

**Examining the Use of a Caregiver Assessment Tool – Barriers, Outcomes and  
Policy Implications**

**(Contract 4500116739 with Health Canada)**

**Final Report  
March 30, 2006**

**Authors:**

**Lucy Barylak**, Centre de santé et de services sociaux, Cavendish  
(lucy.barylak.cvd@ssss.gouv.qc.ca)

**Nancy Guberman**, Université du Québec à Montréal (guberman.nancy@uqam.ca)

**Pamela Fancey**, Mount Saint Vincent University (pamela.fancey@msvu.ca)

**Janice Keefe**, Mount Saint Vincent University (janice.keefe@msvu.ca)

**In collaboration with Marjorie Silverman**

## Table of Contents

Executive Summary	4
Introduction	6
1) <u>The Importance of Assessing Caregivers</u>	6
1.1 Why is this important work?	6
1.2 Evidence of the impacts of assessment	10
1.3 The importance of developing the CARE Tool	12
1.4 How was the CARE Tool developed?	12
1.5 Experiences using the CARE Tool	14
1.6 With what populations has the CARE Tool been used?	15
1.7 Limitations of the CARE Tool	16
2) <u>Assessment of Family Caregivers in Other National Contexts</u>	16
2.1 United Kingdom	16
2.2 Australia	17
2.3 Germany	18
2.4 Japan	18
2.5 United States	18
3) <u>Responses of Key Stakeholders to Using the Original CARE Tool</u>	19
3.1 Method	19
3.2 Feedback from and about caregivers	20
3.3 Feedback from practitioners and managers	23
3.4 Consistency with feedback from original CARE Tool project	24
4) <u>Shortening of the Original CARE Tool</u>	25
4.1 Feedback about structure and length of the Tool	26
4.2 Length of Tool and its link to workloads	26
4.3 Who should assess and impact on the Tool's structure	26
4.4 Caregivers' comments about length	27
5) <u>Issues to be Considered in Implementing Caregiver Assessment</u>	27
5.1 Defining caregivers as clients	27
5.2 The need for a specific caregiver assessment tool	28
5.3 Who should use the CARE Tool	29
5.4 Timing of caregiver assessment	30
5.5 Agency conditions for implementing the CARE Tool	31
5.6 Training and sensitization	31
5.7 Reaching caregivers for assessment	32
5.8 Costs of assessing caregivers	32
5.9 Costs of not assessing caregivers	35

6) <u>Policy Recommendations</u>	38
References	40
Appendix 1: Interview Guides	45
Appendix 2: List of Agencies that Participated in the “Becoming Partners: Tools of Transitions” Symposium in Ottawa in November 2005	48
Appendix 3: Research Team and Advisory Committee for CARE Tool Project	49
Appendix 4: Modifications to the CARE Tool	50
Appendix 5: The Modified CARE Tool	51

## **Examining the Use of a Caregiver Assessment Tool – Barriers, Outcomes and Policy Implications (Contract 4500116739 with Health Canada)**

### **Executive Summary**

The need to develop a caregiver assessment tool emerged from the recognition of caregivers' significant contribution in the care of persons with long-term health conditions and the increased awareness of their need for support. At the same time, an analysis of caregivers' lack of formal status within the health care system indicated the need for specific tools aimed at them. The CARE Tool was originally developed in 2001 with a Health Canada *Health Transition Fund* grant. Since that time, various health and social service agencies throughout Canada and the United States have piloted or implemented the Tool, and more research has been conducted on its efficacy.

The current research project aims to gain more understanding of the barriers and outcomes of implementing caregiver assessment, as well as to develop a condensed and more user-friendly version of the CARE Tool. Since September 2005, individual and group interviews have been conducted with 24 informants – 7 caregivers, 11 practitioners, and 6 managers – to gather feedback regarding the original Tool's usefulness, structure, impact and implementation.

Many of the caregivers interviewed reported that going through the assessment process gave them their first opportunity to talk about all aspects of their caregiving situation and to focus on their needs. This had a significant emotional impact, as it validated them as people as well as significant contributors to the care of others.

Practitioners' feedback was consistent in terms of the Tool's impact on caregivers, and added that the Tool influences service plans. Practitioners also reported that the Tool helped increase their understanding of their clients' situations (and of caregiving in general) but that there are a number of potential barriers to full utilization or implementation of the Tool. They, along with managers, stated that in order for the Tool to be implemented in an agency, there needs to be strong leadership at the management level, adequate training, and clarity around the status of caregivers within the agency.

There were also numerous suggestions regarding the length and structure of the Tool, which were taken into consideration in the development of a condensed version (see Appendix 4 and 5). Comments about the length of the Tool also suggested that its perceived length is directly linked to workloads.

Several countries around the world are also interested in caregiver assessment. However, a brief glance at the United States, the UK, Australia, Japan, and

Germany reveals that none of them have developed a single assessment tool for caregivers. This indicates that Canada could develop avant-gardist practices by piloting a single standardized caregiver assessment tool.

There are a number of issues for consideration regarding the implementation of caregiver assessment. First, the status of caregivers as partners in care, as well as potential clients of health and social service agencies, must be clarified. Once they are recognized as clients, tools must be developed to address their situations. The CARE Tool has been shown to be adaptable to various public and private settings, and for use by a variety of professionals. The CARE Tool can play a role in prevention and is generally positively appreciated by practitioners and caregivers alike, yet to be implemented in a widespread manner it requires strong leadership, training and buy-in at all levels, and a reallocation or reorganization of current workloads. It is recommended that the CARE Tool be promoted to ensure caregiver assessment across the country particularly, but not exclusively, in homecare, day centers, and other public and not for profit services aimed at caregivers.

## **Introduction**

The goal of the current CARE Tool project has been to increase our understanding of the advantages, limitations and context of assessing caregivers within the health and social service system. The project, which involved interviews with caregivers, practitioners and managers, provided feedback needed to not only develop a shortened, more user-friendly version of the CARE Tool, but to increase knowledge about the issues surrounding the use of the Tool in various health care agencies. This knowledge has led to policy recommendations concerning the implementation of the CARE Tool throughout Canada. Based on the feedback presented here and from ongoing work with the Tool, a series of changes were made to the original Tool to reduce its length and to make its format more user-friendly.

This report includes 1) an extensive background information regarding the development of the original CARE Tool and the importance of assessing caregivers, 2) a summary of select countries' approaches to caregiver assessment, 3) a review of the methodology of the current project and a synthesis of feedback from professionals and caregivers, 4) a review of feedback regarding the length and structure of the CARE Tool and a summary of the changes made to the Tool, 5) issues to be considered when implementing the CARE Tool, and 6) recommendations regarding the implementation of caregiver assessment.

### **1) The Importance of Assessing Caregivers**

#### *1.1 Why is this important work?*

Caregivers are the backbone of the current health and social service system and yet they have generally no formal status within this system. Policy and practice must be changed so as to more fully recognize the inestimable contribution of caregivers to Canadian society and to answer to their diverse needs.

Extremely disabled persons requiring complex, long-term care comprising a multitude of technical tasks, specialized skills, knowledge and competencies are being maintained in the community. In 2002, it was estimated that approximately one million Canadians aged 65 and over living in the community reported receiving care because of a long term health problem (Cranswick, 2003), while Quebec reported 480,000 people with disabilities severe enough to require help with activities of daily living (Institut de la statistique du Québec, 2001) in 1998. These numbers are on the rise as the proportion of the Canadian population over 75 continues to increase. Accompanying an aging population will be an increase in the prevalence of chronic diseases and as a result, social services will become at least as important as the provision of medical services (Carrière & Légaré, 2000).

As study after study has shown, care for disabled people in the community is mainly care by families and friends. However, families have undergone major transformations

that raise serious questions as to their availability and capacity to assume responsibility for the care of people with long-term disabilities or illnesses. When one looks to the future, competing responsibilities, mobility and changing family structures and dynamics question the prevailing assumption of available family caregivers (who are primarily women) and the extent of care they may be able to contribute. The increased participation of women in the labour force, declining fertility rates, and increased divorce rates are just a few of the factors that will affect the availability of women caregivers in the future (Carrière, Martel, Légaré & Morin, 2001).

In the recent past and still today, family caregivers have been estimated as assuming between 70-80% of care to disabled people (Chappell, et al., 1986, Stone, 2000) and saving society in general, and the formal health care system in particular, billions of dollars in unpaid labour (Fast et al, 2002; Guberman, 2001). And they are often doing so with little recognition or support from policy makers, health care managers and providers. While it is estimated that at least 4% of adult Canadians are currently providing care to a family member with a long-term condition (Decima, 2002) (and many more are involved in short term care involving injuries, illness or convalescence from surgery), less than one in four of those involved in chronic care are receiving any type of formal home care services to assist them (Decima, *ibid.*).

This is the current back drop for the numerous and significant documented consequences of caregiving on family members, mainly women, including impacts on their mental and physical health, personal, family and social life, finances and employment.

The range of care and services which caregivers offer are extremely varied, specialized and complex, covering all of the care recipient's physical, psychological and social needs. In many cases, caring for a seriously disabled person is a 24 hour a day responsibility (Armstrong et al., 1994; Guberman et al., 1991). Caregivers' roles often go beyond the direct provision of personal care and instrumental activities of daily living and include the work of mobilizing and coordinating professionals and services as well as advocating or interpreting for the care receiver. Caregivers often fulfill these roles while juggling other responsibilities and in a context of changing family structures and formal services' rationalization.

The activities performed and the context in which they are performed results in many caregivers endangering their health and mental well-being and sacrificing their professional lives and economic futures to care for ill and disabled friends and relatives. Years of scholarly research have well documented the consequences of caregiving on family members, who are mainly women. These include impacts on their mental and physical health, personal (Canuscio et al., 2002; Schulz et al., 1995; Yee & Schulz, 2000; Zarit & Edwards, 1996), family and social life (Brody & Brody, 1989; Guberman et al., 1991 1997; Strawbridge & Wallhagen, 1991; Pfeiffer, 1987; Zarit, 1991), and finances and employment (Fast et al., 1999; Metlife Mature Market Institute, 1999; U.S. Department of Health and Human Services, 1998; Wakabayashi & Donato, 2004).

With regard to physical health, an American survey published in April 2004 reveals that 17% of caregivers self-report their health as fair or poor compared to 9% of the general U.S. population and that this proportion escalates to 35% among caregivers doing the most intense caregiving. Documented detrimental effects of caregiving on physical health include back problems from lifting and turning care-recipients, physical exhaustion and stress-related ailments such as ulcers (Horowitz & Dubrof, 1982 in Brody, 1995). Finally, in the case of spouses, it has been shown that caregivers are at greater risk for mortality (Schulz & Beach, 1999). If the levels of stress, distress and illness found in caregivers were found in any other “profession”, health agencies and workers’ compensation boards would undoubtedly be waging major prevention campaigns, but in the case of caregivers, these impacts are barely addressed in public policy. These health consequences interact with the constricted social and leisure time affecting from 33% to 75% of caregivers across empirical studies (Hooyman & Gonyea, 1995). Studies have shown how interrupted sleep and limitations on social life can lead to caregiver chronic fatigue, social isolation, self-neglect and depression (Brody & Brody, 1989; Pfeiffer, 1987; Zarit, 1991).

Other negative impacts of caregiving can include family conflict (Guberman et al, 1991, 1997; Strawbridge & Wallhagen, 1991), financial strain, including employment income loss, out-of-pocket expenditures (e.g. purchase services, money transfers, costs of relocation of the care recipient or the caregiver) and unpaid labor (Fast et al, 1999) and pressure on employment. In 2002 more than 1.4 million Canadians over the age of 45 combined paid employment and care to older adults, and most caregivers worked full time. Employed caregivers feel more anxious when they are at work, modify their work schedules and/or the organization of their work, are interrupted at work more often, and have to use their vacation time and sick leave for caregiving duties. Those that quit their job diminish their perspectives for future employment and reduce their pension incomes (Gottlieb et al., 1990; Guberman et al., 1993; Keefe & Medjuck, 1997; Matthews & Campbell, 1995; Neal et al., 1993; Scharlach, et al., 1990). Changing work patterns and reducing work hours were the most common workplace adjustments (more than 1 in 4 employed women arrived late, left early, or worked at home part time compared to 16% of employed men); less than 3% of employed caregivers declined a promotion and less than 2% quit a job because of caregiving. (Hidden Costs/Invisible Contributions, 2005 “Reworking work: the experience of employed caregivers of older adults”.)

These consequences challenge decision makers on different fronts. The currently uncalculated but evident costs to our health and social service system of the physical, mental and stress-related impacts of caregiving are certainly cause for concern. Caregivers may utilize more health care resources to manage their own health problems and will likely be more costly to the system in the long run if nothing is done to modify their situations. In our current health policy context which increasingly focusing on health promotion and prevention, preventing these health outcomes for caregivers should be a public health concern.



The Conference Board of Canada has signalled the impacts of caregiving on workplace productivity both from worker and the employer perspectives (particularly through absenteeism and the eventual loss of experienced workers) as a disquieting reality. As well, the breakdown of caregiving situations due to caregiver burnout or distress has enormous potential costs to our health and social service system when those requiring care must be moved to alternative settings, often long-term care facilities.

It is within this context that caregivers are increasingly being identified by health and social service practitioners as having specific, often unmet needs for support, respite, information and advocacy, which should translate into interventions aimed specifically at them. Despite this, caregivers' needs are rarely considered in hospital, home care and long-term care practitioners' formal evaluations and interventions (Levine et al., 2004; Guberman & Maheu, 2002). Indeed, when there are services offered to caregivers in these settings, they seem to be based more on the characteristics of the care receiver than on an evaluation of the caregiver's situation and needs. When caregivers are offered support without their own assessment, this support is most often offered on a "one size fits all" basis; that is, programs such as respite or support groups are set up in the hopes that they will correspond to caregivers' needs, despite research to the contrary.

Caregiver assessment has thus emerged as a key issue in ensuring caregiver well-being, which in turn has direct implications for society as a whole.

Caregiver assessment may be justified from complementary yet different perspectives. First, from the caregiver's perspective, assessment is not just a process to understand how to be a better caregiver but rather an opportunity to tell their story, analyze their individual needs, take time from their everyday experience to self-assess their strengths and limitations, and receive recognition that their contribution is important. Caregiver assessment from the practice perspective can be justified for several reasons: to prevent or mediate many of the negative consequences outlined above, to legitimize the right of practitioners to open the door to caregivers, to ensure better quality and more appropriate services, and to sensitize and inform practitioners with regard to the global care situation and the specific needs of caregivers. With respect to prevention, a better understanding of the caregiver's circumstances, worries and difficulties helps to better assess risks to their well being and to the caregiving situation (Audit Commission, 2004; Pickard, 2004), to reduce burden (New Zealand Guidelines Group, 2003) and to counter the negative consequences of caregiving (Gaugler, Kane & Langlois, 2000). Some research (Feinberg, 2003 and Maddock et al. 1998) also points to improved care for the care receiver when caregiver well being is improved through assessment.

With respect to sensitization, caregiver assessment enables practitioners to hear caregivers' stories of their everyday experience and to determine service plans based on a full understanding of the global care situation, not just the needs and reality of the person needing care. This understanding recognizes that caregivers' needs may differ

from those of the care receiver, thus helping them plan support services accordingly (Feinberg, 2003).

From an organizational or systems perspective, caregiver assessment can be the key to getting maximum value from money allotted for caregivers from available resources (Audit Commission, 2004), and supports evidenced based decision making of scarce resources. Spending more time to look at caregiver circumstances and options, with a view to equipping them to make informed choices, may be more effective than a “quick service fix” (Ellis, 1993). While research has clearly demonstrated that no single intervention works for all, without assessment, case managers have no specific way of determining who would best benefit from which type of intervention or service. Assessment enables one to know when, why and how to use different interventions and resources.

As well, assessment can identify low or no cost ways of helping the caregiver (e.g. information, referral, advice, sympathetic ear).

All of these rationales militate in favour of ensuring appropriate assessment practices with caregivers.

### *1.2 Evidence of the impacts of assessment*

The outcomes of caregiver assessment provide the ultimate reason for addressing this whole issue. The few experiences where assessment has been implemented point to extremely positive outcomes for all involved: caregivers, care receivers, practitioners and agencies, and provide strong motives for implementing caregiver assessment.

#### *Outcomes for the caregivers*

At the outset, it should be stated that measuring the impact of assessment, per se (and not the services which do or do not follow) can be difficult. Relief may at times be more immediate from an intervention such as assessment, whereas in other instances change / relief comes over time. Here the caregiver may process the experience for a longer period of time before acting on it. For example, caregivers might receive useful information during an assessment, but not necessarily act on it until “needed” and this may not be captured in any test time frame.

However, a limited number of studies evaluating the experiences in the UK and Australia, including both mandated assessment and pilot research projects, point to the following outcomes for caregivers: recognition of their role; a chance to talk through their issues and consider their own needs; self-understanding of their situation, feelings and the caring role; new insights into why they are caring and what they have achieved; expression of bottled-up emotions; permission to talk about difficult and delicate subjects; validation of their feelings; acceptance of support; peace of mind in

knowing how to make contact in the future; information and referral information; a sense of shared responsibility; increased confidence to take up services; confirmation as people of value; recognition and validation (Carers UK, 2002; Hepworth, 2003; Lundh & Nolan, 2003; Maddock et al., 1998). Studies have documented the therapeutic impact of caregiver assessment (Lundh & Nolan, 2003) that recognizes and validates them and offers an opportunity to have their situation taken seriously. Documented positive impacts of caregiver research-based intervention in the U.S. point to the importance of providing the appropriate service at the appropriate time, based on comprehensive assessment (Gitlin et al, 2005; Hoskins, Coleman & Neely, 2005; Mittleman et al., 2004). This in turn prevents premature placement of the person requiring care in a facility.

In their carer needs assessment trial, Maddock et al. (1998) found that one month after assessment, of the 51 caregivers involved, 67% stated they were more able to continue in their role because of the assistance/support provided by nurses after assessment, 58% had higher perceived levels of social support, 46% had decreased information needs and 50% had decreased levels of strain. A pilot project in Maine appears to show that when caregivers are screened by primary health professionals and referred to AAA caregiver services they have increased knowledge levels and decreased levels of depression at six months after initiation of services, despite increased task frequency and difficulty (Kaye et al., 2003).

#### *Outcomes for care receivers*

There is little research on the impact of caregiver assessment on the care receiver, but subjective appreciations from practitioners indicates that if caregivers' well-being is enhanced this has positive repercussions for the care receiver and there is some research data which supports this (Maddock et al., 1998).

#### *Outcomes for practitioners*

Evaluations of the impact of caregiver assessment on practitioners tend to agree on the following: assessments raise awareness of caregiving situations and provide insights and increased understanding of what it means to be a caregiver and of the daily realities of care; enhance understanding of the complexities of caregiving; challenge existing perceptions/expectations; change taken-for-granted assumptions; enable a better response to caregiver needs; enable going beyond symptoms to understanding the under-lying causes of caregiver difficulties; release innate creativity (Guberman et al., 2003; Lundh & Nolan, 2003; Maddock et al., 1998; Nicholas, 2003).

#### *Outcomes for practice*

The introduction of caregiver assessment into agencies or practice settings has many potential outcomes for practice. Focusing on caregivers changes the notion of client within the health and social service system and transforms the relationship between caregivers and the system. It legitimizes caregivers' right to be heard. Systematic caregiver assessment provides a rationale for directing services to caregivers and justifies practitioners' intervention strategies. It highlights important

information that can provide a rationale for current intervention with caregivers and contribute to future service development (Audit Commission, 2004; Guberman et al., 2003; Lundh & Nolan, 2003; Maddock et al., 1998). Assessment elicits a more comprehensive and accurate profile of caregiving situations, and there is some evidence that it improves care planning and leads to more specific care plans and increased or adjusted services (Guberman et al, 2001; 2003; Nicholas, 2003). As well, a clearer identification of caregivers' needs leads to the development of services and resources to fill the gaps that emerge in attempts to respond to those needs. In terms of systems administration, the inclusion of systematic, uniform caregiver assessment throughout the myriad of home and community-based services can help to reduce fragmentation, and provide uniform aggregated assessment information on caregivers, which will enable administrators to measure the impact of services on caregivers and provide data needed to support and drive decision making (Feinberg et al, 2004).

All of these experiences are based on the use of a separate specific assessment tool, distinct from that of the person requiring care.

### *1.3 The importance of developing the CARE Tool*

The need to develop a caregiver assessment Tool emerged from the recognition of caregivers' significant contribution and their need for support to mitigate negative consequences, as well as an analysis of caregivers' lack of formal status within the health care system and how this translated into the difficulty, and even the impossibility, for the formal system to respond to their well-documented needs. Having a clear rationale, including a holistic understanding of the caregiver's view and desired outcomes, along with the care receiver's perspective, enables limited resources to be targeted appropriately and interventions to be improved in support of healthy caregiving situations.

A systematic review of the literature and practice suggested that while caregiver assessment was becoming widely recognized as an important practice area, few tools, if any, existed which considered the multi-dimensional aspects of caregiving and could support the development of care plans. Assessment instruments exist to determine eligibility for a specific program or service (e.g. respite), measure one dimension of the caregiving experience (e.g. burden), or for a specific target group (e.g. multiple sclerosis). Further, caregiver assessment may be considered fulfilled by including one section in the care receiver's assessment that is usually functional in nature. However, the information gathered in this context is usually quite brief and not always from the perspective of the caregiver. There was limited evidence of existing tools that had undergone rigorous scientific testing to assess their validity and reliability.

### *1.4 How was the CARE Tool developed?*

The CARE Tool was developed between April 1999 and February 2000 as part of a project entitled *Development of screening and assessment tools for family caregiver*” (Guberman, Keefe, Fancey, Nahmiash, & Barylak, 2001). This project was funded through the *Health Transition Fund*, Health Canada. It had two phases – development and testing. The development phase included three approaches: a literature search of validated tools which found 82 useful instruments; the collection of non-validated tools found through a literature search, contact with key informants from around the world; contact with public, private and non-profit agencies throughout North America; and nine focus groups with family caregivers and community care practitioners. This extensive review was undertaken to ensure that the Tool was sufficiently comprehensive, that it could be applied to the array of home care services in Canada and a wide variety of caregiving situations and to ensure that any existing tools were identified.

From the various sources, and drawing on the researchers’ collective research and practice expertise, key components/domains to be included were identified. These included: caring work, relations with formal services, relations and care receiver, personal health, multiple responsibilities, housing, financial contributions, and planning. For each component, individual questions were crafted. Considerations were given not only to content but also layout and design. Various iterations of the Tool were drafted and underwent informal pre-testing. In addition, an Advisory Committee comprised of administrators and government officials from the sectors of home care and gerontology reviewed various drafts of the Tool and provided feedback on its content, design, and relevance for implementation. A final draft of the Tool was formally pre-tested in December-January 1999-2000 and the final test version was ready for the field in February.

The second phase of the project involved testing the Tool in real practice settings, both for its ability to detect caregivers’ needs and the stability of the instrument under variable conditions. A purposive convenience sample of family and friend caregivers identified from the seven home care agencies was used to test the assessment tool (three regions of Home Care Nova Scotia and five CLSCs in Quebec)<sup>1</sup>. Home care practitioners within these agencies were asked to select cases known to have a family member involved and invite them to participate. In total, 168 family caregivers were interviewed twice; first by one home care practitioner and within seven working days by a different practitioner. Practitioners’ information on the summary page of the assessment tool was analyzed to determine inter-rater reliability amongst 15 assessment areas and 18 key areas of concern and the internal congruency between the assessment areas and key areas of concern. In addition, focus groups were held with participating practitioners to obtain feedback on the utility and validity of the instrument to assess caregivers’ needs. Based on

---

<sup>1</sup> Home care programs were selected by the researchers to be part of the testing phase because the assessment was intended for implementation at the community level, and because it was felt that assessors in home care had the experience and training to conduct the assessment appropriately during the testing period. Including practitioners in the research design was intended to achieve greater buy-in for the instrument into practice –if nothing else increase sensitivity of practitioners to caregivers’ needs and situations.

results from this testing phase, minor modifications to the instrument were made. The Tool was also reviewed by plain language experts and revisions made.

### 1.5 Experiences using the CARE Tool

Since its inception, there have been numerous requests for the CARE Tool from researchers and practitioners<sup>2</sup>, and it has been used in several research and practice settings. The latter are identified as follows:<sup>3</sup>

Agency, location	Reason	Context
Home Care Nova Scotia (Eastern, Central and Western regions)	Research conducted by authors (2000)	Practitioners administered an assessment with a caregiver of a home care client; no mandate to provide services to caregiver or adjust client's care plan
CLSCs (La Prommeriaie, René Cassin, Riveriès-des-Prairies, Desjardins, Bellechasse)	Research conducted by authors (2000)	Practitioners administered an assessment with a caregiver of a home care client; no mandate to provide services to caregiver or adjust client's care plan
Home and Community Care, Prince Edward Island (Queens, West Prince, East Prince regions)	Research conducted by authors (2004-06)	Practitioners administered an assessment with a caregiver of a home care client; no mandate to provide services to caregiver or adjust client's care plan
CLSCs (René Cassin, Lachine, Le Plateau, Haut St. François, NDG)	Research conducted by authors(2004-06)	Practitioners administered an assessment with a caregiver of a home care client; no mandate to provide services to caregiver or adjust client's care plan
Veterans Affairs Canada (Charlottetown, Sydney, Kingston, Sherbrooke)	Research conducted by authors (2004-06)	Practitioners administered an assessment with a caregiver of a home care client; no mandate to provide services to caregiver or adjust client's care plan
New Jersey Department of Health and Senior Services (Bergen, Gloucester, Warren counties)	Pilot project conducted by Dept of Health and Senior Services, New Jersey (2001-03)	CARE Tool, one of three instruments, used by practitioners in a project to integrate a focus on caregiving into existing long-term care system
Catholic Charities of	On-going service	CARE Tool is used to develop care

<sup>2</sup> For example, much interest came from practitioners and managers in several CACCs in Ontario and Regional Health Boards in Alberta, but to our knowledge the Tool was not implemented.

<sup>3</sup> The researchers have not conducted a formal or systematic follow up with those organizations or individuals who have inquired about the CARE Tool to fully understand the extent of its use. The table reflects those situations known to the researchers.

the Archdiocese of St. Paul & Minneapolis	delivery	plans for caregivers accessing services in the caregiver support and respite program.
Utah Caregiver Support Program	Their own Tool is used in on-going service delivery	They have developed their own Tool, several sections of which were taken directly from the CARE Tool.
VON	Received training; possibility of implementation	Staff from Ontario VON branches received training, yet the Tool was not implemented. However, it has been recommended as a best practice and there is still interest in implementation.
René-Cassin Caregiver Support Centre	On-going service delivery since 2003	Caregivers who call or are referred to centre are assessed before intervention plan is developed
CLSC du Plateau	On-going service delivery since 2005	Social workers in the homecare department are using the CARE Tool to assess certain clients who have been referred to them from intake or other professionals so as to enable caregivers to present and self-analyze their situation and the practitioners to develop appropriate service plan if needed

It should also be noted that the Tool was recommended by a scientific committee, including representatives from the mental health and disabilities communities, set up by the Quebec Ministry of Health and Social Services to propose a caregiver assessment tool for mandated implementation throughout the province; however, a freeze has currently been placed on the adoption of such tools. The researchers are also pursuing an expression of interest in caregiver assessment from the PEI Department of Health-Community Hospitals and Continuing Care.

#### 1.6 With what populations has the CARE Tool been used?

The CARE Tool has mainly been used with caregivers of publicly funded home care clients, although interest and requests for training have been received from hospitals and non-profit groups such as the Alzheimer’s Society of Quebec. An exception is the use of the CARE Tool as part of regular practice at the Caregiver Support Centre, CLSC René- Cassin. Here, caregivers, regardless of whether the care receiver is an official client, may be assessed by a professional social worker and services and supports implemented. In terms of specific populations, the CARE Tool was developed to be used with individuals providing care or assistance to an adult. In the first research project the study included caregivers of seniors as well as

dependent adults. In the second research project the study included caregivers of seniors with and without Alzheimer Disease.

The CARE Tool, although not specifically tested with caregivers with diverse cultural background, appears to be culturally sensitive. Workers having used the Tool in New Jersey rated its cultural sensitivity on a five point scale (1=not at all sensitive, 5=very sensitive), and the mean score was 3.4 (Tiedmann, 2004).

### *1.7 Limitations of the CARE Tool*

Despite extremely positive feedback on the Tool's strengths (see Guberman, et al, 2001; Tiedman, 2004 and section 3.2 of the current report), some limitations to the implementation of the Tool have been noted.

First, in order to undertake caregiver assessment in a meaningful way, caregivers must be an agency priority. In the current context of stretched human and fiscal resources, any additional work, unless mandated with the addition of concomitant resources, will frustrate both practitioners and caregivers who may have inflated expectations as a result of the assessment. Related to this point is feedback from practitioners that suggests the administration of the CARE Tool in the current home care context is too time consuming. Occasionally, certain sections appear redundant because of like areas being captured from other sources (e.g. care receiver's evaluation). These limitations are echoed by results of the New Jersey evaluation study. Here, about half of the 21 staff did not recommend the CARE Tool for ongoing use. Reasons given included that care managers felt they could serve caregivers without the Tool, difficulty in using it, unfulfilled expectations for services among clients, length and time required to complete and no direct impact on services because programs have not been expanded at the same time (p.18). It should be noted, however, that these limitations are not always shared by the caregivers.

## **2) Assessment of Family Caregivers in Other National Contexts: the U.K., Australia, Germany, Japan, and the U.S.<sup>4</sup>**

Interest in assessment is not limited to Canada and this project thus includes a review of the situation in a sample of other Western countries. Several countries around the world have implemented or are considering implementing caregiver assessment for the reasons presented in section 1. Here, five countries' approaches to caregiver assessment are illustrated to demonstrate the various stages and challenges with caregiver assessment elsewhere.

### *2.1 United Kingdom*

---

<sup>4</sup> Much of this section is drawn from Montgomery, A. (2005) Assessment of Family caregivers : An International Comparison Across Six Countries. San Francisco: Family Caregiver Alliance



The UK is one of the more interesting examples as since 1995, caregivers have had a statutory right to receive an assessment when an adult applying for community services is being assessed, and more recently, the right to a separate, independent assessment. The 2000 Carer and Disabled Children Act addressed certain loopholes in previous legislation and introduced the possibility of providing services for caregivers in their own right, even if the care receiver is not receiving help (as long as it will help them care for the latter). However, caregivers' knowledge of the legislation appears minimal and few separate assessments have been completed (Seddon & Robinson, 2001). A recent survey by the Audit Commission (2003) of carers in six areas of England found that local authorities have made progress in identifying caregivers, providing them with information and referrals, and involving them in the care recipient's assessment, but few had been separately assessed. Indeed, one of the challenges in the U.K. has been that caregivers generally do not self-identify as such and even when they do, they are not always aware of their right to assessment nor how an assessment might help them. In response, the Audit Commission has proposed that primary care providers identify and refer caregivers and suggested that: (1) physicians distribute a letter to all potential caregivers addressing the issues and the right to assessment, (2) posters and leaflets be placed in GP's offices, and (3) promotional activities be organized, such as Carers' Week or Carers' Rights Day. Finally, it should be noted that there is no single caregiver assessment tool and each authority uses a different form of assessment (Seddon & Robinson, 2001).

In Scotland, the Community Care and Health Act, 2002, makes explicit the principle that caregivers are 'key partners' in care who need resources to continue giving care rather than service users themselves. The Act accords them the statutory right to assessment of their ability to care and authorities have a duty to inform them of this right. It also states that the caregiver's and the care recipient's points of view must be considered before deciding on services (Audit Commission/ Glendinning, 2004).

## 2.2 Australia

In the late 1990s, a national, although not mandatory, framework for comprehensive assessment was developed within the Home and Community Care (HACC) program. It states: "the purpose of a comprehensive assessment is to establish a consumer-focused approach to assessment which encompasses client/family/carer participation in the assessment process and leads to individualised care solutions... Separate client and carer assessments are undertaken where required or where the need is apparent. In addition, carers may be assessed in their own right without the person they care for needing to be assessed as well." (Dept. of Health & Aging, n.d.). HACC views carers as clients in their own right, but capturing their use of services in the minimum data set (MDS) separately from service use on the part of the "primary" client has proved very difficult (Anne Howe, personal communication, March. 2005).

There exists, however, a diversity of assessment procedures both within HACC and in other newer community care programs. The federal government is thus attempting to reach consensus with the states to apply a more uniform approach. To date, no agreement exists on a standardized assessment instrument for caregivers. In practice, assessors may choose from a variety of instruments for assessing both clients and caregivers. These assessments serve as a guide for subsequent care planning by providers.

For their part, Carers' Australia calls for an assessment of the care situation which would include the capacities and needs of caregivers as well as the impacts of their caregiving responsibilities. They call for this assessment to be used across the full spectrum of national community care programs.

### 2.3 Germany

Germany's long-term care insurance program for frail elders and persons with disabilities features a standardized national assessment system. Medically trained personnel conduct all assessments in the family home to determine the level of care of the potential user in accordance with national guidelines. The latter state that a caregiver for the person filing for LTC coverage should be present during the assessment if at all possible and that the assessor should document the caregiver's views about needed services. The assessor is not required to ask the caregiver about his/her own needs and health, but a caregiver who agrees to provide at least 14 hours per week of support is entitled to certain benefits, including accident insurance and state pension benefits. Due to privacy concerns, families do not automatically receive a copy of the assessment (Montgomery, 2005).

### 2.4 Japan

A standardized national assessment protocol that classifies the needs of disabled and elderly individuals according to six functional levels is an integral part of Japan's long-term care system. It includes no questions about the caregiver. The protocol is considered to be caregiver-neutral in response to pressure from Japanese feminists who argued that women should be relieved of the historical and cultural expectations to care (Montgomery, 2005). However, recent research suggests that an insufficiency of services still puts much pressure on the family to compensate for unmet needs (Arai et al., 2003). In practice, various providers use different assessment instruments.

### 2.5 United States

Assessment and care planning vary from state to state and from program to program. A 50-state survey undertaken by the Family Caregiver Alliance National Center on Caregiving found that only five states have uniform home and community-based services assessment procedures with a family caregiver component. The National Family Caregiving Support Program (NFCSP) has no

mandate for systematic caregiver assessment and no uniform recommended assessment tool, but a few state-funded caregiver support programs have standardized assessment processes for caregivers (Feinberg et al. 2004). For example, California offers caregiver assessment, in particular an assessment of their mental health by way of a 103 item tool developed by Steve Zarit. Many other States have shown interest in caregiver assessment and have developed specific tools (Utah, Minnesota, New Jersey) for respite services.

### *Summary of the situation*

This brief glance at the situation in other countries reveals that none of them have developed a single assessment tool for caregivers, although caregivers are being assessed in certain countries and for certain programs. The articulation of assessing and meeting the needs of both care receivers and caregivers is a difficult one and none of the countries discussed has developed “model” practices. To that extent, Canada could develop avant-gardist practices by piloting a single standardized caregiver assessment tool.

## **3) Responses of Key Stakeholders to Using the Original CARE Tool**

This section reviews results of the interviews with caregivers, practitioners and managers and examines in detail their responses, in particular around themes related to the impact of the CARE Tool and its implementation. This section also examines how this new feedback corroborates with data from the original development of the Tool. First, however, is information on the method undertaken to obtain the feedback.

### *3.1 Method*

Since September 2005, individual and group interviews have been conducted with 24 informants – 7 caregivers, 11 practitioners, and 6 managers (2 of whom considered using the Tool but chose not to). The 11 practitioners are from varied disciplines including social work, nursing and occupational therapy. Some of these practitioners are currently using the Tool as part of their daily practice, whereas others used it only briefly in the past, or as part of a research or pilot project (as indicated in the Table in section 1.5). The majority of interviews were conducted over the phone, due to geographical distance or time constraints. One exception was a focus group conducted with seven assessors from the Montreal region. Individual interviews lasted between 30-45 minutes and were conducted by either Lucy Barylak or Marjorie Silverman, the project assistant. Nancy Guberman and Marjorie Silverman led the focus group. For a complete list of the interview questions, please see Appendix 1.

The informants came from the following agencies and geographic areas:

*Assessors:*

- 2 social workers, CSSS Cavendish, Installation CLSC René-Cassin, Quebec
- 5 social workers, CSSS Cavendish, Installation CLSC NDG/Montréal-Ouest, Quebec
- 1 occupational therapist, CLSC du Vieux Lachine, Quebec
- 1 social worker, CLSC Sherbrooke, Quebec
- 1 nurse, CLSC Sherbrooke, Quebec
- 1 nurse, Catholic Charities of the Archdiocese of St. Paul & Minneapolis, U.S.

*Managers* (including those who chose not to use the CARE Tool):

- 1 nurse from VON Ontario
- 1 from New Jersey Department of Health and Senior Services, U.S.
- 2 from Catholic Charities of the Archdiocese of St. Paul & Minneapolis, U.S.
- 1 from Utah Caregiver Support Program, U.S.
- 1 from Veteran's Affairs United States

*Caregivers*:

- 6 women from Quebec
- 1 man from Prince Edward Island

*Other sources of data*:

- Transcripts of 3 interviews with managers and 2 focus groups with 9 assessors conducted in Prince Edward Island in the context of another research project utilizing the CARE Tools (Keefe, Guberman, Fancey & Barylak, 2004-2006). Much of the information that was provided by these informants was also useful for the purposes of this current research project.
- Lucy Barylak and Janice Keefe conducted a symposium in Ottawa in November 2005 entitled "Becoming Partners: Tools for Transition". One session related specifically to the development and outcomes of the CARE Tool. Representatives from a variety of national health and social service agencies were present to give feedback. For a complete list of the agencies present, please see Appendix 2.

In addition to conducting interviews, the researchers established an advisory committee for the project. This committee was comprised of representatives of federal government departments and national level organizations with an interest in caregivers (see Appendix 3). The committee provided input about the direction of the project, assisted with the analysis of the findings, and provided direction regarding policy recommendations. The committee met three times through teleconferences (November 2005, February 2006, and March 2006).

### 3.2 Feedback From and About Caregivers

Of the 7 caregivers interviewed, 5 were in the later stages of care, whereas 2 were in the earlier stages of their caregiving journey. All seven were caring for a senior, 5 of whom had dementia or Alzheimer's, one a stroke, and one multiple physical problems. Five of the caregivers lived with their care receiver, whereas 2 did not. All of the caregivers had some degree of contact with their local health and social

service agency and were receiving some degree of in-home services and support. In some cases, the caregivers were utilizing a combination of public and private help to assist them in their caregiving tasks.

### *Emotional Impacts*

Four of the 7 caregivers interviewed reported that the assessment had a significant emotional impact. These caregivers said it was the first time they had been asked about their situation and this felt extremely validating. They also said that it opened their eyes to aspects of their situation that they had never considered. For example, one caregiver stated: “You know, there was one question that asked whether caregiving impacted my relationship with my family and I had to think about that at the time....when I thought about it, yeah, I think I probably felt that my family, in some way, has been a little negligent.” A couple of caregivers also commented on the importance of their interaction with the practitioner who completed the assessment with them. Comments related to the supportive and non-judgemental nature of the practitioner, and one caregiver specifically stated that going through the assessment with a supportive professional led to a greater emotional impact than had she gone through the questionnaire on her own.

The 3 caregivers for whom the assessment seemed to have little emotional or personal impact were people who had been caregiving for a long time, and who stated that they had a good understanding of their situation and the required services in place. To these caregivers, the assessment process felt more like a technicality, and indeed, some originally went through the assessment as part of a previous research study rather than as a result of a need or a request. Although it cannot be stated with full conclusiveness, this may indicate that the Tool works well as a preventive instrument, or has significant impact when someone is either at the beginning of their caregiving journey, or going through important changes in their caregiving situation.

### *Practitioners’ Perspectives of Emotional Impacts*

The comments from caregivers about the emotional impacts are corroborated by what practitioners say they observed in the caregivers they assessed. Many practitioners expressed that these caregivers stated that it was the first time the focus had been on them, rather than on the care receiver. As one assessor in Montreal stated: “The Tool validates them [the caregivers] as people...This gives *them* attention and not just the care receiver...I think that’s one of the best things about the Tool.” Practitioners expressed that the Tool helped caregivers focus on their own needs – physical, emotional and social – and really made them reflect on that they might have given up in their individual lives in order to provide care to a loved one. The Tool validated them as human beings, worthy of care and attention in their own right. One assessor in PEI stated: “I found it [the Tool] most useful too in validating what they [caregivers] do or recognizing what they do for themselves. To say, ‘I do a lot, I am a caregiver’.”

### *Service-Related Impacts*

Of the caregivers interviewed, only 2 stated that the assessment led to changes in services. This may be a result of the fact that this sample of caregivers already had necessary services in place. Of the 2 caregivers that reported changes in services, one was referred to short-term counseling, and the other was able to access an in-home stimulation program for her care receiver.

This could be indicative of a number of things. Many caregivers might not see the assessment process in and of itself as an important service, although for many simply the fact of being listened to by a practitioner is indeed a service and may lead to better ongoing communication with the practitioner which would not necessarily be perceived by the caregiver as a change in service. Secondly, services to the care receiver may have been modified based on the assessment while the caregiver may not have considered these to be changes in services to his/herself. It could also mean that in many agencies there are simply not a lot of services to offer caregivers.

### *Practitioners' Perspectives of Service Related Impacts*

Despite low reporting of service changes by caregivers, practitioners' feedback was consistent in stating that the Tool impacts on service plans. For example, assessors in PEI stated that in several cases there were changes in services as a result of the Tool, such as increased homemaker hours, or recognition of need for respite services. This was echoed by a practitioner in Minneapolis who stated that "services were increased or the case manager was able to be more aware of which stress existed, and that the caregiver may be needing some time and attention also." Practitioners also stated that working with the Tool helped them gain awareness of existing services for caregivers, which was then being offered to the caregivers. As well, practitioners indicated that they were able to identify areas of caregiver need where services did not exist and that this could be useful to their agency for future developments. Many also expressed that the Tool impacted on long-term planning for the caregiver. Therefore even if services were not added or modified at the time of the assessment, often it allowed for planning for possible future services. A few practitioners expressed that they found it difficult to recognize the extent of caregivers' needs, yet not be able to offer many concrete services.

The following case example of a caregiver's experience in undergoing assessment illustrates a combination of emotional and service related impacts.

### *Case Example*

One of the caregivers interviewed for the project is a woman in her fifties who is caring for her elderly mother. Even though the caregiver herself is a social worker in the domain of gerontology, she still felt unfamiliar with all the resources that might be available to her, and had not yet fully reflected on her needs as a

caregiver. She wanted the opportunity to discuss her situation with another professional, and to gain clarity. The caregiver found the assessment to be quite helpful, and felt encouraged by the strong rapport she felt with the practitioner who conducted the assessment. As the caregiver stated, “I came here because I really needed to have a mirror and play it off somebody so that they could...sort of see things that maybe I didn’t see.” The assessment lasted for two sessions (approx. 2 hours total), and at the end the assessor suggested that short-term counselling might be a beneficial next step. The caregiver agreed, as a number of emotional issues had been raised during the assessment and she wished to explore these in more detail. As the caregiver stated, “she [the assessor] kind of drew my feelings to the surface which I didn’t even know I had.” The 8-10 sessions to counselling to which the caregiver was then referred allowed her an opportunity to gain more insight into her situation. The caregiver believes the assessment was instrumental in helping to clarify her needs and leading her to the appropriate service.

### *3.3 Feedback from Practitioners and Managers*

In addition to feedback about the perceived emotional and practical impacts of the assessment process on caregivers, the professionals interviewed also had a lot to say about their overall experience in using the Tool, as well as its implementation within their agencies.

#### *Impact on Practitioners’ Knowledge and Understanding of Caregivers*

Practitioners reported that they found the Tool quite useful in helping them acquire detailed information about the caregiver in a more pointed and concrete way than simply conducting an open-ended interview. For example, many practitioners stated that they appreciated the way the Tool broke down the variety of caregiving responsibilities and tasks, as it made it apparent exactly what the caregiver was doing and where they were having difficulty. In many cases the assessment seems to have raised new issues that were not known before to practitioners. They also stated that questions about family dynamics were useful in allowing caregivers to express without feelings of guilt that perhaps they do not get the help they might want from their families. One assessor in Montreal expressed: “Usually we start knowing a little about the person and then we peel off layer by layer, but that takes a long time and asking these very concrete questions, we get it earlier.” According to practitioners, gaining a better understanding of what caregivers are going through, and learning detailed and intimate information, helps improve the relationship between practitioner and caregiver. As one assessor in PEI stated: “It was a kind of privilege to do the assessment.”

#### *Barriers to Implementation*

Despite the fact that the practitioners using the Tool found it extremely helpful, they nonetheless reported that there were often barriers to its implementation within their agencies. Informants from agencies in which the CARE Tool is currently being

implemented in a widespread way (CLSC René-Cassin and the Catholic Charities St. Paul and Minneapolis) have said that in order for it to be implemented the practitioners needed to buy into the idea. Informants from agencies in which the Tool is not being implemented stated that the practitioners did not buy into it and therefore it did not move forward. According to one manager in Utah, where the Tool was considered but not used in its full version, it was a tough sell: “I thought it was fabulous but very long, I knew that my case managers would never go for it. It was just the length. In terms of content it was fantastic.” Others also expressed that in order for the Tool to be used systematically, it has to really be “sold” to practitioners.

### *Leadership, Mandating, and Training*

According to informants, one of the key ways of “selling” the Tool to practitioners is having managers and supervisors who believe fully in caregiver assessment. In Utah, when they decided not to use the CARE Tool, they pulled certain elements from it and developed their own shortened version. This version was then implemented systematically and was mandated by the administration. Similarly, one of the managers interviewed from Minneapolis stated that at first it was a hard sell but then they “got in a manager who believed in it, had staff changeover, and just mandated it.” That manager herself was also interviewed, and she stated that she was simply “insistent” that the Tool be implemented systematically. She said that it “took someone who is very strong to get in there and really push it.” These comments indicate that agencies may need to begin in a “top down” way to establish the right conditions for implementing caregiver assessments.

The comments from informants speak to the necessity of a strong training component for professionals. In addition to having a supervisor that buys into it completely, practitioners need to be adequately trained and sensitized. The training should not just be about how to use the Tool, but also about fully understanding caregivers’ situations and one’s own value system with regard to family care and its impact on practice with caregivers.. Implementation seems to run much more smoothly if everyone in the agency is sensitized and has a similar perspective on providing services for caregivers.

### *Caregiver as Clients*

According to feedback from professionals, the implementation of the CARE Tool within an agency can raise controversial questions about whether caregivers should be considered clients. At the Tools for Transitions Symposium in Ottawa in November 2005, this issue was debated and many of the professionals felt that caregivers can fluctuate between being clients, resources and partners in care. Although this is a common view among some professionals, not all practitioners are sensitized. According to one manager, “it was very difficult when this program [caregiver assessment] came about for the service providers to think of the caregiver as recipient of services, so I think this assessment helped a great deal in



recognizing the caregiver as client.” Many informants discussed the need for a shift in perspective. One assessor stated that some of her colleagues do not share her outlook on caregivers’ needs: “Some feel, don’t turn caregivers into clients, they feel let them be family caregivers...it’s just a normal part of life, why are we medicalizing it...” Currently many agencies do not open formal files for caregivers.

### 3.4 Consistency with Feedback from Original CARE Tool Project

Much of the feedback received from informants in the current project is consistent with feedback gathered when developing and validating the CARE Tool (Guberman et al, 2001).

Both studies reveal that caregiver assessment is often the first time that caregivers have the opportunity to tell their story and that this in itself is a valuable experience for them on their caregiving journey. Another striking area of similarity is in practitioners’ understanding of the needs of caregivers. The 2001 report clearly states that the practitioners’ involved in the project felt that their understanding of, and sensitivity to, caregivers’ needs increased dramatically (p.35). They felt that this sensitivity would continue and would positively impact their future dealings with family caregivers (p.38). They also reported that participating in the project improved their relationships with family caregivers.

In the 2001 report, practitioners are also cited as stating that the assessment process helped improve intervention plans and service plans (p.37). The Tool allowed them to gain insight into key areas of concern in an efficient and concise manner, and they were then able to translate that information into a justifiable action plan. Yet there was also frustration on the part of practitioners at the lack of available services to offer caregivers. Noticing (many for the first time) the full extent of what caregivers were facing compelled practitioners to want to offer them something concrete. Practitioners also raised concerns about the difficulty within agencies of determining whether caregivers are clients, as well as the lack of resources and heavy workloads.

The consistency of these comments with what has emerged in the current project validates the many positive impacts of the CARE Tool, yet also highlights further some of the difficulties of implementation.

#### **4) Shortening of the CARE Tool**

One aspect of the current project involves developing a shorter, user-friendlier version of the original CARE Tool developed in 2001 that will facilitate its implementation within health and social service agencies. Practitioners who have experience using the original Tool were asked their impressions about its length, structure, and user-friendliness. They were also asked to go through section by section and to comment on the specific content or format.

#### 4.1 Feedback about structure and length of the Tool

Almost all the practitioners interviewed had comments about the length and structure of the Tool, and suggestions for its improvement. Prior to making any suggestions about areas to cut or change, most practitioners expressed worries about the Tool being “watered down”. Everyone felt very strongly that the Tool’s integrity should not be drastically altered – it should simply be made user-friendlier.

Many of the detailed suggestions from practitioners related to making the Tool easier to use. For example, some felt that certain questions were repeated more than once, but simply phrased in a different way. Therefore, there were many suggestions about how certain questions could be consolidated. Other comments related to removing some of the grids and tables, and asking broader, more open-ended questions, rather than many specific pointed questions. Yet despite these suggestions, everyone felt that all the general content and themes should be maintained.

#### 4.2 Length of Tool and its link to workloads

Although almost all practitioners and managers were of the opinion that the CARE Tool is too long, it seems that the reason it is felt to be too long is primarily because of the heavy workloads that practitioners are carrying. As one assessor stated, she feels a “conflict in terms of operational demands and the time that it [the assessment] needs.” Practitioners, both in Canada and the United States, are facing large workloads, heavy demands, and constant time constraints. There is therefore a desire to provide services to caregivers, but in a manner that balances quality and time efficiency. Very few informants were able to articulate what they believe would be an adequate length for the Tool; however, the few that did felt that it should not take more than one hour to administer.

#### 4.3 Who should assess and impact on the Tool’s structure

Informants did not address the issue of which professionals are best suited to using the CARE Tool. Issues around disciplinary differences arose when discussing different types of tools. While social workers tend to call for open-ended questions, they also acknowledge that open-ended interviews are easier to conduct for experienced psychosocial assessors. For those less experienced, and from backgrounds other than social work, it might be difficult not to have concrete guidance from the Tool itself. For example, one assessor who is an occupational therapist stated, “je suis ergo, pas travailleuse sociale, donc c’est pas le même genre d’entrevue.” (I’m an occupational therapist, not a social worker, therefore it’s not the same type of interview.) Therefore, if the Tool is to be used by a variety of professionals, a middle ground is required between concrete and open-ended questions.

#### 4.4 Caregivers' comments about length

Of the caregivers interviewed, only one felt that the assessment was somewhat lengthy, whereas the others felt that it was fine and should not be changed. This *may* indicate that the impetus to shorten the Tool is coming more from practitioners and managers who are facing growing amounts of paperwork and other caseload demands, and lack of resources. However, a few caregivers expressed that some of the questions seemed *repetitive* to them. Many couldn't remember which questions specifically, but they reported having a feeling throughout the assessment of "I've been asked this already". Caregivers did not have more specific suggestions regarding areas to shorten or change, as they did not systematically look through a hard copy of the CARE Tool during the interview.

Based on the various comments from key informants during this study and on feedback already received about the Tool, a series of adjustments were made to the original version to reduce its length and make its format user-friendly. Many of the tables were simplified, some detailed sections were eliminated in favor of open-ended questions, questions that were redundant or did not clearly inform the final assessment were removed, and several questions were simplified or merged with similar questions. The shortened version of the CARE Tool is presented in Appendix 5 and a more detailed explication of modifications in Appendix 4. Plans are currently being made to pre-test the shortened version of the Tool in the near future.

### **5) Issues to be Considered in Implementing Caregiver Assessment**

Feedback from informants has raised a number of important questions regarding the implementation of the CARE Tool within health and social service agencies. What justifies caregiver assessment and a specific caregiver assessment tool such as the CARE Tool? Where should the Tool be implemented and by what types of practitioners? How can practitioners buy into the idea and what kind of training do they require? What is the cost of additional services that respond to needs which the CARE Tool reveals? Below are some policy recommendations for implementing the CARE Tool. Please see Appendix 4 for case studies that cost out potential outcomes of caregiver assessment.

#### 5.1 Defining caregivers as clients

In many agencies the implementation of the CARE Tool raises numerous questions about whether caregivers should be considered clients. These questions have created controversy in a number of agencies. At the Tools for Transition Symposium in Ottawa in November 2005, this issue was also debated and it was felt by many of the professionals that caregivers can fluctuate between being clients and partners in care. Although this is the view among some professionals, not all practitioners are sensitized to see caregivers as partners nor as potential clients. According to one manager, "it was very difficult when this program came about for

the service providers to think of the caregiver as recipient of services, so I think this assessment helped a great deal in recognizing the caregiver as client.” Many informants discussed the need for a shift in perspective. One assessor stated that some of her colleagues do not share her outlook on caregivers needs: “Some feel, don’t turn caregivers into clients, they feel let them be family caregivers...it’s just a normal part of life, why are we medicalizing it...” If there is to be successful implementation of the CARE Tool within an agency, caregivers must be seen as partners in care. Some agencies may also choose to view caregivers as clients, whereas others may not. Theoretically and practically caregivers can alternate between being partners and clients. The assessment process legitimizes these multiple roles and needs.

A few practitioners also expressed that they found it difficult to recognize the extent of caregivers’ needs, yet not be able to offer them more concrete services. Based on comments from informants, within certain agencies there is resistance to assessment based on fear that the results will lead to a flood of demand for services that are not available. This fear has not been supported by experiences in other countries nor by the many experiences in Canada where services directed at caregivers have trouble recruiting sufficient participants. As well, one must consider that the assessment process is a service in and of itself with many potential positive outcomes for caregivers. When assessment does uncover needs that cannot be met by the agency, it acts as an important tool for identifying gaps in services, and possibly preventive responses. It is also important for agencies to recognize that not all services need to have additional budgets attached to them.

### 5.2 The need for a specific caregiver assessment tool

Once it is recognized that as potential clients of the health and social service system caregivers must be assessed, the issue of the appropriate tool to do so must be raised. Some jurisdictions, for example, Minnesota, combine caregiver and care receiver assessment in a single tool with a section specifically aimed at the caregiver. This format raises issues concerning the confidentiality of the caregiver assessment (in privacy from the person requiring care), the comprehensiveness of the assessment tool, the ambiguity of whose needs will be served if they are contradictory and the possibility for the caregiver to get services if the person requiring care does not qualify.

The U.K. and particularly Scotland exemplify the model of using a separate assessment for caregivers, both in terms of the tool employed and the fact that the caregiver is assessed separately from the care receiver. This model opens the door to the caregiver having a right to services in his or her own name even when the care receiver refuses formal help. And in the case of Scotland sets up the opportunity to employ an approach which situates the caregiver as a partner in care. Australia, on the other hand, employs a combined tool, the MDS, and key informants from that country have indicated that this makes drawing conclusions about caregivers’ needs and recommended services very difficult.

### *5.3 Who should use the CARE Tool*

The CARE Tool is adaptable to either publicly or privately funded agencies that assess or provide homecare services or to community organizations who have staff trained in psychosocial assessment. The majority of feedback regarding the use of the CARE Tool has come from professionals working in provincial (or in the case of the United States, state run) agencies that are focused on providing health and social services. In most cases the caregiver or care receiver is already known to the agency (i.e. already receiving services), or begins receiving services from the agency after the assessment process. The process of using the Tool within the public health system is the primary way in which the Tool was designed to be used, as it can identify gaps in services, and there is ideally an infrastructure in place to then implement services in a way that provides continuity. Even if the public agency is not able to meet all the service needs of the caregiver, as is often the case, the caregiver still becomes known to the agency through the assessment process, providing a more complete picture of the family situation and the outstanding needs.

Despite the fact that its primary use is in public agencies, the CARE Tool is adaptable to non-governmental and community organizations, and has potential for employee assistance programs, provided, as is always the case, that the staff receive the proper training. For example, a local Alzheimer's Society may provide support groups and counseling services for caregivers. They may want to fully assess the caregivers before they access one of these services to get a complete picture of the caregiver's situation and needs. The organization itself will not be able to offer the caregiver any concrete services other than counseling or a support group, yet the process will still be valuable for both the organization and the caregiver. If needs arise which the agency cannot fulfill (i.e. the need for homecare services), the organization can then refer the caregiver to his/her local homecare provider. Although both public and not-for-profit agencies may not have all the services and resources required to respond to identified caregiver needs, documenting these gaps can highlight where additional or new services should be developed and make key stakeholders aware of this situation.

The CARE Tool is also adaptable for use by multi-disciplinary professionals. Although a majority of practitioners using the Tool are social workers, it can also be used by nurses, occupational therapists, counselors, or psychologists. Of primary importance is that the professionals be adequately trained (see section 5.6). As discussed in section 4.3, some practitioners have more experience posing open-ended questions and probing than others, yet with the proper training and practice any practitioner working with caregivers could become comfortable using the CARE Tool. The Tool has self-administration possibilities (which can be a time saving device), yet it should still ultimately be reviewed by a professional, given feedback from caregivers regarding the relational and supportive impacts of the

interaction. Face to face meeting with a professional can also serve to screen for conditions which the caregiver may not admit to in a self-administered situation (early stage dementia, risk of suicide).

#### *5.4 Timing of caregiver assessment*

Given that the CARE Tool identifies caregivers' needs and areas of potential risk, identifies gaps in service, and in some cases facilitates the implementing of services that were not previously in place, an assessment process using the Tool can act to prevent caregiver burnout and crisis. It also allows caregivers to plan for their own future by establishing short and long term goals.

Maddock et al. (1998) conclude that commitment from senior management, policy makers and funders to caregivers and to assessment is essential for success. Assessment must be part of a comprehensive strategy for developing a multi-dimensional approach to caregivers that sets out how agencies/governments are proposing to support them.

The experience in the UK has led the Audit Commission to conclude that sound management arrangements are needed if information, services and assessment are to be delivered more systematically. As well, certain experiences point to the advantages of designating specialist staff to lead the development of effective support for caregivers and to shape an overall caregiver strategy (Carers Australia, 2002). It is also suggested that there be a clearly articulated multi-agency local caregiver strategy that translates into an agreed upon action plan with achievable time-limited objectives.

Based on comments from caregivers regarding the impact of the Tool, it seems that the Tool had more impact for them when administered either at the beginning of the caregiving journey or when the caregiving situation underwent a significant change. It could be that the CARE Tool plays an important role for caregivers who are still formulating (or re-formulating) their needs and putting services in place. This speaks to the need for agencies to act early and to provide continuity. It benefits not only caregivers but practitioners as well, who can get an early sense of the situation and continue to monitor it, knowing that in the future the same caregiver may need to be re-assessed should the situation change in a marked way. Even specific sections of the Tool (for example the section related to caregiving tasks) can be used as a review instrument in the lifespan of the caregiving situation. Re-assessment at regular intervals is important, as the caregiving situation is constantly evolving.

Prevention is not easy, especially since many people turn to their health and social service providers only in times of crisis. It is also difficult to deal with prevention within agencies in which there may be resistance to providing services to caregivers, especially when they are not showing signs of intense distress or

burnout. Dealing with these challenges requires proper leadership and training to staff and management (see below).

### 5.5 Agency conditions for implementing the CARE Tool

There can be resistance within agencies to the implementation of new tools that require time, training, and new perspectives. This is especially the case when caregivers have not previously been the subject of attention within an agency. In order for implementation to function smoothly, the right conditions need to be put in place. Informants from agencies in which the CARE Tool is currently being implemented in a widespread way have reported that practitioners needed to buy into the idea and to be “sold”. Similarly, informants from agencies in which the Tool is not implemented stated that practitioners not buying into it was one of the main reasons for it not moving forward. According to a manager in Utah, where the Tool was considered but not ultimately used in its full version, it was a tough sell: “I thought it was fabulous but very long, I knew that my case managers would never go for it. It was just the length. In terms of the content it was fantastic.”

According to the informants, it seems that one of the keys to “selling” the Tool to practitioners is having managers and supervisors who believe in it fully. In Utah, when they decided not to use the CARE Tool, they pulled certain elements from it and developed their own shortened version. This version was then implemented systematically and was mandated by the administration. Similarly, one of the managers interviewed from Minneapolis stated that at first it was a hard sell but then they “got in a manager who believed in it, had staff changeover, and just mandated it.” That manager herself was also interviewed, and she stated that she was simply “insistent” that the Tool be implemented systematically. She said that it “took someone who is very strong to get in there and really push it.” These comments indicate that agencies may need to begin in a “top down” way to establish the right conditions for implementing caregiver assessments. Agencies will likely need to plan ways to mandate caregiver assessments, armed with the knowledge that they improve service plans, increase practitioners’ knowledge of the caregiver’s situation, prevent crises, and help caregivers feel validated within the health and social service system.

### 5.6 Training and sensitization

The comments from informants speak to the necessity for a strong training component for professionals. Within an agency, implementation of the CARE Tool runs more smoothly if everyone implicated, from top management to front line workers, is sensitized and has a similar perspective of what it means to provide services for caregivers. The training cannot just pertain to using the CARE Tool, but it must also encompass comprehensive caregiving issues. It is important that the practitioners involved in using the Tool be fully aware of the potential impacts of caregiving (emotional, physical, financial, social), the resources available to

caregivers, and have the opportunity to reflect on their own values systems and biases. In addition, practitioners who have not had extensive experience in psychosocial intervention need to be adequately trained on how to generally conduct an assessment interview and how to respond to caregivers.

### *5.7 Reaching caregivers for assessment*

An important issue regarding caregiver assessment and services is the difficulty in reaching caregivers, mainly because so many of them do not self-identify with this label. The terms “caregiver” and “assessment” may turn people away because they see themselves as family members, not as caregivers, and because the term assessment is interpreted as a process of passing judgment on their fitness to care rather than on their situation and their needs. Identifying caregivers also is daunting since this population constantly changes. In the U.K., for example, more than one-third of caregivers cease to provide or begin assuming care in any one year (Hepworth, 2003). Even where assessment is mandated, an estimated half of caregivers are not known to service agencies (Audit Commission, 2004). Continual efforts must therefore be employed to sensitize both the public and caregivers themselves to the reality of caregiving and its potential negative outcomes for those who provide it, as well as to the possibility of assessment and services.

### *5.8 Costs of assessing caregivers.*

Changing policies to integrate caregiver assessment, particularly into the daily practice of home care assessors, represent many challenges and opportunities. There are human resource costs associated with training staff and administering the assessment, as well as the human and resource costs associated with the potential increased services that result from the assessment. As one practitioner in PEI mentioned, “well, it’s probably back to resources as everything seems to fall back there. Both human resources and financial resources.” These costs are outlined below while the consequences of not implementing caregiver assessment are presented in the next section.

#### *Human resource costs*

One challenge to implementing caregiver assessment into daily practice is the current context in which caregiver assessment would become an additional responsibility of an already burdened home care professional. Currently, practitioners’ caseloads are sufficiently high as to lead some professionals to challenge that introducing caregivers as clients will jeopardize the allocation of time needed for assessing people with disabilities. What needs to be recognized is that, in many cases, the assessment of caregivers’ needs early on in the process will lead to delay, reduction or even elimination of future crises. As such, assessment can often be more efficient in the long run, as managing crises is often very time-consuming, as well as costly to the agency and to the system in general.



It is acknowledged that the proposed introduction of the Tool will occur only under a series of circumstances, some having direct implications for policy in the delivery of homecare services. Consequently, in order to integrate caregiver assessment, a series of steps need to occur, including the reallocation of cases in order that practitioners are able to integrate caregiver assessment into their daily practice. This may entail the need for additional resources, although some of the agencies that integrated caregiver assessment did not in fact increase staff. Caregiver assessment was often assigned to one or two specific workers who were then liberated from part of their regular caseload.

The cost of human resources ranges are broken down into initial training costs (1.5 days/assessor) and costs to administer each assessment. While the initial training costs are relatively stable (10hours x 28\$ = 280\$ per assessor), the time involved in assessing caregivers will fluctuate depending on the circumstances of the case (although indications are that these costs will decrease overtime as assessors become familiar with the Tool). Based on the following scenarios which we have costed out, the human resource cost per assessment when no follow-up is required would be \$128. Among cases where in addition to the assessment a follow-up telephone call was required either to provide a referral to a non-public agency or to provide emotional support to the caregiver, an additional \$21 is needed.

#### **Scenario 1 - Assessment only**

As many caregivers have indicated, often just going through the assessment process is a service in and of itself. In many cases there is no follow-up or referrals, but just allowing caregivers time to reflect on their situation and their needs can be a valuable preventive tool. It is also important to note that assessments can be implemented into practice without necessarily new money attached. In some cases they may be able to fit into a practitioner's ongoing tasks.

The cost of a social worker doing one assessment is roughly the following: One assessment takes approximately four hour of a practitioner's time, including transportation time to a home visit, writing up the report and any other notes, and exchanging with other colleagues that may be involved in the case.

**4 hours at approximately \$28 / hour (gross) = \$112.00**

#### **Scenario 2 - Assessment plus telephone follow-up**

In many cases the assessment leads to simply telephone follow-up. This follow-up may be to set up referrals to outside (non-public) services, or simply some emotional follow-up with the caregiver.

**45 minutes of telephone follow-up (pro-rated to a practitioner's approximate salary of \$28 / hour gross) would cost approximately \$21.00.**

### *Service costs*

The experience of integrating the CARE Tool into daily practice within agencies revealed that the costs were mainly in the area of human resources. There are examples of situations where services from the public system were added (home maker hours, access to a day centre) increasing costs to the system as an outcome of assessment. But the assessment can also reveal the need for services or support that is currently outside the public system and any costs incurred are the responsibility of the individual family. In the latter case, the human resources time of the assessor to facilitate access to these resources is the only cost to the public system.

### **Scenario 3 - Increased homecare services**

In Quebec, a middle-aged woman is caring for her elderly mother at home. The mother suffers from multiple health problems, and is receiving a few minimal services from their local CLSC. The caregiver goes through the assessment process with a practitioner from the CLSC who then makes the following recommendations: a) Increased homemaker services; b) Increased night-time supervision; c) Access to local community services for transportation and vocal therapy.

**a) Increase of AFS services by 7 hours / week = \$175.00**

**b) Night supervision is not provided by the public system. This is an unmet need that forced the caregiver to seek out services from the private sector.**

**c) These services are not provided by the public system. These were unmet needs that led the caregiver to access community services.**

**d) It took the practitioner who did the assessment approximately one hour of coordination/telephone time to help the caregiver get these services in place.**

**Approximate cost = \$28.00**

### **Scenario 4 - Multiple services recommended**

In Ontario, an 80 year old woman is caring for her 90 year old husband who is suffering from dementia as well as other health problems. The caregiver herself also suffers from health problems. The husband receives services (some allotted money for personal care and housekeeping) through VAC (Veteran's Affairs Canada) and it is with a VAC nurse that the caregiver goes through the assessment process using the CARE Tool. After the assessment process is completed, the nurse recommends three different services: a) Additional respite by getting the husband to a public day centre once a week; b) short-term counselling for the caregiver provided by public services; and c) increased money provided by VAC for transportation costs.

**a) Cost of a day centre once/week = approx. \$60/day**

**b) 10 sessions of counselling by a social worker plus preparation**

time =	<b>15 hours at approximately \$28/hour gross = \$420.00</b>
c)	<b>Cost of increased transportation (VAC rates for providing transportation to and from day centre)</b>

In scenario 3 the assessor recommends an increase in the homemaker services by 7 hours a week. She also recommends night supervision and transportation support, two services that are not covered under the public system. The assessor spends about an hour assisting the caregiver to coordinate these services but the cost for the services is paid directly by the caregiver. In this case the services will cost the system a recurring cost of \$175 per week. The total cost of human resources will be \$128 (as outline above) for the assessment and an additional \$28 for the coordination of services – a one time cost of \$156.

In scenario 4, multiple services are recommended for the caregiver. In this case the major cost is the recommendation for 10 sessions of counseling for the caregiver a total one time cost of \$420. In addition attendance at a day program one a week will cost the public system an additional \$60 per week.

It should be noted that in the study to develop the original Tool, assessment of caregivers did not result in a flood of services being provided to them. This is not to say caregivers do not require support but that the current public system may be somewhat limited to tailor the specific support that caregivers need. Consequently, the costs are relatively moderate, particularly when we consider the costs of not assessing caregiver.

### 5.9 Costs of not assessing caregivers

In addition to the costs of introducing assessment, one must recognize that the inaction of not implementing a policy is also a decision. According to Pal (2006), public policy is defined as a course of action or inaction chosen by public authorities to address a given problem or an interrelated set of problems. Consequences of such inaction also need to be described and assessed. In this case it is important to discuss the implications of not assessing caregivers' needs and the consequences of this inaction for the individual caregiver, for specific system costs affected by the decline in caregiver and care receivers' health, and for the wider implications of retaining and supporting working caregivers and maintaining economic productivity.

#### *Individual costs*

The health and well-being of the caregiver is at risk for deterioration if their needs are not identified. The increased expectation on caregivers to continue to provide care in a caregiving situation that deteriorates over time is ripe for negative effects. In a report of Canadian caregivers widely defined as providing care or assistance in the previous 12 months, one in ten caregivers reported health problems stemming

from their caregiving work. The proportion was much higher for women (one in five) than men (one in twenty). It is likely that caregivers caring for a client of a homecare program would report even higher rates of health problems because of the greater needs of the care recipient. Other research suggests the problems experienced by caregivers extend beyond the caregiving situation. Following the end of the relationship (because of placement in a long term care facility or death) caregivers are at greater risk than the general population of experiencing mental health problems including depression.

The financial implications, both short term and long term, to caregivers were reported by previous research. Short terms costs involved increased expenses related to the care situation (renovations, heating costs, transportation etc), costs related to interruptions from work or career limitations (reducing hours, not applying for promotion etc) and long-term consequences of less savings for retirement (Keefe and Medjuck, 1998). While assessment may not permit to overcome all of these costs to the caregivers, it will enable practitioners to screen for and counsel caregivers around these areas of difficulty and possibly intervene to lessen or alleviate the negative consequences.

#### *Health system costs*

A direct consequence of the individual costs to caregivers of not being assessed is increased utilization of hospital care, primary care, pharmacology, and mental health services. Little research has examined the average cost to the health care system of being a caregiver. A review of research on the cost effectiveness of respite programs reveals limited comprehensive studies that take into account the full menu of costs and costs benefits that may be achieved by accessing this type of service. For example, when only assessing the cost effectiveness of adult day care as the delaying of institutionalization, researcher fail to address the other potential savings to the health care system including the caregivers health, reduced pharmacare and so on (Keefe & Manning, 2005)

Another significant cost factor is assessing the consequences of a break down in the caregiving situation if the caregiver does not receive support. In research projection the future implications of population aging, Keefe, Legare and Carriere report that the cost of providing modest additional respite services (4 hours per week) is three times less expensive than the cost of having the care recipient enter a long term care facility three months earlier. When one considers that the cost to the system of a long term care facilities is conservatively \$3000 per month, the cost effectiveness of providing services to the caregiver becomes far more cost beneficial. This is not to suggest that all caregivers should be encouraged to continue providing care if they are unable or desire placement in a long term care facility; rather, for those caregivers who want to provide care and require support, there is a legitimate financial reason for the state to provide this support.

#### *Wider system costs*

Researcher and workplace analysts already established the “business case” for introducing work place policies for eldercare (Gadson, 2003). Recent data from Statistics Canada suggests that 5-7% of retirees in the previous years left their jobs at least partially because of caregiving responsibilities (Social Trends, 2004). In aging societies world wide there are increasing concerns about having sufficient labour to fulfill market demands. Quitting work or retiring early because of care responsibilities results in decreased productivity and increased costs to employers. Employers must locate and train new employees in an ever shrinking labour force. In addition, as presented in section 1.1, there are serious consequences to the productivity of workers who attempt to combine work and care responsibilities. First, such workers are under increased stress to balance both part of their lives, and second, they are unable to reach their full potential in the labour force because of their care responsibilities. These inter-related levels of costs are illustrated in the following scenario.

### **Scenario 5- Costs of not assessing**

In Nova Scotia, a 54 year old single woman is caring for her 82 year old mother at home. The caregiver works full time, earning approximately \$30,000 / year. As her mother’s condition deteriorates and she needs increasing attention, the caregiver frequently misses days of work, or is not fully present while on the job. Despite her efforts at juggling all these demands, she cannot continue any longer and feels forced to place her mother in an institution. This transition, and the lead-up to it, is incredibly hard on the caregiver, and she herself begins to get sick. Eventually she decides, with her doctor’s recommendation, to take a 6 month leave from her job and to go on public unemployment insurance. During this time, she tries to regain her health, both physically and emotionally, going for numerous types of treatment. Her mother remains in the institution during this time.

#### **Cost to the employer:**

Not only does the employer have to deal initially with absenteeism and lack of concentration from an employee (ultimately leading to a decrease in productivity), the employer also has to hire and train replacement staff when the employee takes a sick leave.

#### **Cost to the public system:**

The caregiver goes on public unemployment insurance, which covers 55% of her \$30,000 salary. For a 6-month period, this costs approximately \$8,250.

The caregiver also sees a number of medical professionals during this time, both for her physical and emotional needs.

#### **Cost of institutionalization:**

The cost of maintaining someone in an institution is approximately \$35,000 / year, of which approximately \$16,000 is assumed by the individual or the family.

Therefore the cost to the public purse of 6 months of institutionalization is approximately \$9,500.

**Cost to caregiver:**

The caregiver not only suffers from a cost to her physical and mental health, but also absorbs a loss of income, loss of pension contribution (this is especially pertinent given that she is close to retirement), and potential loss of seniority or promotion.

Had the caregiver undergone an assessment before her situation became critical, she could have potentially accessed increased homecare services and psychosocial services. This could potentially have prevented the sick leave, and perhaps even the institutionalization of the care receiver.

Understanding costs to the system of introducing the CARE Tool into daily practice needs to be balanced with a greater appreciation of the costs to caregivers and the costs of inaction. We fully recognize that cost-benefit analysis is a complex exercise and that developing a comprehensive cost-benefit analysis of introducing the CARE Tool into the public home care system is beyond the scope of this paper. Nevertheless the preliminary discussion presented here represents an important framework to recognize the costs and the consequences of integrating the CARE Tool into daily practice or the inaction of not recognizing the needs of family and friend caregivers. Moreover, the costs to the system must be balanced with the costs to the individual caregiver and the consequences of inaction on the labour market and the health care system. Failure to recognize these wider system implications results in a myopic vision of future policies to support Canadian caregivers.

## **6) Policy Recommendations**

1. Caregivers must be officially recognized as partners in care and the conditions needed to put this partnership into practice assured. At the same time, some caregivers may have difficulties stemming from their caregiving situation which can only be addressed if they are also officially recognized as clients of the health and social service system. This status must be recognized officially in policy and practice and supported by the allocation of funds and resources for caregiver services such as respite, counselling, system brokering and advocacy.
2. It is recommended that the CARE Tool be disseminated by Health Canada and promoted by the appropriate provincial and regional bodies to ensure caregiver assessment across the country in a variety of settings as a first step in responding officially to caregivers' needs.

3. It is recommended that sensitization to caregivers and caregiving situations be ensured for all managers and front line workers in all agencies assessing for, or offering, homecare services, and other settings where caregivers are in contact with health care professionals. Specific training sessions are one method of ensuring that this occurs.
  
4. As caregivers have difficulty self-identifying, it is recommended that federal ministries of health and social services in conjunction with the appropriate provincial counterparts, spearhead an on-going prevention and promotion campaign to sensitize the public, and caregivers themselves, as to the realities of caregiving. This could be done in conjunction with the Canadian Coalition of Caregivers, its member organizations, provincial caregiver and other health advocacy groups (such as the Alzheimer's Society, Heart and Stroke Foundation, etc.. In addition, professionals who regularly come into contact with caregivers, including physicians and other health care personnel, employers and people working in employee assistance programs, should be specifically sensitized to these issues.

## References

- Arai, Y., Zarit, S., Kumamoto, K. & Takeda, A. (2003) Are there inequities in the assessment of dementia under Japan's LTC insurance system? *International Journal of Geriatric Psychiatry*, 18, 346-352.
- Armstrong, P., Armstrong, H., Choinière, J., Feldberg, G. & White, J. (1994). *Take care. warning signals for Canada's health system*. Toronto: Garamond Press.
- Audit Commission (2003) *Support for carers of older people* London: Belmont Press.
- Audit Commission/Caroline Glendinning (2004) *Support for carers of older people - some international and national comparisons*.  
[www.auditcommission.gov.uk/olderpeople](http://www.auditcommission.gov.uk/olderpeople)
- Audit Commission/PSSRU/Linda Pickard (2004) *The effectiveness and cost-effectiveness of support and services to informal carers of older people*. London: Admiral Print Group
- Brody, E.M. (1995). Prospects for family caregiving. In R.A. Kane & J.D. Penrod (Eds.) *Family caregiving in an aging society*. Thousand Oaks, CA: Sage Publications.
- Brody, E.M. & Brody, S. J. (1989). The informal system of health care. In C. Eisdorfer, D.A Kessler, & A.N. Spector (Eds.), *Caring for the elderly: Reshaping health policy*. Baltimore: Johns Hopkins Press.
- Cannuscio, C., Jones, J., Kawachi, I., Colditz, G., Berkman, L., & Rimme, E. (2002). Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study. *American Journal of Public Health*, 92, 1305-1311.
- Carers Australia (2003) *Our Vision for Carers Support in Community Care*. Carers Australia
- Carers UK (2002). *Carers Assessments: Good Practice*. London, UK: Author.
- Decima Research Inc. *National Profile of Family Caregivers in Canada – 2002*. Decima Research Inc (2002).
- Carrière, Y., & Légaré, J. (2000). Unmet needs for assistance with ADLs and IADLs: A measure of healthy life expectancy. *Social Indicators Research*, 51(1), 107-123.
- Carrière, Y., Martel, L., Légaré, J., & Morin, L. (2001). *Socio-demographic factors associated with the use of formal and informal support networks at older ages in*



Canada. Paper prepared for the Longer Life and Healthy Aging Seminar, Committee on Longevity and Health of the International Union for the Scientific Study of Population, Beijing, China, October 22-24, 2001.

Cranswick, K. (2003). General Social Survey Cycle 16: Caring for an aging society. Statistics Canada. Catalogue no. 89-582-XIE

Department of health & Aging, (n.d.) *National Framework for Comprehensive Assessment in the HACC Program*, Canberra, Australia: Author.

Ellis, K. (1993). *Squaring the Circle*. York, UK: Joseph Rowntree Foundation.

Fast, J.E., Williamson, D.L. & Keating, N.C. (1999). The hidden costs of informal elder care

Feinberg, L, Newman, S., Gray, L., Kolb, K. & Fox-Grage, W. (2004) *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.

Feinberg, L. F. (2004). The state of the art of caregiver assessment. *Generations*, 27 (4), 24-32.

Gadson, A.D. (2003). Neither hearth nor home: the (un)making of elder care responsibility. *Journal of Aging Studies*, 17, 17-29.

Gaugler, J., Kane, R. & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. Kane & R. Kane (Eds). *Assessing Older Persons- Measures, Meaning and Practical Applications*. New York, NY: Oxford University Press.

Gitlin, L., Hauck W., Dennis M. & Winter L. (2005). Maintenance of effects of the home environmental skill-building program for family caregivers and individuals with Alzheimer's disease and related disorders. *Journals of Gerontology A - Biological and Medical Sciences*, 60(3), 368-74.

Gottlieb, B. (1990). *The family support project: Feedback report*. Guelph: University of Guelph

Guberman, N. & Maheu, P. (2002) Conceptions of family caregivers: Implications for professional practice. *Canadian Journal of Aging*, 21(1), 25-35.

Guberman, N., Keefe, J., Fancey, P., Nahmiash, D. & Barylak, L. (2001). *Development of Screening and Assessment Tools for Family Caregivers. Final Report*.

Guberman, N. (2001) *L'apport des proches aidants dans les services à domicile*, Rapport soumis à la Vérificatrice Générale du Québec, document mimeo.

Guberman, N. & Maheu, P. (1997). *Les soins aux personnes âgées dans les familles italiennes et haïtiennes*. Montréal: Les Éditions du Remue-ménage.

Guberman, N., Maheu, P. & Maillé, C. (1993). *Travail et soins aux proches dépendants*. Montréal: Les Éditions du Remue-ménage.

Guberman, N., Maheu, P. & Maillé, C. (1991). *Et si l'amour ne suffisait pas?: Femmes, familles et adultes dépendants*. Montréal: Les éditions du Remue-ménage.

Hepworth, David (2003). *Assessment and Support for South Asian Carers*. York: SPRU, University of York.

Hidden Costs/Invisible Contributions, University of Alberta (2005, June). *Reworking work: The experience of employed caregivers of older adults*. [Brochure]. Edmonton: Author.

Hooyman, N. & Gonyea, J. (1995). *Feminist perspectives on family care: Policies for gender justice*. Thousand Oaks, CA: Sage Publications.

Hoskins S., Coleman M. & McNeely D. (2005). Stress in carers of individuals with dementia and community mental health teams: An uncontrolled evaluation study. *Journal of Advanced Nursing*, 50(3), 325-33.

Kaye, L., Turner, W., Butler, S., Downey, R. & Cotton, A. (2003). Early intervention screening for family caregivers of older relatives in primary care practices. *Family Community Health*, 26(4), 319-328.

Keefe, J., Guberman, N., Fancey, P. & Barylak, L. (2003-2006). From Research to Practice: Assessing Caregivers of Persons with Alzheimer's Disease. An Evaluative Study. Research funded by Alzheimer's Association (US).

Keefe, J. M. & Medjuck S. (1997). The contribution of long term economic costs to predicting strain among employed women caregivers. *Journal of Women & Aging*, 9 (3), 3-25.

Levine, C., Reinhard, S., Feinberg, L.F., Albert, S., & Hart, A. (2004). Family caregivers on the job: Moving beyond ADLs and IADLs. *Generations*, 27 (4), 17-23.

Lundh, U. & Nolan, M. (2003). 'I wasn't aware of that': Creating dialogue between family and professional carers. In M. Nolan, U. Lundh, G. Grant & J. Keady (Eds.), *Partnerships in Family Care*. Buckingham: Open University Press.

Maddock, A., Kilner, D. & Isam, C. (1998). *Carer Needs Assessment Trial*. Adelaide: Royal District Nursing Service of South Australia.

- Matthews, A. M. & Campbell, L. D. (1995). Gender roles, employment and informal care. In Arber, S. & Ginn, J. (Eds). *Connecting gender and ageing: A sociological approach*, Buckingham, England: Open U Press, 129-143.
- Mittelman M., Roth D., Coon D., Haley W. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry*, 161 (5), 850-856.
- Montgomery, A, (2005) *Assessment of Family caregivers: An International Comparison Across Six Countries*, Prepared for the National Consensus Development Conference for Caregiver Assessment. San Francisco, CA: Family Caregiver Alliance.
- Neal, M. B., Chapman, N.J., Ingersoll-Dayton, B. & Emlen, A. C. (1993). *Balancing work and caregiving for children, adults, and elders*. Newbury Park ,CA : Sage.
- New Zealand Guidelines Group (2003). *Assessment Pprocesses for People Aged 65 Years and Over*. Wellington, NZ: Author.
- Nicholas, E. (2003). An outcomes focus in carer assessment and review: Value and challenge. *British Journal of Social Work*, 33, 31-47.
- Pfeiffer, E. (1987). Preventing and treating psychological problems of caregivers. In J.N. Henderson & E. Pfeiffer (Eds.), *The family caregiver: Lifeline to the frail patient*. Tampa: University of South Florida.
- Pickard, L. (2004). *The Effectiveness and Cost-Effectiveness of Support and Services for Informal Carers of Older People*. London, UK: Audit Commission.
- Scharlach, A. E., Lowe, B. F. & Schneider, E.L. (1990). *Elder care and the work force. Blueprint for action*. Lexington, Mass.: Lexington Books.
- Schulz, R., O'Brien, A., Bookwala, J. & Fleissner, K. (1995) Psychiatric and physical morbidity of Alzheimer's disease caregiving: Prevalence, correlates and causes. *The Gerontologist*, 35, 771-791.
- Schulz, R. & Beach, S. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association*, 282 (23), 2215-2219.
- Seddon, D. & Robinson, C. (2001). Carers of older people with dementia: Assessment and the Carers Act. *Health and Social Care in the Community*, 9 (3), 151-158.
- Strawbridge, W.J. & Wallhagen, M. I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist*, 31, 770-777.

Tiedman, A. (2004). *Evaluation of NJ EASE for Caregivers: A National Family Caregiver Support Program Initiative*. New Jersey: Rutgers Centre for State Health Policy.

Wakabayashi, C. & Donato, K. (2004). *The Consequences of Caregiving for Economic Well-being in Women's Later Life*. Houston, TX: Rice University, Department of Sociology.

Yee, J. & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40 (12) 147-164.

Zarit, S. & Edwards, A. (1996). Family caregiving: Research and clinical intervention. In R. Woods (Ed.), *Handbook of the Clinical Psychology of Aging*. Chichester, UK: John Wiley & Sons.

Zarit, S. H. (1991). Interventions with frail elders and their families: Are they effective and why? In M.A.P. Stephens, J.H. Crowther, S.E. Hobfoll & D.L. Tannenbaum (Eds.), *Stress and coping in later-life families*. New York: Hemisphere.

## APPENDIX 1: Interview Guides

### **Caregivers' Interview Guide**

#### Functionality of the CARE Tool:

- What is your general impression/opinion of assessment for caregivers?
- Did you find that the CARE Tool captured the real experience of caregiving?
- Are there any questions in the CARE Tool that are repetitive or difficult to answer? If yes, please explain.

#### Structure of the CARE Tool:

- What sections or questions of the assessment did you find the most useful?
- Were there questions in the C.ARE Tool that you found redundant, or not pertinent?
- What was your impression of the length of the assessment?
- If you had to shorten the CARE Tool what would you take out?

#### Impact of the CARE Tool:

- What impact did going through the assessment have on your understanding of your needs or your situation, as well as your care-receiver?
- Did going through the assessment have any impact on the services that you, or the person you are caring for, receive?
- To what extent did going through the assessment change your relationship with service providers?
- Have there been any other outcomes of going through the assessment?
- Do you think that all caregivers should have access to such an assessment?
- Did going through the assessment have an impact on how you view your own needs as a person?

### **Managers' Interview Guide**

#### Functionality of the CARE Tool:

- What is your general impression/opinion of the CARE Tool?
- From what you observe among your staff, what is it like to use the C.ARE Tool? How easy or difficult?
- Is the CARE Tool useful? Is it a hindrance? In what ways?
- Are there any negative aspects to doing caregiver assessments in your agency? Are there any potential solutions to these problems?

#### Impact of the CARE Tool:

- If the CARE Tool is implemented in your agency, what has the impact of it been on the development of service plans?

- Has your agency's knowledge and/or understanding of caregivers' needs changed? How?
- In what ways has using the CARE Tool impacted on caregivers? Care receivers?
- Have there been any other outcomes of using the CARE Tool?

Implementation of the CARE Tool (For those agencies who received the training):

- What structures or mechanisms enabled your agency to integrate the CARE Tool into practice?
- If the CARE Tool is not fully integrated into your agency, why not?
- What would it take for a shortened CARE Tool to be implemented in your agency?
- Do you anticipate any barriers to making a shortened CARE Tool a permanent and compulsory tool in your agency?
- Would implementing the shortened CARE Tool have any or no impact on your agency's policies?

**Practitioners' Interview Guide**

Functionality of the CARE Tool:

- What is your general impression/opinion of the CARE Tool?
- What is it like to use the CARE Tool? How easy or difficult?
- In what ways is the CARE Tool useful?
- What are the positive or negative aspects of doing caregiver assessments?

Structure of the CARE Tool:

- What sections or questions are the most useful for getting a feel for the caregiving situation? For informing the summary page?
- Are there questions in the CARE Tool that are redundant, or not pertinent?
- Are there questions in the CARE Tool that do not feed into the summary page?
- What would you want to see in a shortened CARE Tool? (i.e. how many pages, how much time should it take, what should it cover, what should be eliminated)

Impact of the CARE Tool:

- From using the CARE Tool did you discover anything that you did not know about the caregivers before?
- Has your knowledge and/or understanding of caregivers' needs changed? How?
- In what ways did using the CARE Tool impact on your development of a service plan?
- What challenges and barriers did you face in acting on the results of the CARE Tool?

- To what extent was the introduction of the CARE Tool linked to changes in services or service delivery?
- In what ways did using the C.A.R.E. Tool impact on the caregiver? The care receiver?
- Have there been any other outcomes of using the CARE Tool?

Implementation of the CARE Tool:

- What structures or mechanisms enabled you to integrate the CARE Tool into your practice?
- If the CARE Tool is not fully integrated into your agency or into your practice, why not?
- What would it take for a shortened CARE Tool to be implemented in your agency?

**APPENDIX 2: List of Agencies that Participated in the “Becoming Partners: Tools for Transitions” Symposium in Ottawa in November 2005.**

Alberta Caregivers Association  
Alzheimer Society of Canada  
Canadian Association for the Fifty Plus  
Canadian Association for Community Care  
Canadian Association for Occupational Therapists  
Canadian Association of Advanced Practice Nurses  
Canadian Association of Speech and Language Pathologists  
Canadian Caregiver Coalition  
Canadian Home Care Association  
Canadian Hospice Palliative Care Association  
Canadian Mental Health Association  
Canadian Physiotherapy Association  
Caregivers Association of BC  
Caregivers Nova Scotia  
Community Living MB  
CSSS Cavendish, Montreal  
Department of Health and Community Services St. John’s  
Developmental Consulting Program  
Family Caregiver Centre of Calgary



### **APPENDIX 3: Research Team and Advisory Committee for CARE Tool Project**

#### Research Team:

- Lucy Barylak, CSSS Cavendish, Installation CLSC René-Cassin
- Pamela Fancey, Mount Saint-Vincent University
- Nancy Guberman, UQAM and CSSS Cavendish, Installation CLSC René-Cassin
- Janice Keefe, Mount Saint-Vincent University
- Marjorie Silverman, CSSS Cavendish, Installation CLSC René-Cassin

#### Advisory Committee:

- Jennifer Greene, Health Canada
- Linda Lysne, Canadian Caregiver Coalition (CCC)
- Sandra MacLeod, Social Development Canada
- Faye Porter, Victorian Order of Nurses (VON) Canada

## **APPENDIX 4: Modifications to the CARE Tool**

Several questions in the **Profile** section were moved into other relevant sections so that they are considered in the overall understanding of the situation (e.g. Co-residency of the caregiver and care receiver).

### Section 2

The format of the tables was simplified while maintaining the integrity of all the tasks and the level of difficulty and amount of support the caregiver has. Some questions were removed which did not inform the final assessment or which were redundant with other sections.

### Section 3

This section was simplified; some questions were combined and others removed.

### Section 4

The title was changed to explicitly include transportation.

### Section 5

Many questions were transformed into open-ended format and the detailed section on the impacts of caregiving on employment was modified to one open-ended question.

### Section 6

This section was simplified from a detailed table to an open-ended question.

### Section 7

The tables were simplified to be more user-friendly.

### Section 8

Some questions were reworded or merged to become clearer.

### Section 9 and Section 10

Changes to section 10 lent to the combination of 10 and 9 with desired services and supports becoming a subsection of future planning.

We have added a question about legal aspects (Have you thoughts of or discussed care-receiver guardianship, wills, advance directives, power of attorney?)

We reworked the questions regarding the caregiver's desire to continue caregiving or not, to ensure a better flow between this desire and the supports they need to continue or not.

### Summary page

This page was simplified to be more user-friendly.

## **APPENDIX 5: The Modified CARE Tool**

<contact the authors or visit [www.msvu.ca/Family&Gerontology/project](http://www.msvu.ca/Family&Gerontology/project)>