

Ontario Caregiver Coalition
Strategic Inquiry: Identifying Areas of Policy Development on Caregiving

Summary of Key Issues and Strategies
September 2010

1. INTRODUCTION

After their successful strategic inquiry processes in 2008, the Ontario Caregiver Coalition decided to repeat the process, in order to better gauge the government's stance on caregiving issues in 2010. Initially, 23 key informants were identified to be interviewed to inform the Inquiry process. Thanks to suggestions from interviewees and others within the Coalition, an additional eight informants were highlighted for a second round of consultations. In the end, a grand total of 12 people were interviewed, providing an in-depth and diverse portrait of the political landscape, and offering many key suggestions to the coalition.

2. PROCESS

The Strategic Inquiry process proceeded as follows:

- Key informants were sent a letter introducing them to the Ontario Caregiver Coalition, describing the objectives of the Strategic Inquiry and asking potential interviewees to participate in the process.
- The project consultant called key informants to set up telephone (and in some cases, in-person) interview times.
- The project consultant used a standard list of questions to initiate the interview. Follow-up questions and prompts were also used by the project consultant to generate additional input and to follow up on ideas articulated by the interviewees.
- Interviews were documented.
- Material from all interviews were rolled up and a summary of key issues and concepts was generated. This follows below.

3. CURRENT POLICY ENVIRONMENT

- **General Awareness:** The government certainly is aware that there is a need for caregiver support policies. Or rather, cumulative knowledge is building in government about the burden of *ignoring* caregivers. However, as of yet the government is "not even close to specific policies".

- speaking generally, the government seems to be interested in keeping people in the community, though they aren't specifically tackling caregiving as of yet.

- **A Changing Demographic:** Factors such as changing family structure and population graying are pointing towards an inevitable point where policy will have to be made, but for now, caregiving is not seen as a "hot ticket" item.

- **Financial Concerns:** The biggest current obstacle to any new social policy is the recession, where extra spending would be a poor move both financially and politically. Hospital costs are also skyrocketing, making the government nervous about injecting any more money into the health sector at present.

- **The Caring about Caregivers Initiative:** Strength is building within the public service sector. This is most strongly shown through the recent Caring about Caregivers Long Range Scenario Planning, completed by the Ministry of Health and Long-term Care (MoHLTC) under the leadership of Adalsteinn Brown. This project used input from current caregivers, as well as innovative data searching techniques and dialogue across government ministries (such as with the Seniors' Secretariat). Unfortunately, some have been led to doubt the government's true level of commitment, since **this report has not yet been released publicly.**

- **Distribution of Leadership:** The MoHLTC has also acknowledged the leadership that CCACs and LHINs will have to play in that area, but once again, no specific directives have been issued.

- Some government agencies with arguably a vested interest such as the Seniors' Secretariat and other select individuals are well aware of not only the push for caregiver policy at the provincial level, but at the national one as well.

Political Parties' Perspectives

- The Liberal government has four years to keep promises, including ones that they made early-on in their term about **reducing ER wait times and alternative level of care (ALC)**. These are both keeping them busy, so caregiving is not a top priority.
- More generally, the current government is generally more favourable of systemic, high-level (read: top down) changes in the healthcare system. Caregiving is interpreted as more of a bottom-up, grassroots approach and thus is a little messier policy-wise.
- The NDP's primary concerns are labour-based (i.e. 3.5h/client/day in nursing homes, etc.) but is prepared to look at other deinstitutionalization options. Some of these may have implications for caregivers. However, caregiving is not seen as a priority going into the next election. Their primary concerns are jobs and strengthening the economy.

Current Government Policies and Programs

- The MoHLTC has made a consistent effort to provide for caregivers in many of its current initiatives. While they might not be the outright "focus" of a program, support for them is expected to "trickle down" in the form of transportation aid, respite, or other services.

- Two such examples would be the recently funded and comprehensive **Diabetes and Mental Health Strategies**. Both of these programs have some consideration for caregivers inherent in their initiatives.
- The Ministry of Labour introduced **Family Medical Leave** a number of years ago which includes paid leave of 8 weeks within a 26-week period. This is definitely important to caregivers.
- Most direct support for caregivers at present is found within the **Aging at Home (AAH)** initiative. This program is designed to keep frail seniors out of long-term care (LTC) facilities or nursing homes for as long as possible, and thus has a significant caregiver component. The very existence of this program also sends a significant message to the Ontarian public that healthcare is essentially moving out of the hospital (and other such facilities) and into the hands of community members.
- The AAH initiative is administered at the LHIN level, and as such, is not uniform across the province. In fact, using this approach, it would not be a stretch to say that quality of caregiver support will vary wildly depending on geographical location.
- The AAH home is designed for seniors, which leaves out a significant chunk of caregivers for people at other ages and ability levels.
- Services for caregivers administered at the CCAC level are also not uniform across the province. These may include (but are not limited to) respite care, case management services, help with household tasks or transportation at low or no cost.
- While they are not specifically provincial programs, the Government of Canada offers some support in the form **of small tax credits** for caregivers, or the recently re-vamped Compassionate Care Leave provisions contained within Employment Insurance.
- Conversely, on a community level, many services provided by **health charities or other organizations** (i.e. Meals on Wheels) can offer support to caregivers at minimal or no cost.
- The Ministry of Child and Youth Services has great respite programs, as well as support services for families of children with severe/complex disabilities.
- More broadly, the MCYS also provides information to families of persons suffering from chronic conditions.

4. FUTURE CAREGIVING POLICY

- If any caregiving policy were to emerge in coming months, it would probably be in either the Liberals' or Opposition Parties' election platforms in 2011.
- The general feeling is that future legislation is going to fall into one of three "buckets": **legislative change** (e.g. legal protection for caregivers under provincial labour laws), **supportive policy** (e.g. building off of successful programs at the LHIN level), and **finance** (e.g. tax breaks for caregivers). Once again, it ties in to caregiving's purported priority, and that's really the job of advocacy groups. At present, it's really seen as an issue for the MoHLTC, but once a stance is made, policy should trickle down to other departments like Social Services, Transportation or Labour.
- The ultimate decision-making body will probably be the Health and Social Policy Committee
- The Ontario Hospital Association (OHA) and Community Care Access Centers (CCACs) have partnered on project called "**Ideas and opportunities for bending the health care cost curve**". One of the key recommendations from their report dealt with care at the most appropriate level. For many people, it determined, this would mean at home. This is exciting because it means that hospitals are suggesting diverting funds from their budgets to caregivers. This may be a sign of things to come.

Support Needed for Caregivers:

- Caregivers are looking for a lot of things right now: Transportation, education, respite, home care, etc. This makes it a very multidisciplinary program, and there is no "magic bullet" approach for it.
- **Training programs** or other benefits would really be a win-win, as they would feel more supported, and take more strain off of the formal healthcare system. For example, knowing how to properly perform medical tasks would reduce caregiver stress and give them some sense of control, therefore reducing respite time needed. This could be a financial goldmine to the government and the overburdened healthcare system.
- Caregivers need to be better aware of the programs and services that are offered in their communities in order to make use of them. The Seniors' Secretariat is currently working on initiatives to improve this awareness.
- **Many caregivers at present don't feel that they need help:** What they're doing is just a familial duty. However, it is felt that over time, caregivers will become more demanding, especially pertaining to their own health needs.

- Perhaps caregivers would benefit from some sort of “**unionization**”, guaranteeing them certain rights and responsibilities. This approach has previously been successful in Sweden.
- There simply isn't time in **med school curriculum** for new doctors to learn how to effectively fit families of their patients into treatment plans. This needs to be changed.

The politics of advancing caregiver issues in Ontario:

- **Cost is by far the biggest obstacle.** The government needs to see that it's getting good value from its investments, and that a maximum number of voters will be affected.
- In a recession, the government doesn't want to repeat the mistakes of previous governments going into debt during times of financial duress. This would not be a smart political move.
- Additionally, in a time of economic recession, the government is trying to attract companies and new investment. “**Expensive**” **policies for caregivers in the workplace could be seen as detracting factors** for new companies who don't look beyond the dollar signs.
- Caregiving doesn't really fit into any one individual scheme. Things that caregivers are asking for (i.e. education, housing supports, respite care) don't fall completely into any one ministry. It's an extremely interdisciplinary problem, and one with **no “magic bullet” solution**. That makes it perhaps less “digestible” for a government.
- **It's also difficult to justify money spent on caregivers** because a lot of people think “well, they'd be doing this anyway”. Caregivers have been around a great deal longer than any formalized system of care, so there is still a question in many people's minds as to why now's the time for financial support. In order to make any financial commitments like this attractive to government, change should start small and increase gradually.
- In attacking this problem, the government needs to see an extremely strong coalition with **caregiving as the first priority** among all of its constituent organizations. If each group has multiple “asks”, they must assure that the government knows that caregiving is of the most importance. Otherwise, the message is in danger of getting “diluted” among the other concerns of the group members.
- Outside of the coalition itself, **caregiver support has to be seen as a priority from other groups**, like the Registered Nurses Association or seniors' advocacy groups.

- **Any policy that happens need to take into account integral social structure**, such as the changing form of families in Canada, and differences in cultural attitudes toward caregiving.
- **The government just isn't really feeling the heat from advocates or voters about caregiving.** A perception that is still unfortunately widely held is that caregiving, especially for women, is a normal part of family support and should be done without complaining and/or asking for help. Until the public perception changes somewhat, the situation probably won't change much.
- **There are also worries about any programs for caregivers could be abused** (aka through elder abuse or virtual enslavement, as with migrant nannies), and this would understandably upset voters.
- If a **united attitude about caregiving** came from all sides (i.e. voters, health providers at LHINs and CCACs, hospitals, LTC Institutions, etc.), then the politics of it will be removed altogether.
- A word of warning: According to some, the government has a history of heavy consultation, then doing nothing with the results. This is a great strategy on their behalf to drain heat from advocacy groups.

Where the Coalition should go next:

- The coalition really needs to spend a lot of time carefully crafting policy if it's going to have a chance of getting through.
- It also needs to show the government that caregiving is the number one priority of the constituent organizations to really strengthen the message. (See above)
- **For inspiration, perhaps the coalition should look at smaller regional organizations doing good things with their programs.** One example is Dryden, where family medical teams have a person whose specific job is to help families navigate the system.
- **International approaches to caregiving could also be examined.** As an example, some countries in Scandinavia actually provide direct funding to family caregivers for education and training.
- **The coalition shouldn't be afraid to think outside of the box**, and search in non-traditional areas for ideas or allies. For example, some groups such as those within the AIDS community have done extensive work on different, non-traditional models of care. These might be helpful in investigating possible policy options.

- There is **no official inventory** of these caregiver-specific services (i.e. at the LHIN or CCAC level), but this might prove very helpful.
- The Coalition should also speak to the **Seniors' Health Research Transfer Network**. They have a network of best practices, which might include caregiver concerns.
- Caregiving issues and their policy-based solutions would best be framed in a cost-benefit analysis, with heavy emphasis on what the government (as well as the people of Ontario) could stand to gain. **It's all about the money.**
- In order to really grab the government's attention, ultimately, **some sort of champion will be needed.**
- Whether we like it or not, **there is strong support behind advocating for caregiving as a "women's issue"**. In fact extensive work has proven time and time again that female caregivers are more likely to suffer a decline in socioeconomic status, or end up being a burden on the healthcare system because of their own caregiving-related health issues. While we may not want to point to women exclusively, this information can still be leveraged.
- The current system appears to see individuals and their families as **two separate entities** care-wise, but in order for effective policy, they need to be considered as one big unit
- Ontario's ombudsman, Andrew Morin has done some great investigative work in other areas related to health policy. If he could be persuaded to look at some issues pertaining to caregiving, it would be extremely embarrassing for the government, and difficult for them to ignore.

Miscellaneous comments:

- The majority of current health policy is being heavily influenced by healthcare providers (i.e. persons working within hospitals), so doesn't necessarily take caregiver issues into account when "prescribing" policy
- However, **speaking to individuals in primary care would be extremely valuable**, as they're often the first people that newly minted caregivers deal with, and end up gaining a lot of support from. These voices at the "front lines" might offer us some important insight.
- **In order to make change, the caregivers themselves have to be mobilized.** Otherwise, "caregiver policy will just be seen as a self-serving exercise on behalf of healthcare providers"

- We should talk to groups that have had success getting themselves recognized as a viable industry (aka nannies), and fighting for their rights.
- ECHO has recently released a Request for Applications to perform a study on the impacts of informal caregiving. They would be more than happy to share their eventual results with us
- **The Age-Friendly Communities Initiative involves a social inclusion piece** (i.e. “Keeping an eye on your elderly neighbour”), which could be tied into any caregiving strategies that arise.
- Caregiving is really exciting, because it aligns with so many things: our values as Canadians, sustainable healthcare, cultural values, supporting an aging population, the Liberal government’s “Family First” approach, Ontario’ Open for Business initiative, etc.
- All of these things provide the base for everything that the government’s doing right now, and any one of them could be leveraged to make a hugely compelling argument
- **Caregiving issues can be “tailored”** for pitching to somebody in almost every government department

Key informants interviewed:

Cara O'Hagan, Advisor, Policy and Outreach, Office of the Minister of Labour

Cheri DiNovo, MPP Parkdale-High Park

Dan Carbin, Senior Adviser, Health Policy Issues, Office of the Premier of Ontario

Diane McArthur, Assistant Deputy Minister and Executive Officer, Ministry of Health and Long Term Care

Elizabeth Esteves, Manager of Policy Initiatives, Ontario Seniors' Secretariat

Jerry Koh, Senior Specialist, Long-Range Scenario Planning (lead on Caring about Caregivers)

Komal Bhasin, Financial assistant, Ministry of Health and Long Term Care and Senior Policy advisor to the minister of Child and Youth Services

Pat Campbell, CEO Echo: Improving Women's Health Ontario

Lori Hale, Senior Research Consultant, The Change Foundation

Margaret McAdam, Associate Professor, University of Toronto, Senior Fellow, Canadian Health Policy Network, and President, The Age Advantage, Inc.

Dr. Vasanthi Srinivasan, Assistant Deputy Minister (acting), Health System Strategy Division