

**Manitoba Caregiver Consultation Final Report
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Executive Summary

Family members, friends and neighbours who provide unpaid care support for Manitobans facing a variety of physical, mental and emotional challenges do so out of a strong sense of responsibility and love. They contribute considerable time, energy, and resources, sometimes risking their own well-being. Such contributions should be acknowledged, and caregiver needs for support recognized. In 2012, the Seniors and Healthy Aging Secretariat, with Dr. Laura Funk (University of Manitoba), obtained the input and guidance of caregivers in Manitoba, through surveys and focus groups. These data, alongside research evidence of promising practices, point to a range of opportunities to better support caregivers in Manitoba.

Consultation Findings - Highlights:

- 400 caregivers participated (311 survey respondents and 89 focus group participants)
- 86.8% of respondents were female, and 59.7% resided within Winnipeg.
- 54.8% were caring for older parents; 21.9%, for a spouse; 11%, for a child; and 12.1% were caring for other family members, friends or neighbours.
- Caregivers provided considerable levels of care, with 43.7% reporting providing care for over 21 hours each week. 43% of respondents lived with the care recipient, and 35% provided care for more than one individual. 34.1% were caring for an individual with some form of dementia or cognitive impairment.
- Caregiver stresses stemmed from the complex emotions involved (e.g. guilt, worry, grief); from time constraints and difficulties ‘juggling’ care provision with other responsibilities (employment, other family, self); and from the challenges in navigating, monitoring and coordinating various health and social care services.
- Though caregivers do not want their work to be taken for granted, approximately 18% were uncomfortable with ‘being recognized.’ Some did not want to be recognized because they viewed what they did as a natural part of their family relationships. Others did not view recognition as meaningful relative to the care recipient’s needs for services.
- Caregivers most frequently mentioned “biggest struggle” was with system navigation and information about existing programs and services. They were frustrated when they could not easily access programs or services for the care recipient. As such, “strengthening existing health and social services” was the most commonly suggested priority.
- Caregivers often feel compelled to provide care yet experienced negative impacts on their own well-being (e.g., 45.3% reported needing “a lot” or “quite a bit” more help managing the impact of caregiving on their mental or emotional well-being).
- Caregivers need to trust service providers to safely care for their loved one in an appropriate manner. In the absence of this trust, they take on the added responsibility of

“constant vigilance” and advocacy to ensure the quality of care. Caregivers wanted providers to recognize their needs in this regard as well as to treat them with respect. They sought meaningful opportunities to provide feedback about care services.

- Addressing the financial burdens of care provision was the second most commonly recommended government priority among respondents. 32.4% needed either “a lot” or “quite a bit” more help with the financial impact of caregiving.
- 72.6% of survey respondents worked in paid employment. There was a moderate but consistent focus on the need for supportive employer policies and practices (especially for flexible work arrangements), throughout the survey and focus groups.

Opportunities for Enhanced Caregiver Support - Highlights:

- Identify ways to enhance the **training and education of health and social care providers, as well as employers/managers**. Sensitivity training and affective learning are encouraged, as are broader public awareness strategies to promote understanding of caregiver needs and experiences.
- Enhance the **formal and informal identification of caregiver needs in practice and policies** (e.g. caregiver needs assessment tools; Caregiver Policy Lens).
- Develop ways to **simplify and streamline system procedures** within various sectors of government, health authorities, social services, and human resources, to make them more sensitive to caregivers and their needs.
- Develop **centralized points of access, referral and information** for caregivers and patients. Provider-initiated, proactive supports for system navigation are encouraged.
- Promote the **development and implementation of peer learning, support group** and other caregiver networking initiatives.
- Develop initiatives for ongoing **caregiver feedback about health and social care**, with appropriate follow-up mechanisms.
- Identify options to enhance **financial supports for caregivers**, such as expanding the Caregiver Tax Credit, specialized assistance programs or grants for out-of-pocket expenses, or a caregiver allowance.
- Explore strategies to promote **supportive workplace policy and practice**, such as flexible work arrangements or expanded family leave (e.g. employment legislation, workplace health and safety policies).
- Implement strategies to enhance **the level, quality, coordination and flexibility of health and social care services** (including in non-profit sector), with a focus on home care/respice, adult day programming, counseling, Emergency Room and in-patient care.

Consultation Process

The Minister of Healthy Living, Seniors and Consumer Affairs, the Honourable Jim Rondeau announced on the first Caregiver Recognition Day, April 3rd, 2012 that the province will begin consulting with informal caregivers from across Manitoba. The information collected on various topics such as caregiver needs, supports and recognition will help inform the province as it continues to support informal caregivers. The Seniors and Healthy Aging Secretariat contracted with Dr. Laura Funk, Assistant Professor in the Department of Sociology, University of Manitoba, who specializes in research on family caregiving. The design incorporated both quantitative (close-ended survey questions) and qualitative (open-ended survey questions; focus groups) data about the needs and perspectives of caregivers in the province.

The consultation included a review of published English-language research on supports for family caregivers (with a focus on ‘promising practices’ and interventions¹); a province-wide survey of caregivers (which was primarily internet-based but with an option for telephone completion); and nine focus groups. For the purposes of the consultations, caregiver was defined as in the Caregiver Recognition Act:

...a family, friend, or neighbour providing unpaid support or assistance to another person who is facing challenges due to mental or physical disability, illness, injury, or aging.

Those who completed the online survey remained anonymous. Steps were taken to ensure the confidentiality of other participants’ identities.

A total of 400 caregivers participated in the consultations through either the survey (n=311) or focus groups (n=89), between April and July 2012. Seven focus groups were held in Winnipeg and two in Brandon. Three groups were targeted to those in the provincial civil service; one to family caregivers who were employees of Brandon Regional Health Authority; one to those caring for older adults with addiction; and one to those caring for persons with dementia. We observed that in practice, many of the focus groups informally worked to help caregivers support and learn from each other while sharing their experiences (some participants even exchanged contact information between themselves after the group had ended).

All data were analyzed and summarized by Dr. Funk. Assistance with conducting telephone interviews was received from University of Manitoba student Ashley Brekelmans. Shannon Kohler of the Seniors and Healthy Aging Secretariat provided overall guidance, organized the recruitment strategy, and assisted with the focus groups; staff of the Secretariat provided administrative and technical support.

¹ Existing research literature on caregiver interventions focuses overwhelmingly on caregivers of older adults; to a lesser extent research on caregiving for terminally ill persons and those with cancer or mental illness is also available; however, there is a dearth of intervention research focused on caregivers to disabled or ill children.

Caregiver Profile

We obtained socio-demographic data for 311 survey respondents as well as some from civil service employees who participated in three focus groups (n=33). Participants were self-selected volunteers (i.e., may differ from those who decided not to participate, which requires caution in generalizing the results). For full details see Appendices B and C.

Socio-Demographic Characteristics

- **Location:** The majority of survey respondents (59.7%) resided in Winnipeg, and 9.7% resided within one hour or less driving distance of Winnipeg. 13.5% resided in Brandon or Portage la Prairie, and 16.4% resided in another location in Manitoba.
- **Gender:** 86.8% of survey respondents and 87.9% of the civil service focus group participants were female. 13.2% of survey respondents and 12.1% of the civil service focus group participants were male.
- **Age:** The average age of survey respondents was 54.19 years (range: 21 to 91 years). For the civil service focus group participants, 15.2% were between 26 and 45 years of age; the majority (54.5%) were between 46 and 55; and 30.3% were 56 to 65 years.
- **Marital Status:** Most (70.7%) survey respondents were in a married or in a common-law partnership; 13.6% were single, 9.7% were divorced or separated, and 5.8% were widowed.
- **Minority Groups:** 13.5% of survey respondents reported being a member of a minority group, including 22 Métis, Aboriginal or First Nations persons. Among civil service focus group participants, the majority (81.8%) spoke English as their first language, and 21.2% reported being either a first or second generation immigrant.
- **Children:** 22.8% of survey respondents had at least one child < 18 years of age who lived with them in their home.
- **Income:** 26.3% of survey respondents reported that their current income did not meet their needs, either 'at all' or 'not well.' For 16.8%, their income met their needs 'very' or 'extremely' well. For most (56.8%), their income met their needs 'fairly' well.
- **Employment:** The majority of survey respondents (59.7%) worked full time, and 12.9% worked part time. A small proportion was on temporary leave (2.9%) or unemployed (3.6%). 20.8% were retired. Civil service focus group participants had worked an average of 4.12 years for the provincial government, ranging between 1 and 7 years.
- **Care relationship:** 54.8% of survey respondents were filial caregivers (adult children caring for a parent, including 51.9% daughters and 2.9% sons). 21.9% were spousal caregivers (14.8% wives; 7.1% husbands). 11% were parents caring for a child with illness or disability (10% mothers; 1% fathers). The remaining 12.1% represented various

relationships (e.g., granddaughter, friend, sibling, etc.). Approximately 59.1% of respondents were providing care for a female, and 40.9% for a male. Among civil service focus group participants, 75.8% were caring for a parent or parent-in-law; 24.2% for other family members or friends.

- **Marital status of care recipient:** 39.7% of those receiving care from a survey respondent were married or in a common-law partnership; 6.9% were divorced or separated; 39.3% were widowed, and 14.1% were single.
- **Care recipient age:** The average age of care recipients was 70.68 years (range: 4 to 99 years). Only 4.8% of survey respondents were caring for a child under the age of 18, and 24.4% were caring for an individual aged 18 to 64 years. 70.7% of survey respondents were caring for an individual aged 65 or over².

Becoming a Caregiver

Family members provide care out of a complex blend of responsibility and love, as expressed in the following quote:

Caregivers do it because they have to. This is your family and it is your responsibility to help out with your family. That doesn't mean you don't love them - of course you do - but because they are family you are put in that spot that says you may not want to but you have to.

The vast majority of survey respondents (95.8%) were comfortable self-identifying as a caregiver – indeed, they all volunteered to participate in a caregiver survey, so this is unsurprising. Yet it is well established in the research literature that some family members provide care without identifying themselves as caregivers; this may create a barrier to their access to potentially supportive services (Albert et al., 1996; Kutner, 2001; O'Connor, 2007). For example, some family members may not view their needs as legitimate in comparison to those of the care recipient (Harding and Higginson, 2001). One focus group participant noted that public awareness-raising is needed, because: “they don't always know that they are a caregiver – they need to know that they are before thinking of a way to get them to go and get helped.”

To explore this issue, survey respondents were asked (in two open-ended questions) when and why they realized they were a caregiver. Respondents described generally becoming aware of a family member's need for help (73 comments), or referred to when a family member had health incident, illness or diagnosis (117 comments), or another family member had died (22 comments). Other caregivers described slower deterioration in the well-being or function of a family member (37 comments); they realized their family member could no longer do the things they used to do because of illness or disability.

² This should be considered when interpreting the findings from this study. It is possible that in part because the survey invitation stemmed from the “Seniors and Healthy Aging” Secretariat, potential respondents may have assumed the focus of the study was on caregivers of older adults (though this was not the case). Alternatively, it may be that parents of ill or disabled children may be less likely to self-identify as ‘caregivers.’ Finally, others have noted that this may be an accurate representation: a minority of caregivers are caring those caring for children (Fast and Keating, 2001).

Other respondents linked their self-identification to their awareness that the care recipient was or had become emotionally and/or physically dependent on them for help (28 comments). Some respondents realized they were a caregiver because there were no other viable primary sources of help for the care recipient (21 comments). For instance: “I knew that I was able to help at a time when there were no other options for the persons who needed help.”

Some caregivers stated that being identified by others as a caregiver played a role in their own self-identification (13 comments). For one respondent, it was the survey itself that sparked this awareness. Others spoke about being identified by family members, medical professionals or the care recipient themselves (e.g. “She has designated me as someone who can claim the Caregiver Tax Credit”).

Respondents explained their self-identification in part through describing the number or nature of tasks they were performing for their family member (87 comments), including those they normally did not or would not do within their family relationship. Examples include: when adult children start making financial decisions for a parent; a wife who has never mowed the lawn starts doing this; or a parent perceives they are doing more than would be expected of a parent with an able-bodied or illness-free child. The following quotes are illustrative:

When I realized that I had taken over most of my wife’s household tasks. I have also increased the frequency with which I have to help her eat and dress.

Both of my children have special needs. ... I am a parent but also one that faces additional challenges other parents do not have to deal with. To me that made me a caregiver.

Respondents also described how their responsibilities were increasing, they were spending more time providing care, and their family relationship had changed (e.g., “When the relationship changed from being a daughter to doing for my parents”). Others describe realizing they were caregivers when the tasks began impacting their lives significantly, and when they sensed they were prioritizing their family member’s needs above their own, had to limit or ‘juggle’ other aspects of their lives, or considerably alter their normal schedules, priorities or decisions (21 comments).

We still know little about why some family caregivers might **not** self-identify, though ideas about ‘realizing’ or ‘deciding’ to care, as well as ‘identifying’ may be rejected when a person interprets what they do as part of a natural way of being in and with family, and expressing affection. Two quotes are illustrative:

To be honest I didn’t really call myself a caregiver as I felt it was and is my duty as a partner to be there for him.

Just now, I thought of myself as helping a friend; I think my friend would be hurt if I referred to myself as a caregiver. I feel more of a friend.

This same phenomenon may help explain some responses to a question about the meaning of ‘being recognized.’ 56 respondents stated they do not want recognition; many of these appeared to be uncomfortable with recognition because they viewed what they did as natural within family relationships. For instance, they wrote:

I don't expect to be "recognized." I did what I did for my husband and would do it all again for any member of my family as I know they would for me.

My sisters and I don't do for the recognition or glory....we don't even like when people give us credits for ensuring our parents have a decent life. That would make them feel worse about being dependent on us.

I have no idea what "being recognized" means - we care for our family out of a sense of responsibility, respect and duty.

Collectively, these data on self-identification and recognition could suggest the need for greater public awareness activities designed to facilitate self-identification; relatedly, some participants expressed a need for broader public awareness of the needs and experiences of caregivers. Dobrof and Ebenstein (2007) suggest that "caregiver" should be defined "broadly and often" in public brochures and advertisements in order to facilitate self-identification. The Caregiver Recognition Act and day could be helpful in this regard. At the time of the survey, only 22.9% of caregiver respondents reported being aware of the Act.

However, we must also recognize that some caregivers may be uncomfortable with identification or recognition. In order to ensure appropriate supports are accessed by those who may not want to explicitly self-identify, providers themselves should reach out to these caregivers in their daily practice and explain how such supports may be useful (Dobrof and Ebenstein, 2007).

Challenges, Sacrifices and Contributions

In part due to resource demands affecting health and social care systems, family members are caring for individuals with higher cognitive and physical impairment than they might have in the past. In addition, women tend to provide the majority of family care but are now also more involved in the paid labour force, which can result in significant demands on their time and energy. As participants noted, part of 'being recognized' as a caregiver means that others understand what is involved – the very high levels of time, energy, commitment, and hard work, the impact on their lives, and their needs for support. Recognition is in this sense about, e.g., "having the difficulty of this journey validated."

Both quantitative and qualitative data from the survey and focus groups provide evidence to describe caregivers' challenges and needs, as detailed below.

- The average length of time survey respondents had provided care was 8.70 years, ranging from 3 months to 55 years. Pinquart and Sörensen (2007) report that longer lengths of time spent providing care were associated with higher risk of negative outcomes among caregivers.
- Care recipients had between 1 and 6 health conditions (average: 1.75). The most common condition was dementia or cognitive impairment (34.08%), followed by mobility or physical function impairments (19.94%), heart or lung conditions (14.47%), and 'frail/aging' (9.97%). Pinquart and Sörensen (2007) note that caregivers of those with dementia face higher risks of negative health outcomes.

- Survey respondents provided, on average, 48.64 hours per week of care. This average is particularly high because 51 respondents reported providing care “24-7” or 168 hours per week. A survey of 70 employed caregivers in Canada (Duxbury, Higgins and Schroeder, 2009) reported that they provided approximately 30 hours per week of care on average. Data obtained by the Health Council of Canada (2012) indicated that family members provided about 15 hours of care per week to home care clients within the Winnipeg Regional Health Authority. The Canadian Institute for Health Information (2010) reported that levels of distress tend to be higher for family members providing more than 21 hours of care per week. A total of 44% of survey respondents and 18% of civil service focus group participants reported providing more than 21 hours of care per week.
- 43.0% of survey respondents co-resided with the person they providing care for. At least 8.0% of survey respondents noted that care recipient lived in a personal care home or other supportive housing situation.³ Co-resident care is normally associated with higher risk of negative caregiver outcomes (Pinqart and Sørensen, 2007).
- 34.8% of survey respondents provided care for at least one other family member; most of these participants (75.5%) cared for just one other individual.

Participants described care work as “dedication far beyond the call of duty” and as involving complex and often challenging emotions such as guilt, grief, and worry. Care frequently requires immediate responses to needs rather than being “put off until it’s convenient.” Caregivers often find it stressful to juggle the many demands on their time, which include not only care provision but navigating the complexities of health and social care systems, coordinating various services and ensuring the quality of that care. They often put the needs of the care recipient above their own, restricting their own involvement in social and other activities. The following excerpts are illustrative:

I worked part-time so that I could take my dad to all his appointments. Every decision regarding my work and my life was made after I had figured out if it would impact my dad or my caregiving ability.

Understanding what things my family has had to put aside with me looking after a sick parent and a sick grandparent. It broke my heart when my son couldn’t go to hockey windup with his friends because I was at the hospital with my very ill mom, and my hubby was at home with flu. Just not enough of me to go around.

Participants often referred to personal “burnout” and the effects on their well-being, as in the following excerpts:

I’m beside myself and don’t know if I will ever get over it. I feel like I won’t make it before his name comes up at the care home.

I have a hard time asking for help. I do not know to who I should turn to. I keep pretending all is OK when it is not.

I have suffered a major depression, caregiver stress syndrome, weight loss as a result of caregiving.

³ This is likely an under-estimation, as the question was not asked in the survey. Rather, this was calculated based on what was revealed in respondents’ answers to other open-ended survey questions.

Caregiving affects us physically, as well as mentally. I was off work this winter due to stress/depression/burnout issues. I returned to work, and I can already feel myself slipping.

Caregiving can be quite exhausting because of stress and emotional worry. It is sometimes not the physical care as much as the responsibility and perceived pressure from others that affects me.

Participants emphasized the importance of the caregiving issue, and expressed that their work alleviates fiscal constraints on the health care system and in many cases helps the care recipient to live independently. They want their important contribution, and their sacrifice of time and energy, to be recognized and respected by others. As detailed later in this report, this could involve a combination of public awareness, provider education, and the ongoing development of supportive services to alleviate some of the challenges of caregiving.

Support Needs

Caregivers described feeling recognized and respected when others (including service providers) acknowledge and understand that they are individuals with other responsibilities and needs for support. They do not want their contributions to be taken advantage of, as when others assume that a caregiver will complete the task, or pressure them to continue. The following quotes are examples:

I often feel that things are automatically assumed that I will take care of it. Others being thoughtful before assuming that it is automatically your responsibility.

That hospitals, home care, and even nursing homes recognize the contribution that is being made which assists them with their jobs. In some cases, they began to expect you would be there every day and even make comments when you were not there.

Caregivers often find it difficult to ask for help (e.g. “we do not necessarily like to ask people to help us”) and emphasized that when they do ask, it is needed. As one participant wrote: “we are not looking for handouts. We are asking for the tools to do the job.” Others expressed, as examples:

I am not looking for ‘Cadillacs’ - just would be lovely to have the occasional ‘horse and buggy’ to help out.

If caregivers are not adequately supported in terms of the types of services or programs available to them, then they may end up costing the health care system more money over the long term because the stresses that caregivers experience may end up undermining their own health. Caregivers may then become the “casualties” of their caring for others.

That services recognize family members often already stretch themselves to the limit before waving the white flag and asking for help.

When I finally ask for assistance, it means I do need it. Respect the fact that I am living the life of a caregiver and know my limitations and needs and those of my spouse. That I am competent in caregiving, but not superhuman either.

Caregivers felt recognized and respected when their expressions of needs for support were taken seriously by case coordinators and other primary providers (doctors, hospital staff, etc). Other participants recounted some negative experiences, such as being told by providers: “what do you

expect *me* to do?"; "are you *sure* you need more?"; "you're on your own" or "why didn't *you* do this?" In these examples they spoke of feeling as if their expressed needs for help (i.e., their input) were negated and undermined. In contrast, feeling recognized and respected means, for example:

Having more services that people don't have to beg for would be an important step to recognizing that caregivers need the support and more often than not, do not ask for help.... therefore, for the system to be proactive and have services for respite for example that people can rely upon, would go a long way to help matters.

Caregivers are appreciative of support they do receive, and identified a wide range of over 30 different kinds of helpful programs and services. The most commonly cited were home care (identified by 40.5% of respondents), personal care homes or supportive housing (10.3%), voluntary societies such as the Alzheimer's Society (9.3%), and day programs (7.1%). In total, 61.1% of survey respondents reported receiving any unpaid help with caregiving from other family, friends or neighbours; 40.5% paid for services 'out-of-pocket,' 15.3% received help from volunteer service organizations, and 71.9% received help from public services.

Respondents were asked to state how much more help they needed, if any, in each of a list of areas. Percentage distributions and average scores for all areas are summarized on the following page, ranked in order from most to least help needed (based on the average score for each area; higher average scores equate with more help needed).

Help is needed with...	No more help needed (0)	Little bit more help needed (1)	Quite a bit more help needed (2)	A lot more help needed (3)	Average
Managing the impact of caregiving on your own mental and emotional well-being	12.9%	40.4%	26.5%	20.2%	1.54
Planning for the future care of this person	20.5%	31.1%	28.6%	19.8%	1.48
Juggling caregiving and other responsibilities (e.g., work, family)	17.3%	37.5%	27.6%	17.7%	1.46
Having time for yourself	20.4%	36.4%	23.6%	19.6%	1.43
Working through health or social service systems on their behalf	26.7%	37.2%	21.3%	14.8%	1.24
Managing the impact of caregiving on your relationships with other family members	29.0%	35.5%	19.4%	16.1%	1.23
Managing the impact of caregiving on your finances	31.3%	36.4%	17.3%	15.1%	1.16
Managing the impact of caregiving on your relationship with the person you care for	30.1%	42.6%	16.0%	11.3%	1.09
Helping the person with everyday tasks (e.g. toileting, lifting, feeding, driving)	34.9%	41.9%	14.4%	8.8%	0.97
Managing their symptoms (including giving medications)	51.7%	32.5%	10.0%	5.8%	0.70

Though such collective data can help in the identification of priority areas from a policy perspective, caregivers are an incredibly diverse group, and from a programmatic or practice perspective, the preferred approach is to individually assess each particular caregiver's needs and respond to these in a tailored way (Brookman et al., 2011). To this end, several innovations have emerged that involve developing and implementing formalized caregiver needs assessments (Ewing and Grande, 2012; Feinberg, Wolkwitz and Goldstein, 2006; Guberman et al., 2003; Keefe et al., 2008). This aligns with researchers who have recommended the need to tailor

intervention programs to individual circumstances (Cameron, Massuch and Wishart, 2008). Assessment tools help to make caregiver needs more ‘visible’ to providers, who normally focus on the patient or client. Protocols for caregiver needs assessments have been developed in Australia, Sweden and the UK (Colombo et al., 2011). The latter has even legislated caregivers’ rights to have their needs assessed in community care practice, and to have these taken into account in client care planning. Though some suggest this has had minimal impact on practice for a variety of reasons (Sedden and Robinson, 2001), the legislation of caregiver needs assessments, alongside provider awareness and training activities, may help promote recognition of caregivers’ needs for support. Caregivers’ right to have their needs assessed and addressed is a key element of policy that supports caregivers (MacCourt and Krawczyk, 2012).

System Navigation

As noted earlier, some survey respondents were uncomfortable with ‘recognition’ because they viewed what they did as a normal part of their family relationship. For others however, recognition was not meaningful relative to what they viewed as more imperative needs, as in the following statements:

I do not have any expectation of any award or “being recognised.” I just want my husband to be safe and comfortable without his or my stress levels being raised, or our savings being drained.

I don’t need to be recognized- please save the dollars that would be spending on recognizing caregivers and put it towards more service for those requiring care.

Just being recognized doesn’t help me - what would help is if someone stepped in and did what was required, when required, and without me having to plead for help.

Reflecting a common sentiment that “I just want more help for the person I care for,” participants in both the surveys and focus groups strongly emphasized the stresses that can be involved in and the need for help with accessing and negotiating health and social care services for the care recipient. This was the most frequently mentioned ‘biggest struggle’ (118 comments), and constituted the third largest emphasis in responses to an open-ended question about government priorities (113 comments). 36.1% of survey respondents reported needing either ‘quite a bit’ or ‘a lot’ more help with system navigation, and 48.4% desired ‘quite a bit’ or ‘a lot’ more help with planning for the future care of the care recipient. Similar emphases on system navigation emerged in response to questions about what would be the “most helpful” (37 comments), and the meaning of being supported (22 comments), being respected (18 comments), and being recognized (40 comments).

Likewise, Brookman and colleagues (2011) note that “caregivers often find it challenging to navigate the system and access services due to a lack of knowledge about how the system actually works, what services and resources are available to them and how to access these services” (p.24). As an example, a recent study of Canada’s Compassionate Care Benefit (Williams et al. 2010) noted extensive concerns among family caregivers with a lack of accurate information about the program, as well as complex and challenging application processes. The Special Senate Committee on Aging reported that “witnesses emphasized the important role voluntary sector organizations play in helping individuals navigate through complex eligibility criteria” (Carstairs and Keon, 2009: p.121). However, others recommend that enhancing caregiver well-being involve more targeted innovative strategies to assist with administrative, information, and coordination needs (Colombo et al., 2011). A system navigator role is a potential model identified in one review, and would involve the use of “healthcare workers to facilitate safe and effective transitions across healthcare settings” and help broker the patient’s access to care (Manderson et al., 2012: p.14).

Consultation participants appreciated being able to get help when needed by themselves and/or the care recipient, and were frustrated when they had to spend time researching options and trying to navigate the bureaucratic maze of services. System navigation can add to the stress of providing care for a family member, expressed in the following excerpts:

It is so frustrating when dealing with the various organizations as you get bumped from one service to another, constantly being told – “we don’t do that”!

It is very difficult to understand the process and what is required to ensure we are not in an emergency state before it is handled. As we are new to the process, there doesn’t appear to be easy information to obtain.

I as a caregiver would not need support if I wasn’t constantly needing to: make phone calls, spend inordinate amounts of time documenting, arrange & attend meetings, write letters in order to access necessary services for my mother.

When caregiver energy is spent on system navigation, their family relationships can be affected (“you don’t have anything else to give, you can’t be ‘a daughter’”). Caregivers who work ‘within the system’ even find it difficult to navigate, and expressed concern about those without existing system knowledge or strong coping skills. Since caregivers are already often highly stressed, requiring them to complete overly lengthy forms or documentation requirements and navigate within uncoordinated systems can represent additional burdens.

Respondents sought clear, accurate information about available resources and services, including details about eligibility, application processes, contacts, program guidelines and rules. Only 24.1% of respondents stated they were receiving the information they need about caregiving; 36.5% said they were not, and 39.5% were unsure. When asked about their information needs, 100 comments focused on information about a wide expanse of existing services, programs and resources, and how to access these; such information was also the most common suggestion regarding a Caregiver Recognition Day event (125 comments). Some participants further sought information about services local to their area, specific to their situation or the care recipient’s condition, or their cultural background.

Caregivers described their struggles trying to find information about available programs and services, especially as they often felt they had to discover this information on their own:

We had to search it out for ourselves. No one from Cancer Care met with us to inform us of what services were available to us. We felt totally alone and overwhelmed after receiving the diagnosis.

Gathering information and finding out what we qualified for. For 8 years everyone (pediatricians, CFS, etc.) all assumed someone had told me about respite care and other services we qualify for yet no one checked to make sure we knew or received assistance.

Finding out the needed information is challenging, and caregivers often don’t know where to start or “which questions to ask” to receive services (or in which cultural or literacy frame). They are extremely busy, without much time to research service options. As a result, they described learning about existing options “as you go,” in “bits and pieces,” “by chance,” “by word of mouth,” by “digging and scrounging for possibilities” or “in crisis situations” or when they are “already in desperate need.” MacCourt and Krawczyk (2012) identify system navigation supports as supporting at least three important principles of policy that supports caregivers, including choice (e.g., “whether or not the caregiver is informed about and offered services available to the care recipient proactively and prior to crises”: p.27), accessibility (e.g., having program staff available to “‘interpret’ policies and programs and assist with applications when needed”: p.28), and sustaining caregivers (“information about community resources and support to navigate the system”: p.30).

Some participants believed that they needed to be a vocal and persistent advocate in order to access existing service options (“we have to ‘prompt’ the system to work for us”), and/or incredibly skilled at filling out confusing forms. System navigation, as well as service coordination, requires considerable time and energy, as in the following quote:

It takes huge amounts of time to phone everyone, make sure they know what needs to be done, how long they can be there for, to not leave until the next person shows up, making up lists, etc. etc.

Caregivers expressed a desire to avoid having to “beg, threaten, fight for necessary services,” spend time “convincing them that I actually need the help,” or “fighting to get her the care that [care recipient] needs.” They preferred “quick, easy, uncomplicated and equitable access to support and services” with less “red tape” or “bureaucratic hoops.” A desire for support in system navigation was commonly cited:

Instead of spending time researching what is available, coordinate and present the process, options and services. There is no-one helping you navigate the system. My vote is for an advocate or advocates to be available or assigned, or more assistance given to non-profits who do this informally but not terribly well.

Someone I could phone or visit that is knowledgeable of the WHOLE home care/respice/personal care home/medical system, provide me with more information than I am getting at this point. I have made phone calls to people for information, and some have never phoned me back.

Transitional planners to assist families put supports in place to assist parents live better and more safely in the community. Resources in place and options explained. There are some private social workers who do this - but they are very expensive and only work with you if you do what they say - they are not open to options - at least that was our experience for a one hour meeting and a cost of \$150.

Accessing supportive services for the care recipient contributes to feelings of being recognized and respected, and alleviates caregiver stress. For instance, one participant spoke of his positive experience with Golden Lakes staff who assessed his wife and “realized the importance” of having her panelled – in their written comments on the assessment, staff noted the urgent need for his wife to be admitted, not only for her own well-being, but also for his (as the caregiver). A desire to get help when needed (home care, respice, transportation, etc.) and have supportive options available also dominated respondent comments about the meaning of choice (97 comments in total) and to a lesser extent, being supported (47 comments).

Conversely, caregivers were frustrated when their access to home care or other supportive programs or services was limited due to what they viewed as inflexible, restrictive policies or practitioners (a “here’s what we offer, take it or leave it” approach). For instance, caregivers wrote about being denied access to particular programs or services if they did not co-reside with the care recipient; if a care recipient with early onset dementia was under age 65; if the care recipient had multiple conditions or their condition did not fit the precise definition used by the program; if the assessing nurse visits when the care recipient is having a ‘good day’ (e.g. fewer visible symptoms) or relies on the care recipient self-reports of function⁴.

⁴ The input of family caregivers to cognitive and competency assessments was noted as important for service providers to gain a holistic picture and enhance the accuracy of assessments (e.g., those with dementia and/or addictions may ‘present’ well or be less forthcoming).

The Personal Health Information Act was also noted as a challenge for family members who sought information about the care recipient but lacked a Power of Attorney or directive/documentation. Some caregivers desired greater information about the care recipient's care plan and condition, but could not easily access it for these reasons, and suggested the need for greater flexibility in the act, as well as greater sharing of information more widely (e.g. if caregiver could communicate directly with GPs e.g., by phone).

Given caregivers' concerns regarding access to services for the care recipient, it is not surprising that the most commonly suggested government priority among respondents was to strengthen existing health and social services (166 comments). This emphasis is represented in the following quote from one participant:

The most important way to care for caregivers is to provide care services for the person who needs it.

Participants emphasized a need to strengthen home care, residential care settings, and a wide variety of community health and social services,⁵ as well as the health care system more generally. Asked what kind of service or organization would be most helpful, the most frequent comment expressed desire for greater and/or enhanced access to existing health and social services (49 comments). Commonly cited were social activities for the care recipient (21 comments) such as day programs, and home care help and respite (46 comments).

Several participants further expressed a need to address individuals that 'fall through the cracks' – that support should be given where needed, regardless of whether one exactly fits the eligibility criteria, and that there should be improved access to services that bridge these gaps. As one caregiver wrote, "each person's case is different so stop stating if you have listed things wrong then we will help ...when the things that are wrong with a person are more serious than listed." Another wrote: "frustrated with the inflexibility of current system for the out-of-the-ordinary individual who doesn't fit the norm." Several participants cited supports for adult children with disabilities as a particular area of concern, as in the following excerpt:

After children transition from Children's Special Services into adult services things drop off drastically, yet parents are older, they are often playing multiple caregiving roles, have less income in some situations, have failing health due to aging and are just plain burned out. The individuals with disabilities needs are not less, but in fact are likely also escalating due to aging, early onset dementia, but they get less support and dollars than when they were children.

Various potential strategies could help in recognizing and addressing caregivers' needs for help with issues of system navigation, access, and information needs, as detailed below. Strategies could in some cases dovetail with initiatives around advance care planning, which be viewed broadly as a kind of 'anticipatory care mapping' occurring throughout the illness trajectory. Further, there is potential to build active strategies into existing caregiver support and education programs, an option identified by Brookman and colleagues (2011).

⁵ Including supports for aging in place and those with disabilities, mental health services, assistance with instrumental activities of daily living (e.g. transportation, housekeeping, yard care), recreational and leisure activities, social activities and day programming, and palliative care.

- **Enhance the training and education of health care and social service providers.** As one caregiver wrote: “primary health care providers should be more informed of programs available and be able to pass on the information to those in need.” General practitioners and their office staff were emphasized as being the first ‘point of contact’ for many caregivers, especially in rural areas. Greater education of these and other providers (e.g. case coordinators, home care providers) about available services (coupled with affective learning strategies) would help reduce inconsistencies and ensure that providers are forthcoming with caregivers about available services (which caregivers view as respectful) and can answer their questions. Providers could also be further educated as to the ways they can assist family members in obtaining needed information about the care recipient. One individual health or social service worker can help a caregiver enormously with ‘simple things’ that require little time (e.g., printing off information; making a call on their behalf, or helping them fill out a form). GPs and other health professionals are ‘well placed’ to identify and refer carers to specialized sources of information and advice (Colombo et al., 2011). Pilot workshops in the UK were successful at enhancing GP and other primary care workers’ knowledge about and confidence and awareness in assisting caregivers, and increasing specific actions to help caregivers (Jones et al., 2012). Greater use of formal caregiver needs assessment tools may also be helpful (see Caregiver Profile – Support Needs).
- **Develop a centralized point of access and referral** to available services (i.e., “one door of entry to the system”) and greater coordination of services. The Alzheimer Society’s FirstLink Program⁶ was noted as an ideal exemplar. A proactive, independent office could provide a consultation service to help caregivers to access services and navigate the health care system, and assist them with problems or questions (Colombo et al. 2011). Consultation participants also appreciated system navigation support obtained through the LIFE program (available to those using the managed care program “In the Company of Friends”) and Winnipeg’s Independent Living Resource Centre.
- **Develop a centralized point of information** about available services: an information ‘clearinghouse’ was suggested, though ideas varied about whether this could take the form of a “one stop shop” office (as above), **resource handbook** (e.g. expanding the Caregiver Guide), pamphlets or brochures, print or email newsletter, or Provincial Caregiver **website**.⁷ 73.2% of survey respondents supported a Provincial Caregiver website, and 56.2% a resource guide. Participants emphasized a need to ask questions and get answers, preferably speaking with a person. Information would need to be kept up to date and disseminated at a wide range of places. Some suggested a website could be organized by common issues (e.g. driving, mobility concerns, etc), utilize mixed informal and formal formats, and include a “FAQs” section and a moderated comments section where caregivers could share advice between themselves.

⁶ <http://www.alzheimer.ca/en/on/We-can-help/Information-and-referral/Information-for-health-care-professionals/First-Link>

⁷ The Canadian Virtual Hospice and Manitoba Parent Zone were cited as positive examples.

- **Consider implementing a “411 style” telephone line⁸** for guidance with system navigation and direction to resources. However, survey respondents tended to express less support (33.4%) for this option in comparison to a website or resource guide. They emphasized that a phone responder would need to be well trained, and have time to listen. Pre-recorded or automated messages would “add more stress to an already stressful life.” One participant suggested a phone line would be helpful for guidance in completing complex application forms for services.
- **Promote the development of system navigation positions and programs.** Participants suggested a designated system navigator could help guide caregivers to and through their interactions with existing resources, helping them access supportive services (e.g. a case manager, social worker, professional mentor or advocate). Reviews by Colombo and colleagues (2011) and Manderson and colleagues (2012)⁹ also appear to support this direction. In-person contact over time was emphasized by participants, who valued receiving system information and support from specialists and program providers. Designated system navigation support could also further assist in situations where care recipients are reluctant to access formal services (e.g., “they feel if family loved them they would provide all these services”). Providers could negotiate with care recipients in these instances, in order to ease the strain on the caregiver.
- **Promote the development of peer learning and support group initiatives.** Support groups can enhance caregiver knowledge of existing resources and system navigation (See Emotional Support, Peer Support, and Respite Section). As one caregiver wrote, “sometimes caregivers are just too tired or overwhelmed to be proactive and to advocate and they just settle because they don’t know what else to do or where to go. They need a support network to help them to get what they need.” Related suggestions for facilitated, ongoing peer to peer learning included ‘roundtable discussions’ between caregivers or local/regional/provincial caregiver committees.
- **Identify opportunities to disseminate information about resources.** Conferences, guest speakers, workshops, and information sessions were also suggested ways to disseminate information about existing resources. For employed caregivers in particular, Organization and Staff Development or ‘lunch and learn’ seminars were cited as potentially supportive. More broadly, the Caregiver Recognition Day event¹⁰ could be helpful, although only 31.3% believed it would be “somewhat” or “very” useful. 32.6% of survey respondents stated it would be either “not at all” or “somewhat not useful” (i.e., challenges arranging respite, time off from work, or transportation; some viewed it as a waste of money) and 36.2% were unsure. Ideally, the provision of information should move beyond a traditional classroom-format and integrate group discussion and active learning participation (Pinquart and Sörensen, 2006). Efforts to provide information

⁸ The FirstLinks system for Alzheimer’s caregivers, or “Manitoba at your Service” were cited positive examples.

⁹ In their review of the research on navigation models for chronically ill older adults, Manderson et al. (2012) reported that five of nine studies identified positive economic outcomes, two higher patient satisfaction, and five increased patient quality of life or function. Though two Canadian studies indicated little to no effect, the Canadian intervention models “were more passive” than the others they examined.

¹⁰ Caregivers also offered several suggestions for the format of the day – see Appendix D.

could be of enhanced benefit if they incorporate other elements of more traditional psycho-educational interventions (such as disease-specific information and skill development: Sörensen, Pinquart and Duberstein, 2002) or problem-solving training (Grant et al., 2002).

- **Develop ways to streamline and simplify system procedures.** A less commonly mentioned strategy, implicit nonetheless in participants' focus on system navigation, is to simplify the system, including application processes, forms and program guidelines. Caregiver stress could be alleviated if they could access services without "having to go through bureaucratic hoops and having advocates working with me." Another participant stated: "Cut all the piles and piles of paper that need to be filled out in order to get help. Quite frankly I don't have the time or energy to figure out how to fill out the forms." Simplifying the system would also help promote equity for patients without family members or whose caregivers are less empowered or system literate, who may be less likely to successfully access services as a result.
- **Identify strategies to enhance access to existing services.** This approach would be embedded within existing attempts to enhance health and social care services in the province, and (based on participant suggestions) could include reducing wait times and wait lists, enhancing access to services in rural areas, enhancing flexibility within the system (e.g. addressing the 'one issue per visit' GP policy, or expanding operating hours for existing services beyond normal working hours), broadening eligibility criteria for various programs and services, improving the accuracy of patient assessments, and addressing those people who may 'fall through the cracks' in terms of available support. Access to home care and mental health and addictions services were particular areas of concern for respondents.

Emotional Support, Peer Support, and Respite

Sustaining caregivers involves ensuring they are equipped with appropriate tools, including respite, personal counselling, and support groups (MacCourt and Krawczyk, 2012). Though most of participants' specific suggestions for support focused on meeting the needs of the care recipient (which would indirectly support them), it was evident throughout the survey and focus groups that many caregivers were also in need of more direct support. Indeed, 46.7% of respondents reported needing either 'quite a bit' or 'a lot' more help with managing the impact of caregiving on their mental and emotional well-being. 45.3% reported needing 'quite a bit' or 'a lot' more help with juggling caregiving and other responsibilities such as work and family, and 43.2% wanted this level of help with acquiring more time for themselves. Further, caregivers commented extensively throughout the surveys and focus groups on the particular stresses they faced in trying to manage multiple, competing responsibilities with care provision and maintaining their own personal life. As reviewed earlier, they described time constraints, a lack of freedom, exhaustion, getting 'maxed out,' and feeling alone or depressed (see Caregiver Profile - Challenges, Sacrifices and Contributions).

Emotional and Peer Supports

Some caregivers identified a focus on caregiver self-care supports, including accessible counselling and emotional support, support groups, and easier access to preventive and health promoting services, as an important government priority (43 comments). Others identified such supports as most helpful for them (20 comments), or as key to the meaning of being supported (10 comments). Additional survey comments appear to more indirectly imply a need for counselling and emotional supports, such as the following quotes:

I need to not feel so guilty about the time I spend away from the family as I always do.

Someone to help me not to feel sorry for myself as I just want a normal life - travelling and planning things with my husband. Which in reality will never happen.

Family members who cared for older adults with addictions spoke about the challenge involved in trying to cope with feelings of anger and guilt, and appreciated both individual (counselling) and group/peer support for caregivers available through Christie House (connected with the Addictions Foundation of Manitoba) and Al Anon. Counselling and psychoeducational interventions frequently improve caregiver outcomes in existing research (e.g., Gallagher-Thompson et al., 2000; Sörensen, Pinquart and Duberstein, 2002; Visser-Meily et al., 2005). Both professional and informal counselling may be needed, and some participants expressed that emotional support for caregivers was a particular gap in existing services.

Brookman and colleague's (2011) review of caregiver education and support programs in Canada concluded that the most promising programs provide and facilitate opportunities for peer support (e.g. small group discussions, support groups, live online chat rooms, facilitated social networking). Support groups provide informal counselling and emotional support through "a listening ear and a forum to exchange experiences" (Colombo et al., 2011, p.21). However, the effectiveness of support groups for mental health outcomes still needs to be conclusively demonstrated (Colombo et al., 2011); one study reported only minimal impact on burden and

morbidity (Hébert et al., 1994), and another reported that social support alone is insufficient to generate positive outcomes (unless combined with education, counselling or direct services: Pillemer and Sutor, 2002). Further, there may be low uptake of support groups among some groups of caregivers, such as those caring for family members at the end of life (Harding and Higginson, 2003) or who are less able to obtain respite care (Pasascrreta and McCorkle, 2000).

Nonetheless, research also suggests that peer support is generally valued by caregivers, who report positive experiences (Bank et al., 2006; Stoltz, Uden and Willman, 2004). Other studies report positive outcomes among caregivers of persons with schizophrenia (as reviewed by Wai-Chi Chan, 2011), dementia (Fung and Chien, 2002), and neurodegenerative disease (Marziali and Donahue, 2006).

Having ‘someone else to talk to’ who was experiencing similar circumstances and understands the emotional experience of providing care (e.g., frustration, guilt) was strongly emphasized by consultation participants. Interacting with other caregivers helps remind them that they are not alone, and helps make them, in one participant’s words, “feel normal.” Members of an Alzheimer’s caregiver support group (many of whom participated in one focus group) described how their group emerged ‘by accident’ as they interacted together when the care recipients were in programming. Participants expressed a need for support groups to be organized through formal mechanisms. Other participants also generally valued support groups, although they recommended that these groups:

- Be tailored or specific to the stage of caregiving and age or illness of the care recipient
- Remain informal and ‘fun’ in contrast to more formal and structured (e.g. each speak in turn; others ‘shushed’).
- Be available after hours for employed caregivers (with access to sufficient evening respite).

Support groups are also a source of learning about caregiving and system navigation. A peer mentor program (e.g. with the help of bereaved caregivers as mentors to current caregivers) could serve a similar function, and participants supported this idea when asked. Caregivers of seniors with a recent stroke perceived a peer support program (including home visits and emotional and informational support) as beneficial (Stewart et al., 1998). In a later study (Stewart et al., 2006), a telephone peer support intervention led by experienced family caregivers was reported favourably by participants.

Further, 25 comments about the Caregiver Recognition Day emphasized that the value of the event was in how it could facilitate meeting, sharing, and learning between caregivers (e.g., “examples of how someone else deals with the same situation I am dealing with”; “sharing your own concerns and stories”).

Respite Services

Almost all OECD member¹¹ countries have respite care policies, though legal entitlements to such services vary considerably, and “direct public provision and financing of respite care is uneven across countries and respite care remains scarce” (p.128). The Health Council of Canada (2012) reports that caregiver respite needs are often not met with existing services, and a national respite program (with flexibility and uncomplicated eligibility criteria) was proposed by the recent Special Senate Committee on Aging (Carstairs and Keon, 2009). Increased access to respite care for caregivers was also recommended by the Mental Health Commission of Canada (2012).

Research evidence demonstrates that caregivers appreciate respite, and it has been identified as moderately effective in improving outcomes, although the evidence base needs more development (Colombo et al., 2001; Knight, Lutzky and Urban-Macofsky, 1993; Stoltz, Uden and Willman, 2004). In one review, Jeon, Brodaty and Chesterson (2005) concluded that respite care is helpful for caregivers of those with mental illness, yet requires expanded access as well as greater flexibility in meeting the needs of caregivers. Grant and colleagues (2003) further reported that an in-home respite intervention with at-risk spousal caregivers of those with Alzheimer disease reduced some biological markers of stress, suggesting that respite “may reduce morbidity and mortality in certain caregivers” (p.62).

Keefe and Manning (2005) reviewed research on respite services for five different groups of caregivers (dementia; chronic disease; mental illness; children with complex needs; palliative care). They concluded that such services “provide optimum impact to caregivers under certain conditions - availability at times convenient for and by type preferred by caregivers, service usage beginning early in the caregiving life span and continuing frequently, regularly, and in sufficient amounts over its lifecourse.” (p.22)

When consultation participants were asked what would be most helpful, 46 comments focused on a desire for more home and/or respite care, including evening or weekend respite for social activities, self-care, doing errands, or when the caregiver is ill. Others identified enhanced access to or expansion of respite services as an important government priority (41 comments). The following excerpts are from respondents who identified access to respite as their biggest challenge:

Support from homecare during day while I'm at work but no actual respite for myself on evenings, nights or weekends.

Accessing appropriate respite on short notice when I have had surgery.

There is never a moment where I can plan to have some time alone, or that I know he is having a great time while I just have a day at home.

Other respondents connected respite to the meaning of being supported (7 comments). Further, 46 comments emphasized a need for choice over the level and extent of their

¹¹ Organization for Economic Co-operation and Development (34 member countries in Europe, North America, and around the world – including primarily more advanced but also emerging economies).

involvement in caregiving, including the choice to have a break, to stop altogether, or pursue other activities. For instance, it means having “options as to how, when, how long and what type of services I can provide” and to have time away for themselves, particularly if one is ill, stressed, exhausted, or becoming ‘burned out.’ The following quote is illustrative:

Being able to pass off some tasks when you are ill or stressed. I work full time and if I am sick and stay at home, the home care people expect you to cancel the worker. Sometimes it would be good to have them continue to care for the person so you can just rest.

Increased access to publicly funded respite was viewed as helping caregivers maintain their well-being, for instance, through continuing their own social activities/connections (e.g. “I want a social life”). This helps them combat the isolation that can develop, as expressed by one respondent: “I get tired and drop certain activities. Caregiver tunnel vision results from thinking about someone much of the time.” Another caregiver wrote: “often, there is little time and energy for caregiver to pursue activities other than work and caregiving.” Finally, another participant emphasized “the importance of implementing an accessible free respite program to prevent burnout, depression, and anxiety attacks.”

Participants in one focus group expressed that health authorities should have increased capacity to respond more quickly to caregiver strain and burnout – when a caregiver expresses a need for help, there should be immediate response, whether through respite, or placement assistance and transfer, or admitting a care recipient to the hospital if necessary. As one participant noted: “when a caregiver says they’re done, they’re done, and you don’t have the luxury of waiting.” A caregiver emergency needs to be recognized as a serious issue within hospitals in particular, rather than a “social” concern or “just stress.” When the balance has been tipped for the caregiver, there are safety issues for both the caregiver and care recipient.

In-home services were appreciated for helping the caregiver accomplish particular tasks (e.g. doctor’s appointment, errands, etc) for 1-2 hours; out of home services provide an actual break or escape that was also appreciated. However, for some participants, the time provided for in-home respite may be insufficient; others desired more options that would allow them to get away for a weekend or extended time or to have respite overnight (e.g., “would like to be able to get out for more than a couple of hours, maybe a weekend”). There was a concern that in-home respite care requires enhanced flexibility and responsiveness to the needs of the care recipient and caregiver. For instance, caregivers should not be necessarily required to leave the house if they wish to rest or sleep in their home. Further, policies appear to prohibit workers from taking the care recipient out in a vehicle or for coffee. Respite workers may also need more training about those with complex care needs: one participant spoke of her concerns about a worker who had never before cared for someone with dementia and was visibly afraid of being left alone with the care recipient. A variety of other concerns with home care more generally were raised (See Respect and Recognition in Health and Social Care Systems), including inefficiencies, quality concerns, and problems with particular workers.

In addition, participants noted that respite can be difficult to arrange or access, a challenge of system navigation (e.g., playing ‘telephone tag’; needing to book six months in advance; ‘paperwork nightmare’). Some participants also noted that respite involves out of pocket/per diem costs that may limit accessibility for particular families. It was also expressed

that there should be an increase in residential respite beds (and staffing), especially in rural areas such as Brandon.

Participants valued respite that involved the care recipient being taken out of the home. Day care programs were acknowledged as an important respite with added benefits for care recipients (social interaction). However, they are not helpful for all caregivers, unless reluctant care recipients can be convinced to attend, or transportation is easy to arrange. There may also be restrictions for clients with addictions.

Specific opportunities to support caregivers through both emotional and social support and respite were identified as the following:

- **Expand access to adult day programs**, with more frequent access for a longer term, to specialized programs. Enhance the ability of adult day programs to meet the individual needs of caregivers and care recipients, through **enhancing service flexibility and program specialization**.
- **Expand and strengthen both in-home and residential respite** (e.g. reduced costs, more frequent opportunities to access). Simplify the application process, and enhance the ability of respite services to meet the individual needs of both caregivers and care recipients, through **enhancing service flexibility**.
- **Consider developing or facilitating educational or training initiatives** targeted to Emergency Room and other primary care providers, designed to enhance their awareness of the serious, emergent nature of caregiver burnout.
- **Enhance the capacity** of voluntary sector and other agencies to offer **professional counselling** at low costs for caregivers
- **Enhance the capacity** of voluntary sector and other agencies to organize and facilitate **support groups** or **peer mentor programs** for caregivers.
- **Design the Caregiver Recognition Day** event to facilitate networking opportunities between caregivers.

Respect and Recognition in Health and Social Care Systems

Supporting caregivers includes recognizing (a) their strong need to feel secure in knowing that their family member is safe and well cared for. This is particularly the case during periods of acute illness or injury, or in situations of life-limiting or terminal disease. In addition, caregivers also have strong needs to (b) be treated respectfully in health and social care systems, and (c) to provide meaningful feedback on the quality of care. Consultation responses indicated that recognizing and responding to these needs within existing health and social care systems can help reduce caregiver burden and stress. For instance, 42 responses to a question about the “biggest struggle” described caregivers’ concerns about the quality of care received by the client. This was also a theme encompassed within respondent comments about strengthening health care services (e.g., re: government priorities – 166 comments), as well as the majority of focus groups.

First, caregivers want to **trust service providers to safely care for their loved one in an appropriate manner**. They view a key part of their role as monitoring the care received by the client, which requires “constant vigilance” and advocating on behalf of the care recipient and their needs within service systems. When participants did not trust health and social care services, this enhances their stress and anxiety and compels them to advocate. Some felt they could not leave the care recipient alone with institutional staff; others believed health care providers lacked appropriate knowledge about the care recipient’s condition. As noted in the Caregiver Policy Lens (MacCourt and Krawczyk, 2012), sustaining caregivers involves addressing their “need to feel that they can trust service providers,” necessitating efforts to facilitate positive relationships with providers and the continuity of care (p.29). Further, a system that supports and sustains caregivers ensures that “service providers have the appropriate knowledge, skills and supervision to provide sensitive and competent care to care recipients” (p.31).

Caregivers were frustrated when they repeatedly had to “tell the story” of the care recipient’s needs to different professionals involved in their care (or to train some direct care workers themselves). This is exacerbated when there are many different providers, inconsistent providers, or when information is not communicated between providers (e.g., providers do not read patient charts).

Consultation participants were particularly concerned about the quality of hospital care (medical mistakes and lack of basic medication checks in-hospital; lack of response to alarms in dialysis unit, etc.) and personal care homes (e.g. lack of staff empathy; poor standards of care; poor quality food; lack of social and mental stimulation). Some expressed frustrations at having to do the work of paid staff within in-patient settings (“doing things that people are being paid to do” such as bathing etc). One participant noted that though hospital stays for the care recipient should be a respite for home-based family caregivers, they actually require a good deal of monitoring and advocacy work. However, caregivers may be too exhausted to perform this role, or may resent it because it takes time away from their ability to meet other care recipient needs. As another participant stated, “too much energy is wasted fighting over simple things.” One participant described a grieving family who had to ensure that hospital staff adhered to doctor’s orders for pain management at the patient’s end of life. This work was an added burden for them during this difficult time.

Concerns about home care included, for example, inconsistency of home care workers, poorly trained workers or those unable to adapt to the client's circumstance or needs, workers arriving late or not all (with little or no notice), workers not doing the jobs they were supposed to, and the lack of time that workers are assigned to complete tasks ("15 minutes to bathe a person who has restricted mobility?"). Two further quotes are illustrative:

It was difficult to have workers who took advantage such as washing their personal laundry at dad's apartment, turning the heat way up... I came over early one day and the Health Care Aide was walking around in boxer shorts and t-shirt... or spending their time on a smartphone.

At one point ... home care did not call us for almost six hours and the person who did the bath did not even notify the supervisor they couldn't get in. I found my father in law at the bottom of the staircase full of urine after a heart attack. He fell down two flights of stairs. Sometime they would not even show up, would not call and sent temporary help from agencies who would just lay down and sleep on the couch their whole shift and not take care of my step father.

Secondly, **caregivers wanted to be treated respectfully in their interactions with health and social care professionals.** Participants described respect as conveyed through interactions and communications – that they are treated kindly, fairly, politely, patiently, sensitively, without judgement, in a way that respects their dignity and unconditional worth as a person. Disrespectful interactions were described as those in which they feel themselves or their concerns are 'dismissed' or 'belittled' by service providers, as opposed to being heard and responded to. Indeed, the meaning of being recognized (19 comments), respect (51 comments) and support (16 comments) were linked by respondents to having their knowledge, concerns, and input valued by others (e.g., professional providers). Caregivers generally desired to be viewed as an expert in the patient's care needs, and to have their concerns and viewpoints heard and responded to by others. This recognition could mean, for instance, being treated as "someone who needs to be informed" by service agencies, or "having a say in the decision-making" or care planning. The following excerpts are illustrative:

That medical staff listen to me if I have suggestions or comments about my husband's condition as I know him better than anyone. Medical staff usually listen to me and I really appreciate that.

Professionals in the field need to listen and really hear the family of the person that is being cared for as well as listen to the person. Most of the time you are made to feel incompetent and/or an inconvenience.

The system more often than not, does not ask caregivers what their experience is, whether they can take on the responsibility that health care expects them to take on, or whether the caregiver has needs that have not been accounted for.

In contrast, caregivers described the stresses involved in communications and interactions that conveyed for them a lack of respect, compassion, sincerity and professionalism. One focus group participant tearfully explained how her husband could die at any time during dialysis because of a heart condition. On one occasion, she arrived for his dialysis and was screamed at by a nurse for being early, though her husband was in a bed at that time. The nurse then called security on her (and never apologized for her error). The incident has upset this caregiver so much that she is troubled to even see the nurse on the unit. Another caregiver with a nursing background took her family member, who had a history of heart problems, to the Emergency Room when she was having chest pains, and was told sternly "she's gonna have to wait her turn!" Lastly, another caregiver spoke of struggling to access the incontinence supplies she

needed for her husband. She was sent diapers instead of the incontinence pads he needed, and the company never returned at the agreed-upon time to retrieve them. Following this, she was told by home care that she would have to meet with an incontinence specialist because she had been using too many diapers.

Thirdly, caregivers wanted **meaningful opportunities to provide feedback** about the quality of care and their health and social care experiences. Several participants expressed a fear of repercussions for the care recipient, if they advocated in either home or residential settings. For instance, one participant was yelled at for expressing her concern about the care in a personal care home. Another stated that “I’m assertive in my own life, but I fear retribution for my family [if I’m too assertive on their behalf].”

Other caregivers do not feel heard when they provide input or feedback, which they perceive as disrespectful. For instance, one family member believed she was not taken seriously when she wanted to have a staff member held to account for a disrespectful interaction. A hospital representative she met with told her: “well... I was not there” and the hospital’s patient care representative told her: “I’m not really an advocate.” Another respondent wanted her input on the care recipient’s behalf to be respected “without having to be so forceful. I find myself having to be a ‘squeaky wheel’ at almost everything in regard to his care.” Finally, another participant tried to provide feedback to a personal care home through a patient comment line (and also through Protection for Persons in Care Office) – though told in both cases that what she had observed in the home should not be occurring, no change was made to fix the problem.

To enhance family caregivers’ experiences and interactions with health care services, several possibilities were raised:

- **Continue attempts to ensure that basic standards of patient care** are met (at home, in hospital or residential care settings), and to maintain quality in, for instance, personal care homes and home care.
- **Enhance the training and selection of health care and social service workers, as well as their evaluation and monitoring.** Enhanced provider awareness and understanding of and sensitivity to family caregiver experiences, and a related “culture” or “attitude” shift may help ensure that services are delivered in a way that supports caregivers. Having supportive professionals who understand the emotional experiences of caregiving and have knowledge of particular care recipient conditions was emphasized by participants. Educational and training initiatives for health and social service workers should incorporate strategies for affective (i.e., attitudes, values) learning in their design. Particularly important targets for training include health and social care professionals who represent important points of access to health and home care systems, such as General Practitioners, Case Coordinators, and Emergency Room staff.
- **Develop stronger accountability and feedback mechanisms** for service providers, agency managers and directors, when basic rules and standards of patient care are violated. Incidents should be documented. Workers should be protected when they hold another worker to account for poor care or disrespectful communications.

- **Consider developing or facilitating appointed professional advocate** or system navigator roles (See System Navigation). Provide families with a written list of advocates.
- **Solicit caregiver input into and feedback about patient/resident care;** ensure that complaints about care are heard and responded to. For example, patient relations staff could proactively seek out patients/caregivers to talk with them before complaints might arise; there could be periodic review through an independent organization that actively solicits family feedback in an anonymous or confidential way. A Community/Family experience and solutions-seeking council could “honestly and candidly record the experiences of those in care, and their families.”
- **Support initiatives to enhance service coordination and communication of information** between different providers and departments, including consistency of provider and of information and documentation. For example, respect is conveyed through ensuring the development of protocols “between agencies and workers so that caregivers do not have to repeat information over and over” (MacCourt and Krawczyk, 2012: p.26). One intervention designed to enhance the cooperation and coordination of services for terminally ill cancer patients (thereby enhancing the quality of end of life care) was successful at improving the quality of life of home-based family caregivers (Smeenk et al., 1998).

Financial Recognition and Support

Financial support for caregivers is a key component of a proposed National Caregiver Strategy (Carstairs and Keon, 2009), and is further supported by the Mental Health Commission of Canada (2012). A 2011 Pollara poll¹² indicated that 88% of Canadians perceive that providing care or support to a family member would negatively affect their financial situation, with 57% envisioning a “major” negative impact. Dore and Romans (2011) report that 27% of family members providing care for those with mental illness reported lost income, and 29% reported major financial costs of care provision. An estimated 40% of caregivers incur out-of-pocket expenses (Fast and Keating, 2001; Health Council of Canada, 2012), and this was confirmed among survey respondents in these provincial consultations. Additional analyses reported by Fast, Eales and Keating (2001) suggest that existing policies, programs and services (e.g. user fees, low-ceiling means tests) “probably have the greatest potential to affect caregivers’ out-of-pocket costs,” because family members often absorb health care and other expenses for low-income seniors (p.47).

A need for financial support was consistently expressed in both the survey and focus groups. 32.4% of survey respondents stated needing either “a lot” or “quite a bit” more help managing the impact of caregiving on their personal finances. Addressing the financial burdens of family care provision was also the second most commonly recommended government priority (127 comments). Financial concerns were also identified for some as their “biggest challenge” (21 comments) and financial support as the most helpful program or service (30 comments), as well as being an important aspect of caregiver recognition (33 comments) and support (22 comments).

Financial strain adds to the stress of care work. This includes out-of-pocket expenses such as medications, ambulance trips, supplies and equipment (equipment loans or rental programs may be helpful), travel costs (gas, hotel, etc), home renovations, and in some case, certain services for the care recipient (e.g. dental care). In the following quotes, respondents describe the effects:

Finances. My husband and I will never retire together. He lives in a care home 2 blocks from where I live alone. I am unable to save money for my retirement as his money all goes to the care home. Extra expenses are constantly being incurred.

Financially it was very hard. I had to draw all my life savings when taking care of my mother...there should be more compensation for caregivers in my position because I was unable to work the hours needed to cover my bills...The added stress is not healthy, as I’m dealing with losing my mother and rebuilding my financial position.

Financial assistance, I was recently told we are just floating on what I make and I can’t even pay most of my bills regularly, I worry about rent and feeding my family. Even using food banks is barely helping.

Trying to juggle the family finances while still making sure that my husband gets the best treatment that is possible for him has been very hard. Finding out that he needed daily injections that cost \$1,200 a month was almost enough

¹² http://www.cancer.ca/canada-wide/about%20us/media%20centre/cw-media%20releases/cw-2011/caregiver%20poll.aspx?sc_lang=en

to put me over the edge and yet I didn't want to burden him with my worries... Caregivers DO NOT need this kind of stress!

Those caring for adult children with disabilities were also particularly concerned about the ongoing and long-term financial well-being of their adult child.

Participants reported feeling recognized through the Caregiver Tax Credit, which they appreciated, as in the following quote:

Being given a small Caregiver Tax Credit this year made me feel as if at least someone in CCRA or Health Authority acknowledges/realizes what costs could be involved to the health care system if I was not able to be a caregiver.

The British Columbia Law Institute (2010) praises Manitoba's government for making the refundable tax credit available to caregivers that do not have a familial connection to the care recipient; for allowing caregivers to claim the credit for multiple care recipients; and for a definition of caregiver which focuses on the labour involved rather than the dependency of the care recipient.

Yet, when some caregivers learned they were ineligible for the tax credit, they felt unrecognized, as in:

I just recently started to claim the caregiver amount on my income tax, but my mother was over the net income amount by \$200.00 and I didn't qualify for any deduction. So much for government recognition of caregivers¹³.

There was also considerable uncertainty about system navigation to obtain the credit (e.g., whether care recipients were required to be home care clients; whether and how one needed to log caregiving hours: "record keeping is too much"). Colombo and colleagues (2011) note that tax credits "can be complex for those most in need" of claiming them (p.132), and Keefe and Fancey (1999) suggest eligibility restrictions often mean that tax credits do not reach most caregivers.

Respondents suggested a wide range of forms of financial assistance and compensation for their time or out-of-pocket expenses, especially for those who have had to quit work to provide care, or rural and low income families. Specific strategies are noted below:

- **Consider the development of targeted grants, discounts, and assistance programs for out of pocket expenses.** This could include parking passes, financial grants (e.g. for equipment or medications), and gas discounts or transportation cost assistance (e.g., a medical appointments refund/assistance program for those outside Winnipeg).
- **Consider a caregiver allowance or subsidy¹⁴** such as recommended by Keefe, Légaré, and Carrière, (2007). Slightly less than half of OECD countries currently have a direct

¹³ Such data represent participants' experiences and perceptions; however, the Primary Caregiver Tax Credit is not income tested. Accurate information about the tax credit could be more widely disseminated. For more information on the Caregiver Tax Credit, see: <http://www.gov.mb.ca/finance/tao/caregiver.html>

¹⁴ "Nova Scotia is the only Canadian jurisdiction that provides a direct monthly government subsidy to family caregivers. We encourage the governments of BC and Canada to similarly explore income replacement measures

payment for carers, such as a caregiver's allowance (Colombo et al., 2011). One participant explained how this would enhance his capacity to provide care: "If I could afford to retire, or take time off, I would in a heartbeat to support my parents without being given a nickel but financially I am not in that position hence it is then that I think some kind of 'caregiver subsidy' needs to be considered." Colombo and colleagues (2011) note that the policy "trade-off in designing a carer allowance is generally between providing a token recognition to a broader group of carers, including some involved in low care intensity, and providing more meaningful support to a narrowly targeted subset of carers. Most countries have opted for the latter" (p.134). Keefe and Rajnovich (2007) noted that financial compensation has not been a popular direction in Canada, in part because of jurisdictional issues related to home care.

- **Expand dissemination of information about the provincial and federal caregiver tax credits** (and other programs such as the Compassionate Care Benefit, as recommended by Williams et al., 2010) through education and/or awareness activities to the wider public, providers, and financial professionals.
- **Simplify the information and the application process** for the Caregiver Tax Credit, such that it requires less time and effort (e.g. clearer, more understandable directions and application forms; perhaps on online registration process). The current process may overwhelm some caregivers, who may give up ("it's just another system to navigate; I'm navigating the medical system, that's all I can do"). A telephone helpline could provide guidance to caregivers wishing to apply for the credit (See System Navigation).
- **Consider increasing the deduction/credit amount of the Caregiver Tax Credit¹⁵ and/or broadening eligibility criteria.** For instance, some caregivers were unable to apply if they did not co-reside with the care recipient, were a secondary (not a primary) caregiver, or if the care recipient resided in a personal care home. Participants noted that some of these currently ineligible caregivers may still contribute substantially to care provision and this should be recognized. For instance, when a care recipient enters a personal care home, the "demands on the caregiver do not decrease, only change"; another respondent added "you still have many different caregiving duties that cost you time and money."

for low-income family caregivers through the creation of a caregiver allowance payable into retirement and during the years of the life course when a caregiver maintains paid employment (British Columbia Law Institute, 2010: xi)

¹⁵ "In Manitoba and Quebec the caregiver tax credit is worth more than in other provinces ... but even these higher numbers may be low in relation to the value of the labour of family caregivers in terms of lost employment earnings, loss of freedom and compromises in their own health and the corresponding benefit to other family members, the health care system and the province" (British Columbia Law Institute, 2010: p.77).

Employment Recognition and Support

A 2011 OECD report stated that “policies which reduce the dual pressure from work and care for employed caregivers” such as family leave and flexible work hours “might improve their employability, making caring a viable option for more potential carers” (Colombo et al., 2011: p.122). For instance, these strategies appear to have a positive effect on the likelihood of employment retention for women (Pavalko and Henderson, 2006). The need to support caregivers’ ability to participate in paid employment has been identified as a broader human rights issue (Ontario Human Rights Commission, 2006).

The following participant identified managing work and caregiving responsibilities as her biggest struggle, adding:

Often there is a belief that caregivers may be older and at home during the day. Of course these people need support. However there are many of us who work full time and caregive all the hours we don’t work. We also need support and maybe even more support as we caregive AND work outside the home, sometimes for long hours.

Indeed, the majority (59.7%) of survey respondents worked in full-time paid employment; an additional 13% worked part-time and 2.9% were on temporary leave. A small proportion (3.6%) was unemployed (we do not know whether they gave up work to provide care) and 20.1% reported being retired.

There was a moderate but consistent focus on a need for supportive employer policies and practices throughout the survey, where it was articulated in responses about caregivers’ biggest challenge (5 comments); most helpful program or service (15 comments); suggested government priority (43 comments); and as key to being respected (18 comments), recognized (23 comments), and supported (15 comments).

Provincial civil servants in three caregiver focus groups (n=33) were asked specifically about the particular employment practices and policies they experienced as supportive or unsupportive. We further asked them to complete a targeted survey questionnaire (for full details see Appendix B). Findings from those focus groups, combined with the full survey and other focus groups were summarized and presented to the Seniors and Healthy Aging Secretariat. Many of the findings further align with those from a recent survey of 81 employed caregivers in Winnipeg (Sutton and Krawczyk, 2012).¹⁶

Employed caregivers feel torn between their employment and family responsibilities, and expressed sentiments such as: “we’re not getting cared for”; “we are all trying to balance care for everyone and we are not caring for ourselves”; and “we are all trying to cope.” In a recent survey of 81 employed caregivers in Winnipeg: Sutton and Krawczyk, 2012 only 24.2% felt they could continue in their caregiving role without additional supports.

¹⁶ The *Employed Caregiver Survey* was developed and piloted by family living educators and a program specialist in aging, at the University of Wisconsin. For more information: <http://www.extension.org/pages/27975/employed-family-caregiver-survey>. The survey instrument was adapted with permission by Wendy Sutton of the Manitoba Caregiver Coalition and Marian Krawczyk, Project Coordinator of The Caregiver Toolkit.

Employed caregivers reported having to at some point miss work due to their caregiving responsibilities (relying most frequently on vacation time, flex time or sick leave to do so). They also reported having to leave work early, being unable to focus while at work, needing to respond to calls or emergencies during work hours, missing days of work, and using breaks or lunch times to arrange for caregiving services. In addition, some reported having considered leaving work entirely to provide care.

Respect and recognition of caregivers in the workplace includes recognition and support of their needs for various accommodations in order to respond to care recipients and provide care (such as attending medical appointments, emergencies, etc.). Consultation participants did not want their caregiving role to have negative repercussions for their employment. When caregivers believed their employers minimized the demands of care work or assumed they were trying to “cheat the system,” they felt disrespected and unrecognized. Those who cared for elderly parents further expressed a desire to feel as valued as parents of small children in the workplace (e.g. who have access to supports such as parental leave). Indeed, in contrast to widely available parental leaves for children, paid leave for carers is only available in about half of OECD countries, often limited to less than one month or to situations of terminal illness (Colombo et al., 2011).

Caregivers described how, when their needs are not recognized and supported (e.g. through granting requests for this leave or providing options for employees to make up missed time), their stress is enhanced, with potential implications for productivity, sick time, stress leaves and employee turnover. The following excerpts are illustrative:

I asked my employer if it would be possible to work from home for a while following my husband’s discharge from hospital...He still required some help at home post-discharge. I have the type of job that would have allowed me to do quite a bit of my work from home. My employer would not accommodate me. This greatly added to my stress levels and worry.

I would also like to be recognized by my work so I don’t get attitude from my boss when I need to take time to accompany my Dad to an appointment. I work lots of unpaid overtime and always complete my work. It’s the negative attitude I receive when I ask for flexibility that makes the caregiving more difficult.

When employers are understanding and supportive, caregiver stress is reduced, and employee loyalty and commitment is enhanced. Positive comments included, for instance:

I have very much appreciated my manager understanding when I have to leave the office to offer my mother assistance. I guess in my mind that is sufficient recognition.

Eligibility criteria and the application process for family leave were viewed as overly restrictive. For example, family members¹⁷ must be co-resident (i.e., care for a grandmother or friend would not be recognized). Caregivers may find it difficult to use family leave for emergency situations or for medical appointments. The application process adds to caregiving stress, because it involves considerable paperwork and requires employees to explain why they do not have ‘a back-up plan’ (“the form is heartless”). Questions must be answered using very specific wording (“not an easy process”). As one participant wrote: “I pretty much have to

¹⁷ Indeed, problems with the definition of family member were noted in general, because these tend to vary between government departments, or between governments and employers.

disclose my parents' personal information that in my opinion is illegal, let alone inappropriate." Then there may be several weeks of waiting to know whether the leave is granted (until then, it is indicated as vacation leave). Though some participants described their managers as supportive, others experienced challenges getting family leave requests approved, particularly where managers lack appropriate knowledge of the policy, or do not understand caregivers' needs.

When employees cannot access family leave or the five days are insufficient, they seek other ways to meet their caregiving responsibilities. Participants desired workplace flexibility that would enable them to meet their caregiving responsibilities, including expanded options for flexible work hours, flex time, location (e.g. working from outside of the office), or using overtime or banked hours. Sample excerpts include:

It would mean so much to me to be able to be with my father when he needs me - and to be given freedom to make up the lost time at work - rather than constantly using my vacation leave.

Supportive assistance to have work time managed outside of regular hours for caregiver or to use different types of leave to allow time off of work to attend to caregiving duties.

A flexible work schedule for times that I needed to be at home and at hospital with dad I have used up my vacation time as well as family leave If I could have worked part time and then had the option to resume full time and not jeopardize my pension

Flexible working hours in particular have demonstrated potential to lower the chances of reduced hours of work for carers, while helping them meet their caregiving responsibilities (Colombo et al., 2011). Other forms of flexible work also have potential, including allowing caregivers to "use leave on a part-time basis or returning to work part-time" (p.125). Some employees in the consultation focus groups used their personal appointment time to attend appointments with the care recipient, but the policy was recently changed such that employees must use their sick leave for personal appointments. Further, this time is usually only for 'medical' appointments (rather than physiotherapy, optometrist, etc). Some caregivers also use vacation time, though this often cannot be used for emergencies – requires, e.g., 3 days before approval. Further, relying on this option means that some caregivers are afraid to schedule their vacation time, in the event that they need it for caregiving emergencies. Some employed caregivers occasionally find it easier to call in sick/use their sick time, but are frustrated that they must compromise their own integrity to provide care ("don't want to lie").

There were reports of considerable variation between departments and managers regarding interpretations and response to caregiver requests for family leave and other accommodations. As one participant stated: "I would like a clear policy rather than relying on my current flexible manager and on good will." Though some participants felt supported, others described unsupportive reactions from managers, supervisors or directors, and felt intimidated, or always having to justify their situation. One participant was asked by Human Resources when she was going to put her mother in a personal care home; on another occasion a manager tore up her application form in front of her. Another participant expressed how, when her mother was admitted to the hospital with a stroke, "I was contacted by HR and asked why someone else couldn't be there in my place - I felt interrogated." Several participants were also concerned that coworkers may perceive them as unfairly getting "time off" while leaving them to pick up the extra work. Some did not disclose their caregiver status at work in part due to this concern.

Supportive workplaces were described as those in which managers demonstrate empathy through granting requests for more flexible work arrangements, family leave or other accommodations. This can also involve having broader, supportive policies (Mental Health Commission of Canada, 2012). Points of note are summarized below:

- **Clarify family leave policy and practice:** ensure that employees within and outside the civil service can consistently use family related leave for caregiving purposes. Consider an increase in number of days. Employer policy regarding family leave could be made clear and consistency within departments promoted. Consider having an HR specialist who can advise managers and supervisors. Enhance the sensitivity of the wording of questions on family leave forms.
- **Consider expanding paid caregiver leave initiatives/income replacement programs** (e.g., modeled after parental leaves or the Compassionate Care Benefit). However, another respondent emphasized the potential inequity in this approach: “Not everyone works therefore not everyone can tap into this resource.”
- **Explore options where possible to support greater work flexibility within the civil service and more broadly**, including expanded options for flexible work hours, flex time, location (e.g. working from outside of the office¹⁸), or using overtime or banked hours.
- Consider offering **caregiver support workshops or seminars** within the workplace. This may be helpful for delivering information about system navigation in particular (See System Navigation), as well as other information about caregiving. For example, one worksite-based internet multimedia program for family caregivers of persons with dementia (educational information, cognitive and behavioural skills training) reduced depression, anxiety and stress, and enhanced self-efficacy (Beauchamp et al., 2005). Facilitated support groups are another option (See Support Groups).
- **Promote training and awareness-raising within the workplace.** Sensitivity training, awareness-raising, and ongoing educational strategies could enhance workplace recognition of and compassion for the experiences and needs of family caregivers, among managers, supervisors and non-caregiver employees (e.g., blast emails; workplace roundtable dialogues; lunch and learns). Organizational mandate and leadership could promote a culture of the civil service that is more sensitive to caregivers. This could involve targeted hiring strategies; awareness-raising/training workshops, and organizational enforcement of the culture. The Caregiver Recognition Act could be a useful tool in this regard. Caregiver Recognition Day could celebrate employers who set a high standard for caregiver support.
- **Develop provincial labour legislation, employment standards or workplace health and safety policies** “that would ‘compel’ employers to consider more flexible workplace

¹⁸ One participant suggested that if managers could access \$ for a VPN account for employees with caregiving obligations, for certain periods of time, and if this \$ did NOT come out of the department budget, that this would be helpful (to allow an employee to work from a laptop and have access to files).

arrangements to accommodate elder care as well as child care responsibilities of their employees.” Labour legislation could be used to expand entitlements to paid family leave days (Carstairs and Keon, 2009). Employment legislation could specifically protect caregivers from losing their job or being discriminated against while providing care to a family member.

Conclusions

Findings from these consultations must also be interpreted with the knowledge that particular groups of caregivers may be under-represented in the findings. For instance, caregivers of disabled or ill children represented a small proportion of participants. There is also a relative lack of research evidence regarding which interventions, programs and policies are most effective in supporting these caregivers. Similarly, “interventions with caregivers to chronically ill patients remain undocumented and not systematically researched” (Glasdam, Timm and Vittrup, 2010: p.22). Finally, caregivers who are members of minority groups (including immigrants) are not well represented in the findings, or again in the research evidence more broadly. Developing policies and services to recognize and support these groups of caregivers should be done in close partnership with existing agencies and community groups that work with and include the viewpoints of these groups of caregivers.

The opportunities identified within this report align well with the Caregiver Recognition Act’s general principles. Several illustrations of such points of alignment are provided below:

- System navigation professionals could negotiate with care recipients to encourage them to access formal services if this is needed by the caregiver, which **recognizes and respects the family relationship** (Principle 1).
- Public and provider awareness-raising activities could **promote the recognition and support of caregiver contributions** (Principle 2).
- Activities to facilitate self-identification and the identification of caregivers by individual providers (e.g. needs assessment tools) would **acknowledge caregivers as individuals with their own needs** (Principle 3).
- Expanding and strengthening respite services and day programs would allow caregivers to **participate in activities outside of their caregiving role and enhance their well-being** (Principle 4).
- The development of mechanisms to solicit anonymous caregiver input and feedback regarding patient/resident care would **acknowledge their unique knowledge and experience** (Principle 5).
- Enhancing the training of health and social care workers would help ensure that caregivers are **treated with dignity and respect** (Principle 6).
- Expanding the Caregiver Tax Credit and/or broadening eligibility criteria would help caregivers **achieve greater economic well-being and sustainability** (Principle 7).
- Promoting the development of no/low cost, specialized support groups or peer mentor programs for caregivers in local communities, at various times and with available transportation, would reflect the concepts of **timely, responsive, appropriate and accessible supports** (Principle 8).

Just as ‘multi-component’ interventions (e.g. those that combine education, skill-building, problem-solving, counselling, and social support) have proven to be the most successful at improving caregiver outcomes in existing research (Cameron, Massuch and Wishart, 2008; Meier Hamilton, 2001; Zarit and Femia 2008), a ‘multi-dimensional’ approach is needed in policy and practice. Further, implementing the Caregiver Recognition Act will require not only new strategies and policies, but a reflection on existing strategies and policies. In both respects

we recommend the use of the Caregiver Policy Lens framework¹⁹ (MacCourt and Krawczyk, 2012).

In conclusion, we would like to express our appreciation of the 400 caregivers who contributed their valuable time and energy towards these consultations. Their input will help inform the development of targeted short and long-term strategies to better recognize and support caregivers through practice, programs, and policies in Manitoba.

¹⁹ With potential revision to ensure its feasibility for caregivers of those who are not older adults.

References

- Albert, S., Moss, M., and Powell Lawton, M. (1996). The significance of the self-perceived start of caregiving. *Journal of Clinical Geropsychology*, 2(3), 161-174.
- Bank, A.L., Arguelles, S., Rubert, M., Eisdorfer, C., and Czaja, S.J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist*, 46(1), 134-138.
- Beauchamp, N., Blair Irvine, A., Seeley, J., and Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist*, 45(6), 793-801.
- British Columbia Law Institute (2010). *Care/Work: Law reform to support family caregivers to balance paid work and unpaid caregiving*. Canadian Centre for Elderly Law, Vancouver, B.C.
- Brookman, C., Holyoke, P., Toscan, J., Bender, D., and Tapping, E. (2011). *A Guide to the Promising Practices and Indicators for Caregiver Education and Support Programs*. Markham, ON: Saint Elizabeth.
- Cameron, M., Massuch, L., and Wishart, D. (2008). *Research-based recommendations for effective caregiver interventions*. Michigan Dementia Coalition, University of Michigan.
http://www.dementiacoalition.org/pdfs/Recomm_Eff_CG_Interventions_3_6_08.pdf
- Canadian Institute for Health Information. (2010). *Supporting Informal Caregivers - The heart of home care*. Ottawa, ON: CIHI.
- Carstairs, S., and Keon, W.J. (2009). *Canada's Aging Population: Seizing the Opportunity: Special Senate Committee on Aging Final Report*. Ontario, Canada.
<http://www.parl.gc.ca/Content/SEN/Committee/402/agei/rep/AgingFinalReport-e.pdf>
- Colombo, F., Nozal-Llena, A., Mercier, J., and Tjadens, F. (2011). *Help Wanted? Providing and paying for long-term care*. OECD Health Policy Studies, OECD Publishing.
- Dobrof, J., and Ebenstein, H. (2003). Family caregiver self-identification: implications for healthcare and social service professionals. *Generations*, 27(4), 33-38.
- Dore, G., & Romans, S. (2001). Impact of bipolar affective disorder on family and partners. *Journal of Affective Disorders*, 67 (1), 147-58.
- Duxbury, L., Higgins, C., and Schroeder, B. (2009). Balancing paid work and caregiving responsibilities: a closer look at family caregivers in Canada. Victorian Order of Nurses Canada: Ottawa, ON.
http://observgo.quebec.ca/observgo/fichiers/37864_PSOC-9.pdf
- Ewing, G., and Grande, G. (2012). Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliative Medicine*, published online before print March 26, 2012. Doi: 10.1177/0269216312440607

- Fast, J., Eales, J., and Keating, N. (2001). Economic Impact of Health, Income Security and Labour Policies on Informal Caregivers of Frail Seniors. Catalogue No. SW21-67/2001. http://www.rwmc.uoguelph.ca/cms/documents/73/Fast_1-79.pdf
- Fast, J., and Keating, N. (2001). *Informal Caregivers in Canada: A Snapshot*. Report to the Health Services Division, Health Policy and Communications Branch, Health Canada. http://www.rapp.ualberta.ca/en/Publications/~/_media/rapp/Publications/Documents/Informal_caregivers_in_Canada.pdf
- Feinberg, L.F., Wolkwitz, K., and Goldstein, C. (2006). *Ahead of the Curve: Emerging trends and practices in family caregiver support*. American Association of Retired Persons, Washington, D.C. http://www.pascenter.org/publications/publication_home.php?id=380
- Fung, W., and Chien, W. (2002) The effectiveness of a mutual support group for family caregivers of a relative with dementia. *Archives of Psychiatric Nursing*, 16(3): 134–44
- Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., and Thompson, L.W. (2000). Impact of psychoeducational interventions on distressed family caregivers. *Journal of Clinical Geropsychology*, 2000, 6(2): 91–110
- Glasdam, S., Timm, H., and Vittrup, R. (2010). Support efforts for caregivers of chronically ill persons. *Clinical Nursing Research*, 19(3), 233-265.
- Grant, I., McKibbin, C.L., Taylor, M.J., Mills, P., Dimsdale, J., Ziegler, M., and Patterson, T.L. (2003). In-home respite intervention reduces plasma epinephrine in stressed Alzheimer caregivers. *American Journal of Geriatric Psychiatry*, 11(1), 62-72.
- Grant, J.S., Elliott, T.R., Weaver, M., Bartolucci, A.A., and Newman Giger, J. (2002). Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke*, 33(8), 2060-2065.
- Guberman, N., Nicholas, E., Nolan, M., Rembicki, D., Lundh, U., and Keefe, J. (2003). Impacts on practitioners of using research-based carer assessment tools: experiences from the UK, Canada and Sweden, with insights from Australia. *Health and Social Care in the Community*, 11(4), 345-355.
- Harding, R., and Higginson, I. (2001). Working with ambivalence: informal caregivers of patients at the end of life. *Supportive Care in Cancer*, 9(8), 642-645.
- Harding, R., and Higginson, I.J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17(1), 63-74.
- Hébert, R., Leclerc, G., Bravo, G., Girouard, D., and Lefrancois, R. (1994). Efficacy of a support group programme for care-givers of demented patients in the community: A randomized controlled trial. *Archives of Gerontology and Geriatrics*, 18(1): 1–14.
- Health Council of Canada (2012). *Seniors in Need, Caregivers in Distress: what are the home care priorities for seniors in Canada?* http://www.healthcouncilcanada.ca/rpt_det.php?id=348
- Jeon, Y-H., Brodaty, H., and Chesterson, J. (2005). Respite care for caregivers and people with severe mental illness: a literature review. *Journal of Advanced Nursing*, 49(3), 297-306.

- Jocelyn, L.J., Casiro, O.G., Beattie, D., Bow, J., and Kneisz, J. (1998). Treatment of children with autism: a randomized controlled trial to evaluate a caregiver-based intervention program in community day-care centers. *Journal of Developmental and Behavioral Pediatrics*, 19(5), 326-334.
- Jones, R., Mackenzie, A., Greenwood, N., Atkins, C., and Habibi, R. (2012). General practitioners, primary care and support for carers in England: can training make a difference? *Health and Social Care in the Community*, 20(2), 128-136.
- Keefe, J., and Fancey, P. (1999). Compensating family caregivers: an analysis of tax initiatives and pension schemes. *Health Law Journal*, 7, 193-204.
- Keefe, J., Légaré, J., & Carrière, Y. (2007). Developing new strategies to support future caregivers of older Canadians with disabilities: Projections of need and their policy implications. *Canadian Public Policy*, 33(S1), S65-S80.
- Keefe, J.M., and Manning, M. (2005). *The Cost Effectiveness of Respite: A literature review*. Report prepared for the Home and Continuing Care Policy Unit, Health Care Policy Directorate, Health Canada. <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-keefe/index-eng.php>
- Keefe, J.M., and Rajnovich, B. (2007). To pay or not to pay: examining underlying principles in the debate on financial support for family caregivers. *Canadian Journal on Aging*, 26 (Supplement 1), 77-90.
- Knight, B.G., Lutzky, S.M., and Urban-Macofsky, F. (1993). A meta-analytic review of interventions for caregiver distress: recommendations for future research. *Gerontologist*, 33(2), 240-248.
- Kutner, G. (2001). *AARP Caregiver Identification Study*. American Association of Retired Persons, Washington, D.C. Accessed at: http://www.aarp.org/relationships/caregiving/info-2001/aarp_caregiver_identification_study.html
- MacCourt, P., and Krawczyk, M. (2012). *Supporting the Caregivers of Seniors through Policy – The Caregiver Policy Lens*. Vancouver, British Columbia: British Columbia Psychogeriatric Association.
- Manderson, B., McMurray, J., Piraino, E., and Stolee, P. (2012). Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. *Health and Social Care in the Community*, 20(2), 113-127.
- Marziali, E., and Donahue, P. (2006). Caring for others: internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *Gerontologist*, 46(3), 398-403.
- Meier Hamilton, 2011. *Evidence-Based Caregiver Support*. Rosalynn Carter Institute for Caregiving. Americus, Georgia. http://www.nysaaaa.org/Caregiver_Forum/2011%20Forums/FALL%202011/Evidence-Based%20Caregiver%20Support.pdf
- Mental Health Commission of Canada (2012). *Changing Directions, Changing Lives: The mental health strategy for Canada*. Calgary, AB: Author. <http://strategy.mentalhealthcommission.ca/>
- O'Connor, D.L. (2007). Self-identifying as a caregiver: exploring the positioning process. *Journal of Aging Studies*, 21(2), 165-174.

- Ontario Human Rights Commission (2006). *The Cost of Caring: Report on the consultation on discrimination on the basis of family status*. <http://www.ohrc.on.ca/en/cost-caring-report-consultation-discrimination-basis-family-status>
- Pavalko, E.K., and Henderson, K.A. (2006). Combining care work and paid work: do workplace policies make a difference? *Research on Aging*, 28(3), 359-374.
- Pasacreta, J.V., and McCorkle, R. (2000). Cancer care: impact of interventions on caregiver outcomes. *Annual Review of Nursing Research*, 18(1), 127-148.
- Pillemer, K., and Suito, J. (2002). Peer support for Alzheimer's caregivers: is it enough to make a difference? *Research on Aging*, 24(2), 171-192.
- Pinquart, M., and Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18(4), 577-95.
- Pinquart, M., and Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *Journals of Gerontology*, 62B, P126-P137.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russell, D., Swinton, M., Zhu, B., and Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), 626-636.
- Seddon, D., & Robinson, C. (2001). Carers of older people with dementia: assessment and the Carer's Act. *Health and Social Care in the Community*, 9(3), 151-158.
- Smeenk F.W., de Witte, L.P., van Haastregt J.C.M., Schipper, R.M., Biezemans, H.P.H., and Crebolder, H.F.J.M. (1998). Transmural care of terminal cancer patients: effects on the quality of life of direct caregivers. *Nursing Research*, 47(3), 129-136.
- Sörensen, S., Pinquart, M., and Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.
- Stewart, M.J., Doble, S., Hart, G., Langille, L., and MacPherson, K. (1998). Peer visitor support for family caregivers of seniors with stroke. *Canadian Journal of Nursing Research*, 30(2), 87-117.
- Stewart, M., Barfather, A., Neufeld, A., Warren, S., Letourneau, N., and Liu, L. (2006). Accessible support for family caregivers of seniors with chronic conditions: from isolation to inclusion. *Canadian Journal on Aging*, 25, 179-192.
- Stoltz, P., Uden, G, and Willman, A. (2004). Support for family carers who care for an elderly person at home – a systematic literature review. *Scandinavian Journal of Caring Sciences*, 18(2), 111-119.
- Sutton, W., and Krawczyk, M. (2012). *Developing Supports for Employed Caregivers*. Winnipeg, MB.
- Visser-Meily, A., van Heugten, C., Post, M., Schepers, V., and Lindeman, E. (2005). Intervention studies for caregivers of stroke survivors: a critical review. *Patient Education and Counseling*, 56(3), 257-267.

- Wai-Chi Chan, S. (2011). Global perspective of burden of family caregivers for persons with schizophrenia. *Archives of Psychiatric Nursing*, 25(5), 339-349.
- Williams, A., Crooks, V.A., Giesbrecht, M., and Dykeman, S. (2010). *Evaluating Canada's Compassionate Care Benefit from the Perspective of Family Caregivers*. Hamilton, Ontario. <http://www.coag.uvic.ca/eolcare/documents/CCB%20evaluation%20final%20report%20-%20English.pdf>
- Zarit, S.H., and Femia, E.E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging and Mental Health*, 12(1), 5-13.