Caregiver & Poverty Stakeholder Forum

Summary Report

HOSTED BY THE MULTIPLE SCLEROSIS SOCIETY OF CANADA

December 7, 2009
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Summary Report

What if Canada was the best in the world in meeting the needs of family caregivers?

Executive Summary
Family caregivers provide care and assistance for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability. A family caregiver’s efforts, understanding and compassion enable care recipients to live with dignity and to participate more fully in society.

Caregivers and care recipients are not separate groups – “we are them and they are us”. Caregiving is a natural part of life and an experience that most will encounter over the course of their lifetime. Caregiving is a labour of love, often both enriching and demanding; almost always isolating. With the increasing evidence of undue hardship borne by family caregivers as they struggle to balance the demands of caring for a loved one, work, and raising a family, the Multiple Sclerosis Society of Canada convened a forum to examine the issues particularly as they relate to caregiving responsibilities for those with long term conditions. The financial burden and economic consequence was the focus of discussion.

Some would debate the conclusiveness of the research evidence and the obligations of society on family matters such as caregiving. It is convenient to think about caregiving as a family problem. However, looking after one another is a fundamental underpinning of society. In his remarks to the group, social visionary Ric Young asked “what if Canada was the best in the world in meeting the needs of caregivers? What would be possible?” Forum participants accepted the challenge and committed to initiating action which could result in changing the conditions of caregiving in Canada within the next three to five years.

The details of what and how caregiving will become a responsibility for all of society are not yet defined. The challenge is complicated and there is no singular solution. Forum participants were passionate and purposeful in committing to creating a change in Canada’s social mindset through smart and passionate advocacy. Immediate next steps were identified. The intent is that family caregivers no longer be subject to excessive financial burden but rather have the economic security to live a life they can fully value.
Overview

On November 24th and 25th, the Multiple Sclerosis Society of Canada (MS Society) hosted a two day forum in order to share knowledge and develop recommendations that would contribute to lessening the financial burden borne by many who undertake to provide care for a loved one. This event was made possible through a generous unrestricted educational grant from Pfizer Canada. The MS Society’s motivation arose from their experience with clients and caregivers with multiple sclerosis. Recognizing that the financial impact of caregiving is an issue that transcends all groups supporting family caregivers, the MS Society saw the forum as an opportunity to develop common messages across organizations so that meaningful change for family caregivers could be sought.

A diverse group of approximately 30 participants (see Appendix 1) representative of caregivers supporting a loved with a chronic illness in Canada met to:

- Examine issues related to caregiving and economic security related to chronic illness
- Present research and information on poverty as an outcome of caregiving
- Engage in dialogue about how to decrease the likelihood of poverty as a result of caregiving
- Develop recommendations that will achieve a more favourable balance of caregiving and economic security.

The format was a mix of lecture and discussion. Presenters (see Appendix 2) provided evidence and challenged the group to consider the facts and imagine the possible. Participants spoke to the needs of their stakeholders, their programs and their advocacy efforts. As the group shared their experience and knowledge they developed energy and a willingness to work together to achieve social change for family caregivers.

The group committed to changing the conditions of caregiving in Canada within the next three to five years through smart and passionate advocacy so that family caregivers are not subject to excessive financial burden but rather have the economic security to have a life they value. An immediate action was to broadly disseminate details from one Forum participant’s organization titled the “Gift of Time” program to as many employers as possible.1

A Vision for Caregiving in Canada

Caring for family is not new. Our society assumes, and in fact expects, that families and/or friends will provide the necessary supports when a loved one needs care. It is typically only when needs escalate to a crisis that the formal health care system intervenes. Family caregiving is a crucial part of the network of private and public assistance to those requiring support, providing personalized care in familiar

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1 "Gift of time" was a concept presented by the National Multiple Sclerosis Society (US) whereby an employee is able to donate up to ten days of unused accrued vacation and/or sick time to a bank for use by colleagues who have caregiving responsibilities.
surroundings and relieving governments of substantial public costs that might otherwise be incurred. The contribution of family caregivers is often at the expense of their own personal health and financial wellbeing.

The context for family caregiving in Canada however, has changed in response to the evolution of the family unit. Families are smaller\(^2\) and more dispersed; there is increased participation of women in the labour market; marriage and childbearing occur later in life; retirement is delayed. At the same time, the demand for care is increasing in response to the aging population paired with increased disability rates; preference of care recipients to be independent at home for as long as possible; health human resource shortages limiting capacity of the formal health care system; and, health system reform across the country resulting in the movement of care from the acute system to the community. Today’s reality is that the formal and informal system for caring are, and will continue to be, challenged to meet the needs of Canadians with health care related needs.

Canada is a country where disadvantage and financial hardship as a result of health care need should not be tolerated. By extension, forum participants believe that disadvantage and financial hardship should not be a likely or inevitable outcome of caregiving. There is a financial impact to caregiving and people in Canada should not have to choose between caring for loved ones and economic security.

**Discussion**

The economic consequence of family caregiving from the perspectives of government, research, employers and individuals were presented and discussed. For the purpose of the discussion, poverty was equated to economic hardship resulting in deprivation of the essentials for a minimum standard of well-being and life.

Without longitudinal research in the area of caregiving, it is very difficult to track the cumulative impacts of caring and difficult to state conclusions about the likelihood of poverty exposure as a result of the caring role. The only comprehensive national data set on caregiving (GSS 1996) is now 13 years old. While the more robust data sources (e.g. GSS 1996, 2002, 2007 and Census) provide a good demographic profile, they do not give very detailed information about health, social and economic consequences of caring.\(^3\) However there are many studies that provide important insight to the issue of caregiving and financial consequence that forum participants agreed command attention and action.

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\(^2\) The fertility rate in 2006 was 1.5 compared 2.1 in the 1970s and 3.4 in the 1950s per Nora Spinks, WorkLife Harmony.

\(^3\) R. Lindsay, HRSDC, Presentation to the Forum
The Evidence

Family caregivers come from all walks of life — old and young; female and male; and of all income strata. In total, 2.85 million Canadians were identified in 1997 as providing care for a family member with long-term health problems. Subsequent analyses suggest that the numbers of caregivers are doubled today.

Family caregivers provide more than 80% of care needed by individuals with ‘long-term conditions’ and as such are essential to society and are the backbone to the health care system. In 2006, Canadians provided unpaid care to an adult relative, on average, for 4.4 years.

Caregivers of both sexes experience employment consequences as a result of their responsibilities. A study by Health Canada suggests that 27% of caregivers have been affected. Consequences include reduced earnings and hours of work; and opportunity costs such as forgone training, promotion, overtime etc. As the table below presented by Dr. Janet Fast of the University of Alberta shows, the incidence of employment accommodation varies widely.

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>Women</th>
<th>Men</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced hours</td>
<td>21.5%</td>
<td>12.7%</td>
<td>12-45%</td>
</tr>
<tr>
<td>Changed work patterns</td>
<td>28%</td>
<td>15.8%</td>
<td>18%-58%</td>
</tr>
<tr>
<td>Changed from full to part time</td>
<td>28%</td>
<td>15.8%</td>
<td>18%-58%</td>
</tr>
<tr>
<td>Quit job</td>
<td>2-48%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absent from work (1-3 days)</td>
<td>6-58%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missed meetings</td>
<td>15%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missed promotion or special projects</td>
<td>2.9%</td>
<td>2.5%</td>
<td>8-29%</td>
</tr>
<tr>
<td>Used personal days</td>
<td>9-22%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work disrupted (some significant)</td>
<td>19-33%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additionally 8.3% of women and 6% of men postpone education/training; 6.2% of women and 2.4% of men decline a job transfer or promotion; and, 4.2% of women and 1.8% of men decline a job offer.

Dr. Fast estimates that each year during the period 2002 to 2006 some 623,000 Canadians accommodated their employment to elder care demands in some way. Three times as many women as men reported eldercare-related employment consequences ranging from cutting back from full time to part time hours which of course has an impact on learnings and benefits.

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5 1996 GSSS per R. Lindsay, HRSDC
6 Census 2006 per R. Lindsay, HRSDC
7 R. Lindsay, HRSDC, Presentation to the Forum
The estimated annual lost wages due to eldercare-related employment disruptions collectively amounted to approximately $360 million annually during the first half of this decade, up more than 70% from the previous five years.\(^9\)

**Financial Strain – Policy Considerations**

Drawing on her recent op ed article in the Toronto Star, Sheri Torjman highlighted three aspects to the financial strain that can be experienced by family caregivers:\(^10\)

1. **Income security of care receivers** – many seniors and persons with disabilities live on low incomes with no option but to rely on income security programs. An approach would be, at a minimum, to reform the current disability income system increasing / indexing the social assistance; and ideally to create a new federal income program.

Increasing the flexibility of the Employment Insurance (EI) sickness benefit and the Canada Pension Plan (CPP) benefit would help those with chronic disabilities that typically have acute exacerbations followed by periods of remission, such as cancer, AIDS, multiple sclerosis.

Finally more communication and education of caregivers regarding the Registered Disability Savings Plan (RDSP) is vital to helping families to prepare for the future needs of a loved one.

2. **Employment status and income of caregivers** – caregivers jeopardize their current income and future pension when they leave the workforce to fulfill their caregiving responsibilities. To protect caregiver income there need to be reforms to enhance the EI Compassionate Care Leave provisions; extend Child Disability Benefit; and expand CPP drop-out provisions. Employers also need to be informed and educated about the emerging needs of their workforce that will, potentially on very short notice, be placed in a caregiving role.

3. **Costs of disability supports** – there are direct and hidden costs, only some of which are offset by tax credits for those with taxable income. The return on investment to supporting families with the additional expenses linked directly to age or disability is significant. An estimate of costs in personnel alone to fulfill the care provided by family caregivers in Canada is estimated to be $25 billion.\(^11\)

Options to support caregivers include making the current federal disability, caregiver and infirm dependant tax credits refundable; converting these tax credits into an allowance; and investing in the supply of disability supports.

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\(^{9}\) J. Fast, HCIC, Presentation to the Forum  
\(^{10}\) Torjman, S. (2009) The Three Ghosts of Poverty, Caledon Commentary  
\(^{11}\) Hollander, M., et al. (2009) Who Cares and How Much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly.
Employer Accommodation of Caregivers

Nora Spinks explained the business case for employer accommodation of family caregivers. It includes:

- Compliance and competition – the need to adhere to legislation and manage the organization’s reputation
- Productivity and performance – in response to public pressure for bottom line performance including taxpayer value for public services
- Resiliency and sustainability – where individual contribution is critical to the organization
- Corporate social responsibility – recognizing the individual’s need to work and balance family, social and community responsibilities

The emerging principle to support family caregivers is “customization”, the opportunity to adjust work without sacrificing job and career advancement. Workplaces that support family caregivers recognize and respect the employee’s caregiving obligations. They are prepared to make accommodations to support the employee’s needs and have programs, policies and practices that are caregiver friendly.

Innovative employment practices include those that:

- Build on flex programs offering ‘future leaves’, ‘return to work’ transitions, ‘trauma leave’ and ‘career customization’
- Enhance family care policies providing compassionate care top up, expanded benefits, respite care, meals to go
- Add to the counseling, advice and resource services for employees by including other family members and providing online resources and counseling.

Experience

The Forum participants work closely with family caregivers, employ family caregivers or are presently engaged in family caregiving responsibilities. Their stories and experiences provide an important and compelling opportunity to put a face on the facts.

- 41% of families use their personal savings in order to survive during their illness - Canadian Cancer Society
- Financial need is the greatest plea through our Caregiver Portal - Victorian Order of Nurses
- The hidden cost to me was the loss of my job - Caregiver
- We can donate up to ten accrued days (vacation or sick days) as a “gift of time” for colleagues with caregiving responsibilities – National Multiple Sclerosis Society
- People who provide support to those with Alzheimer’s experience social exclusion - Alzheimer’s Society
- Because of the downturn of her health (she) has become my full time job - Caregiver
- It’s not if…. It is when you will be a caregiver – Canadian Caregiver Coalition
- We see the poverty in their lunch boxes – Young Carers Initiative
- I wish I could just have a break – Caregiver
The Dilemma

There is no question that the demands on caregivers are set to increase over the coming years. The potential impacts to the caregiver, the family and society are interconnected and include health, economic and personal and social consequences as outlined in the following table presented by Rachael Lindsay, HRSDC.

<table>
<thead>
<tr>
<th>Economic / Productivity Implications</th>
<th>Caregiver</th>
<th>Family</th>
<th>Society</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced wages, pensions/benefits, and curtailed job advancement</td>
<td>Added costs that caregivers could result in reduced family income: • Less saving for education • Less savings for retirement • Impact on family vacations • Increased debt loads • Reduced discretionary income for family activities</td>
<td>Costs from absenteeism/presenteeism (reduced hours; quit to care; retire early…)</td>
<td>Increase in public expenditures from use of income support programs &amp; publicly funded pension income</td>
</tr>
<tr>
<td>39% providing financial assistance to parents – average $498/month (a 2009 survey)</td>
<td></td>
<td></td>
<td>Full labour market potential not realized</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health &amp; Social Implications</th>
<th>Caregiver</th>
<th>Family</th>
<th>Society</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher rates of morbidity &amp; mortality for caregivers with high stress</td>
<td>Family stress – potential for marital breakdown; violence; impact on family functioning/child development</td>
<td>Increased cost of institutional /formal home care</td>
<td>High caregiver strain /burnout --Costs healthcare system in additional physician &amp; emergency visits</td>
</tr>
<tr>
<td>Increased rate of health problems (risk of injury, high blood pressure, depression)</td>
<td>Disrupted social relationships</td>
<td></td>
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</tbody>
</table>

The consequences of caregiving threaten the sustainability of the family/friends care sector on which our society relies to address the majority of care for the frail and vulnerable. Dr. Fast’s research indicates that the factors that put caregivers at particular risk of consequences include:

- **Gender** - Women are more likely to have work interruptions; men's financial losses are greater when they have interruptions
- **Those in ‘marginal’ jobs** - the lower wage earners, temporary workers and self-employed
- **Those caring for someone with a severe disability**
- **Those caring for close kin** (spouse or child)

The challenge is to determine the caregivers most at risk and institute measures to enable them to continue to provide the care that is natural and a reflection of their compassion and not deprive them of the balance necessary to living a life that they have reason to value.
A Call to Action

The Canada we want is an inclusive society where caregivers are not so economically disadvantaged that they do not experience a life they value. Canada is capable of creating the conditions where caregiving is not only possible, but celebrated and valued as core to our social construct. There is no singular solution and as such, all levels of our society need to work to achieving this reality.

The challenge is complicated – it pulls at our minds, hearts and resources. Foundational to the work is a Canadian Caregiver Strategy that addresses income security as a key element. The Strategy needs to be national, accessible, cohesive and collaborative. Actions should be strategic, focused, multi-purposed, building on and leveraging existing services and delivery mechanisms. It should eliminate any and all economic disadvantage related to caregiving.

Forum participants agreed to work together to change the conditions of caregiving in the next three to five years. Many participating organizations at the Forum maintain comprehensive strategies in support of family caregivers, however, all agreed that broader understanding of the issues and a stronger representative alliance must be forged at all levels of society and be:

- **People-based** - services and supports reflecting individual/family unique needs, priorities, and preferences. Income security and labour force attachment are key elements.
- **Community-based** – recognizing the geographic diversity across the country and leveraging the services, capacity and imagination within each community
- **Public policy-based** – setting the framework for universal access across the country or province/territory and enhancing government programs and labour/employment standards.
- **Market-based** – so that innovative solutions can be developed
- **Work-place based** – employers who promote incentives to provide caregiver supportive policies and practices.

The next steps will be to:

- Create awareness of the issue and its multiple dimensions – health and wellbeing; financial burden; access to information; workplace accommodation and respect
- Brand and shape the core message through effective language, stories and ‘declarations for change’ around which support can be garnered
- Leverage the Canadian Caregiver Coalition to engage support from all sectors and regions within Canada
- Build on the examples of excellence
- Create an Innovation Team to imagine the possible and develop tactics to advance the agenda.

All committed to spreading the concept of a ‘Gift of Time’ as one small and yet very tangible way of engaging employers in a dialogue about the simplest of initiatives that can have a profound impact. There was agreement to meet again in order to sustain the momentum and advance the agenda.

*We need to be the change we want to see.*
Conclusion

Although there is an absence of longitudinal Canadian data on caregiving making it difficult to draw conclusions about the long term impact, there is no doubt that the economic consequence of caregiving for families can be profound.

Canada is a country with social policies that prevent destitution as a result of poor health. The changing demographics challenge us to consider the ethics of leaving people without the supports and resources to balance their caregiving responsibilities with work and raising a family.

Caregiving is a life-transitioning and life-altering experience that will be experienced by virtually everyone. The commitment arising from this Forum was to place a spotlight on this important issue which for so many Canadians is a labour of love. The intent arising out of the Caregiver & Poverty Forum is to create a culture of respect, support and caring available to all in Canada when their time to be a caregiver arrives. It will be one of the most important legacies of this generation to build for future generations to come.
Appendix 1

Organizations represented at the Caregiver & Poverty Stakeholder Forum hosted by the Multiple Sclerosis Society of Canada:

- ALS Society of Canada
- Alzheimer Society of Ontario
- Canadian Cancer Society
- Canadian Caregiver Coalition/Canadian Homecare Association
- Canadian Council on Social Development
- Caregivers Nova Scotia
- Multiple Sclerosis Society of Canada
- National Multiple Sclerosis Society (US)
- Parkinson Society Canada
- Pfizer Canada
- Schizophrenia Society of Canada
- The J.W. McConnell Foundation
- Victorian Order of Nurses Canada
- Young Carers Initiative, Powerhouse Project

Presentations by:
- Caledon Institute of Social Policy
- E.Y.E. – Social Projects Studio
- Hidden Costs/Invisible Contributions Research Project, University of Alberta
- Human Resources Skills Development Canada, Government of Canada
- Work-Life Harmony Enterprises
Appendix 2

Presenter Bios

Eric (Ric) Young
Ric Young has been called “one of our leading thinkers and practitioners of social change…a social visionary, whose career has been a tireless practical pursuit of the possible.”

A pioneer in the field of social marketing, he cut his teeth on the early stages of the PARTICIPation campaign, and was co-founder of Canada’s first dedicated social marketing agency. He left that company in the mid-90s to start E.Y.E. | The Social Projects Studio™ – a company dedicated to the creation and development of breakthrough social change initiatives.

Over the years, he has worked with leading government, corporate and not-for-profit clients to address some of the major challenges facing today’s society. But working on issues ranging from HIV-AIDS to climate change, from poverty to violence, he became increasingly frustrated by the inadequacy of the tools, models and methods society has at hand for tackling our most complex problems. This led him, in the year 2000, to propose to DuPont Canada that they embark on an initiative “to foster new mindsets, new skill sets, and a new culture for social innovation in Canada”. He worked with DuPont over several years to develop the Social Innovation Initiative, eventually forging a partnership with McGill University to create one of the world’s first social innovation think tanks. This think tank gave rise to the best-selling book, Getting To Maybe.

In the foreword to that book, Young writes: “This book is about the art, the science and the experience of possibility. Its bold purpose is to change the way we change the world.” This is the same spirit that drives all Young’s work.

He has written and lectured extensively across North America about the challenge of change and the remaking of community in the 21st century.

He is on the faculty of the Boston College Centre for Corporate Citizenship. His current voluntary roles include: membership on the board of Ecotrust Canada, the Canadian advisory board of Right To Play and the editorial board of the Social Marketing Quarterly. He is a fellow of The Royal Society of the Arts and a member of Massey College’s Quadrangle Society. In 2008 he became a fellow of SiG (Social Innovation Generation) at the University of Waterloo.

Sherri Torjman
Sherri Torjman is Vice-President of the Caledon Institute of Social Policy. She has written in the areas of welfare reform, customized training, disability income and supports, the social dimension of sustainable development and community-based poverty reduction. Sherri is the author of the book Shared Space: The Communities Agenda. She has also written many Caledon reports including Caregivers and Dementia; Proposal for a National Personal Supports Fund; What Are Policy-Makers Saying about Respite?; Poverty Policy; Community Roles in Policy; Reclaiming our Humanity; Strategies for a Caring Society; Survival-of-the-Fittest Employment Policy; The Social Dimension of Sustainable Development; The Social Role of Local Government; The Canada Pension Plan Disability Benefit; Reintegrating the Unemployed through Customized Training; and How Finance Re-formed Social Policy.

Sherri wrote the vision paper In Unison: A Canadian Approach to Disability Issues for the Federal/Provincial/Territorial Ministers Responsible for Social Services. She has authored four books on disability policy: Income Insecurity, Poor Places, Nothing Personal and Direct Dollars. Sherri wrote the

Sherri was co-Chair of the Technical Advisory Committee on Tax Measures for Persons with Disabilities that reported to the Minister of Finance and the Minister of National Revenue in December 2004. She has worked for the House of Commons Committee on the Disabled and the Handicapped, the House of Commons Special Committee on Child Care and the Royal Commission on New Reproductive Technologies.

Sherri taught a course in social policy at McGill University and is a former Board Member of the Ontario Trillium Foundation.

Nora Spinks
Nora Spinks is President of Work-Life Harmony Enterprises, an international consulting and training firm based in Toronto. For more than 20 years, Nora has been providing leadership to leading corporations, governments, labour and community groups on work-life issues by focusing on creating supportive work environments, strengthening families and building healthy communities.

An experienced researcher and consultant, Nora has developed and implemented a variety of unique federal, provincial, community and corporate programs focusing on employee health and well-being, family care, workplace flexibility and work-life harmony. She developed Canada’s first national Family Care resources and referral program and the first national network of employer-supported short term and seasonal childcare services. She is currently involved in the development of back-up childcare centres in Toronto and advocating for workplace and community supports for families with extraordinary care needs.

As a recognized leading authority on work-life issues Nora is a sought after media contact and is quoted and profiled widely in print, and on radio and television nationally. She is the author of The Manager’s Work-Family Tool Kit, and frequent contributor to Canadian HR Reporter and HR Professional, as well as to the recently published texts Advancing Women’s Careers, and Managing Human Resources. She is regularly quoted in the national and international press, including in The Toronto Star, The Globe and Mail, The National Post and The Wall Street Journal.

Nora has been actively involved in the development of the Centre for Families, Work and Well-being (CFWW) at the University of Guelph. Her other community endeavours have included active involvement with the Centre for Workplace and Community Well-being, Canadian Child Care Federation, The Learning Partnership, Conference Board of Canada, and Eva’s Place; North York’s Emergency Home for Youth.

Janet Fast
Dr. Fast’s research addresses family, health and continuing care policy issues. A major theme is the paid and unpaid care work of family members. She currently co-leads a large international, multidisciplinary research team investigating the risk factors for, and pathways to, social exclusion for aging adults, with a strong focus on caring for family and friends as one such pathway. Of particular interest are the risks of exclusion from the labour market and its associated economic consequences.

For further information please visit http://www.hecol.ales.ualberta.ca/Fast.cfm?CFNoCache=TRUE
The Multiple Sclerosis Society of Canada would like to thank Pfizer Canada for their generous support and funding through an unrestricted educational grant that made this important dialogue possible.