver gives legitimacy to the role as well as a voice at the political table.

It is communicated that, “We’ve never given the issue of informal caregiving the fundamental place in public conversations that most families feel it deserves. Not like the way there has been over child care, and early childhood development. Part of the problem has been that caregiving is seen as a family responsibility, that it’s just something we do as families. I think it is a public policy issue. Providing the same opportunities to all families is a public policy issue.” It is important to recognize that two notes of caution were expressed during discussions: not to confuse the future role and functions in the community support services sector with the caring for caregiver policy development, and be aware of how much caregivers can legally do given the Regulated Health Professions Act³⁰.

The Continuing Care Strategy “Shaping the Future of Continuing Care in Nova Scotia” is a 10-year strategy³¹ rolled out by the Nova Scotia government in June 2008. As part of the strategy, the Government of Nova Scotia will “acknowledge the role of individuals and families have in achieving maximum health and independence” as well as ensuring “that caregivers and health providers are well supported.” In order to support individuals and families, the Nova Scotia government recognizes that “caregivers are partners in care and clients in their own right.”

Unlike the child welfare system in Ontario, there is no systematic approach towards a proactive, early warning method of legal protection for vulnerable adults and seniors. With an increase in the number of aging parents and informal caregiving arrangements, the number of incidents of identified and unidentified abuse, neglect, and unsafe or inappropriate living conditions will grow. Jurisdictions such as Scotland have recently adopted legislation and monitoring mechanisms in recognition of existing problems and in anticipation of the future growth of such problems as the population ages³². A related approach, drawing on Scotland’s experience, could be initiated for Ontarians.

Theme 2 – Competing and Caring in Shifting Economies and Demographics

Policies and benefits which intercede and interact across the boundaries of private and public policy require a thoughtful approach towards balance, trade-offs and shared gains. Actions in one domain inevitably impact the other, often in unanticipated and unwanted ways. As part of a dialogue on Ontario’s future economic policy, there is a need to include the economic and social goal of caregiving as not simply an altruistic value, but as a vital element of a competitive workforce. In 2033, the Corporate Social Responsibility movement (CSR) and the Sustainability imperative acquired the third leg of an economic stool – “Communities that work.”

The changing nature of work, and a shifting definition of what constitutes a “competitive advantage”, needs to be reflected in Ontario businesses. Government’s role in this dialogue may be to identify the ways in which provincial businesses can leverage and build on their existing programs to incent family and caregiver-friendly behaviour. Evidence-based corporate tax credits, in recognition of internationally competitive progressive policies, may help to associate these policies with a tangible fiscal value.

Institutionalizing the value of caregiver-friendly policies may be the catalyst that is required to spark businesses' self-directed adoption of these policies. Many stakeholders who participated in the LRSP project indicated that businesses were interested in improving their caregiver policies, but that they didn't want to "go out on their own". Stakeholders believed that the scenarios would be "increasingly compelling if government and business were to engage in dialogue over the fiscal incentives to enhance and promote caregiving culture."

What remains to be addressed are the economic needs of those who might prefer to exit the labour market by choice, or because the person for whom they are caring has physical and social needs that are too intense to allow for the continued employment of the caregiver. Under these circumstances, Employment Insurance (EI) is not viewed as the appropriate social program. Further consideration should include examination of how income credits can be instituted through other programs such as providing an income allowance so that becoming a caregiver does not result in unfair economic penalty or an increased risk of poverty. Suggestions include flex hours, job sharing, working from home, where possible, and tax benefits.

"Many of the caregivers I speak with want to stay in the workforce, but the person they are caring for can't be left alone."

The role of government, in relation to informal caregiving, was a fundamental theme, and robust across all of the scenarios. What was not apparent across the scenario themes was exactly what the role of government should or could be. The potential roles for government are diverse and, at times, even potentially in conflict: fostering an equitable and fair Ontario; building a competitive workforce and economy; supporting the evolution of recognition and social supports; and funding a modern integrated system that is flexible and responsive.

The failure to implement some public policy measures reflects a number of potential equity challenges:

- a. Growing income inequality as persons suffer a financial penalty for reducing employment in order to care for a challenged child or aging parent;
- b. Growing income inequality in wealth and savings as persons sacrifice future retirement income to provide informal caregiving;
- c. Increased health costs due to the economic and social strains of unsupported informal caregivers; and

- d. Increased number of persons living in circumstances of neglect and abandonment as families or friends chose not to assume informal caregiving responsibilities.

If there is a consensus on the role of government that is consistent across scenarios and from key informants, it is government as an enabler of choice rather than deliverer of services. The role of government is most frequently described as a facilitator of social action and adaptation, as well as having responsibility for bridging gaps, through balanced consensus-based solutions. This includes awareness and management of gaps across and within: changing family dynamics, evolving technology, shifting social connections, and the role of private industry.

The existing distribution of employee benefits, including extended health care coverage (e.g. prescriptions), is inequitable. While up to half of Ontarians do have access to such benefits, these tend to be concentrated in higher level, permanent positions.³³ Conversely, those in low-end non-skilled or precarious labour markets, despite having a higher prevalence of social, health and economic need, tend to have less or no access to such marketplace-driven protections and assistance.³⁰

The challenge is how best to create a balanced set of policy options among multiple informal caregiver stakeholders. Some options may include employer required options, social long-term care insurance, or tax-based systems of financing. While there are many choices for action, the outcome of inaction is relatively clear -- a further reduction in informal caregiver supply and an increased inequity among those who must choose between family responsibility and their other social and economic roles. Government has an active role to play in leveling the playing field and finding solutions which are balanced and mutually beneficial for both the caregiver and the provincial health care system.

At the turn of the 21st century, the federal government introduced the Compassionate Care Program under the umbrella of Employment Insurance. Most recognize and acknowledge the limitations of the current program in terms of eligibility criteria and use (e.g., the program consists of a one-time six week period), as well as lack of visibility and understanding of the program among both employees and employers.

Primarily defined as an “end-of-life” care initiative, there are major limitations on the Compassionate Care Program as a support for informal caregivers, whose role is neither predictable nor time-limited. Most view this innovative program as an early investment in creating a platform which expands eligibility and coverage to meet the demographic needs and employment challenges of an aging population.

The Compassionate Care Program is also structured to address the needs of those who ultimately wish to remain in the employment market -- a desire which will become increasingly important as the size of the labour market changes (e.g. a spike in the number of retirements). This is done through its integration within the Employment Insurance program structure, in a manner similar to maternity/paternity benefits. The same could occur for new caregiving programs and integration with existing family services.

Ensuring equity will also require consideration of the role of employers. Across Canada, there are a number of “best employer” lists which serve to both challenge other employers to strengthen their human

resource policies and their workplace environments. Introducing eldercare and informal care components to the “best employer” criteria would help stimulate a private sector response to shifting the social norms and benchmarks for what constitutes a desirable employer. Best employer lists to be engaged in this option may include Maclean’s “Canada’s Top 100 Employers”; the Financial Post’s “Ten Best Companies to Work For”; the Toronto Star’s “Greater Toronto’s Top 75 Employers”; Today’s Parent’s “Canada’s Top 10 Family Friendly Employers”; and the ‘Top Employers for Canadian’s Over 50’ (an appendix list to “Canada’s Top 100 Employers”). Criteria for best employer lists should include provision for informal caregiving for employees.

The importance of benefits and flexible workplace policy was identified as a robust theme in the long-range scenario planning exercise. Few participants felt that the role of businesses could be ignored, or that businesses, in turn, could ignore informal caregiving. However, there was strong recognition that carrying the economic burden of informal caregiving employees should not be left to private workplace policy. Most feel that doing so would lead to a patchwork of private sector policies which would create inequities (e.g., for those in low-paying high labour force supply positions), or uneven competitive disadvantages for employers in the marketplace.

Much of this work has focused on creating incentives for industry innovation and growth, as well as on ways to facilitate the availability of a skilled and educated labour force. However, U.S. research has indicated that the unacknowledged consequences of informal caregiving can affect competitiveness in a very different way. One recent study estimates that failure to recognize and manage the informal caregiving needs of employees can decrease productivity by approximately \$17.1 billion.³⁴ Recruitment of new employees is also increasingly viewed as a costly and avoidable expense.

Since the mid-1990s, British Telecommunications (BT) has recognized the challenge of maintaining a stable, skilled workforce, and has worked to accommodate the caregiving requirements of its employees. BT has 160,000 employees in 61 countries, of which 81% work flextime, and 18,000 are home-based workers. The net result of these policies is a 20% increase in production, and a savings of £180M per year (approximately \$375 million CDN). Similarly, BT retains 99% of 1000 pregnant women a year, compared to the industry average of 60%. This represents another cost savings to BT, as they estimate minimum recruitment/induction costs to be £10,000 pounds (over \$20,000 CDN) per employee.³⁵

BT implemented a variety of flex policies (e.g., emergency leave) and eldercare benefits (e.g., access to counselors) across the company. In the words of vice president Carol Waters: “you need the policies in place first, before policy implementation becomes expensive”. In partnership with government, BT has now assumed a leadership role, and is helping to lead a change process across the business community. This includes the development of supportive legislation and policy, such as the “Employers for Carers” initiative, which was implemented in conjunction with the association Carers UK.³⁶

BT is confident they have helped dispel the myth that addressing the needs of their informal caregiving employees is a corporate expense, and instead continues to produce hard evidence that such actions are an investment in the company’s productivity and future earnings.

One other consideration is found in Nordic studies aimed at enhancing the role of men in child-rearing. Findings point to the structural disincentives of taking advantage of existing time-off and benefit options; the decision is heavily influenced not only by economic considerations, but also ramifications for future career opportunities.³⁷ In a reverse result, rather than dropping out of the labour market, men “drop out” of informal caregiving roles. The implication is that structural change and incentives should be gender-neutral so that men as well as women increasingly see the opportunity to be an informal caregiver as a safe career move without negative consequences.

FIGURE 1 Potential Employer-Sponsored Elder-Care Supports		
<p>Flexible or Customized Work Arrangements</p> <ul style="list-style-type: none"> ▶ Informal or occasional flexibility ▶ Part-time work and job sharing ▶ Voluntary reduced time ▶ Phased retirement ▶ Compressed schedule ▶ Flex time ▶ Telecommuting or flex place <p>Paid Time Off</p> <ul style="list-style-type: none"> ▶ Sick days ▶ Vacation ▶ Sabbatical ▶ Personal days ▶ Paid time off bank 	<p>Paid or Unpaid Time Off</p> <ul style="list-style-type: none"> ▶ Family leave ▶ Medical or emergency leave ▶ Personal leave ▶ Bereavement leave <p>Policies</p> <ul style="list-style-type: none"> ▶ Time off ▶ Relocation policies <p>Insurance Coverage</p> <ul style="list-style-type: none"> ▶ Health insurance ▶ Dental insurance ▶ Life insurance ▶ Unemployment insurance ▶ Workers' compensation insurance ▶ Long-term care insurance <p>Financial Assistance</p> <ul style="list-style-type: none"> ▶ Publicizing federal or state tax credits ▶ Dependent-care reimbursement plan ▶ Subsidized dependent-care reimbursement plan ▶ Subsidized care or vouchers ▶ Discounts for care 	<p>Access to Information</p> <ul style="list-style-type: none"> ▶ Distribution of educational materials ▶ Resource library, possibly online ▶ Workplace caregiver fairs ▶ Workplace caregiver workshops and support groups ▶ Elder-care counseling and referral ▶ Promotion of elder-care locator ▶ Elder-care counseling through employee assistance program <p>Direct Service Programs</p> <ul style="list-style-type: none"> ▶ Geriatric case or care management ▶ On-site adult-care center ▶ Near-site adult-care center ▶ Intergenerational program ▶ Community resource development

Figure 4 Potential Employer-Sponsored Elder-Care Supports (Source: Rose, K., Work-Life Effectiveness: Bottom-Line Strategies for Today’s Workplace, WorldatWork 2006)

Aging in the Right Place was released by the Alberta government on December 15, 2008. The strategy sets out to improve health and personal care service options for seniors and persons with disabilities by enhancing supports to help them live within the community. The Continuing Care Strategy, *Aging in the Right Place*, was rolled out by the Minister of Health and Wellness with the support of the Minister of Seniors and Community Supports.

Through Manitoba’s Ministry of Finance, the government offers a Primary Caregiver Tax Credit. It is “an annual, refundable tax credit that can be claimed by a caregiver who is providing ongoing voluntary care to a family, friend or neighbour, verified through the Home Care program and assessed either by the regional health authority (RHA) or a Health Care Professional (e.g. Nurse, Social Worker) acceptable to the RHA. The caregiver can claim up to \$1,020 per year per client for up to three clients. The application is completed once unless there is a three-year absence from caregiving.³⁸”

The caregiver must be designated as the primary caregiver by the person receiving care. The caregiver can receive a tax credit for up to three people at any time as long as they are the designated caregiver.

The tax credit is only offered to those who are providing home care. A three-month qualifying period must be completed by each caregiver before being eligible to receive the tax credit³⁹.

“The tax credit is intended to support caregivers who work with individuals who require more intensive forms of assistance. The intent is to help these individuals – who might otherwise have to move to a personal care home or be hospitalized – live successfully independently for as long as possible.⁴⁰”

In Quebec, if a caregiver needs to obtain specialized respite services, they can claim a refundable tax credit for expenses incurred. “The maximum tax credit is \$1,560 per year. The credit is equal to 30% of the total expenses you paid in the year (to a maximum of \$5,200 in expenses) for specialized respite services for the care and supervision of a person.”⁴¹

Theme 3 – System Navigation and Education

System navigation is rarely used as an administrative term in either policy documents or academic research related to healthcare. Academic papers will sometimes discuss *patient navigators* or *caregiver supports*; while policy documents will often address access to information or education for caregivers.

Navigation refers to a centralized system of information to assist caregivers in navigating, discovering and learning about the options and choices for purchases, methods of monitoring quality etc.

In light of the above and for the purposes of this report, system navigation can refer to two related, but distinct activities. One implies the presence of trained personnel to ensure that caregivers have access to all available information and services. The second is directed at the creation of an information hub containing all of the necessary information about caregiver-related issues as well as available support services. The government plays a more passive role in the latter option as caregivers are responsible for accessing this database and making use of its resources.

Patient navigators have been defined as “someone who helps assist patients overcome barriers to care.”⁴² The creator of the patient navigator model emphasized that “Patient navigation connects individuals to real people rather than systems or buildings. Person-to-person contact is essential.”⁴³ Voluntary organizations can frequently assume this role. There is some evidence that patient navigators and similar personnel can improve medical outcomes. However, this research is very preliminary. Australia maintains a national network of Commonwealth Respite and Carelink Centres as well as a national toll-free number to provide information and assistance for caregivers. The British NHS also has a national toll-free number for caregiver assistance.

Most jurisdictions have some type of information hub online. However, there is enormous variance in the quality and accessibility of these databases. Most government hubs in Canada are low-profile pages on ministry websites. Australia has a dedicated website for caregiver services and information. The British government has special sections for caregivers on the government services and NHS websites. The research on technological caregiver supports is limited and largely inconclusive.

Currently, Ontario's health care system has multiple points of entry, multiple service options, some with eligibility criteria, some publicly funded, some only available through referral from a family physician. Respondents indicated that a structure needs to be in place to help caregivers navigate through Ontario's health system, whether the person being cared for is in an institution, in the community or in the home. It is crucial that tools be put in place for people to navigate the system with the help of a 'navigator' or through self-navigation. Physicians and caregivers both need improved understanding about what is available and how to access these resources.

Current systems are tightly bound to existing program structures and processes, with little cross-system capacity and flexibility. They focus almost exclusively on the 'client' or care recipient's needs and undervalue the informal caregiver. A forward-looking health and social system bridges program lines and the public/private divide, and creates a formal role for this function. Information programs can be used to create virtual and interactive online system navigation putting the caregiver in control of the navigation process on a 24/7 basis. This 24 hour accessibility is important given caregivers' time constraints, and difficulty fitting into the '9-5' working hours of human services.

Stakeholders indicated that "The way the current system is constructed caregivers have to do this incredible dance to access services. It's an incredible burden on them. When are we going to do something about streamlining access to information and services? This is a huge stress on these families. From my 35 years of experience at all levels, I can tell you: it's just nuts."

Respondents described the Alzheimer Movement that includes supports for caregivers, as one that has been crucial to the beneficiaries of the Alzheimer Society Chapters since inception in the 1970's and 1980's. In assessing caregiver needs, chapter support staff work with caregivers to identify support networks and encourage links with identified individuals to help with the caregiving roles. As well, consideration ought to be given to founding Family Resource Centres that are staffed by volunteers who are family members and who have lived experience that guides them in their assistance with other family members. They could help by providing information, helpful tips about how to navigate through the system and provide support for other family members so that their caring role continues.

Respondents also noted current structures that may prove useful in developing a system such as Service Ontario, E-Health, and the Chronic Disease Management Initiative. It is recommended that consideration be given to leveraging current funded programs and services rather than creating a new layer in the system.

Education is a powerful policy lever with the capacity to inform, engage and shift public attitudes. The Canadian Caregiver Coalition describes "Enabling access to user friendly information and education" as one of the essential elements of a Canadian Caregiver Strategy⁴⁴. The Special Senate Committee Report on Aging⁴⁵ agreed and identified access to information and education as significant components of a national caregiver strategy. It also identified two existing programs as potential models for patient navigation. The East Kootenay senior caregiver network supplies information and support to caregivers in a large, mostly rural, area of British Columbia through regular group meetings, a buddy system, a

newsletter and a toll-free telephone line. The First Link program here in Ontario was also cited. First Link coordinators are assigned to identify people within their region who suffer from impairment and inquire if they require any assistance or support.

A system of education for informal caregivers is lacking. Creating a system for both virtual and person-to-person education would add value to the informal caregiving initiative and supports available for the caregiver role. These supports may include setting up caregiving resources and how to find assistance; how to access and monitor the quality of support; and more complex and sophisticated learning on medical issues etc.

Respondents indicated that caregivers face an information deficit in that they do not receive timely, accurate information about where to go for services or support. Improving the quality of information available and making caregivers aware of how to access a full range of resources in the community is key to improving the lives of caregivers. However, respondents also cautioned that consideration must be given to recognizing that not all caregivers have access to a computer. Thus, information for caregiving and caregivers must be available in print form as well.

Respondents indicated that a caregiver's educational needs can be identified through an assessment. For example, we need to ask: 'Can you do this work and perform the care required with intravenous therapy, oxygen delivery systems and catheters in the home if you haven't experienced them before?' Once the caregiver's education needs are identified, s/he can be directed to the relevant education tools or information.

A lack of information is often cited by informal caregivers as a major system deficit in Ontario. Closing the information deficit is viewed as a critical step in enhancing the capacity of informal caregivers to effectively deal with future challenges. Ironically, the information deficit is sometimes a consequence of an information surplus. This discrepancy between quantity and accessibility can be the result of fragmentation, contradictory content, and sheer overload. At other times, the deficit is caused by the absence of an informal caregiver lens applied to the available material.

Today's technology, using virtual approaches and telephone services, is able to support an information and support network built around a provincial portal or virtual hub that can then be integrated and linked to localized supports. The private sector offers many successful models of a centralized point of access to localized services (e.g. hotel and restaurant reservations; customer support lines).

As part of Alberta's *Aging in the Right Place* strategy⁴⁶, the "Caregiver support and enhanced respite" initiative focuses on caregiver support and enhanced respite for caregivers. In some cases, informal caregivers in Alberta provide around 80% of the required care. A provincial caregiver education, skills training and counseling program will be in place. In addition, a mechanism to pay caregivers for out-of-pocket expenses and respite care will be implemented. This initiative is targeted to be completed in 2009.

Additionally, the second initiative of the *Aging in the Right Place* strategy calls for a health system navigation system to support seniors, persons with disabilities and their families with making appropriate, informed care arrangements – knowing their limitations and choices. From 2009 to 2012, a health system patient navigation system will be implemented with a province-wide navigation system in place by 2012. In 2012, an evaluation and continuous improvement system will be in place to support navigation⁴⁷.

The Nova Scotia strategy⁴⁸ also outlines improving how individuals and their families can access and move through the continuing care system so that the right care is received at the right time (e.g. a directory of services in multiple languages).

Theme 4 – Building on Social Networks

With the shrinking size of the average Ontario family,⁴⁹ and its implications for how informal support is organized and supported, a common theme is how to encompass the role of friends, neighbours and the community, and how to support the sustainability of these roles. There are few places where an informal caregiver can find assistance with the strains and challenges of their role.

Most existing social policy is linked to the concept of neighbourhood as the basis for service delivery and social connection. One of the prevailing policy concepts related to this is the ‘hub’, a centralized location with a wide mix of integrated services. The ‘hub’ compliments the neighbourhood approach and lays the groundwork for future needs when exclusively neighbourhood-centric approaches will no longer meet a community’s needs.

Investment in this area should include a framework focused on strategic coordination, advice and outreach. With harmonious implementation, ‘hubs’ that build on existing platforms will provide alternative supports at the community level. These geographically based ‘hubs’ should be attached to known locations in the community such as schools, community centres, Legions or Community Health Centres.

Included in the infrastructure are co-operative living and ways to integrate community members and the service system. Two ideas suggested throughout the LRSP process were: enabling peer support for caregivers in the form of “Family Resource Centre” and neighbourhood networks of caregiving based on models like “Share the Care”⁵⁰ and intergenerational care programs (which would recruit and educate young people as caregivers to the older generation and vice versa). The “Share the Care” model in particular is a proven method of engaging and creating networks to help distribute the burden of care for someone who requires support over a medium to long period of time.

In a Canadian context, social cooperatives can evolve from existing models of social connection. Unions, professional groups (e.g. teachers and civil servants), and demographic communities could facilitate opportunities for shared informal caregiving and volunteerism -- building on groups that are already closely aligned in background, experience and preferences.

In Japan, a nation at the forefront of the elder explosion and a dramatic undersupply of family informal caregivers, “Senior Co-operatives”, by and for seniors, have grown to more than 100,000 members over the past decade.⁵¹ In the Koreikyo model, the active elderly (roughly 55 to 75 years old) provide care for the frail elderly (generally 75 and older) in the care receiver's own home, through the co-operative's home-helper dispatch centers.

Social connection amongst caregivers can also be mirrored with the development of technological connection. Contrary to the prevailing perception of older adults and technology use, there is online activity in this demographic cohort.⁵² Rather than Facebook and MySpace, older adults engage with online social network services such as Rezoom, Multiply, and Boomertown.⁵³

The current dominant ideal of social connection is based on a strong sense of geographical-based neighbourhood community. The neighbourhood approach reflects a time in which people were geographically, socially and economically located for life in a single geographic area of close proximity. However, considering the forces of the modern economy, globalization and technology, The neighbourhood community as policy platform needs to evolve to capture the dynamic forms of social connection, now and in the future.

Despite best efforts, many people will remain vulnerable to a future in which their limited social network does not translate into a robust caregiving network. This risk is particularly prevalent among those who are already economically and/or socially marginalized due to extreme poverty, homelessness, serious mental illness, substance abuse or similar challenges. Research tells us that often among these individuals, social networks are non-existent, small or dysfunctional.⁵⁴

There are demographic cohorts in Ontario who have also, broadly speaking, not been reached by a generic service structure, which lacks the capacity for outreach and/or specialization. In the case of northern, and northern Aboriginal communities, accessibility is a constant issue.⁵⁵ Services which have the flexibility to be culturally relevant and responsive were also highlighted by respondents as a critical step in building an inclusive system.

Ensuring equitable support among vulnerable populations will continue to require the services and attention of professional and community agencies. At the same time, a philosophy of enabling and strengthening existing and building new forms of social support should guide the formal service models. Current service models tend towards being professionally intensive, at the same time as being fragmented and disconnected. New forms of “wraparound” care -- social networking and integrated services -- need to become the dominant mode for modern caregiving support models.

“My grandmother mostly spoke Ojibwa. She was placed in a room with an Italian woman who didn't speak much English. This was upsetting to her. All she did was cry, she didn't want to be there. Her home community was tough, she had plumbing but no water. But when her ties to community and culture were broken, her spirit was taken away. It's more than just where we live, it's our culture. If there had

been a resource or opportunity for her to be with other First Nations people, it might not have been so bad for her."

Consideration should be given to finding an Office that relates well with the Seniors' Secretariat and other relevant bodies that would include the broader populations of children and adults so that concerns, studies, policies may be discussed, and dialogue, coordination and best practices continued and strengthened. It is necessary to begin to build a network of expertise across Canada. As well, the idea of organizing cooperative living complexes is a variation of social supportive housing which is an option for LHINs to develop under the "Aging at Home Strategy". Patient Centred Medical Home is a complementary approach that has been utilized effectively in a number of jurisdictions to maintain people in the community, as they prefer, rather than going into residential care⁵⁶. Establishing an "Office for Caregivers" is an option for coordinating the support system for caregivers. This would offer more flexibility to work across multiple population groups (and not just seniors) and look beyond the health system for a broader strategy.

Noteworthy is 'Caregivers Nova Scotia,' an association dedicated to providing recognition and practical supports for family and friends giving care. It is a not-for-profit association with a volunteer board of directors and a staff of three. Their vision is "Caregivers are supported as essential partners in care." They receive financial support yearly from the Nova Scotia Department of Health – Continuing Care Services. They provide education to caregivers (workshops newsletters, book and lending library), telephone caregiver assistance and community-based peer support groups. In addition, the Association helps influence public policy for caregivers by working on Task Forces and Working Groups⁵⁷.

Social connection over the next thirty years will most likely progress in many ways, perhaps even less shaped by the restrictions of geography and proximity. While discarding and neglecting the local community model is neither desirable nor logical, it is necessary to explore structures and processes of cooperation that support the social connections of a mobile society.

Conclusion

Ontarians “value many aspects of health care. It can contribute to good health and a good quality of life. We value the system’s role in comforting and caring for people when they are in poor health. We value a system built on principles of fairness, equity and universality. Beyond those basic values, tougher questions emerge”

(Health Council of Canada. Value for Money – Making Canadian Healthcare Stronger. Health Council of Canada, Feb 2009 p4. www.CanadaValuesHealth.ca).

Caregivers are critical partners in the health system. Recognizing the value and contribution of caregivers, as well as their emerging challenges, Ontario initiated the Caring-About-Caregivers project.

A new perspective on informal caregiving is needed – one that would describe the interconnected opportunities that would sustain informal caregivers, and, by extension, improve the quality of care. Government, experts, patient advocates, service providers, caregivers, neighbours, business and the community, with all the bridging social networks, should all have a stake in sustaining informal caregivers and caregiving.

This project identified five positive and plausible principles that framed the informal caregiver initiative. First, minimizing the social, economic and health costs of informal caregiving increases the likelihood that families will willingly assume the responsibility of caring for challenged and dependent children or aging parents, as most do now. Second, fostering balanced capacities and responsibilities between men and women will stimulate a larger supply of persons to care for children and aging parents. Third, with respect to caregiving provisions and policies, the productive capacity and economic prosperity of Ontario is dependent on creating a reciprocal and flexible partnership between labour force participants and business – a caring Ontario is a competitive Ontario. Fourth, creating choice empowers informal caregivers and the care recipient, thus establishing a system that is more effective and efficient. Fifth, changes in social connections do not represent a breakdown in caring and caregiving but a different form of how these occur.

Through the LRSP planning process, stakeholders, who were actively engaged in consultations, strategic discussions and interviews, surveys and collaborative sessions, described a new vision for the future of

informal caregiving that can inform future policy direction. The 8 themes and 23 options were deemed essential key components for providing appropriate and sustainable support for informal caregivers and, as such, should all be considered. Based on further consultations with partners, this report is recommending development begin first on options in the following 4 themes:

- Adapting the Definition of Caregivers to Changing Families and Communities
- Competing and Caring in Shifting Economies and Demographics
- System Navigation and Education
- Building on Social Networks

This will help lay the foundations for the subsequent 4 themes.

Continuing support from the government, employers and community is needed to develop and sustain informal caregivers in the future. Caregiving as a social responsibility needs to be valued across society. Social networking, a strength yet to be ‘tapped’ to its full potential, is a source that can positively impact informal caregiving within the economic reality of Ontario’s health care system. “The challenge for policy makers is to determine how best to meet the range of needs, insure that families are not overburdened and, at the same time, control publicly funded costs”⁵⁸.

References

- 1 Stobert, S. And K. Cranswick, “Looking After Seniors: Who Does What for Whom”, Canadian Social Trends, Autumn 2004
- 2 Statistics Canada. 2006 Census.; Available from: <http://www12.statcan.ca/census-recensement/2006/rt-td/index-eng.cfm>
- 3 Pitkeathley J. A View of the Caregiver Movement: Today and Tomorrow; Available from: http://www.aarpinternational.org/usr_attach/Pitkeathley-KeynoteSpeech.pdf
- 4 Statistics Canada. Family Portrait: Continuity and Change in Canadian Families and Households in 2006. 2006 Census, Ottawa, 2007.
- 5 Deloitte Inc. 2009 Survey of Health Care Consumers - A comprehensive assessment of consumer attitudes, behaviors and unmet needs. Deloitte Center for Health Solutions.; Available from: pmacmillan@deloitte.ca
- 6 Zukewich N. Unpaid informal caregiving. Canadian Social Trends [Internet]. 2003;(Fall 2003, no. 70). Available from: <http://www.statcan.gc.ca/bsolc/olc-cel/olc-cel?lang=eng&catno=11-008-X20030026622>
- 7 Hollander MJ, Liu G, Chappell NL. Who Cares and How Much? The Imputed Economic Contribution to the Canadian Healthcare System of Middle-Aged and Older Unpaid Caregivers Providing Care to The Elderly. Healthcare Quarterly [Internet]. 12(2):42-49. Available from: <http://www.longwoods.com/product.php?productid=20660>
- 8 Ministry of Health and Long-Term Care. Health System Sustainability 2026. Health Results Team for Information Management, 2007.
- 9 Canadian Caregiver Coalition . Caregivers: Essential Partners in Care; 2008.
- 10 Wilkins, K. And M. P. Beaudet, “Changes in social support in relation to seniors. use of home care “, Health Reports, Spring 2000, 11, 4; Trottier, H., Martel, L., Houle, C., Berthelot, J.M. t and J. Légaré, “Living at home or in an institution: What makes the difference for seniors?”. Health Reports, Spring 2000, 11, 4

11 McMullin, J.A., Cooke, M., and R. Downie, Labour Force Ageing and Skill Shortages in Canada and Ontario, Canadian Policy Research Network, 2004

12 See 3 above.

13 Smitherman, George, Media Release, MOHLTC, 2004.

14 Miriam Hirschfeld. The "Canadian Model" in the International Context. HealthcarePapers [Internet]. 1(4):103-107. Available from: <http://www.longwoods.com/product.php?productid=17360>

15 See 16 below.

16 Commission on the Future of Health Care in Canada. Commission on the Future of Health Care in Canada - Final Report [Internet]. [cited 2008 Apr 24]. Available from: <http://www.hc-sc.gc.ca/english/care/romanow/hcc0086.html>

17 Armstrong P, Kits O. One Hundred Years of Caregiving. In: Caring for/caring about: women, home care, and unpaid caregiving. Garamond Press; 2004.

18 See 2 above.

19 See 2 above.

20 Government of Ontario MOF. Census 2006 Highlights - Ontario [Internet]. [cited 2008 Sep 15]. Available from: <http://www.fin.gov.on.ca/english/economy/demographics/census/>

21 See 17 above.

22 Aronson P. "Just Fed and Watered": Women's experiences of the gutting of home care in Ontario. In: Caring for/caring about: women, home care, and unpaid caregiving. Garamond Press; 2004.

23 Cranswick K. Help close at hand: relocating to give or receive care. Canadian Social Trends. 1999;(Winter 1999, no. 55).

24 See 5 above.

25 Ward-Griffin C, McKeever P. Relations between nurses and family caregivers: partners in care? Advances in nursing science. 2000;22(3).

26 Varga-Toth J. A Healthy Balance: A Summary Report on a National Roundtable on Caregiving Policy in Canada. Canada: Canadian Policy Research Networks; 2005.

27 See 26 above.

28 See 7 above.

29 Canadian Homecare Association, Human Resources Development Canada, Canadian Homecare human resources study. Canadian home care association, 2003.
<http://www.cdnhomecare.ca/content.php?doc=33>

30 Government of Ontario. Regulated Health Professions Act, 1991, S.O. 1991, c. 18. http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_91r18_e.htm

31 Government of Nova Scotia. Shaping the Future of Continuing Care in Nova Scotia . Spring 2006.
https://gov.ns.ca/health/ccs_strategy/SFP_Provincial_Steering_Committee_Report.pdf

32 Scotland, Adult Support and Protection Act, 2007

33 Hurley, J. and G. E. Guindon, Private Health Insurance in Canada, CHEPA WORKING PAPER SERIES Paper 08-04, 2008; Vosko, L., "Precarious Employment In Canada: Taking Stock, Taking Action," Just Labour, 3, 2003

34 MetLife Mature Market Institute®/National Alliance for Caregiving, The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business, July 2006

35 Interview with Caroline Waters, Director, People & Policy, British Telecommunications Group, 2008-12-15

36 See 35 above.

37 Smith, A.J., Parental leave: supporting male parenting? A study using longitudinal data of policy variation across the European Union. Paper given at the EURESCO Second Demographic Transition in Europe Bad Herrenalb, Germany 23-28 June 2001

38 Government of Manitoba (Ministry of Finance). Frequently Asked Questions About the Primary Caregiver Tax Model. p. 2 of 6. www.gov.mb.ca/finance/tao/faq.html

39 Government of Manitoba (Ministry of Finance). Frequently Asked Questions About the Primary Caregiver Tax Model. p. 3 and 4 of 6. www.gov.mb.ca/finance/tao/faq.html

40 Government of Manitoba (Ministry of Finance). Frequently Asked Questions About the Primary Caregiver Tax Model. p. 5 of 6. www.gov.mb.ca/finance/tao/faq.html

41 Government of Quebec. Tax credits for Informal Caregivers.
<http://www.revenu.gouv.qc.ca/en/citoyen/clientele/aidant/default.aspx>

42 Fowler et al. Reducing Disparities in the Burden of Cancer: The Role of Patient Navigators. *PloS Medicine*. July 2006, 3(7)(e193): 974

43 Freeman, Harold. "Navigating Cancer Care and Research." *Journal of Oncology Practice*. September 2006, 2(5): 243.

44 Canadian Caregiver Coalition. A Framework For Canadian Caregiver Strategy. December 2008.
<http://www.ccc-ccan.ca/media.php?mid=229>

45 Carstairs S, Wilbert Joseph K. Canada's Aging Population: Seizing the Opportunity - Special Senate Committee on Aging Final Report [Internet]. Canada Senate; 2009 [cited 2009 Apr 24]. Available from: <http://www.parl.gc.ca/40/2/parlbus/commbus/senate/com-e/agei-e/rep-e/AgingFinalReport-e.pdf>

46 Government of Alberta. Continuing Care Strategy: Aging In The Right Place. 2008.
<http://www.health.alberta.ca/documents/Continuing-Care-Strategy-2008.pdf>

47 See 46 above.

48 See 31 above

49 See 4 above.

50 Share The Care – How To Organize A Group To Care For Someone Who Is Seriously Ill.
<http://www.sharethecare.org/>

51 Marshall, R., "Of, By and For Seniors: Japanese Seniors Co-operatives", *YES Magazine*, Fall 2005

52 Richtel, M., Social networking sites take notice of seniors, *New York Times*, September 6, 2007

53 See 52 above.

54 Cranswick, K and D. Thomas, "Elder care and the complexities of social networks", *Canadian Social Trends*, Statistics Canada, Summer 2005; Krause N. and E. Borawski-Clark, "Social class differences in social support among older adults", *Gerontologist*, 35. 1995; Seeman T.E., and L. Berkman, "Structural

characteristics of social networks and their relationship with social support in the elderly: who provides support”, *Social Science & Medicine*, 26 1988; Berkman L, and T. Glass, “Social integration, social networks, social support, and health” in *Social Epidemiology*. Edited by Berkman L, Kawachi I. New York: Oxford University Press; 20

55 Laurent, S. *Rural Canada: Access To Health Care*, Health Canada, 2002

56 *Canadian Medical Association Journal*. Family physicians urge creation of “medical homes” for every Canadian. 2009-10-30. http://www.cmaj.ca/earlyreleases/30oct09_medical_homes.shtml

57 Caregivers Nova Scotia. About Us. <http://www.caregiversns.org/aboutus.php>

58 Health Canada. *The Future of Caregiving*. Seniors Info Exchange, Winter 1997-98 p6

Appendices

Project Products

The reports and presentations of this project can be downloaded at:

<http://www.box.net/caring-about-caregivers>

Phase 1 - 2

PESTEL Primer Summary

<http://www.box.net/shared/static/bq44x8mxra.pdf>

PESTEL Primer

<http://www.box.net/shared/static/4xqx432zoo.pdf>

In 1983 ... (video)

<http://www.box.net/shared/static/zkqre7psmb.wmv> (For PC)

<http://www.box.net/shared/static/b8co7gbofb.mov> (For Apple/Mac)

Phase 3

Future Scenarios of Caregiving

<http://www.box.net/shared/static/0nl16dkhjo.pdf>

Did You Know 3.0 (Copyright 2008 Sony BMG)

<http://www.box.net/shared/static/liudqodoty.wmv> (For PC)

<http://www.box.net/shared/static/3i7yyvpv75.mov> (For Apple/Mac)

Phase 4

Discussion Paper: Robust Themes and Ideas

<http://www.box.net/shared/static/2dyc5giozr.pdf>

Phase 5

Prioritization Results and Findings

<http://www.box.net/shared/static/5hvnjvlzqu.pdf>

Final Report

<http://www.box.net/shared/static/qklbs1131q.pdf>

