

Respite for Family Caregivers Program: Final Evaluation Report

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Background

In the 1990's Montreal's J.W.McConnell Family Foundation began funding a number of projects in support of family caregivers including, with Health Canada, a major initiative of the Canadian Association for Community Care (CACC) that focused on the critical and growing need for flexible *respite*. Through applied research, the CACC examined a number of respite programs and strategies across Canada. The final report concluded that:

“Respite should be seen as the *outcome* derived by the caregiver as a result of being given either time off from caregiving duties, or direct support for his/her needs ... Respite is the break/time off/relief experienced by the caregiver, not the replacement service provided to the care recipient.”

The CACC's conceptualization of respite as an outcome challenges traditional health care institutions and volunteer organizations alike to move beyond thinking in terms of a set of fixed services. Moreover as the research confirmed, many caregivers believe that genuine respite or relief can come from a wide range of supports or activities, not simply from removing themselves temporarily from their caregiving role.

In June 1999, the Foundation's Trustees approved a national call for proposals to caregiver organizations, voluntary health agencies and service providers supporting family caregivers. The objective was to uncover, test and spread some of the innovations that have the potential to create respite as an outcome, significantly easing the lives of family caregivers, and at the same time benefiting the people for whom they are providing care.

The three key themes the Foundation's initiative sought to address were caregiver “voice”, “choice”, and “respite as outcome”:

- Voice is defined as caregivers' views related to what they believe will enable them to obtain respite
- Choice is defined as caregivers' views related to whether the project intervention(s) provide them with a range of options
- Respite as Outcome is defined as anything that contributes to a family caregiver's emotional, spiritual, physical and/or social rejuvenation, enabling them to have the reserves and resources they need to provide care.

The Foundation selected eight projects from across Canada. It deliberately chose a range of organizations and initiatives in order to learn as much as possible about how to apply the concept of respite as outcome in practice. These projects took three broad approaches to creating respite: providing information to caregivers; influencing health professionals and health systems; and directly working with caregivers to create respite. Each used a variety of strategies to focus on Voice, Choice and Respite as Outcome.

Providing Information

One group of projects tackled the issue of respite through addressing caregiver isolation and lack of information, recognizing that in many communities across Canada people have difficulty obtaining information about programs that support people with health or social challenges, or the people who care for them at home.

Influencing health professionals and health systems

A second group of projects turned their attention to health professionals, the health system, and their relationship to caregivers. These projects focussed on developing strategies to change the way that health professionals work with caregivers, as well as the way that the various components of the health and social systems work with each other in communities.

Direct interventions with caregivers

A third group of projects developed specific support strategies for caregivers aimed at directly creating respite *as an outcome*. These strategies were developed through extensive consultation with caregivers.

Brief Program Descriptions

The **Seniors Resource Centre** of Newfoundland and Labrador (St. John's) developed a province-wide strategy to provide information and support to both rural and urban caregivers. This included a toll-free information line, newsletter, membership, web site and the development of five Regional Caregiver Networks.

Providence Centre (Scarborough, Ontario) created more effective ways of providing support to Tamil speaking caregivers from war-torn Sri Lanka or South India who presently live in Toronto, with the objective of disseminating their experience to Canadian institutions and organizations working with family caregivers from other cultural communities.

Family Caregivers Network Society (Victoria, B.C.) targeted information and supports to caregivers who are employed, and raised awareness among health care professionals of caregiver issues in long-term care facilities.

The Hamilton Caregiver Respite and Support (CaReS) Project (Ontario) surveyed caregivers, physicians, clergy, parish nurses and social service providers to identify the needs of caregivers and developed tools for caregivers and service providers that will improve respite and support services for caregivers and that can be easily adapted by other communities across Canada.

The **Multiple Sclerosis Society of Canada** (National Office) piloted a caregiver special assistance fund providing responsive and flexible funding to caregivers for a variety of self-identified purposes such as transportation, house and yard work, recreation, and tuition for courses.

The **Victorian Order of Nurses** (National Office) consulted caregivers to identify factors that should be used in transforming the traditional orientation of VON nurses from one that focuses only on the care receiver, to one that encompasses the caregiver(s).

Le Phare/The Lighthouse (Montréal) created a volunteer delivered in-home recreation program to support the family caregivers of terminally and chronically ill children.

Family Caregivers Association of Nova Scotia raised awareness of caregiver issues, provided direct support in the form of information to help rural caregivers in particular to access the supports they need, and supported several community projects for caregivers.

Evaluation

Evaluation of the McConnell strategy and the eight projects was completed at two levels. The individual organizations conducted their own project evaluations. Four of the projects contracted external evaluators to review their programs while the others completed the evaluations internally. In addition, an independent evaluator was engaged to monitor the program at the national level, to aggregate the results of the eight projects, and to analyze the results against the following objectives:

1. To develop and test strategies under the guidance of caregivers as approaches for hearing the voice and choice of caregivers and for creating respite;
2. To identify barriers to projects being caregiver driven, to caregiver voice or choice and to achieving respite as outcome;
3. To identify the factors that supported the innovative strategies, and factors that have limited or undermined these strategies;
4. To identify types of collaboration between organizations implementing the projects and factors that supported collaboration, as well as barriers to collaboration.

The following analysis focuses primarily on the objective of developing and testing strategies under the guidance of caregivers as approaches for hearing the voice and choice of caregivers and for creating respite. There are also some comments regarding the 3rd and 4th objectives above. The analysis is complicated by a number of factors including differences in the strategies used, and differences in the social and health systems in which the strategies are being implemented. As well, there are important variations among the target caregivers. While a substantial proportion of the caregivers are providing care to elderly relatives, some of the caregivers are parents of very young, terminally ill children, while others are spouses of young adults with MS. Each of these differences is likely to have an impact on the effectiveness of the various strategies, making common themes and successes generalizable to the objective of creating respite as an outcome a challenge. Nevertheless, a number of common themes did emerge from the projects and are highlighted in the following pages.

Results

The projects used a variety of strategies to identify and engage caregivers, to hear their voices and enable them to choose the types of supports that they believed would result in respite for themselves as caregivers. According to the reports, approximately 220 caregivers were involved in program development and management and over 5000 caregivers were served by the projects in a variety of ways. The average age of these caregivers was approximately 55 years. In most projects 75 to 90% of the participants were women with the exception of the MS Society project in which representation of men was approximately half. (See charts in Appendix I).

The results of each of the three broad project approaches are described and analyzed in greater detail below.

I. INFORMATION PROVISION

Information is a critical resource for creating respite for many caregivers. For example, 90% of the caregivers who used a caregiver telephone line provided by the **Seniors' Resource Centre (SRC) of Newfoundland and Labrador** said when surveyed that the telephone support enabled them to experience some relief. Information provided by the **Family Caregivers Network Society** project in Victoria through workplace strategies resulted in caregivers becoming more aware of resources in the community, as well as feeling that "there was someone out there to help." The method of providing this information through workplace based newsletters and workshops also enabled caregivers to obtain support from co-workers, and reinforced the participants' sense that they were not alone. The **Family Caregivers Network Society** found that information assisted the Human Resources Department of Camosun College to gain a better understanding of caregiving in the work context, and prompted the College to investigate and provide further information to

employees about options. “Brown bag lunch” workshop participants indicated that they found more support from co-workers in the workplace, and the information provided to the caregivers reduced their stress. Employers improved access to education resources for employees and discovered how to find relevant resources regarding caregiving. All of these resulted in a sense of respite.

It is important to note however that information alone may not create respite as an outcome for caregivers. A number of the projects found that additional strategies were required along with information provision. **The Seniors Resource Centre** found, for example, that services and informal supports were almost non-existent in many of the communities they serve, and that information is not adequate when caregivers have no access to services or supports. As a result of this finding, the **SRC** is helping to create a number of regional support networks for caregivers across the province. The **SRC** also found that increasing information about caregiving throughout the health service community increased the ability to mobilize health service organizations to provide additional supports.

An independent evaluation of the **SRC** project confirmed that it is important for those who wish to assist caregivers to:

- Recognize caregivers as an important asset to our community as well as our health care system;
- Include caregivers in the development of the programs.

The evaluation also noted several elements that are essential in the development of caregiver resources including:

- Showing respect for the caregiver and their role, and recognizing the value of their time and contribution;
- Obtaining caregiver input and feedback, finding out what they feel is needed and providing opportunities for participation and empowerment;
- Providing a variety and choice of information resources, making options as convenient and flexible as possible, and adapting to the changing needs and demands of caregivers;
- Developing strategies to reach caregivers who do not identify themselves as being caregivers and those who are most burdened, who are also often those who are most isolated.

The Providence Centre’s Tamil project found that the concerns, difficulties and problems faced by the Tamil caregivers were not very different from those of other caregivers. However, information about services available through main line communication channels was not reaching this cultural community, a situation believed to be similar for many other cultural communities in Canada. The Tamil project leaders found that they needed to use established and trusted Tamil communication channels to reach the caregivers while at the same time identifying that these caregivers faced cultural and values barriers to respite. For example, while in the traditional Tamil culture the extended family provides care and respite for family members, such support is not possible within the large city environment of

Toronto, away from many extended family members. This causes friction in family relationships and results in stress.

To support the need for respite, the Tamil project provided information sessions in a variety of locations on a wide range of health topics to seniors, families, community and faith leaders. The choice of language for these sessions, and knowledge of the culture, were important in supporting the development of these initiatives. During the education sessions, project staff were able to identify caregivers through participant surveys, leading to the development of respite strategies. Initiatives ranged from hosting a caregiver appreciation event, to developing a curriculum for a Hindu Spiritual Support Worker program, advocacy for provision of culturally sensitive long term care beds for Tamils through to creating a Tamil/English Caregiver website.

A primary focus of the **FCgANS** project was information provision that linked caregivers to services. An external evaluator completed a survey in January 2003, contacting 70 caregivers who had called the office for information and successfully surveying 34 caregivers. (Twenty-nine (29) additional caregivers were contacted but most did not remember calling the FCgANS office, indicating that they had been in crisis at the time and had made calls to many organizations.)

Approximately 56% of those surveyed indicated that the information provided by the **FCgANS** office was *useful*, and 32% indicated that it had been *somewhat useful*, while 12% said it was *not useful*. Those who said it was *useful* indicated that it made their caregiving situation more manageable as a result of less stress, or time off, or both. They also indicated that knowing the care receiver is happy makes their life easier. As stated by one caregiver, ***“when I get respite I’m able to go out without worry... I welcome the time away... Since getting more help for my parents and myself I am better able to cope on a daily basis.”***

Another said ***“I’m able to get out more often and I’m less worried about my mom’s health... Having two or three people involved in her care has helped tremendously. I’m not stressed all the time.”***

Overall they indicated that:

- They received clear information about home care, respite, financial and legal issues
- They were told about support groups that they later joined
- They received help in making difficult caregiving decisions
- They received emotional support that helped get them through difficult times.

Those who indicated that the information was *somewhat useful* said that the office was unable to provide a solution because they were already receiving the services recommended by the office, or because there were no services available to meet their needs. Three caregiver comments quoted in the report noted that the respite services available did not meet their needs as caregivers. One caregiver indicated that for her to get away for respite the care receiver required an RN due to their

specific health problems, but that RNs were not available to provide respite. Another caregiver was told that she would have to leave the house during the respite period, which she was uncomfortable doing. The third caregiver was already receiving the maximum time permitted.

These comments from the FCgANS project survey highlight that while providing information can be beneficial, leading caregivers to obtain available respite services, there are many caregivers for whom the existing respite services are too rigid and inflexible to meet their specific needs and circumstances. One caregiver said ***“They referred me to the Department of Home Care Services. I called and was told it was like a babysitting service and that I would be expected to leave the house when the worker was there. I wasn’t comfortable doing that. I’m still trying to cope.”***

Common Themes:

The major common themes emerging from these various projects include:

- Knowing that services, supports and resources are available can provide a sense of relief, reducing worry about the future.
- Information must be able to lead to services and supports when these are needed. When no services are available, the information becomes useless and may have the opposite effect of what is intended by creating frustration for the caregiver.
- Information about caregiver respite must be presented in such a way that it is culturally and demographically acceptable.
- Communication channels differ in cultural communities and appropriate channels need to be used in order for the information to get to the people who need it. Learning about and using these channels is time consuming, at least at the start.
- Peer to peer information sharing can be effective in many situations.
- Inflexibility in the way many services are provided reduces the usefulness of these services to a substantial number of caregivers.

II. INFLUENCING PROVIDERS AND THE HEALTH SYSTEM

A number of different strategies were used to influence providers and the health system.

Victoria's Family Caregivers Network Society held workshops for health-care providers and caregivers to sensitize them to caregiver needs and to encourage a team approach to the provision of care for their charges. The care facility forums and workshops, in particular, opened up the relationships with staff and helped many family caregivers feel more welcome and comfortable visiting their family member. In some cases family caregivers increased their visits to their family members in facilities. The project report commented that "while this may seem to be the opposite of respite, in fact these people had an increased sense of comfort with the facility as a result of the workshops and experienced greater peace of mind."

VON Canada completed a series of focus groups to identify how to better listen to caregivers. Through this they identified how caregivers would describe "respite as an outcome" and what contributes to this, from a professional perspective. Respite is described as "the period in which the stress and responsibility of caregiving is temporarily transferred to trained professionals so that one may enjoy that time with peace of mind." This definition includes four important components that can potentially contribute to respite as an outcome: time; worry-free/ guilt free caregiver; small breaks from responsibility; sharing of the workload. From the focus groups VON Canada found that caregivers understand the concept of "respite as outcome" although it is difficult to achieve on an ongoing basis. Most of the caregivers who participated were "coping" but wanted more control over opportunities to experience respite. Through the interviews a number of factors that contribute to the achievement of respite were identified:

- Caregivers are focused on the needs of the care receiver. Caregivers appreciated providers who acknowledged the unique situation, characteristics, personalities and feelings of the care receiver.
- Caregivers are willing to help with the care, but expressed a desire to learn from the professionals and to negotiate what they are willing to do for their family member. Not only did they want to be involved in the planning of care, but in the decision-making of care. They wanted their relationships with their family member to be taken into consideration.
- Caregivers believe relationship building is an important aspect of the care negotiated with the provider. Communication, information sharing, and working together as a team contributed to solid working relationships that are respectful of the care receiver and the caregiver.
- Matching and scheduling consistent providers with families can decrease anxiety, increase caregivers' sense of respite, and increase the quality of care. It was extremely important for the caregiver to have a consistent provider to plan for the respite and share the work and responsibility more equitably.
- In addition to relationships and trust, caregivers want providers to be competent.

- Caregivers want providers to be “like family”: knowing their family members is being cared for ‘by family’ reduces concern and worry.
- Families want providers to be consistent in what they do, but also want them to be flexible to each unique family situation.
- Families want providers to live within the rules of the caregiver’s home, and not disregard household practices.

Through the focus groups VON Canada concluded that there are often systems issues that impede caregivers from experiencing respite, but through working respectfully as partners, listening to the caregiver’s interests and preferences, and trusting their knowledge, opportunities for respite can be created.

The Seniors Resource Centre is promoting the development of a network model of support, called Regional Caregiver Networks. These networks enable community groups, caregivers and service providers to identify common concerns, share information and advocate for solutions. The Networks are fostering collaboration between informal and formal caregiving sectors and stimulating the development of community supports for caregivers. The collaboration among service providers is raising awareness of how to more effectively help family caregivers especially in communities with few existing supports, and has generated interest in the provincial government.

Hamilton’s CaReS project surveyed caregivers, asking about the use of family physicians and clergy to support their caregiving. While the caregivers all had family doctors and two-thirds of the caregivers reported that the family doctor knew they were caregivers, approximately 75% said that family doctors do little to support them. Of the caregivers that belong to a religious group (approximately half of the caregivers) almost three-quarters indicated that they were comfortable talking to their faith leaders about their caregiving role. A significant portion indicated that faith leaders had been supportive, visited, provided practical help, or prayer that helped in their caregiving role. These findings suggest that family doctors and faith leaders are potential avenues for providing support and information.

Caregivers were asked what would ensure they could take time just for themselves. While thirty-six percent indicated that they already take time for themselves,

- 16% indicated it would help if other people provided some of the care that the caregiver currently provides.
- 10% said it would help if more services or more hours of service were available.
- 6% said they could use more informal support.

Discussion about factors that would result in respite as an outcome highlighted the need for flexible approaches as well as concern for the care receiver. As stated by one caregiver “... ***you’re comfortable at home. If you want to have a shower, go to bed, you can do that. I don’t want to go away. I want to be home and do***

what I wanted to do. I can't tell her I'm going away . I've learned that now. ... Once she knows I'm not going to be there, she's so afraid of being alone and dying on her own. So when I'm away I'm constantly phoning her anyway to let her know..."

This survey also asked which types of services and supports would be most helpful. The responses indicate that approximately half want:

- Information about changes in the laws related to caregiving
- A tax break
- Financial support
- Information on services for people in their situation
- Some free time to be able to take a break

In response to these findings CaReS developed a website that enables caregivers and service providers to access information on a variety of services and supports in Hamilton. CaReS believes that sustainable change in caregiver quality of life requires further community capacity building, the nurturing of relationships between caregivers and other stakeholders to stimulate collaboration and cooperation. They believe that additional research and action projects will support the process of “building catwalks between silos”- creating bridges of understanding between the people and organizations in the health and social supports systems that provide support to caregivers .

Nova Scotia's **Family Caregivers' Association of Nova Scotia** also found that community strategies were needed to support caregivers and it provided seed funding to nine community projects. These included three projects specifically aimed at respite, as well as community strategies for information and training for caregivers. One of these projects involved collaboration between a mental health agency and the VON in providing a weekend away for caregivers and replacement care for the family member. The nine projects are currently being evaluated and results will be available shortly.

Common Themes:

The experience of the projects focusing on influencing health care providers and the health system point to the following common themes:

- Caregivers focus first and foremost on the needs of the person for whom they are caring. They will not experience respite unless they know the person is both safe and comfortable.
- The relationship between health care providers and caregivers is very important.
- Caregivers want to be partners with health care providers in planning care, learning from the providers, as well as deciding who and how care will be provided.
- Caregivers and care receivers want to have access to and support from the same providers on a consistent basis.

- Caregivers want the health providers to be both technically competent and responsive to the preferences of the caregiver and care receiver.
- Caregivers want the health providers to become like trusted family members who are partners in providing care rather than solely professionals determining care to be provided.
- Caregivers want health providers to respect the rules of the house, and to discuss and get agreement when the rules need to be modified so that the provider is able to work safely and effectively.

III. DIRECT INTERVENTION

The **MS Society's** Caregiver Special Assistance Program (CSAP) enabled caregivers to apply for modest grants and provided them with an opportunity to voice their views regarding what would allow them to obtain respite and enhance their quality of life as caregivers. CSAP found that many caregivers had trouble focusing on and expressing their own needs. Caregivers tended to think about the needs of the person they were caring for and had to be encouraged to think about their own needs and to identify those things that would enable them to get respite.

When this support was provided caregivers identified the benefits that they wanted and expected to achieve through their funding request. This was viewed by the program as an expression of how the caregivers define "respite" or "respite as outcome" for themselves.

According to information provided by evaluation respondents, almost 75% of the requests were for services and activities rather than items. The largest number of similar requests were for:

- Assistance with costs of vacations and other "breaks away" ranging from a few hours to a couple of weeks. (With these types of funding requests, funding was used for transportation, accommodation, meal and/or entertainment/recreation costs related to these "breaks".)
- Hobby or recreation equipment and supplies.
- House/Yard Cleaning and Maintenance.
- Caregiver's exercise programs.
- Replacement/Alternate Caregiving Services.

Caregivers' responses on the follow-up evaluation survey indicate that an overwhelming majority of participants place a high level of importance on the fact that they were able to select services, activities or items for their funding request with very few limitations. In fact, over 95% of respondents felt that it was of quite a bit or considerable importance that they could exercise choice through the Caregiver Special Assistance program.

This is important when the choices made within the **MS Society** program are compared to the options available within the health system which most frequently provides support for replacement caregiving services and house/yard maintenance.

These were respectively the fifth and third most frequently chosen in the **MS Society** program. The more frequently requested supports in the CSAP were for activities and equipment that would not be available in most formal respite programs in Canada. For example, assistance with costs for vacations and breaks away would not be accepted by most programs (although the replacement care costs would be permissible). Similarly, hobby or recreation equipment and supplies would not generally be considered relevant to a caregiver's respite, nor would exercise programs or gym memberships.

Caregivers' comments included:

"I think the program was excellent. The best feature is determining your own needs and not fitting in to how others define it".

"The fact that it allowed the caregiver flexibility to choose what is perceived to be helpful for themselves is a very strong point".

An overwhelming majority of CSAP respondents (94.4%) indicated that the funding enabled them to access their identified service, activity or item and achieve the benefits that they had intended. Some of the caregivers who indicated that they did not achieve the benefits that they had hoped for suggested that this was due to unexpected changes in personal circumstances rather than any difficulties with their chosen service, activity or item or the program (e.g. death of another family member, own disease diagnosis).

One of the key benefits was the importance of caregiver recognition. While the program was initially described as a financial assistance program, the description used by staff evolved to reflect a caregiver recognition focus. This focus appears to have contributed to the outcome of respite:

"It gave me a sense that my role of being a caregiver is not taken for granted, for example, it is my job and that it was recognized that I also need a break, do something for me that I enjoy and not feel guilty for doing so for me. It was much needed, more than I realized until I allowed myself to give in to not only my husband's needs but my own to prevent burn out physically and mentally".

"It was all kind of a "mental thing". It was nice to be recognized as a caregiver".

Almost three-quarters of caregivers reported that they felt the support received through the CSAP program also benefited the person with MS for whom they care. They indicated that a more relaxed, healthier and/or less stressed caregiver results in continued care at home, better quality care and/or a caregiver who is more willing, less irritable, more patient, easier to be around, etc.

- *“When I came back I was much happier and more eager to help her out so she was glad that it helped me be a better caregiver”.*
- *“I have more energy, strength and stamina with which to help”.*
- *“Improvement in my health helps in very obvious ways as I can assume more of the work load...”*

Through a series of program development consultations **Le Phare/The Lighthouse** found that the parents of seriously ill children wanted respite, but that obtaining respite was very difficult within the health system, and that the few moments of respite that parents get, do not provide any real chance to re-energize. Within the Montreal environment the respite services available provided baby-sitting for the child, but little else. When describing respite, parents defined respite in terms of being re-energized and having peace of mind, but also indicated that they cannot obtain respite unless the approach used also brought enjoyment to the ill child. The parents indicated that this second component tended to be ignored in the existing respite programs for seriously ill children. Similar to the MS Society program, parents tended to think first and foremost about the needs of the ill child.

To address these challenges, **Le Phare/The Lighthouse** developed a program aimed at offering respite to parents while bringing enjoyment to the sick or disabled child. The objectives of the program included:

- Providing families time to re-energize
- Giving the children regular access to recreational programs adapted to their health condition and home environment
- Encouraging parents to participate actively in identifying needs and finding solutions
- Training, supporting and supervising volunteers to provide the programs and to assist the families

To achieve these objectives the program-developed strategies for assessing the families' needs, personalizing the program of activities to the child's abilities and interests as well as their health, and the parent's concerns. The pairing of volunteers with families was a key activity, incorporating the mutual interest of all participants: the child, the parents, and the volunteer.

The experiences described in the evaluation completed by faculty from the University of Quebec at Montreal indicated that parents and children benefited tremendously from the program. Parents reported that they had experienced positive effects from the program even though most did not use the time to relax or enjoy themselves: they more often used the time to complete domestic chores and tackle family matters. They perceived the program alleviating their regular burden as a form of respite that afforded greater peace of mind and lessened their feelings of stress and guilt.

The parents commented that the quality of their relationship with the volunteer was critical to the feeling of respite. The evaluation noted that in order for parents to

break out of their daily routine and take advantage of the respite time, they needed to be able to trust the volunteer to replace them in caring for the children.

The benefits of the program to the family were noted as going beyond the parents and the sick child, extending to all the children in the family. In many cases other siblings became involved in the recreational programs. The parents saw the sharing of the playtime as creating moments of normal life within the family, something that the families find to be difficult due to the severity of the illnesses and the burdens these place on the parents. The children were also asked about the benefits and stated that the program helped them feel less alone, increased family activities and gave the parents respite.

Among the factors identified as being important to success were:

- The relationships between the volunteers and parents
- The consistency by the volunteer including being available at agreed-upon times
- The quality of the program
- Communication between the program coordinator and the parents

One of the real challenges noted in the program was that it placed a toll on volunteers. The children were often very sick or terminally ill, resulting in considerable emotional stress for the volunteers.

Respite for Tamil Caregivers at Illahee Lodge:

The Tamil project has also developed a five-day respite program for 18 Tamil caregivers which was piloted this fall at Illahee Lodge, a seniors' recreation centre run by the Family Services Association of Toronto. The Tamil project staff found that even the design of this respite program faced a number of challenges to providing respite as an outcome.

Firstly, many caregivers said that they could not leave the person for whom they are the caregiver for so long a time. As a result, the program was modified to include the care receivers including the provision of personal support workers able to work with this cultural group. This modification, however, resulted in the exclusion of the more seriously ill and bed-ridden care receivers who need higher levels of care than can be provided by the Lodge. It also resulted in a modest increase in the fees to cover part of the cost of participation by the care receiver. This fee increase made it impossible for some caregivers to participate.

Secondly, some said that they could not pre-plan for an event so far into the future as anything could happen at any time. These were caregivers who live from day to day, and could not avail themselves of this opportunity. In fact, eight caregivers and care receivers who had registered had to withdraw owing to medical emergencies.

In the fall, following the completion of this first pilot, the project evaluated the effectiveness in creating respite as an outcome and found that many of the caregivers felt less isolated and “appreciated the opportunity to share with those who understand their pain.” As said by one caregiver, ***“our stay at Illahee Lodge was very happy, relaxing and enjoyable. We were enjoying as one family, and had a very peaceful sleep in that time.”***

The evaluation highlighted important themes also identified in other strategies:

- The importance of including concern for the care receiver in the planning of programs.
- The need for flexible services.
- The importance of having culturally and spiritually trained staffing.
- That even modest fees can reduce the ability of some caregivers to participate.

Common Themes:

The projects focusing on directly providing support to caregivers demonstrate a number of common themes:

- Caregivers tend to think first and foremost about the needs of the person they are caring for. Caregivers need to be encouraged and supported to think about their own needs for respite.
- Caregivers want to identify and choose the services that will support them in obtaining respite as an outcome.
- Services need to be flexible.
- In most situations the caregivers’ choice does result in respite as an outcome for them.
- Caregivers appreciate being recognized for the work that they do and this recognition in itself is revitalizing.
- Caregivers recognize that their own well-being has an impact on the care-receiver.
- When health care providers or volunteers are providing a respite service or program for time away, relationships, communication (including language choice), consistency and program quality are all key to the caregiver’s ability to achieve respite as an outcome.

Key Lessons

In spite of the differences in approaches taken by the projects, a number of themes and lessons that are common to all or most of the initiatives have emerged.

1. **Information is necessary, but not sufficient, for creating respite as an outcome.**
 - Knowing that services, supports and resources are available can provide a sense of relief, reducing worry about the future.
 - The information and services should be available in accessible formats and presented in such a way that they are culturally acceptable.
 - Communication channels differ in communities and organizations need to take the time to identify appropriate channels (e.g., trusted sources) in order for the information to get to the people who need it.
 - Information should lead to supports when these are needed.
 - Peers can be effective as information providers in the workplace and in some cultural communities.

2. **Caregivers will not achieve respite, as an outcome unless they trust that the person they care for is content, well cared for and supported.**
 - To enable caregivers to get respite requires, first and foremost, that the caregiver be confident the person they care for is in good hands. This requires:
 - I. the building of relationships and trust between the person being cared for and the professional or volunteer caregiver;
 - II. the building of relationships and trust between the family caregiver and the professional or volunteer caregiver. Every time that individual changes, trust must be rebuilt.

3. **Providers and volunteers should strive to become partners and like “trusted family members”.**
 - The professional or volunteer must be both trustworthy and competent
 - The family caregiver should be aware of the training and skills that the provider or volunteer brings so that he or she is confident that appropriate care and safety are assured.
 - The provider or volunteer should understand that the family caregiver has knowledge and skills about caring for the individual that should be respected and drawn upon.
 - Rapid turnover of providers and volunteers should be avoided.

4. **Providers, volunteers and programs should be as responsive as possible to the priorities of caregivers and care receivers.**
 - Enabling caregivers to get respite requires that providers, volunteers and organizations develop new approaches to working with caregivers.

- Paid and volunteer providers should recognize that they are a resource for supporting an existing family caregiver capacity that already provides 80 to 90% of the care. That capacity must be respected.
- The family and community environment has a culture and rules that the provider or volunteer needs to work within. When adjustments are necessary (for example, because of safety concerns or in order to adhere to professional standards) this should be explained to the caregiver.
- As much as possible, the activities through which the caregiver gets a break or rejuvenation should match the caregiver's interests and occur at a time which is suitable to the caregiver and the person being cared for.
- Many of the activities and expenditures that result in respite as an outcome challenge the traditional, professional thinking of respite service and health care providers. In some situations the caregiver will want to be in the home. In other situations they won't. Some caregivers' priorities are for time off, a vacation or a break from normal activities and routines while others may want a break from isolation, time to connect with friends, education programs, support for hobbies, personal health and relaxation activities.

5. The same strategies will not work for everyone. More attention is required to support caregivers in identifying what will result in respite for them.

- Caregivers need to be supported and encouraged to identify their own needs and then to identify what would enable them to get respite.
- In some situations, caregivers find it helpful to have a range of options presented to them, from which they can choose, while other caregivers prefer to build their own support options rather than choosing from a fixed 'menu'.
- While flexibility and responsiveness are key, further exploration could identify respite strategies that will work for those for whom existing programs are ineffective.

6. Respite initiatives need not be costly. Caregivers often want quite inexpensive supports and recognition.

- Many of the activities and expenditures that result in respite as an outcome are less expensive than the majority of current programs offered through the health care system.
- The community's acknowledgement of the critical role played by family caregivers, in itself re-energizes and rejuvenates many caregivers.
- Some provinces and communities may already have adequate resources to support caregivers, but require program changes to enable greater flexibility so that these programs result in respite as an outcome. Other provinces and communities across Canada may require additional resources.

- Simple changes in attitudes on the part of health care providers, such as encouraging staff in long term care facilities to learn the names of caregivers and to welcome them, are often enough to result in a sense of relief for caregivers.

These lessons are consistent with and strongly support the assumptions that The J.W. McConnell Family Foundation used as the base of its Respite for Family Caregivers strategy. Caregiver “Voice” and Choice” are important to achieving “Respite as an Outcome”. At the same time, the lessons take the work further...

Key Implications

Most chronically ill and disabled people of all ages in Canada are cared for by family members and friends. Studies have estimated that 80 to 90% of this type of care is provided by family and friends, allowing the ill and disabled to live in their local community, in their own homes or in the homes of relatives and friends, and generally supporting their quality of life. However, providing care can have a significant impact on caregivers, sometimes resulting in exhaustion and collapse. Family caregivers will benefit from support that enables them to continue to provide care. Supporting family caregivers is a collective responsibility, with appropriate roles for governments, the voluntary sector, communities, employers, private funders and others. Below are a number of implications emerging from these projects for a range of actors in Canadian society with a commitment to the well-being of the millions of caregivers in our country.

I. Governments (federal, provincial, territorial and local)

- i. The formal health and social systems are able to cope only through the care provided by family, friends and the local community. This work must be recognized, acknowledged and supported. For example, family caregivers should be included in relevant health care policy development processes; health care providers can be trained on ways to support caregivers in their role, etc.
- ii. Federal, provincial and local levels of government should ensure that information about existing respite strategies and services to support caregivers is available across Canada and in different cultural communities.
- iii. Government funded programs in support of family caregivers should be increased and become more flexible so that programs can be tailored as much as possible to the interests and needs of individual caregivers.

II. National Voluntary Organizations

- i. National organizations like VON Canada and health charities like the MS Society can expand their traditional focus on the person with the illness to more systematically include caregivers in their services and programs. These organizations, along with groups like the Canadian Caregiver Coalition, can also play an important role in supporting innovation and in disseminating lessons learned about how to address respite as an outcome for family caregivers across Canada.
- ii. Given their wealth of knowledge and capacity, caregivers should be included in the governance, policy directions and service delivery focus of national organizations.

III. Community Organizations

- i. Community organizations with an interest in helping caregivers should as much as possible coordinate their activities at the local level and ensure that caregivers have easy access to information and supports.
- ii. Supports should be adjusted to respond to the realities of different cultural and linguistic communities, and age groups.
- iii. Acknowledging the contribution of caregivers is an important aspect of rejuvenating and motivating caregivers and is simple to implement, for example through awards, the media, social events, etc.

IV. Health Care Institutions (hospitals, palliative care, mental health and long-term care facilities, etc.)

- i. Service providers should continue to recognize that caregivers will only be able to achieve respite as an outcome if they know that the family member for whom they provide care is content, well cared for and safe.
- ii. Providers should respect the caregivers' role, allowing and encouraging caregivers to voice their own needs and interests, and then creating or referring caregivers to programs that are most likely to provide them with what they are looking for.
- iii. Providers can evaluate the effectiveness of their programs and services by including caregivers in their surveys.

V. Corporate and Philanthropic Funders

- i. Supporting family caregivers is a vital component of building healthy, vibrant communities. This is especially important given that caregivers have been largely invisible and unsupported in the past. There are many opportunities to fund local, regional and national programs that are implementing strategies to support caregivers to achieve respite as an outcome.

- ii. Funding should favour those programs that engage the voice of caregivers and allow choice that matches the needs and interests of individual caregivers with appropriate supports.
- iii. There are opportunities to fund innovation, research and evaluation of programs that are implementing responsive respite strategies to identify and disseminate exemplary practice models.

VI. Employers:

- i. Employers should recognize that the caregiving role influences people in the workforce. Caregiving can lead to additional stress, increased absenteeism, job turnover and reduced productivity.
- ii. Reducing the stress of caregiving and increasing the retention of valuable employees may be achieved through strategies such as providing flexible work hours, adding other supports through human resource departments such as counseling and information referrals, and peer support programs.
- iii. Peers are often able to provide support and information to each other, reducing stress in the workplace, sometimes through on-line discussion groups or anonymous information provision, sometimes through “brown-bag lunch and learn” programs, and sometimes through support outside the workplace.

VII. Researchers:

- i. Additional work is required to identify and evaluate strategies that result in respite as an outcome. Researchers should engage caregivers and front-line service providers as partners in creating and evaluating these strategies.
- ii. Further work is needed to create the evidence that demonstrates the effectiveness of strategies and documents effective practices.
- iii. Researchers should use appropriate research models that include caregivers as participants in the research design, enabling individual caregivers to identify the types of supports they consider to be priorities and allowing the caregivers’ choice of these supports, and then determining which strategies result in respite as an outcome.
- iv. More work is required to demonstrate the cost-effectiveness of strategies that support caregivers.

Conclusion

The J.W. McConnell Family Foundation’s support to the eight projects across Canada enabled each project to develop and evaluate approaches to increase the voice and choice of caregivers and to assess the impact on respite as an outcome. Each of the projects worked to achieve these objectives in different ways in their own communities.

Based on the project results, the McConnell strategy has demonstrated that voice and choice are important contributors to creating an environment in which respite as an outcome can be attained. Conversely, when caregivers are not consulted, listened to, and provided with options that respect their priorities, they generally do not get the rejuvenation that they need to be able to carry on in their caregiving role.

One of the crucial findings from a number of the projects is that the first priority of caregivers is the person they care for, not themselves. The projects found that supports will not result in respite as an outcome unless caregivers know the person they care for is both safe and secure, and if possible, engaged in positive activities. Information is important to caregivers and can support them in achieving respite as an outcome but must be provided using approaches that match the culture and communication preferences of the caregivers. The information must also be useful in leading caregivers to the supports that they require when these are needed.

In the delivery of supports and services, caregivers want providers and volunteers to be responsive to the priorities and concerns of the caregiver and care receiver. Caregivers want the health and social services systems to respect them by, for example, developing a partnership in care that incorporates the knowledge and preferences of family caregivers and care receivers. Often the supports and services requested are not expensive or are no more expensive than current services, but they do require flexibility.

These findings are crucial for all the participants in the health and social services system. The findings are important to all levels of government because family caregivers are essential to the care of people who are chronically ill or disabled. They are also important to governments, national and local organizations, long term care institutions, communities and corporate and philanthropic funders, because these groups develop or influence the policies that determine the flexible use of resources for existing respite programs. At the present time it is often the lack of flexibility and availability that limit programs from achieving the objective of actually creating respite as an outcome.

The results are important for employers and for governments because inadequate respite supports can lead to significant impacts in the workforce that will only increase with time, including reduced productivity, and loss of workers from the labour force.

Most importantly, caregivers and the people they care for will benefit from the use of these findings because people, who choose to provide care, as well as those who have no alternative, will be better able to continue in their vital role.

APPENDIX I

Caregiver Involvement in Projects

Project Development and Management	CARES - Hamilton	Family Caregivers' Network Society - Victoria	Family Caregivers Nova Scotia - Halifax	Lighthouse - Montreal
Board or Community Advisory Team	4 caregivers full time, 4 part time	3 caregivers of 16 members	Approximately 7 (more than half of board)	2 parents
Program design	Survey Design - 20 caregivers Survey coding- 8 caregivers		Strategy Evaluation- 36 caregivers, board members, staff, community partners Pictou Advisory - 18 caregivers	Program development - 5 parents Care Committee - 2 parents
Survey/ focus group participants	300 caregivers	30 families interviewed	63 caregivers	50 family members, including parents of sick children, adolescents and bereaved parents
Program participants	78 family caregivers at workshop 15 telephone calls 1000 website hits as of Aug 26/ 03	approximately 57 family caregivers and 104 other participants in workshops and forums 55-65 caregivers in workplace strategies	Newsletter – circulation 900 copies Caregiver telephone inquiries - 243 calls (approximately 55 completed telephone intake forms and 2/3rds of these were regarding respite) Web – 300 per month	60 families have actively participated in the in-home volunteer delivered recreation program
Caregiver Demographics	Average age: 51 years Gender: 80% female Relationship of Caregiver to care Receiver: 41% offspring 20% Spouse 17% other family member 11% parent 10% friend or neighbour	Long term care facility workshops involved primarily women aged 35-80 years Workplace strategies included men and women aged 30- 65 years	Survey participants - 20% 18-49 60% 50- 65 20 % - 65+ Relationship - 29% parent 24% spouse 24% adult child 9% grand parent 18% other	Average age of caregivers - 40 years Average age of care receiver - 9 years Relationship -parents

Caregiver Involvement in Projects (cont'd)

Project Development and Management	MS Society - Toronto	Seniors Resource Centre - St. John's Newfoundland	Tamil Project - Providence Centre	VON Canada - Ottawa
Board, Steering or Community Advisory Team	National Steering Committee - 2 caregivers of 10 members	Over 30	5 Caregivers of 14 members	1 caregiver
Program design	Divisional Advisory Groups - 18 caregivers of 22 members Educational Component Development Working Group - 21 Caregivers	Over 50 participants	Approximately 9 on the 5 program design subcommittees	Best practice team – 2 caregivers
Survey/ focus group participants	Focus groups - over 100 caregivers	110 caregivers	75 caregivers and family members 7 Key Informants Research studies – 69 participants	38 caregiver participants in focus groups
Program participants	382 caregiver respite applications approved: 188–Atlantic Region 84–Manitoba 110–Saskatchewan	Caregiver membership - over 300 Telephone inquiries - 198 year 1, 194 year 2 Newsletter - circulation 1000 copies Regional Caregiver Network - 30 organizations	Direct caregiver calls - 220 Educational seminars about broad health issues – 1677, including 167 caregivers Caregiver support, recognition and respite events – 156 Tamil Service Provider Coalition - 40 organizations Inventory of Tamil Friendly Services - 156 Agencies and Programs Surveys – 1327 Tradeshows > 2000	450 caregivers surveyed 8 trainers completed training program 120 providers involved in education sessions
Caregiver Demographics	Average age of caregivers - 55 yrs Relationship - 80% spouse 14% daughter 6% other Gender: approximately 50/50 male/female	Average age (of 52 survey participants) - 55 years Gender: 91% women Average length of time caregiving: 8.5 years Relationship - 45% daughters 24% spouse	Average age - 69% between 50 and 80 yrs Gender: 77% women Relationship - 59% spouse 22% parent Average length of time caregiving - 64% more than 5 years	<i>focus groups</i> Average Age - 46 to 64 years of age Gender: 75% women, Relationship - 60% spouse 40% other Length of time caregiving - 7 months to 47 years

APPENDIX II

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