

WORKING CAREGIVERS AND LABOUR MARKET CHANGES A CAFÉ CONVERSATION WITH STAKEHOLDERS

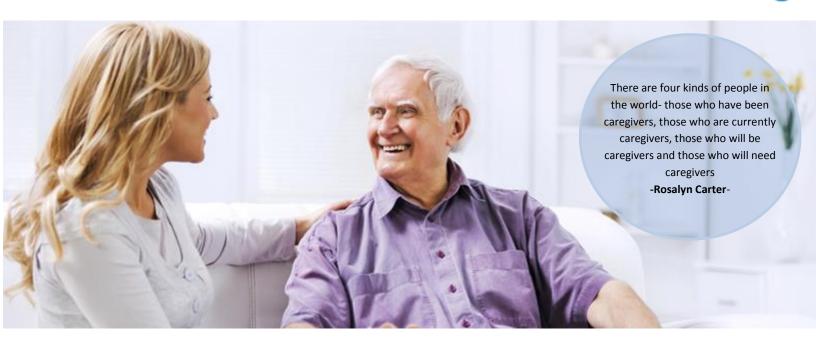
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The Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training



INTERNATIONAL FEDERATION ON AGEING Global Connections



#### CONTEXT

THE RAPID INCREASE IN THE NUMBER OF WORKING, PREDOMINANTLY FAMILY, CAREGIVERS IS AN EMERGING TREND THAT HAS SERIOUS SOCIAL AND ECONOMIC CONSEQUENCES FOR CANADA, ADVERSELY AFFECTING EVERYTHING FROM THE STABILITY AND FUNCTIONING OF THE FAMILY UNIT TO THE PRODUCTIVITY OF THE LABOUR MARKET.

To address the consequences of this rapidly evolving social change "The Reitman Centre CARERS Program for the Workforce" has been developed. Funded by the Ministry of Human Resources and Skills Development Canada, now encompassed in the newly named Employment and Social Development Canada, this five-year project was financed within the portfolio of the Social Development Partnerships Program, Children and Families Component.

A primary objective of the project is to explore whether labour market system capacity can be enhanced through the implementation of evidence-based interventions, tools and resources that enable working caregivers to better cope with the pressures of balancing multiple concurrent roles such as employee, caregiver, mother and partner. There is a critical need to maintain a productive workforce by sustaining employed persons in their roles of providing care to their family members while simultaneously working.

Contributing to the issues facing working caregivers are a number of linked and significant facts, namely: population ageing; increased prevalence of chronic conditions (and in this project specifically Alzheimer's disease and other dementias); and the precarious balance and tension between the need for adult children and spouses to assume increasingly more complex care-roles to complement (and often substitute for) the formal health and social care system—a system which may not be consistently available or able to address the needs of a person with dementia and the inevitable and profound impact of the disease on the family (Sinha, 2012; Turcotte and Schellenberg, 2006).

The complex array of stressors and pressures related to being an employee, a caregiver, a mother or father, and partner have only relatively recently been named and acknowledged in the literature (Canadian Institute for Health Information, 2010; Craswick and Dosman, 20008; Turcotte, 2013) but are untested in the realm of employee entitlements and support systems that respond to employee needs.

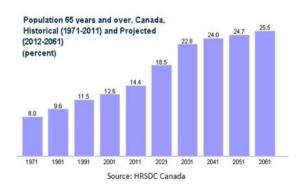
At best, some employers may recognise and support working caregivers through generic policy and program initiatives, but these are not tailored to the unique needs of individual working family caregivers nor evaluated for their impact and outcome. According to one survey, only one in four workers stated that the employer provided supports such as group discussions, nursing consultations, financial and legal advice and assisted living counsellors (Witters, 2011).

Tools and services offered through Employee Assistance Programs (EAPs) require careful examination and reform in order to respond to the issue of working caregivers toward positive and enduring outcomes. In addition, the stark reality is that small business enterprises generally do not have the capacity to engage EAPs, so novel strategies are required to ensure that effective and well-tested interventions are available and accessible to all working caregivers. Developing and implementing evidence-based programs to enable caregivers to remain in the workplace is an increasingly necessary perquisite for recruiting and retaining a productive and experienced workforce (Duxbury and Higgins, 2012; Silliker, 2013).

## THE FACTS

Ageing is one of the most challenging megatrends of the 21st century. Preparing for an ageing society is now a vital part of policy agendas across the world and governments must have the capacity and capability to respond to a variety of interconnected trends such as low fertility growth and longer life expectancy, increase in the prevalence of chronic non-communicable diseases such as Alzheimer's disease and increased pressure on formal and informal care services.

Today, one in every seven Canadian citizens is over the age of 65 years. The well-known acceleration in population ageing guarantees an inevitable and dramatic increase in the numbers and proportion of seniors in Canada over the next 25 years (Turcotte and Schellenberg, 2006).



In 2036, more than one-quarter of all Canadians (10 million citizens) will be over the age of 65 years, a trend rivalled only by the ever increasing proportion of oldest-old Canadians (those over the age of 85 years) (Statistics Canada, 2011). Between 2021 and 2056, as the baby boomers reach the age of 85 years, the number of persons in this sub-population is expected to increase from 800,000 to 2.5 million; and their share of the total population is expected to almost triple, rising from 2.1% to 5.8% (Turcotte and Schellenberg, 2006). As this cohort is the age group most prone to dementia, a concomitant sharp increase in the prevalence of Canadians diagnosed in its with this condition is inevitable, assuming our current capacity to treat or prevent dementia does not improve.

Furthermore, between 2015 and 2021, for the first time history, Canada's population will be comprised of more seniors than children under the age of 14 years. This parallels the projected steady decrease in the working-age population from 70% in 2009 to 62% in 2036 (Statistics Canada, 2011).

The never-before-seen shifts in the labour markets in both public and private sectors are trumped only by the changing shape and form of family and family care. In the United States,

> Today, one in every seven Canadian citizens is over the age of 65 years. In 2036, more than one-quarter of all Canadians will be over the age of 65.

more than one in every six full or part-time workers is now a caregiver of an older or disabled person and faces the requirement of meeting socioeconomic challenges as well as 'care' challenges and expectations (Cynkar and Mendes, 2011; Family Caregiver Alliance, 2012). Caregivers working at least 15 hours per week said that these pressures significantly affected their work life (Cynkar and Mendes, 2011).

In the face of increased demands on employees to provide caregiving at home, maintaining a productive and viable workforce will be a critical challenge for employers and governments alike.

## THE JUSTIFICATION FOR EMPLOYERS TO PARTICIPATE AS PARTNERS

Caregiving is an issue which faces all of us. In Canada, close to half (46%) of those aged 15 years and older who participated in the 2012 General Social Survey (GSS) reported providing care to a loved one coping with a chronic health condition, a disability or an age-related concern at some stage in their lives (Sinha, 2012).

In large part, research about caregivers in the workforce has focussed on the employee, although evidence from the United States, Europe and Canada has suggested that industry outcomes related to caregiving include lost productivity, employee absenteeism, high employee turnover, in addition to the immeasurable human and social costs that result from the creation of a conflict between work-life and family-life (Cynkar and Mendes, 2011; Duxbury and Higgins, 2012; Feinberg et al., 2011; Sinha, 2012; Witters, 2011). "Whether the economic climate is good or bad, it does not change the fact that with a rapidly ageing population the caring responsibilities will continue to grow"

-Caroline Waters, BT Group 2009

Estimates of the proportion and age of employees with multiple roles and responsibilities, including caregiving for a loved one with a chronic condition such as Alzheimer's disease, vary greatly perhaps because there are no commonly accepted gold standards of definition and measurement. Moreover, the nature of the struggles and their impact on working caregivers remains somewhat invisible and unspoken. There is a general lack of research on working caregivers, their needs, roles, and management of dual roles which impact on the development of industry and governmental policy.

In their 2012 report about balancing work and caregiving within Canada, Duxbury and Higgins report that one in six "knowledge workers" is providing care to someone who is ill or disabled (Duxbury and Higgins, 2012). These results are reinforced by the GSS report that most Canadian caregivers (60%) are also engaged in paid employment (Sinha, 2012).

The age and gender of working caregivers is of importance in the development of programs

and policies, yet comparative studies are not available. In the United Kingdom, 90% of working caregivers are aged 30 years and over and the peak age of a family caregiver is 45-64 years. In the United States, the "typical" caregiver is a 49-year-old woman who is in paid employment and commits to almost 20 hours per week providing unpaid care to her mother for nearly five years (Feinberg et al., 2011).

Most employees have gained valuable skills and experience and are most capable of making significant contributions in the workplace at this phase of their life which coincides with the competition of time and resources to unpaid work in the form of family caregiving.

In addition to age and gender "culture" in the broadest sense impacts the nature of the caregiving experience. For instance, the likelihood of being a caregiver is higher among those with less education and lower income (AARP, 2009; Cynkar and Mendes, 2011). Furthermore, people from ethnic minority groups are more likely to be caregivers, provide more care and report worse physical health than their white counterparts (AARP, 2009; Cynkar and Mendes, 2011; Pinquart and Sorenson, 2005).

Within some cultures, there is a firm expectation that children will assume the caregiving role of their parents and the idea of hired care is considered taboo.

While globalisation and urbanisation is somewhat affecting the cultural norms the role of child caring for elders remains relatively intact. For this reason cultural diversity must be a primary overarching factor in the design of new programs for working caregivers.

The literature on working caregivers from culturally and linguistically diverse backgrounds is sparse. Considering the heterogeneous nature of the Canadian population, this is clearly a serious, unaddressed, and emerging issue which needs to be placed firmly on the policy agenda. The economic climate and corresponding impact on the labour market presents a further lens through which to consider the impact of caregiving roles on working caregivers. There has never been a more important time to focus on the benefits of retaining skilled workers – and supporting employees to work healthily and productively rather than incurring the costs of recruiting and retraining new staff.

Existing employer-led initiatives such as flexible work arrangements, options for leave, and income and job protection simply do not respond to the underlying problems associated with the increasingly complex caregiving role.



## THE NEED TO ESTABLISH PARTNERSHIPS WHICH ENABLE SOCIAL AND ECONOMIC CHANGE

It is clear that the increasing numbers of working caregivers in Canada will have serious and long term consequences for businesses of all sizes and in all sectors. Yet, on an aggregate level, these consequences may be even more alarming though largely invisible.

In 2011 in the United States, caregivers in the workforce reported missing an average of 6.6 work days per year; the equivalent of \$25.6 billion in lost productivity annually (witters, 2011).

Furthermore, 54% reported that caregiving responsibilities negatively affected their job performance to some degree with 10% describing the impact as "great" and 24% saying that providing care prevented them from devoting more hours to their paid employment (Witters, 2011). The negative impact of caregiving duties on paid work increases as a result of the amount of time devoted to care. Four in ten (43%) Canadian caregivers providing 2 – 4 hours of care per week reported arriving at work late, leaving early or taking time off during work hours and this number increased to 54% among those devoting 20 or more hours to caregiving weekly (Sinha, 2012).

# The cost to businesses of replacing women who have left the workforce because of caregiving responsibilities has been estimated at \$3.3 billion.

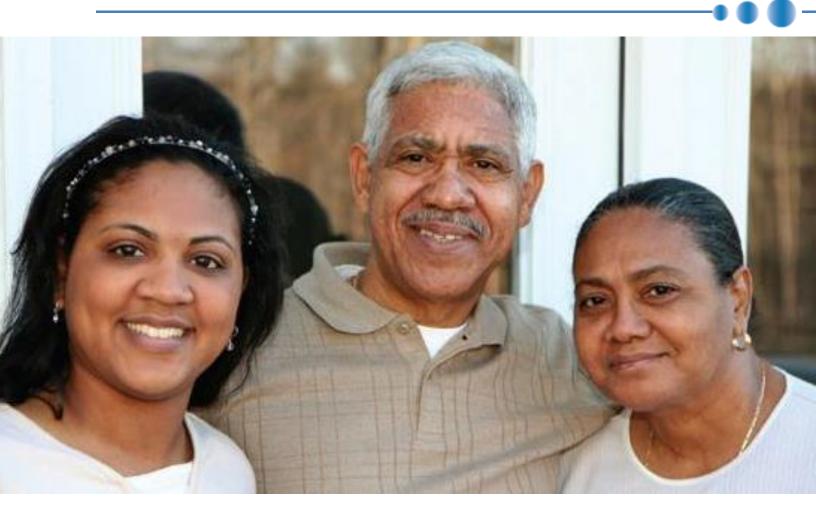
Additionally, absenteeism among women caregivers in the workforce due to caregiving responsibilities costs businesses almost \$270 million and the cost to businesses because of partial absenteeism (e. g., extended lunch breaks, leaving work early or arriving late) for the same cohort is estimated at \$327 million. Caregiving-related workday interruptions add another \$3.8 billion to the costs borne by businesses (Metropolitan Life Insurance Company & National Alliance for Caregiving, 1997).

An investment in the future productivity of business, first through an improved understanding of the impact of caregiving on working caregivers; and second by creating solutions with expert partners, is anticipated to pay lasting dividends (Witters, 2011) in terms of economic productivity.

Additionally, employers who support employees in their pursuit of a sustainable work-life balance report having higher rates of employee retention (Duxbury and Higgins, 2002).

Employers who help employees to balance paid work with unpaid caregiving responsibilities could also be considered as being 'ahead of the game' and the demographic curve that is currently forcing many families to reassess the family caregiving proposition. As governments around the world make changes to employment legislation to protect and support family caregivers in the workforce, a new style of Employee Assistance Program (EAP) tailored to the needs of family caregivers is necessary. Not addressing the consequences of employees having multiple roles and responsibilities which include being a caregiver for a loved one with a chronic condition such as Alzheimer's disease and working full-time is to risk a future that is unsustainable, both as a society and as a competitive economy.

Employers who support employees in their pursuit of a sustainable work-life balance report higher rates of employee retention.



## THE CAFÉ CONVERSATION

THE BROAD AIM OF THE CAFÉ CONVERSATION WAS TO 'EXPLORE QUESTIONS THAT MATTER' TO WORKING CAREGIVERS OF PEOPLE WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS AND BETTER UNDERSTAND THE POTENTIAL IMPACT OF THE STRESS ENCOUNTERED BY THIS GROUP ON THE LABOUR MARKET SYSTEM CAPACITY. The primary question posed at the Café Conversation:

"Can an evidence based caregivers program respond to labour market changes consequent to population ageing; and thereby reduce the personal, economic, and workplace impact of the demands of caregiving on working caregivers?"

Through the course of the Conversation the following objectives were met:

1) Engaging participants in dialogue and exploration of the potential for an evidencebased caregiver program to positively influence the labour market system in an ageing society. 2) Gaining insights from the range of perspectives and experiences of participants from various sectors and disciplines.

3) Enabling participants to connect with and learn from one another.

## STRUCTURE

In order to best achieve its intended objectives, the Café Conversation was structured as an open discussion; an homage to the World Café model, in which all participants can contribute equally and openly.

Representing a broad spectrum of sectors, the Café Conversation involved a diverse range of participants including policy experts, representatives of industry, representatives from relevant NGOs, academics, caregiving experts, and caregivers themselves.

Participants were divided into individual tables with 6-8 people at each and then prompted with leading questions to facilitate discussion.

After participants had sufficient opportunity to discuss each question at their individual tables, a representative from each group synthesized



the main points of discourse followed by a broader discussion to 'unpack' the various complexities. Inevitably, the responses to the leading questions were dynamic and transformative, sometimes veering off into unanticipated areas, and sometimes provoking the creation of new questions altogether. Still, each question covered unique territory and the design of these questions enabled the diverse array of delegates to bring their respective sets of expertise to the discussion, creating an insightful, thoughtful, and productive conversation.

## DISCUSSION

WHAT ARE THE CURRENT LABOUR MARKET CHALLENGES FOR WORKING CAREGIVERS IN CANADA?

The intersection of paid employment and family caregiving is an emerging trend with serious consequences at a societal and national level which has not yet received formal acknowledgement from either the public or private sectors. Indeed, in one survey, more than one quarter of all caregivers stated that they believed their employer was unaware of their caregiving responsibilities (Witters, 2011).

# The labour market is by its very nature heterogeneous and so too are the roles and responsibilities of a family

**Caregiver.** As such, the size and nature of businesses and their capacities and capabilities to respond to the specific needs of employees who have assumed the role of family caregiver for a loved one with dementia are difficult to compare.

Small businesses with few employees are likely to experience substantially more challenges in accommodating flexible work arrangements or even allowing 'time off' for employees who are also caregivers to fulfil their various caregiving duties. In contrast, employees holding executive positions or those employed in large companies are: more likely to have access to an Employee Assistance Program (EAP); able to negotiate flexible work arrangements; and, more likely to have the financial resources to sustain any income lost while providing care.

Similarly, while the opportunity to work flexible hours in order to accommodate caregiving requirements is one option for someone who can complete his/her work assignments at any time of the day, there are many employment roles in which a person is required to work set hours each day -- flexible hours are simply not a viable alternative.

The flexibility afforded by higher workplace status and the nature of one's work may explain why caregivers who are visible in the community are more likely to hold professional or managerial positions while as few as 5% are employed in the transportation, construction or maintenance sectors (Witters, 2011).

Caregiving and the caregiving relationship have a diverse and difficult reality for all: An inevitable by-product of the growing prevalence of working caregivers coinciding with the increasing likelihood that most Canadians will either provide or receive care from a family

> Effective intervention programs must be adapted and shaped to meet specific sector and employer needs.

member at some point in their lives. The broad range of caregiver experiences makes it particularly difficult to design a universal and scalable program to respond to the specific needs of working caregivers.

Working caregivers (representing the gamut of the population) are characterised by divergent socioeconomic status, differing living arrangements, a multitude of caregiving responsibilities, as well as differing capacities, capabilities and willingness to respond to caring situations that for people with dementia may mean a commitment of years rather than days. It is vital that effective intervention programs which include but extend beyond 'education and training' are developed, or adapted and shaped to meet specific sector and employer needs.

Programs may need to be developed to target specific sectors, and perhaps even specific industries, and it may be a challenge to ensure that these programs meet the needs of their intended targets.

The integrity of the CARERS Program is built around a clear set of defined principles and tools that guarantee the efficacy of the Program. At the same time, a central tenet of the CARERS Program is the commitment to tailor interventions to the specific needs of each individual caregiver. Flexibility, adaptability and responsiveness are features of the Program enabling its adaptation to many situations and varied circumstances.

# Scalability of a tailored intervention program is possible,

albeit challenging because at the heart of the issue are the fragile relationships among family members, between employer and employee, and between demand and supply. Raising the profile of the unique issues facing working caregivers while at the same time More than one quarter of caregivers stated that they believed their employer was unaware of their caregiving responsibilities

educating industry on the importance of being a partner in creating a solution, is a key element in creating innovative, dynamic interventions that are sustainable within an economically driven climate.

The core issue of formal recognition lies in garnering acceptance from all employers that some of their workforce will inevitably assume the role of working caregiver. In today's society being a parent to a child with a chronic condition seems to be eminently more acceptable to employers compared with being a paid employee and caregiver of a parent in an advanced stage of dementia.

Despite the fact that working caregivers is an emerging trend, there is limited awareness amongst employers about the proportion of employees who are caregivers, the adverse effects that caregiving can have on a caregiver, and the potential impact that caregiving can have on one's relationships with his/her employer and family.

The lack of awareness is evidenced primarily in the widespread absence of employer-assisted programs and a general unwillingness amongst employers to invest in helping to enable employees to effectively balance various roles, while simultaneously ensuring that there is no compromise to company and business productivity.

WHAT NEEDS TO CHANGE IF WORKING FAMILY CAREGIVERS ARE TO REMAIN IN THE WORKFORCE?

Change commences with the formal acknowledgement of the dual role that working caregivers fulfil within society as providers of family care and providers of family income. This formal acknowledgement must occur at all levels of engagement and, most importantly, systemically across the labour market, health systems, and care systems.

# Multisectoral and multidisciplinary cooperation and engagement can be the precursor to innovative and

dynamic solutions. The engagement of government with the corporate sector, academia, non-governmental organizations, and working caregivers are optimal for establishing and disseminating consistent messages about: the increasing numbers of working caregivers within society; the unique challenges experienced by this sub population; and the way in which economic growth can be hindered at an aggregate level.

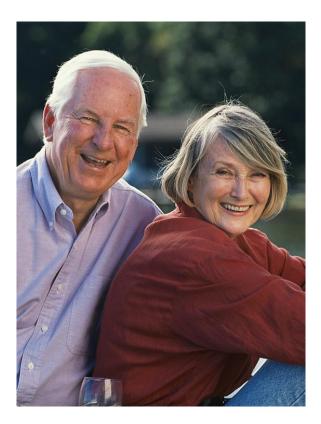
A basic level of awareness is a necessary prerequisite and starting point before the implementation of strategies to impact systemic change and stimulate logical system changes. This process is not only dynamic but iterative occurring over years and sometimes decades. It is, contingent upon the level of interest and political will, level of industry involvement, and level of advocacy efforts undertaken by and on behalf of working caregivers.

Unsurprisingly, change-agents may well be representatives from the aforementioned sectors who work in collaboration to promote a better quality of life for working caregivers; or in some cases a 'champion' whose experiences provide not only credibility but also leadership regardless of sector or discipline. Each sector and each discipline has a distinct role to play in achieving systemic change.

## The role of public policy is

**imperative.** Policymakers must be encouraged to craft legislation which provides cost effective solutions (both socially and economically) to the specific challenges facing working caregivers. For example enacting legislation or developing policy which, offers subsidized retraining programs or recruitment practices for working caregivers who would like to or need to re-enter the workforce after leaving paid employment to fulfil caregiving responsibilities (Williams et al., 2012).

The Province of Manitoba's "Caregiver Recognition Act" is a case in point. The Act has stimulated interest towards enhancing the quality of life of working caregivers through its core provisions of: "proclaiming the first Tuesday of April in each year as Caregiver Recognition Day; creating general principles relating to caregivers that outline how they should be treated and considered when interacting with the public, health staff and in the workplace; instituting a progress report every two years, which evaluate[s] caregiver



needs and supports; establishing a Caregiver Advisory Committee to provide the minister with information, advice and recommendations; and consulting with the minister and caregivers, organizations that provide care, appropriate government departments, the advisory committee and others" (Province of Manitoba, 2011).

In the United Kingdom and Australia, the formal recognition of the role and responsibilities of caregivers has been a pivotal point in societal and governmental engagement towards dispelling myths about caregiving but also a catalyst for the creation of meaningful dialogue across stakeholders.

Public policy as a method for stimulating change is a top-down process and one that is inherently political unless driven by a coherent strategy from stakeholders with an investment in the outcomes. The lag time between policy development, implementation, and evaluation is often long and the outcome often less responsive to the affected cohort. Further to this challenge is the possibility of a policy reversal by a future government with different priorities. There is a need for a more immediate and certain method of generating change that has partisan support.

# Change can also be catalysed by champions from the corporate

**Sector.** Once employers are endowed with the knowledge of what it means to be a working caregiver and the impact that this has on productivity, implementation of effectively designed EAPs for working caregivers is more likely, although, realistically, will always be pragmatically balanced, based on the cost versus dividend scenario.

Technology, as a solution, is relatively new and its long term impact on the use of health and social services is still untested on a large scale. Moreover, while technology can enhance and support some solutions, it is not the ultimate fix because assistive devices and 'smart homes' (as examples) will never be able to replace the human touch.

Working caregivers require programs that help to build their capacity and capabilities; programs that enable them to respond to dual roles, and the very specific and sometimes special behavioural needs of the loved one(s) with whom they have a caring relationship. Access to emotional supports in the workplace, flexible work arrangements, learning opportunities provided within the workplace to develop new skills to manage the behavioural manifestations of dementia, and education for those in managerial positions regarding the challenges caregivers face in balancing responsibilities at home and on the job are some of the critical elements of a successful program (Williams et al., 2012).

If specifically designed programs are unavailable within the workplace, employers must at the very least have a basic awareness of the extent and nature of care and support systems available within the community so as to provide a pathway to employees who may be struggling in their pursuit to effectively manage their various roles (Witters, 2011).

Equally vital as the emergence of champions is the need to recognize the pioneers; The Bank of Montreal (BMO) Financial Group and Ceridian HCM Canada are the first partners of the Reitman Centre Working CARERS Program which seeks to enable working caregivers by "[giving] caregivers practical skills and emotional support to deal with the complexities of caregiving" (Mount Sinai Hospital, 2011).

Change-agents are also those industry partners that recognize the significant and unrelenting dilemma experienced by working

**Caregivers.** The Reitman Centre, in the development, implementation, and evaluation of a therapeutic intervention, is by its nature a change-agent.

Much progress will be generated through the unique developments at The Reitman Centre that demonstrate the effectiveness that the said program will have on the quality of life of employees in the program, but also on the economic output and productivity of involved companies. Without leaders like BMO Financial Group and Ceridian HCM Canada who are prepared to take risks, challenge the norms and inspire through action, the prospect of attracting more employers to act as changeagents is virtually non-existent.

Working caregivers themselves also have a distinct role to play in driving change. As awareness about the challenges that this sub-population experience grows, a gradual decrease in the stigma shrouding the caregiver experience and an increase in the ability of employees to ask their employers for support in their caregiving duties is anticipated.

Working caregivers as a subpopulation with a unique set of characteristics also represent a united and authoritative voice. Moving forward, it is these people who will be the most important agents of change, as it is their voice which must ultimately be reflected in new and adapted support systems or legislation.

WHAT FACTORS AND CONDITIONS ARE ESSENTIAL TO ENABLING OR INDUCING INDUSTRY CHANGES WHICH IN TURN FACILITATE POLICY CHANGES PROVINCIALLY AND FEDERALLY?

Change within industry is driven by a confluence of factors; yet, the reality is that profit is a motivational factor for action. For systemic change to take place within industry, the costeffectiveness of any proposed working caregiver intervention must be tested, replicated in a variety of settings, and scalable. Somewhat counter intuitively, however, is the fact that corporate champions emerge to exercise corporate responsibility and to take the initial risk and act as leaders in an effort to collect essential baseline data. In examining the issue of the dual role fulfilled by working caregivers in Canada, it is the aforementioned BMO Financial Group and Ceridian HCM Canada who have stepped forward to accept the challenge of being ground breaking agents of change. Once champions have emerged, a familiar chain of events is stimulated.

> The most fundamental factor which drives change in industry and government policy is awareness.

Consider the example of Google, which is well renowned for being the pioneer of implementing large-scale employee benefit and support programs within the workplace setting. Through providing such employee benefits, Google has been able to attract an exemplary standard of employee, increase its productivity, and ultimately increase its profit margins. Competitors within the software industry are aware that, a similar set of benefits is necessary to attract the same calibre of employee. Google's policy has precipitated a permanent shift in the industry standard. The BMO Financial Group and Ceridian HCM Canada are laying the foundation for a similar chain of events to occur for workplace caregiver support systems in Canada.

Evidence based programs such as the Reitman Centre CARERS Program and the RCWCP that are developed under strict conditions and rigorously tested within the corporate sphere inform effective policy and scalable models. Government is not inherently a risk taking entity and legislation is rarely passed until it has been comprehensively confirmed that a need for a particular policy exists and that there is a demonstrably effective way of addressing this need. Industry standards as they relate to supporting working caregivers represent interventions that can be scaled up and embedded into public policy and society.

This being said, the most fundamental factor which drives change in industry and government policy is awareness. The reality is that a majority of causes within society are driven by a constituency of people who lobby, protest, and form coalitions to advocate for the change they desire. A greater constituency of people must be made aware of the challenges which surround the working caregiver experience so that they can champion organizations which accommodate for working caregivers and support politicians who vote to table legislation that would entrench such support into policy.

# KEY MESSAGES

## THE CAREGIVING RELATIONSHIP IS UNIQUE, caregivers are a heterogeneous

population, and the roles and responsibilities of caregivers range in complexity and can sometimes occur over a long duration of time.

The caregiving experience and its impact on an individual and their family are not generalizable nor is the labour market. Instead, both are influenced by gender, location, culture and socioeconomic conditions to mention a few variants. Any working caregiver support system must have the flexibility to accommodate the diversity of both caregivers and the corresponding labour markets.

### THE "WORKING CAREGIVER" IS LARGELY INVISIBLE because the role and

responsibilities seem to be assumed within the gender or familial role.

Developing a universal definition of working caregivers depends in large part on systematic data collection and analysis toward a sound understanding of the demographic and socioeconomic parameters of the cohort. To date national and regional data do not exist.

## AWARENESS ABOUT WHAT IT MEANS TO BE A WORKING CAREGIVER,

both amongst employers and employees is largely lacking in both the public and private sectors.

Evidence-based educational resources are essential to establish effective advocacy efforts toward influencing and shaping effective policy. Educating employers on the increasing number of working caregivers in the workforce will affect the quality of life of employees and profit margins, while the general public must be made aware of the prevalence of the issue to remove any remaining stigma which still shrouds the working caregiver.

PUBLIC POLICY IS ESSENTIAL if the role and responsibilities of caregivers are to be formally recognised.

Public policy is the framework through which emerging issues are recognized, interventions are legitimized, and sustainable funding models are created. Pilot projects, while providing insight and an opportunity to translate concepts into action, are not a substitute for strategic, well-funded responses to population-based issues that impact the social and economic fabric of Canadian society.

## TECHNOLOGY IS A GAME-CHANGER.

In designing interventions, an examination of how modern technology can provide cost-effective solutions is integral, but so too is foresight of what technology will be available five years from now and a need to tailor interventions to account for this future technological capacity. Technology, while enabling, cannot substitute for the human touch.



A MULTI STAKEHOLDER APPROACH across sectors and disciplines will stimulate system change.

Through demonstrated effectiveness, champions and change-agents will self-identify in order to promote, position, and evaluate the CARERS program in the workforce. Informed policy will be sustainable policy that safeguards the needs of working caregivers to enable them to remain in the workforce. Viable solutions are multi-sectoral and multi-disciplinary, bringing together individuals, industry, government, community, and non-governmental organizations.

The partnership between the Reitman Centre, BMO Financial Group and Ceridian Canada is a gold standard example of multi-stakeholder engagement whereby the CARERS model is scientifically tested to ensure that the correct and measured foundation blocks are built which are necessary to implement and scale-up the working caregiver programs.

# THE WORKING CAREGIVER DILEMMA EXISTS in every industry, every sector, and every community.

Raising awareness (which occurs first through identification of the problem), in concert with the creative solutions across private-public sector partnerships are the necessary prerequisites for industry and government to fully appreciate the serious social and economic consequences of this dilemma. Investment today means a sustainable workforce, social and economic stability within industry and community, a decrease in premature admission of family members with Alzheimer's disease into health care institutions, and ultimately, an improved quality of life for working care.

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The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.



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"THERE ARE FOUR KINDS OF PEOPLE IN THE WORLD- THOSE WHO HAVE BEEN CAREGIVERS, THOSE WHO ARE CURRENTLY CAREGIVERS, THOSE WHO WILL BE CAREGIVERS AND THOSE WHO WILL NEED CAREGIVERS"

-Rosalyn Carter-

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