C A R I N G - A B O U T - C A R E G I V E R S

POLICY IMPLICATIONS

OF

LONG-RANGE SCENARIO PLANNING
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Summary
Introduction

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 of caregiving is a social one, with deep connections and dependencies with community, government and business.

Each social component overlaps and interacts with the other, achieving benefits, addressing risks and minimizing losses. A discussion on the future of informal caregiving is based in the roles and relationships between individuals and families, government, community and market, and how these components 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.

One of five Canadians is an informal caregiver with women still being the dominant demographic group. Over 70% of caregiving (e.g. meal preparation, driving for errands, housework, personal care) is provided by family, friends and others. The contributions of these caregivers are fundamental to maintaining a person in their chosen home environment. Canadian research estimates informal care represents well over $80 billion 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 industries. There is also a growing awareness that as the baby boomer population ages over the next thirty years, the need for informal caregiving will increase - testing the limits of family and public policy alike.

Current research clearly indicates that declines in informal caregiving contributions result in either heightened spending on formal community care services or in costly and unnecessary institutionalization. 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 on caregivers themselves, all of which are potentially affected by the caregiving role.

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1 Informal caregivers are those who provide care for one or more family member, relative or friend who may be a child or an adult who has a long-term physical or mental condition or who is frail or disabled, needs care, attention or similar

2 Social architecture is the term used to describe the roles and responsibilities that are used to design and implement relationships among family, market, community and state from, Jane Jenson, Canada’s New Social Risks: Directions for a New Social Architecture, Canadian Policy Research Network, 2004

3 Pyper, W., “Balancing Career and Care”, Perspectives, Statistics Canada, November 2006


5 Zukewich N. Unpaid informal caregiving. [Internet]. Canadian Social Trends. 2003; (Fall 2003, no. 70): Available from: http://www.statcan.gc.ca/bsolc/olc-cel/olc-cel?lang=eng&catno=11-008-X20030026622

When quantifying the need to support informal caregivers, another important consideration is the cost to economic production. Recent U.S. research (2006) suggests that $17.1 billion in productivity losses can be correlated with employees balancing their work and their informal caregiving responsibilities. 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. 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.

How Ontario and Canada have perceived and responded to the family role and capacity in child-rearing offers an analogy for the possible future of informal caregiving. Over the past three decades, there has been increasing policy focus placed on raising children. What had long been viewed in western countries as a narrow family responsibility is in transition to being viewed in the context of community, society and economy.

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: political, economic, cultural, social and technological. 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.

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. This is a task which starts in 2009.

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About Long-Range Scenario Planning and the Caring-About-Caregivers Project

About Long-Range Scenario Planning (LRSP)

Long-Range Scenario Planning (LRSP) 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 this Report

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. This report uses LRSP to address these thematic questions — questions posed by over 150 participant stakeholders and experts alike.

Areas of 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 carer, and for those who receive care

How we address these challenges will be a major test for our society — a society which is both aging and which includes many people (adults and children) who have long-term chronic care needs.

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

Unless otherwise indicated, all quotes in this report are from the stakeholders who participated in this LRSP process.
About Scenario Integrity

An important element in long-range scenario planning is testing the plausibility and integrity of future scenarios, and the commonality of the common themes.

There is a risk of unintentionally excluding some demographic cohorts when looking for ‘common’ 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, thought leaders 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 the resulting policy decisions.
Adapting to the Changing Demographics of Family

A fundamental theme, which was present in all four Caring-About-Caregivers LRSP scenarios, is the changing configurations of families and how they function. Most participants felt that the forces of change which transformed the family (from the extended family to the 1950s nuclear family structure and since then into increasingly different and divergent forms) will continue, if not accelerate.

Due to fertility patterns, the average Ontario family is smaller. This necessarily shrinks the number of potential informal caregivers within a family. There are also large numbers of families with no children, as well as those who are unmarried or without children. These are demographic trends which are already in place. The “baby boomer” population will comprise an increasing share of demand for informal caregiving by 2033 and will be directly affected by this demographic fact. In reviewing the scenarios and background material, participants suggested:

- There will be an uneven ratio of children to aging parents however, some of the impact can be mitigated by how the role of men in caregiving might alter over time.
- Geographic distance may increase as children grow up and move nationally and even internationally; conversely, aging parents are also increasingly mobile. An increasingly diverse immigrant population and globalization has the potential to further push the physical space of families, as family members live and work further apart from each other.
- The “sandwich generation” will continue to grow as women choose to have children later in life, increasing the likelihood that families will have to care for young children and care for aging parents simultaneously.
- Divorce and re-marriage rates will continue to be a factor: both shrinking and expanding the definition and size of what constitutes a family, with the presence of single parent family units, and the inclusion of stepchildren.
- The ethno-cultural makeup of the family is increasingly diverse (e.g. the GTA’s growth of new immigrant populations). This has implications on the definition of “family” as in many situations “family” commonly refers not just to the nuclear family, but extends to include at least three generations.
- Increased legal acknowledgment of diverse sexual orientations is increasing the number of persons recognized as living in a family arrangement, with and without children.
- Family complexity and dysfunction will continue to be an issue, affecting the willingness of many children to provide direct financial or informal caregiving support.

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With the changing dynamics and composition of the “family”, it is necessary to revisit and reconstruct the assumptions and rules that currently comprise the multiple and complex systems of government and employment support and benefits.

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.

**Strategic Option 1: Reconstructing the Policy Definition of “Caregiver”**

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. Many existing policies reflect an attempt to narrow and constrain the definition, typically identifying a sole carer, who is often required to co-reside with the care recipient. Similarly, alternative informal caregiving arrangements or approaches can be constrained, limiting supply and choice of caregivers. An important determinant in a future supply of informal caregivers is the reconstruction of legislation, rules, and eligibility criteria to an open definition of “informal caregiver”: one which includes non-family members and support networks.

A ‘gender impact analysis’ will also improve the support and benefits infrastructure, by ensuring that caregiving incentives are gender neutral, and support and encourage both men and women.

**Strategic Option 2: Ensuring a System of Protection for Care Recipients**

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 future growth of such problems as the population ages\(^\text{11}\). A related approach, drawing on Scotland’s experience, could be initiated for Ontarians.

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\(^{11}\) Scotland, Adult Support and Protection Act, 2007
The Importance of Social Networks: Changing Forms of Social Connection

Another robust theme identified across all four scenarios was the need to engage with those informal caregivers who are not immediate family members. Caregiving is not an isolated process. Most informal caregiving is provided through a network arrangement, three to five persons on average, and much larger when including forms of support beyond direct personal care and instrumental help. Members of these extended caregiving networks can provide social support for the care recipient, and include providing assistance and maintenance to the informal caregiver.

“There are changing family patterns. There are lots more non-traditional families, serial marriages, people living together without getting married, children with multiple people they identify as parents, even if they’re not birth parents. We don’t know how this will impact informal care.”

With the shrinking size of the average Ontario family, and its implications for how informal support is organized and supported, a common theme is how to encompass the role of friends, neighbourhood and community, and how to support the sustainability of these roles.

The current dominant ideal of social connection is based on a strong sense of neighbourhood and community. However, considering the forces of the modern economy, globalization and technology, there is a looming question of whether neighbourhood/community is a sufficient policy platform to capture the dynamic forms of social connection – for now and in the future. 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.

Today, most people spend the majority of their day well beyond the confines of a traditionally defined ‘neighbourhood’. Children often attend schools a significant distance from home, and participate in sports and activities well beyond a local geography. Their social connections are not geographically bound, and electronic communication is further extending the boundaries. The implication is that future models of informal caregiving should consider complimentary approaches to the neighbourhood model: adapting new forms of social cooperation and informal support which reflect the new forms of social connection.

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Strategic Option 3: Strategic Investment in Neighbourhood “Hubs”

“One of the things that's happened in the past 40 years is an increase in female workers. Currently in 70% of households with children, both parents work. That's not going to change.”

Most emerging social policy is linked to the concept of neighbourhood as the basis for service delivery and social connection: finding ways to reinvigorate and reinvent social capital within a geographic boundary. With structural approaches such as the “hub” as a centerpiece for service location, volunteer recruitment and development, and similar organizational actions, neighbourhood/community is one approach among many for increasing the supply of informal caregiving. Such neighbourhood “hubs” should cut across service and target population boundaries and house multiple types of services for diverse populations. The “hub” strategy is complimentary to the neighbourhood approach, but also lays the groundwork for the future needs, when exclusively neighbourhood-centric approaches will no longer meet a community’s needs.

Strategic Option 4: Strategic Investment in Social Cooperatives

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.

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 rapidly to more than 100,000 members over the past decade.\textsuperscript{14} 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. Berlin has opened Germany’s first playground for seniors. Inspired by fitness parks in China, the idea is to encourage elderly to keep fit and socialize, in a way that is integrated naturally with existing environments.\textsuperscript{15}

In a Canadian context, social cooperatives can evolve from different 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.

Interviewees from the LGBT community highlighted their experience at self-organization into resilient support groups. There is an opportunity for provincial government services to tap into and facilitate this type of effective, self-organized, informal networking. Groups which are initially organized around social ties such as friendship could receive formal recognition as a social cooperative, and their caregiving activities be better supported by formal service structures.

\textsuperscript{14} Marshell, R., “Of, By and For Seniors: Japanese Seniors Co-operatives”, YES Magazine, Fall 2005

\textsuperscript{15} \url{http://www.spiegel.de/international/zeitgeist/0,1518,481962,00.html}
Strategic Option 5: Building a System for Social Networking

Contrary to the prevailing perception of older adults and technology use, there is extensive online activity in this demographic cohort. Rather than Facebook and MySpace, older adults engage with online social network services such as Rezoom, Multiply, and Boomertown.16 Online approaches to connection, communication, information and even navigation – both self-managed and professionally assisted – can be facilitated by mirroring social connection with the development of technological connection. This can be achieved through the promotion and support of use and adoption of social networking technology amongst carers. Critical in facilitating this shift is attention to the potential socio-economic gap (ease-of-use/familiarity and cost implications), which may widen or narrow depending on access.

Strategic Option 6: Implementing “Good Neighbours” Legislation

There are problems associated with fostering a large, diverse number of informal caregivers: risk and liability. While existing ‘good Samaritan’ laws provide some legal protection from liability (e.g. in the cases of helping at the scene of an accident), there is little protection for those who are involved in more long-term caring and helping relationships.

Existing insurance protections are limited and represent costs to a person who cares. Through a ‘Good Friends and Neighbours Policy’, public liability of third-party coverage could be considered, shifting some of the risk off of the non-familial informal caregiver and reducing the personal cost of caring and volunteering.

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

17 Ibid
Valuing Caregiving

“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.”

The recognition of informal caregivers is a critical theme identified across all scenarios and by many interviewees. 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. Affording caregiving a prominent status helps safeguard against a (perceived) diminishment in social position.

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.

Strategic Option 7: A Public and Political ‘Voice’ for Informal Caregivers

A first step in the direction of moving informal caregiving from the shadows of family could be the establishment of a provincial organization to represent the public policy voice of caregivers.

In contrast to other jurisdictions such as the United Kingdom and Australia,18 Ontario lacks a strong, high profile voice for caregivers. In these jurisdictions, and others, independent representative associations are prominent in the national dialogue. These associations help connect to, and represent, isolated caregivers who have little time to participate as individuals in politics and policy. While the absence of such a voice seems to affect the intangible value of “social respect”, it also appears to account for the lack of current priority given to Ontario’s threatened caregiver role, in the form of tangible services and supports.

Strategic Option 8: Strengthening Ontario’s Awareness of the Informal Caregiving Role

Social marketing and education are two powerful policy levers with the capacity to inform, engage and shift public attitudes. Implementing a social marketing campaign to increase awareness of the value and contribution of informal caregivers would be a valuable step in increasing overall understanding of how informal caregiving contributes to Ontario.

At the same time, a social marketing campaign can influence the current gendered perceptions of informal caregiving – recognizing and encouraging the role of men. Similarly, promoting an understanding of many different lifestyles and partnerships or cultural arrangements in relation to informal caregiving would also help advance social value.

The new norm of caregiving is not embedded in a traditional nuclear family. It is rather seen in networks, extended and re-constituted families, in workplaces, neighbourhoods and in electronic space -- all of which complement the traditional face-to-face experience. The need for these vibrant forms of caregiving and their valued place in our society is an emerging 2033 norm which requires catalytic support throughout the next decade.

“My sister is 54, and her husband has MS. She is a support worker with CCAC, but she isn’t allowed to do the same work at home. So because she’s a spouse, her labour for him is unpaid. This seems odd. There is all this false compartmentalization, between working, volunteering and family obligations.”

Further steps to integrate the value and importance of informal caregiving in school curricula could form the basis for preparing children and youth to take on a caregiving role: either family-based or in a community capacity. An example of this curriculum integration is “Roots of Empathy”, an organization interested in the social diffusion of their program to promote “other”-centered behaviours and sensibilities amongst young school children. Classes “adopt” an infant which cultivates their awareness of “other”, especially of the relatively helpless “other”.

At present most people are unaware of the economic and social value of informal caregiving. While there exists information on 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. There is emerging research on developing methods and approaches of measuring social value. Such research should be built on and engrained in a system of public reporting, becoming the metric for measuring success of any social marketing efforts.

Strategic Option 9: Expanding the Meaning of “Best Employer”

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”).

Strategic Option 10: Reanimating Volunteerism for the 21st Century

There are concerns that Ontario’s future supply of volunteers is threatened. Much of the current volunteering capacity is made up of today’s seniors. An essential question is what happens when these seniors are in need of care themselves. There is concern that future generations will show less commitment

19 http://www.rootsofempathy.org/
towards volunteer activities, and that this will have a considerable impact on Ontario’s health and social service capacity.\textsuperscript{20}

A provincial program to reanimate the volunteer sector for today and into the future is seen as an important investment.

Such a program could consider:

- Enhancing the capacity of the non-profit sector to recruit, train and manage volunteers;
- Stimulating volunteerism amongst young people through improvements and modifications to current secondary school requirements;
- Offering incentives to young adults with tuition offsets for recognized volunteer work;
- Increasing the ability of working adults to volunteer through employment-based volunteer programs and flexibility; and
- A system of quality of care which is monitored to ensure protection and provision of appropriate care.

\textquote{On one side you have highly-trained, highly-paid, highly-specialized, highly-regulated, highly-respected. On the other you have caregivers with no formal training, who learn on the job, have no organization that represents them, no pay, no benefits, no support, no regulations, and are usually under-appreciated. If all informal caregivers went on ‘strike’ tomorrow, or booked off sick, the entire long-term care, if not the entire health system would collapse.}

Improving the Scope and Efficiency of Informal Caregiving through Technology

For many participants, technology and the pace of technological change was viewed as the one “given” of all the possible social, political and economic drivers. This does not imply that one can easily predict what types and forms of technology will evolve by 2033, but rather that the pace of innovation and change will inevitably open up opportunities. Opportunities for changing how and with whom we communicate; how acute care might be provided; how to enable people to live more independently; and challenge all our assumptions regarding social connections, government and business. Overall, technology has one of the greatest capacities to increase the “efficiency” of informal caregiving and to reduce the impact of fewer future caregivers.

Even without knowing what the technology of thirty years into the future looks like, there is already compelling evidence that the technology of 2009 can and is transforming aspects of aging in the community, and, by extension, informal caregiving. Communication technology opens up channels for a social interaction which is not bound by geography. Monitoring devices similarly can reduce or eliminate physical and geographic limitations. In 2009, mobility devices can already re-open a world that has been closed by disability.

Aspects of technology appear to be out-stripping even our collective imaginations. Few anticipated the arrival of the internet, let alone its nearly immediate impact on how we find information, how we self-organize and manage actions, and how and with whom we interact.

The cell phone transitioned from a technical novelty to a necessity, even a fashionable accessory -- and who imagined the Blackberry? Even today a Japanese company has created an ‘eco-skeleton’ that can be worn by a fragile or physically limited person and provide them with balance and strength. What is presently only in the laboratory or in the domain of the very wealthy can quickly disseminate and become accessible, even ubiquitous. Particularly when there is a high volume of potential users.

As outlined in the chart below, even a relatively modest estimate for technological advancement points towards a powerful transformative potential. According to one stakeholder: “Technology becomes the measured standard of care – not patient-worker ratio”. What this compelling and provocative quote suggests is that our current productivity indicators and measures of inputs and resources are heavily biased towards a labour contribution. For a fictitious example, 1 registered nurse for every 25 persons. Yet such a measure can act as a barrier to the introduction of efficiencies through technology, leaving technological advance outside the realm of public sector investment. Although highly optimistic regarding the potential of

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technology to improve care, it similarly points to the need for creating measures that allow for such potentials to become acknowledged and recognized through the allocation of resources. Not that the contribution of labour and “human touch” can or will be replaced in full, simply that traditional benchmarks by which we measure productivity and performance might dramatically shift in the future (or perhaps more accurately, need to be purposively re-designed as new technology arises).

With communication and monitoring technology, informal caregivers can be in two places at once, even in a different city or country. Services can be researched, organized and even paid for through online channels. It is not difficult to envision a set public funding allocation which caregivers can simply draw from online: transferring from the budget to a caregiving service; or configured for automatic monthly withdrawals. Technology has the potential to allow caregivers to reallocate the substantial time spent organizing and monitoring, into providing companionship and a human touch.

Technology was a dominant theme across the scenarios, but for each technological solution, the optimism was moderated by concerns over negative impacts.
Most participants were concerned that technology not take the place, nor discount the value, of the human touch and direct personal connection. Especially apparent was the concern that technology could create an economic and social gap between those with the financial resources and knowledge to incorporate technological solutions and those without such resources or knowledge. To mitigate this, it would be critical to manage the introduction and growth of technological solutions as much as encourage them.

Our existing capacity for evaluating the effectiveness and benefits of new medical technology and assistive devices is perceived as an inadequate infrastructure to deal with future demand and need. As innovation stimulates new technology, Ontario needs to create incentives and allocate resources to ensure equitable access to these new forms of care and caregiving.

Stakeholder consensus was that the role of technology in caregiving services is at its best when used as an enabler, but not as a solution in and of itself.

Strategic Option 11: Stimulating the Development of Technology-Enabled Systems

At the forefront of modern technology development is an uncoordinated patchwork of private and public mechanisms. A formal strategy would need to both assess existing local potential for new technologies for aging, as well as stimulate new growth potentials in a manner that is aligned with informal caregiving public policy concerns and economic issues. Ontario has the opportunity to become a world leader in developing technology as tools for an aging population – a massive market over the next thirty years. The following may be considered as core components in support of this strategy:

- Founding a Research Centre/Consortium for Technology & Aging:
  - Guided by a research strategy, a centre or consortium for research and development to create future growth opportunities. Building on elements of our existing infrastructure of technology and health technology strategy (e.g., MaRS), the government of Ontario can facilitate becoming a ‘creator’ rather than an ‘adopter’ of technology.

- Creating an Evaluation Infrastructure for Assessing Public Funding of New Technology for Aging
  - In the 20th and early 21st centuries, in response to the driver of medical technology, Ontario became a world innovator by establishing an evaluation function within the Medical Advisory Secretariat. This function assesses the effectiveness and benefits of new technologies and provides expert/evidence-based advice on public funding. This evaluation function is widely viewed as an essential step in health care sustainability, while it maintains the principles of fairness and equity of access. However, there is an increasing need to facilitate convergence in technology assessment and evaluation for social care and assistive technologies of all types. For example, The Consortium for Assistive Technology Outcomes Research (CATOR) was established in 2001 by the United States Department of Education, National Institute on Disability and Rehabilitation.

“We often think about the high-end when we talk about ‘technology’. But if we really understand what’s available now... people can use existing technologies in very creative ways.”
Research. The purpose and function of CATOR is to improve measurement science for assistive technology (AT): reducing barriers to the use of AT outcome measures; and understanding the processes for AT adoption and abandonment. A modern evaluation infrastructure is necessary to protect against adoption of ineffective technologies (through market pressure), and/or growing inequities if public funding for informal caregiving fails to maintain pace with private utilization of effective technology.

Strategic Option 12: Using Virtual Technology to Reduce Information Deficit

The technology of today, including virtual approaches and telephone services, can support an information and support network built around a provincial portal or virtual hub. A hub which can then be integrated and linked to localized supports. There are many successful models in the private sector of providing a centralized point of access to localized services (e.g. hotel and restaurant reservations; customer support lines). A similar “single point of access” model could be applied to the provincial coordination of respite care, following on the initial needs assessment process.

“One of the things that does us in are the silos -- we don't share across disciplines. Information is protected, not shared. Are we moving towards breaking these silos down? If you want to know what it's like to use the system, ask a parent of a disabled child how many different disciplines she had to deal with, and how many times she had to tell her story over and over again.”
Timely Access to Reliable 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. Closing the deficit requires consideration of three complimentary options.

**Strategic Option 13: A Structure to Enable System Navigation**

Provincially-supported case managers or system navigators can help caregivers organize their responsibilities, including linkages to formal caregiving support services. Current systems are tightly bound to existing program structures and processes, with little cross-system capacity and flexibility. Current systems focus almost exclusively on the “client” or care recipient’s needs and undervalue the informal caregiver (e.g. referral and advice is centred on public services such as home care and long-term care facilities).

“A forward-looking health and social care function bridges program lines and the public/private divide, and creates a formal role for this function. An example of this is the ‘community matron’ program in England. Sophisticated information programs can be used to create virtual and interactive online system navigation, which increasingly puts the caregiver in control of the navigation process on a 24/7 basis. This 24-hour accessibility is an important consideration given caregiver’s additional time constraints, and difficulty fitting into the “9-to-5” working hours of human services.”

**Strategic Option 14: A Provincial System of Caregiver Education**

Over the last four decades, there has been steady growth in education and learning opportunities for parenting and childcare: from birthing classes to parenting education to babysitting certificates. There is little if any such system of instruction and support for informal caregivers. Creating these supports (in both virtual and in-person options), would add significant value to the system. These supports may include support on: the basics of setting up caregiving arrangements (including where to find assistance); how to assess and monitor the quality of support; and more complex and sophisticated learning on medical issues.

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22 United Kingdom, Department of Health, How a community matron can help you with your long term condition, February 2006
Promoting Opportunity and Choice for Support

“The boomer generation is more active and involved, more demanding and selective, and they may well want more participation (in 2033) in their role and how this is decided.”

In the United Kingdom, the Princess Royal Trust for Carers provides the most comprehensive example of community-driven support for informal caregivers. Through a network of 144 independently managed Carers’ Centres, support is provided to almost 354,000 carers. Activities range from: information and advice on benefits and respite; emotional support and counseling; advocacy assistance (e.g., tribunals); and training and education.

Ontario noticeably lacks such a support network. To date, health and social care has not responded quickly and comprehensively to the demographic shift associated with an aging population. Adequate supply and flexible access to vital resources such as respite care remain scarce, and the resources that exist lack visibility. Identifying the needs of informal caregivers is relatively easy; the long-term strategic challenge is how to design a system of services and supports with the flexibility to adapt over time.

Strategic Option 15: Creating a Formal Process for Caregiver Assessment

“Caregivers often have to figure these system out for themselves. But many don’t know how to find out how it works. Very few informal caregivers actually utilize the services that are available. One main reason is that no one has told them about those programs.”

Currently, for most services the ‘client’ is seen as the care recipient, with few formal provisions which acknowledge the informal caregiver as a separate ‘client’ with distinct needs. The consequence of this is that recognition of informal caregiver needs is inconsistent across different programs and services. Provisions for the caregiver may even be variable within a service, depending on the particular professional provider.

Development and implementation of a valid and reliable informal caregiver assessment tool, standardized across health and long-term care organizations, would improve this situation. In jurisdictions such as Scotland, legislation and regulation have been introduced to recognize informal caregivers and entitle them to an assessment in their own right. Canadian work on such a tool is on-going, but consistent and standardized implementation of such a tool is dependent on public policy. The province has a role in valuing this practice, by rewarding, enabling and expecting its use amongst its transfer payment service providers.

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24 Scotland, Community Care and Health Act, 2002

25 [http://www.msvu.ca/Family&Gerontology/Project/](http://www.msvu.ca/Family&Gerontology/Project/)
Strategic Option 16: Empowering the Choices of Informal Caregivers through Self-Directed Care

Service organizations typically play a gate-keeping role in decision-making and allocation of human service resources: who gets in and what resources they can access. In a number of jurisdictions, there is a growing trend towards an alternative funding approach: self-directed or direct payment. Self-directed funding creates the possibility for the system to build in more choice points for caregivers, and provide them with the desired flexibility.

Two jurisdictions, Israel and Germany, have entrenched within their social long-term care insurance a system of self-directed care. Systems have been put in place for services for the physically disabled, with growing services for the families of the developmentally challenged.

An Ontario-based platform of self-directed care and direct payment might include:

a) A self-directed/direct payment system for public funds which is open and flexible to input from informal caregivers (e.g. spouses, children, or others assuming legal responsibility). This may include: the payment of oneself; payment of family or friends; and/or purchases from professional caregiving organizations.

b) Information and navigation: A centralized system of information to assist caregivers in navigating the options and choices for purchases, methods of monitoring quality etc.

c) Quality control: A system of quality standards and reporting to guide the decisions and actions of informal caregivers in the purchase of professional services.

d) Funding flexibility: A full range of options and providers across the spectrum of public and private, for-profit and non-profit. This would be designed to enable care recipient and informal caregiver choice, and create market signals to stimulate supply (e.g. the evolution of a system of respite care hotels).

Strategic Option 17: Building a System of Support through Stable and Efficient Investments

The non-profit sector has experienced considerable turmoil in the past decade. Urged to pay more attention to what is sometimes characterized as more "bottom-line" thinking (i.e. a private sector influence), non-profits have struggled to pay attention to their "top line" thinking. "Top line" thinking in the non-profit sector, for health, social services and community support organizations, is represented in their efforts to enhance the quality of life for individuals and communities. However, in order to thrive, and in some instances merely survive, many non-profits have experienced "mission drift" and adopted a disproportionate focus on funds-chasing behaviours as a survival strategy. Scale seems to be a mitigating

"I'm a sophisticated consumer, but I have felt completely disoriented as a person using the system. You don't feel empowered to ask 'wait, I don't know what to do next.' A lot of otherwise capable people feel disempowered by the system."

"Part of the problem is putting the right services in place, but a big part of it is that we don't know how to access what is currently there. All I know is that if my mother has dementia, someone, or something has to help me figure out what she needs."
factor for some non-profits: at a certain size they are able to focus on both the efficiencies and the effectiveness of their work. These organizations need to be able to seamlessly manage their information, measure its impact, and meet their service expectations, without one task compromising the others.

Some non-profits have taken advantage of economies of scale, effectively merging "back office" functions (i.e. payroll, finance, human resources, information technology) while differentiating their "front door" capacities to reflect particular niche strengths and community offerings. However, there are larger long-term questions for non-profit personal support and community service organizations regarding their long-term organizational vitality.

Over the past 25 years, it has been strategically beneficial for government to partner with the non-profit sector, as a cost effective means for delivering community services and supports. Over the next 25 years, some non-profit sector stakeholders believe it is critical that government clearly indicate its strategic intent with respect to a struggling non-profit sector. Previous round-table conversations have not resulted in commitments of substance. Many assumptions regarding care for caregivers make explicit reference to community support. The question for many is whether that organized community capacity, represented by a vital non-profit sector, will be sufficiently robust in the future.

Strategic Option 18: Adopting a “Triple Bottom Line”

A flexible, adaptive, and integrated value chain, one which considers and weighs the environmental, economic, and social impact, would move Ontario towards a “positive deviant” social accounting structure -- where social value is translated into financial value.

Corporate Social Responsibility (CSR) is rapidly becoming standard practice in profit and non-profit sectors. Organizations like the Grameen Bank are fledgling “curious exceptions” in the migration away from output-based scorecards, towards outcome-based approaches. Ontario has an opportunity to adopt these “imbalanced scorecard” methodologies, and measure caregiving support success with “leveraged scorecards” -- tracking the success of incentives and supports against the overall environmental, economic, and social improvements.

“Rather than government putting up barriers and controlling everything, they provide direction and guidance. It's like a plane, people have some choices about their seat, but the airline figures out everything else. You are flying the plane. This can only happen when there is an effective and profound understanding of needs, and appropriate planning. This is government's critical role.”

Strategic Option 19: Building a System of Support through Flexible and Portable Hubs

There are few places where an informal caregiver can find assistance with the strains and challenges of their role. The risks associated with this include: dysfunctional family dynamics such as abuse or neglect of the care recipient; loss in employment productivity; “dropping out” of the labour market; or relinquishing

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26 http://www.positivedeviance.org/about.html

27 http://www.grameenfoundation.org/
responsibility of the caregiving role (with cost implications to the health and long-term care systems). The capacity to cope has direct consequences for public policy resources.

The absence of established and effective services and supports for informal caregivers in 2009 means there is relatively clear pathway for new approaches, premised on modern technology and concepts. One of the key prevailing social policy concepts is the “hub”: a centralized location with a wide mix of integrated services. For most stakeholder participants, the “hub” is an appealing model for the future and should form the basis of pilot projects and other forms of policy experiments.

Key strategic points for “hub” development to consider are:

- Shifting the system through integration: Planning for a network of informal caregiving supports could consider horizontally (i.e. mix of services – social, health, education) and vertically (across differing age cohorts) an integrated approach rather than establishing a parallel network. Informal caregiving is currently primarily a role taken on by family members. This means that it could be considered in relation to the existing range of services and supports for families and seniors. The current planning horizon for considering informal caregiving is long-term care and community services for seniors. Expanding the horizon could be achieved by integrating caregiving support service options with Early Year Centres/ Parent-Child Centres, mental health services and other family resources in collaboration with long-term care and seniors.

- Flexibility and portability: A physical location will always play a role in the provision of supports and services. But virtual communication and connectivity offers another avenue for evolving a responsive system. Virtual systems are well-suited to incorporating the dynamics of geography and population demographics in the context of planning. The ebbs and flows of school populations – and other types of services - are a marker of future change: a physically convenient location next to a concentration of “need” today can be a remote and inconvenient program location in 10 years time. Services and structures should be designed to move in accordance with the predicted demographic shifts.

The hub model has the additional, and essential, benefit of simplifying interaction with a complex system. Caregivers have limited resources in many respects -- including time. The more government can internalize logistical coordination, and adopt a “single point of entry” model, the more effective the system is perceived to be.

Feedback from stakeholders is that caregivers don’t want to manage their own services, they are doing so only because there are “no other options in our fixed and rigid supply chain”. They expressed frustration over “waiting for the supply chain system to change” to meet their needs.

A “single point of entry” has the added benefit of being more accessible for more communities. Complex systems are difficult to navigate for people with no extra challenges; a straightforward access point is near essential in cases where literacy, education or cultural differences make it more challenging to understand and access the services available.

"What comes across is still this (obsessive) focus on beds, which is almost always too late, instead of looking at the changing thresholds of needs."
Flexible Benefits and Supports: Competing and Caring in the Context of Shifting Demographics

The importance of benefits and flexible workplace policy was identified as a robust theme in this 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.

"Ontario outperforms its peers on measures of diversity and tolerance, but this advantage is not translating into economic success. We need to design a social safety net system for the creative age -- one that partners with those who have the determination to participate fully in the creative economy. Not to do so is a terrible waste of human potential."

-R. Martin & M. Florida, 'Ontario in the Creative Age'

Ontario continues to identify and consider which government and business policies are critical to future provincial competitiveness and prosperity. To date, 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 employee’s informal caregiving needs can decrease productivity by approximately $17.1 billion. Recruitment of new employees is also increasingly viewed as a costly and avoidable expense.

Since the mid-1990s British Telegraph (BT) has recognized the challenge of maintaining a stable skilled workforce, and has worked to accommodate the caregiving requirements of their 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 similar firm 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.

"We've got to allow people to make decisions for themselves. Some individuals will make poor decisions, but those few negative decisions need to be weighed against the advantages to a vast majority of recipients who will make informed decisions. When aggregated across many people, the potentially negative effects are more than offset. It does entail some degree of risk, but we need to bite the bullet and say that overall, people would be better off with choice."


29 Interview with Caroline Waters, Director, People & Policy, British Telecommunications Group, 2008-12-15
BT took a long-range perspective in their employment policies, and anticipated a surge in the number of their employees who would become informal caregivers as the population ages, and the risk of women dropping out of the workforce for parental and/or child caregiving.

BT developed a business case in 1999, and 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 the 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.30

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.

With the gaining traction of ideas such as Richard Florida’s “creative class” [footnote], there is a strong focus on attracting such a pool of labour to the GTA and southern Ontario, including workplace environments which foster flexibility. Less acknowledged is a timeline on the changing needs and wants of the creative class of the future: to younger workers such as the NetGen [footnote] population workplace flexibility is likely to transform from the desire for a personal work-life balance, to the responsibilities of caregiving (for both their children and aging parents). Failure to acknowledge the future, rather than current, needs of the young “creative class” risks labour market drop-out, reduced employee productivity, or migration from Ontario to a more ‘family friendly’ jurisdiction.

The experience of women in the workforce, particularly in relation to career progression and senior management roles, points to a critical problem that can affect both the supply and quality of Ontario’s future workforce. By example, the lack of women as partners in law firms calls attention to the type of incentives and expectations in this industry (e.g. where requiring job flexibility is perceived to conflict with one’s career opportunities).31 The net effect in the world of law is a lack of progress in the numbers of women reaching partnership levels as they often leave the firm (or the profession) when there is conflict between caregiving responsibilities and career expectations.32

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30 Ibid

31 Melnitzer, J., “Injustice rules; Qualitative data show women lawyers haven’t come as far as first thought”, Financial Post, June 20 2007

32 ibid
This effect does not exclusively impact women. Nordic studies on enhancing the role of men in child-rearing points 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. 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 with no negative consequences.

<table>
<thead>
<tr>
<th>Source</th>
<th>Potential Employer-Sponsored Elder-Care Supports</th>
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<tbody>
<tr>
<td>Flexible or Customized Work Arrangements</td>
<td>Paid or Unpaid Time Off</td>
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<tr>
<td>Internal or occasional flexibility</td>
<td>Family leave</td>
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<td>Part-time work and job sharing</td>
<td>Medical or emergency leave</td>
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<td>Voluntary reduced time</td>
<td>Personal leave</td>
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<tr>
<td>Phased retirement</td>
<td>Bereavement leave</td>
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<tr>
<td>Compressed schedule</td>
<td>Policies</td>
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<tr>
<td>Flex time</td>
<td>Time-off</td>
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<tr>
<td>Telecommuting or teleplace</td>
<td>Relocation policies</td>
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<tr>
<td>Paid Time Off</td>
<td>Insurance Coverage</td>
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<td>Sick days</td>
<td>Health insurance</td>
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<td>Vacation</td>
<td>Dental insurance</td>
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<td>Statutory</td>
<td>Life insurance</td>
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<tr>
<td>Personal days</td>
<td>Unemployment insurance</td>
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<td>Paid time off bank</td>
<td>Workers’ compensation insurance</td>
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<td>Financial Assistance</td>
<td>Long-term care insurance</td>
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<td>- Publishing federal or state tax credits</td>
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<td>- Dependent-care reimbursement plan</td>
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<td>- Subsidized dependent-care reimbursement plan</td>
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<td></td>
<td>- Subsidized care or vouchers</td>
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<td></td>
<td>- Discounts for care</td>
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<tr>
<td>Access to Information</td>
<td>Resource library, possibly online</td>
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<td></td>
<td>Workplace caregiver fair</td>
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<td></td>
<td>Workplace caregiver workshops and support groups</td>
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<td></td>
<td>Elder-care counseling and referral</td>
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<td></td>
<td>Promotion of elder-care locator</td>
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<td></td>
<td>Elder-care counseling through employee assistance program</td>
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<td>Strategic Option 20: Initiating a Government – Business Dialogue for Informal Caregivers</td>
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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 CSR movement (Corporate Social Responsibility) 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 on 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.”

**Strategic Option 21: Building Benefits and Employment Protection for Informal Caregivers**

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 Employment Insurance (EI) program structure, in a manner similar to maternity/paternity benefits. The same could occur for new caregiving programs and integration with existing family services.

However 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 they are caring for has physical and social needs that are too intense to allow for continued employment of the caregiver. Under these circumstances, EI is not viewed as the appropriate social program. Future consideration should include examining how income credits can be instituted through other programs: providing an income allowance, so that becoming a caregiver does not result in unfair economic penalty, or an increased risk of poverty.

“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.”
Promoting Equity and Enabling Vulnerable Populations

As is strongly suggested by the policy implications considered and discussed above, the role of government in relation to informal caregiving was a fundamental theme and robust across all 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 inequity and poverty as access to benefits and flexibility through employers is concentrated among high paying jobs and occupations;

b) Growing income inequity as persons suffer a financial penalty for reducing employment in order to care for a challenged child or aging parent;

c) Growing income inequity in wealth and savings as persons sacrifice future retirement income in exchange for providing informal caregiving;

d) Increased health costs due to the economic and social strains of unsupported informal caregivers;

e) Unnecessary institutionalization of the cared-for individual for those with little capacity to pay for care and/or provide informal care; and

f) 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.

**Strategic Option 22: A Provincial Program with ‘Universal’ Benefits and Protections**

The existing distribution of employee benefits, including extended health care coverage (e.g. prescriptions) are inequitable. While up to half of Ontarians do have access to such benefits, these tend to be concentrated
in higher level, permanent positions. 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.

There is little reason to expect this historical pattern to change without active policy management and solutions. Against the liberal democratic principle of fairness are the unintended and perhaps perverse incentives that arise from not addressing labour market inequity. Failing to address disparities in protection and benefits creates unfair health and social risks for the poorest members of society, and/or the withdrawal of people from the world of paid employment.

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 healthcare system.

**Strategic Option 23: Strengthening Outreach, ‘Wraparound’ and Services for Informal Care Needs of the Vulnerable**

"For the North... Will we always have to outsource, and send people south? Will MoH work to make resources more accessible? We often have children who have to go to Ontario or Manitoba for treatment. Our families don't have a lot of money, and it's difficult for family to stay down with them because hotels are expensive."

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.

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.

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36 Laurent, S. Rural Canada: Access To Health Care, Health Canada, 2002
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 own grandmother was relocated by the government a number of times until she was 90. She became ill and even though her needs could have been addressed by in-home care, she was moved to Thunder Bay into a nursing care facility.

My grandmother mostly spoke Ojibwa. She was placed in 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."
Summary

Looking ahead three decades, the future of informal caregiving is a fundamental challenge for Ontario. Much as Ontario adapted its social, educational and economic structures to accommodate the baby boom surge in the 1950s and 1960s, this next demographic shift requires a new vision. The shifting demographic poses many risks to existing system design. But long-range scenario planning is about thinking of the future and acting today. Ultimately this planning mindset is optimistic and opportunistic: building on the belief that choices made individually and collectively, can make a difference.

A first actionable variable is that the supply of informal caregivers, whether family, friend or community, can be influenced. This influence is not inherently dependent on more public spending, but on relationships. Relationships between child and parent. Relationships between employees and business. Relationships among social networks, or between community members. From the lessons of the last thirty years in child development and fertility patterns, there is ample evidence for creating a better future by influencing personal choice. In other jurisdictions such as Japan, that are already facing an aged population and dramatic shortage of family caregivers, there is already evidence of successful new ways of forming reciprocal relationships and social connections to increase alternative sources of support.

In reviewing the literature and testing various long range scenarios, the often prevailing assumptions around aging and informal caregiver supply are re-examined. A new set of positive and plausible assumptions emerge which can help establish principles and practice for the future:

1) Minimizing the social, economic and health costs of informal caregiving increases the likelihood that family members will willingly assume the responsibility of caring for challenged and dependent children or an aging parent – as most do now.

2) Fostering balanced responsibilities between men and women will stimulate a larger supply of persons to care for children and aging parents.

3) 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.

4) Creating choice empowers informal caregivers and the person they care for, and establishes a system that is more efficient and effective.

5) Changes in social connections do not represent a breakdown in caring but a different form of how caring happens.

The policy implications of an aging population and informal caregiving have been identified through literature reviews to generate an evidence-based perspective; through engagement of varied stakeholders to capture their thoughts; and in consideration of all these inputs. Such policy implications consider how future trends can be used to enhance rather than threaten the supply of informal caregivers. Moving from these extensive policy implications, a broad basis of dialogue and the shared, exploration of our preferred futures can evolve.