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What Are Policy-Makers Saying about Respite?

by

Sherri Torjman

February 2003

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This survey was carried out on behalf of the J.W. McConnell Family Foundation in January and February 2003. It is being released in September 2003 in preparation for the next stage of a national project on respite.

ISBN 1-55382-067-3

Published by:

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Purpose

This report presents the findings from interviews with selected key informants who have a policy interest in respite for caregivers. The purpose of the interviews was to identify whether policy-makers readily could understand and apply the major results from the National Respite Care Project. The Project had been undertaken by the Canadian Association of Community Care with financial support from the J.W. McConnell Family Foundation and the Seniors Independence Program of Health Canada.

One of the most important conclusions of the National Respite Care Project was the need to understand respite as an *outcome* for the caregiver rather than simply as a *service* to the caregiver. Respite effectively is a break or relief for the caregiver that can be derived from a number of possible interventions delivered in the home or at another site. These include, for example, a temporary break, adult day care, personal emergency system, information on care receiver needs, adult day care, housekeeping, outdoor home maintenance, counselling and peer support.

Key informants were asked whether they were aware of this early work on respite and of the National Respite Care Project in particular. They were asked about their understanding of the concept of 'respite as outcome' and whether it readily could be applied from a policy perspective. Input also was sought about possible instruments to translate the notion of respite as outcome into policy terms. Respondents were invited to identify what they would need in order to better understand this concept and give it some policy momentum. Finally, key informants were encouraged to comment on a related conclusion on the importance of 'voice' and 'choice' for caregivers.

While the interviews focused upon the major findings from the National Respite Care Project, respondents raised other issues as well. These include the dimensions of respite around which more research is required, the scope of respite needs, the complexities in devising suitable policies in this area and the appropriate federal role.

Background

The Canadian Association for Community Care carried out the National Respite Care Project between 1994 and 1997. (In 1994, the original sponsoring organizations, Home Support Canada and the Canadian Long-Term Care Foundation, merged to form the Canadian Association for Community Care.) The initial phase included a literature review as well as a major national survey with facility- and community-based respite care providers and with seniors/consumers of respite care.

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While the final report on the Project represents a wealth of information, two findings in particular stand out. The most important conclusion is that respite should be understood as an outcome derived by the caregiver as a result of relief from caregiving duties or direct support for his or her needs. Another key and somewhat unexpected finding was that respite supports tend to be underutilized.

There could be many reasons for this underutilization. For one thing, it is possible that many caregivers are not even aware of what supports are available. In other cases, caregivers may be afraid to abuse the system and typically understate rather than overstate their service requests. Finally, several respondents noted that caregivers themselves may fear that respite represents the ‘thin edge of the wedge’ – that asking for help could mean that a caregiver is losing hope or simply giving up.

In September 1994, the National Respite Care Project hosted a national symposium involving more than 80 individuals from government, home care, home support and seniors groups. Following the symposium, the coordinators met with 10 advisors to help design the next phases of the project. Instead of testing a single respite model, projects were established in three pilot communities – Nanaimo, Ste. Thérèse and Winnipeg – to seek answers to the questions posed by the earlier work.

The McConnell Foundation subsequently issued a broader call for proposals. In the spring of 2000, McConnell approved eight projects over a three-year period to help develop various models of support to family caregivers. These projects seek to ensure that the voices of family caregivers are heard, that they have choice regarding the supports that afford them respite and that they experience some relief from their day-to-day responsibilities. The projects embody the key themes of *relief, voice and choice*.

The eight projects are being linked to promote the sharing of collective experiences and learning. Representatives from the eight respite projects gathered in Halifax in May 2002 for their third annual meeting. They spent some time discussing evaluation during the final year of the program and designing a communications strategy to highlight key lessons. This strategy is to be launched in Ottawa in October 2003.

Methodology

For the purposes of this study, representatives from several national organizations were asked to help identify prospective interviewees. The proposed key informants were contacted by phone and/or by e-mail to arrange an interview. Twenty-five respondents participated in the discussions. All meetings were held in person, except for the consultation with the contact from Veterans Affairs in Prince Edward Island.

The initial request to participate in an interview included a brief description of the National Respite Care Project and the purpose of the meeting: to explore the resonance of the findings and their policy application. Key informants were invited to bring additional colleagues to the meeting if they felt it would be helpful to the discussion. This happened on three occasions, with very positive results. Preparation for the interviews included a review of the two major reports produced by the Canadian Association for Community Care: the Final Report of the National Respite Care Project and the study entitled *Give Me a Break!* funded by the Population Health Branch of Health Canada. Other reports that were reviewed include the *National Evaluation on the Cost-Effectiveness of Home Care* [Hollander and Chappell 2002], the *Report of the Romanow Commission on the Future of Health Care in Canada* (Romanow Report) [2002], the Report of the Senate Standing Committee on Social Affairs, Science and Technology (Kirby Report) [2002] and the *National Profile of Family Caregivers in Canada-2002* [Decima Research 2002].

A brief scan of legislative initiatives in selected OECD countries also was carried out to identify policy precedents outside Canada. This work was completed in the event that the issue of international experience was raised during the interviews.

Using this information and these reports as background materials, a set of notes was prepared as introductory remarks and as context for the discussion. Typically, each meeting started with an overview of the work and major findings of the National Respite Care Project. Discussions then focused upon respondents' awareness of the broad concept of respite as outcome and its policy implications. While all key informants addressed these issues, they also raised other concerns that are highlighted below.

Current Policy Structures

The policy structures that 'house' respite care currently fall into two main streams. The first stream of work focuses primarily upon the physical health and mental well-being of caregivers. Various branches of Health Canada take responsibility for these dimensions of the issue – generally within the context of home care and long-term care. However, concerns regarding the health and well-being of caregivers with children with severe disabilities fall under the purview of the Office of Disability Issues within Human Resources Development Canada (HRDC).

The second stream of work deals with the labour market aspects of caregiving. HRDC assumes primary responsibility for these areas. Staff from Employment Insurance helped design the compassionate care leave provision announced in the 2003 federal Budget. Throughout the design phases, however, HRDC staff sought input from Health Canada on the caregiving realities that needed to be addressed in the new measure.

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Another collaborative effort currently under way takes the form of an interdepartmental committee concerned with palliative and end-of-life care. The collaboration likely is due to the fact that a Secretariat on Palliative and End-of-Life Care has been established within Health Canada as a central focus for all issues related to this form of care. It is accountable to both Health Minister Anne McLellan and Senator Sharon Carstairs who chaired the Senate Committee on Palliative Care. There is no analogous policy conversation focused only upon respite.

One key informant pointed out that there is “no real synergy” in this interdepartmental working group. Representatives from the various departments that comprise the committee are concerned with very different issues. Corrections Canada, for example, worries about its ability to provide palliative care for incarcerated inmates – clearly an issue unique to its mandate.

One respondent noted that the Department of Finance is not – but should be – at the interdepartmental table. The complexities of the tax system with respect to caregiving are not well understood by policy-makers and by the public. Conversely, Finance officials tend not to be familiar with the problems that many caregivers experience in claiming these benefits. (While this point did not arise in the discussions, it should be noted that the Department of Finance has a new interest in respite through its responsibility for the Child Disability Benefit announced in the 2003 federal Budget.)

Several federal government departments also have a limited but unique role. As noted, Corrections Canada focuses upon palliative care for prisoners. Status of Women is concerned about caregiving from both health-related and labour market perspectives. Industry Canada has just embarked upon the creation of a Canadian Virtual Hospice website. It is intended to enable caregivers and professionals from various disciplines to talk with each other about common concerns.

Veterans Affairs is actively involved in direct service provision, with an extensive program of home care. The Department’s description of its services fits well with the notion of respite as outcome – though it is not expressed in this way.

Under the Veterans Affairs program, Canadian veterans have access to a wide range of supports and services including dental benefits, prosthetics and orthotics, technical aids and equipment, physiotherapy, medications, massage, health-related transportation, homemaker services and diverse forms of respite for their caregivers. While family needs are assessed by a caseworker, these may be broadly defined and usually are approved if considered reasonable. The identified needs are then translated into a given amount of money that the family can use to purchase required supports.

The Findings

Overall Awareness

Few respondents had ever heard of the National Respite Care Project and not many were familiar with the work of the Canadian Association for Community Care. While unfortunate, this finding should come as no surprise. Only a handful actually could identify the diverse streams of research under way with respect to respite, let alone the foundational pieces of work carried out in the 1990s under the auspices of the McConnell-sponsored project. Many were aware of individual studies – but typically only those funded by their own branch or department. There is a clear knowledge gap in this area.

Lack of awareness of the National Respite Care Project, in particular, is likely due to several factors. The first relates to personnel change within government. Several individuals indicated that they are new to their positions and are just beginning to understand the scope of relevant issues in respite.

This problem is not unique to the field of respite or community care more generally. It is true of all major policy areas – and in fact comprises a major barrier to deep structural and systematic policy reform. Typically, few individuals remain in the same substantive area over the period of time required to create an appropriate legislative and policy context in a complex and multidimensional field like community-based supports.

It may be unrealistic, however, to expect that a stable group of bureaucrats will stay in place over an extended period. The federal government functions increasingly as a managerial operation in which personnel move frequently not only to related positions within the same department but also to areas with entirely different knowledge requirements. This reality highlights the need for a stable repository of core knowledge both within and outside of government that maintains the history and conceptual integrity of all substantive policy areas.

The lack of awareness of the foundational work in respite is an important lesson. It means that any organization which assumes the policy ‘stewardship’ for a given issue must continually update relevant government colleagues who likely will be new players after a few months and almost certainly after a year or two. It is now incumbent upon the voluntary sector, as is the case in other fields, to keep alive the policy issue and to ensure that policy-makers in government – at both political and bureaucratic levels – remain informed of major developments.

Another challenge arises from the fact that respite typically is treated as a subset of other policy domains, such as home care. There does not appear to be a principal body or group of officials concerned only with respite. It generally is seen as a component of home care or long-term care. The one exception is the newly announced compassionate care leave provision, which is a policy measure intended explicitly for caregivers.

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As a result, the area of respite does not have a strong and independent policy presence. It tends to be treated as a secondary component of other ‘primary’ issues. One respondent even commented that we should not be talking about respite alone because it is linked intrinsically – in both concept and practice – to the delivery of home care.

Finally, a key informant raised a general question about the word ‘respite.’ She noted (and others in the meeting agreed) that the term ‘respite’ is not commonly used by the public. If policy-makers are not familiar with the term ‘respite’ or even with the concept of respite as outcome, they certainly are not alone. The voluntary sector, researchers and policy-makers all must be conscious of this language gap if they want to engage with the public around this issue.

Specific Concerns

Accurate representation

Only a handful of respondents had ever heard of the term ‘respite as outcome,’ let alone understood what it means. It is not a concept with which policy-makers are readily familiar. But it required only a few sentences of explanation for most key informants both to grasp the concept and to agree that it is an accurate representation of the need for a range of supports and services to provide relief to caregivers.

After the initial exploration of the concept, it was clear that most liked the broad scope and flexibility that it implies. In the words of one respondent: “This discussion has made me think about respite in a way I have never seen it before.” She felt that a “new window on the world” had been opened for her. While it is important to be precise about what is meant by respite, one key informant stated that: “My concept of respite was so narrow prior to this discussion.”

One Member of Parliament suggested that the concept of respite as outcome conjured up the image of a “buffet.” She believed that this kind of image would help communicate the need for a range of services and supports to provide relief to caregivers. Typically, governments fund the individual plates on the buffet (i.e., single services) rather than the wide spectrum of choices that, in this case, is required. Governments should instead support the buffet approach – i.e., the infrastructure which enables the provision of a broad array of supports.

Another key informant compared the concept of respite to that of hospice, referring to the multiple dimensions captured by this term. She felt that the concept of respite as outcome should be understood more as a philosophy or way of thinking rather than as an individual service or specific program.

In short, the concept of respite as outcome opens up the range and scope of supports that caregivers might require. When asked, respondents also noted that the notion of ‘voice and choice’ is embedded in this concept because it implies that caregivers themselves should be the ones to define and choose what they need. While several respondents agreed with this concept, they acknowledged the potential problems associated with consumer-defined services. Policy-makers typically see demand-driven supports as “bottomless pits” with limited fiscal brakes – a real policy challenge.

Substitution effect

But not all responded entirely positively to the notion of respite as outcome. One key informant expressed reservation about defining respite so broadly. She gave the example of caregiver training – and placed her remarks within the context of persons caring at home for individuals with a mental illness in which there are ongoing concerns about possible violence. She noted that caregivers may express their need for relief in the form of better training to help them handle their caregiving responsibilities.

Proper training can, indeed, be understood as a crucial means of relief. Her objection to the notion of respite as outcome was that training (to give just one example) is an essential component of at-home care. In her view, caregivers need relief in the form of an actual physical and mental break – *over and above* appropriate training.

The respondent worried that a broad definition of respite inadvertently could result in one form of support becoming *a substitute* for another – i.e., caregivers who received training assistance may not be considered eligible for other forms of help, like taking some time off during the day or going away for a weekend. These caregivers would be deemed to “have had their respite” or “used up their quota” – in this case, training to reduce the stresses of their particular caregiving circumstances.

Similarly, caregivers may experience a sense of relief because they receive some assistance in transporting the care receiver to various medical appointments. But the question then remains – if the care receiver requires help with transportation, should that not be part of the package of essential services? Again, the respondent felt strongly that the caregiver needed relief *in addition to* the services considered an integral component of at-home care.

Her views can be summed up as follows. Essential components of at-home care should be seen as just that: essential. They should not be confounded with the *separate need* that caregivers have for physical relief and time off *for themselves*. While some of the services and supports labelled as ‘respite’ might improve the quality of caregiving and thereby reduce caregiver stress, they may not provide the actual *physical and mental break* that most caregivers require.

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Workforce dimensions

Another key informant involved primarily in labour market issues pointed out that respite as outcome typically translates into the provision of some form of social service or support. The latter may include recreation, socialization (e.g., playing bridge) or personal time (e.g., for a dental appointment or haircut).

The respondent pointed out that the ability to volunteer, do paid work or even continue to work for several hours or days a week actually might be a form of respite for some caregivers. But workforce attachment – whether paid or not – generally is not recognized as part of the respite equation. For some, the ability to volunteer, study, train or go to work a few hours or days a week helps them feel good about themselves. Their relief comes in the form of reassurance that they are protecting their employment status. While respite as outcome may be a broad concept, it also has been interpreted somewhat narrowly in terms of support for work and community participation.

This respondent also noted that the primary concern of respite is the health and social well-being of the caregiver because: “It is the right thing to do.” But from a policy perspective, this “moral and ethical” reason for investing in respite may not carry enough weight. The health and social outcomes are “soft reasons” which would be bolstered greatly, in his view, by labour market outcomes as well.

Supports for respite likely would have good labour market outcomes, allowing some people to maintain their employment and enabling others to complete their education, upgrade their training or look for a job. The problem is that while we have an intuitive sense as to the positive impact of respite supports upon labour market participation, there is a lack of solid evidence in this area.

The respondent felt that if we could answer some of these central questions, then respite might one day be offered as an essential work-related support, available to virtually any person of working age. Its importance would be acknowledged in the same way that we appreciate the value of high-quality child care.

Another noteworthy point was raised about the economic dimensions of respite. If it is made available in one standardized form (e.g., time off for a holiday), it may create an economic burden for caregivers, who would have to leave work in order to receive that support. One respondent who is also a caregiver said that she could not afford to make use of the respite in the form in which it had been made available. The respite actually would have created an economic burden rather than providing any relief.

Differences in respite needs

i. Time frame

Another set of issues arose around the importance – from a policy perspective – of thinking less simplistically about respite as a generic concept (even when broadly defined). Several respondents pointed to the need for more precision about the differences in respite needs that may arise from diverse conditions of the care receivers. Two variables were identified as particularly important: length of time over which care is required and the precise circumstances of the care receiver.

With respect to the time factor, several respondents noted that the respite needs of caregivers providing palliative care are different, for example, from those caring for children with severe disabilities. Palliative care typically does not last beyond six months. While exhausting and stressful, the caregiving time frame is relatively short. Sometimes the time limit makes caregivers even more determined to provide the best possible quality of care. By contrast, most parents caring for children with severe disabilities know that they must provide care for life.

This finite time frame makes the need for respite distinct from parents caring for a child with a severe disability – a circumstance that usually will not improve over time (it may even deteriorate) and is expected to continue indefinitely. In fact, these caregivers face the added pressure of ensuring the continuation of supports after their death. Several key informants noted that the concept of respite as outcome – no matter how broad – inadvertently may not capture the nuances of caregiver needs. These should not be grouped together as though the underlying circumstances of care are unimportant or irrelevant.

ii. Needs of care receivers

Another significant factor arises from the needs of the care receiver and the precise condition for which care is required. One respondent pointed out, for example, that those caring for persons with mental illness have both caregiving and respite needs that are distinct from those caring for persons with cancer, cerebral palsy or Alzheimer. Respondents identified the importance of differentiating the supports, based on the required care.

The concern was that important dimensions of need could be lost if the concept of respite as outcome is employed too bluntly without recognizing or making explicit reference to the unique circumstances of both the caregivers and the care receivers. This concern generated some discussion about the appropriateness of dealing with respite or caregiving, more generally, apart from the specific condition. In fact, several respondents believed that the respite needs of caregivers of the elderly and of those who require end-of-life care should be kept separate from the needs of those

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caring for children and other family members with severe disabilities. The current policy environment tends to reinforce this distinction.

But there was no consensus on this point. Several agreed that while caregiving responsibilities may differ dramatically, the overall needs of caregivers for occasional relief are fundamentally the same.

In fact, one key informant argued that it is these distinctions which have kept the issue of respite and caregiving, more generally, so hidden. It is difficult to get something onto the public agenda if there is no concerted effort or common theme coming forward to policy-makers. The respondent noted by way of example that the reason why there has been so little progress on the disability agenda is that the community groups themselves never seem to agree on common directions.

This dissension has made it easy for policy-makers, in his view, to use the divide-and-rule tactic in which they can point to a lack of consensus as an excuse for their own inaction. Respondents acknowledged that it is important not to create a scenario in which the needs of certain caregivers are considered more pressing or more worthy than those of other caregivers. An appropriate policy solution should seek to avoid a competing-interests scenario.

Finally, respondents noted some of the other factors associated with family circumstances. Low-income caregivers tend to get preferential treatment because of the substantial targeting for at-home services. Some households are not eligible for any form of respite because both parents live at home. The eligibility rules inadvertently create an incentive for family break-up. One key informant noted that it is easier to get access to various forms of support at home if the care receiver is considered at risk. It is almost essential to exaggerate needs and conditions in order for the system to pay attention. Any policy development in this area should address some of these built-in perversions.

iii. Urban and rural differences

Several key informants noted that the needs of caregivers in rural settings are different from those in urban settings. Caregivers in rural areas often are asked to provide care beyond what they have the capacity to do. The 'young old' are caring for the 85-plus group – the fastest growing segment of the population. Many 70- to 80-year-old volunteers, for example, are delivering Meals on Wheels. These respite providers themselves are exhausted and in need of respite.

The problem is particularly acute in rural areas because of several complex demographic factors. Many retired and elderly Canadians are returning to rural areas where they grew up. At the same time, young people are moving increasingly to cities. As a result, rural areas appear to be aging even

more rapidly than the rest of the country. (One respondent noted that some research is being carried out at Queen's University on the geographic dimensions of aging.)

It also was pointed out that the needs of caregivers in northern and remote areas of the country are not well understood. There is a large gap in overall life expectancy between residents in northern and southern parts of the country. Several respondents wondered about the implications of this reality for the design of home care and related respite supports. On this note, one key informant pointed out that neither the National Respite Care Project nor the follow-up *Give Me a Break!* report adequately captured this dimension of respite.

Problems in the Broader System

A common thread that emerged was that problems related to respite are linked intrinsically to deficiencies in the broader health care system. It is difficult to solve concerns in one dimension, such as respite, when so many fundamental weaknesses remain unresolved.

They noted that in formal home care, for example, no distinction is made in the staff training for the diverse supports that different caregivers may require. How can appropriate training be available for informal caregivers if the differentiation is not even made at the formal level? How can formal caregivers properly train informal caregivers? Many family members are providing care in areas around which they are not sufficiently prepared.

Several key informants worried about the offloading of professional responsibility to families and communities. The services currently in place are not adequate in terms of persons who are medically fragile. When special needs arise, such as bladder infection or pneumonia, the required supports usually are not available. This lack of supports opens the door to serious medical errors and clearly causes stress for families.

Another weakness in the broader system relates to the fact that relatively few doctors specialize in palliative care. There are limited numbers of specialists upon whom caregivers or even community workers can call if they require help. The shortage of available professional specialists creates pressures that could be relieved not so much through respite for caregivers but through improvements in the formal delivery of palliative care.

There is also a need for training additional general practitioners in the basics of palliative care. In the absence of sufficient trained specialists, GPs have had to assume primary responsibility for sick and dying patients. These physicians usually are ill equipped for this role, creating yet another burden on informal caregivers.

Policy Application

Availability of Evidence

Respondents were asked what policy-makers require in the way of information, dialogue or other interventions in order to understand and promote the concept of respite as outcome. Several factors were identified. Policy-makers require more information on the need for respite. They should have more direction on the interventions proven effective – i.e., the wide range of supports and services that have been shown to provide relief to caregivers. They need to understand more about the policy levers that can help translate this concept into practice.

In their day-to-day work, few respondents actually had singled out the issue of respite from a policy perspective. Most are working in related areas. Respite typically is treated as one element within a broader spectrum of services.

One key informant was not too concerned by the fact that respite did not have its own focus or that it is a complex area. In his view, a focus for this area simply needs to be created. In terms of complexities, the respondent argued that policy development should be characterized as a problem-solving process. Policy is all about solving problems and he believed that no challenge is too complex.

He argued that the first step in solving problems involves presentation of a clear definition of the problem, an estimate of how many Canadians actually or potentially are affected and a compelling explanation as to why the lack of supports for respite is a concern. The formulation of policy options and their associated strengths and weaknesses are also essential components of problem-solving. The scope and limitations of the federal role then must be considered relative to the role of other actors, particularly provincial and territorial governments.

The respondent also identified the need to determine the potential costs of providing a range of respite supports. He noted that it is difficult for policy-makers to come to grips with the scope of an issue in the absence of cost data – even if it is only a set of estimated costs based on factors such as number of hours of a given service. Although recent studies have been conducted on the costs and benefits of home care, there is no analogous data on respite.

While providing sufficient evidence is the essential first step in the policy-making process, most respondents identified substantial knowledge gaps in this field. The first National Respite Care Project and the *Give Me a Break Study!* were foundational pieces of work in the country and helped pave the way for a wide range of subsequent studies.

Marcus Hollander and Neena Chappell, for example, have carried out research on the cost-effectiveness of home care. A study is being undertaken at the University of Toronto on whether the

home is always the most appropriate venue for the delivery of a medical service. Tools for assessing the needs of caregivers have been developed at Mount St. Vincent University. Work on care for caregivers is under way at the University of Ottawa and McMaster University. Queen's University is exploring the geographic dimensions of aging. The Social Sciences and Humanities Research Council is carrying out a five-year project headed up by Nora Keating at the University of Alberta on the conceptualization of care. The Association of Canadian Medical Colleges is considering the submission of a proposal for developing training modules on palliative care to be taught in medical schools.

Several voluntary organizations are also involved in research. The Canadian Mental Health Association, for example, recently has completed a research project assessing the mental health needs of seniors and the role of home care in meeting those needs.

Health Canada is undertaking an environmental scan of current provincial and territorial respite services. This scan will include only those services delivered by provinces and territories – it will not capture initiatives such as caregiver support groups set up by voluntary organizations. But the study will make a special point of asking about services in rural parts of the country.

Again, several respondents noted that work on the cost-effectiveness of respite is missing; the Secretariat on Palliative and End-of-Life Care plans to fund some research on the economic and social costs associated with caregiving. The Secretariat will be supporting two researchers – a social worker from Quebec and an economist from Alberta – to work with five participating centres across the country. It will be a prospective study in which a survey will be repeated every two weeks during the course of the care. Respite costs are expected to vary significantly by region and by form of delivery – e.g., someone coming into the home to enable the caregiver to get away for a week or occasional relief. The Secretariat currently is looking for additional funding for a full-scale project to complement its initial investment.

One key informant pointed to the need for more work on the ethics of informal caregiving and the provision at home of various forms of care that used to be delivered in a hospital setting. There is a tendency to assume that the availability of respite is a good thing without taking into account whether the home is actually the most appropriate and safe venue as a “medical arena” for the provision of care. She noted that many people now receive precarious forms of care and that discussions of respite must recognize the potential dangers in the shift to the provision of at-home care. The prevalence of respite actually may prolong a situation that is fundamentally unsafe for the care receiver.

Another respondent echoed the concern and raised an associated worry related to the deferral of care. While respite for caregivers helps their stress, an at-home arrangement actually may delay essential treatment that the care receiver requires. It is unclear whether the availability of respite delays or hastens the rate of placement in institutions.

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There has been relatively little research on mental health home care needs and associated respite supports. Several respondents were pleased that the Romanow Report identified this area as a priority. We have limited understanding of the needs of caregivers when potential or actual violence is involved.

Finally, it was noted that little is known about the needs of male caregivers. While the majority of informal caregivers are female, the proportion of male caregivers is growing (an estimated 15 percent of caregivers are male). Many spouses are now looking after their wives who have Alzheimer or various forms of cancer and mental health conditions, such as depression.

There was a question as to whether we know enough about the most effective forms of respite. Outcome data on the effectiveness of various types of respite would be helpful. One respondent wondered whether there is sufficient information on best practices. She felt that if we really want to look at outcomes (which she noted is implicit in the concept of respite as outcome), it is essential to tease out and evaluate various factors that appear to lead to the desired outcome. She cited as one effective model a respite project for the caregivers of children with disabilities undertaken in London, Ontario, in the 1990s.

Once the theoretical and practice evidence for good decision-making is in place, it then must be strategically disseminated. It was clear from these interviews that policy-makers had not received any of this information.

In addition to research and practice evidence, policy-makers also should have a clear idea as to who is doing what – both within and outside the federal government. This awareness does not exist even within single departments, let alone across the entire government. There is a need to house together the wide range of evidence that is accumulating on respite and on the profiles and needs of caregivers.

Policy-makers indicated that a succinct description of the concept of respite as outcome would be helpful and could assist them in articulating this idea to others. They also need to understand the range of policy options, their associated strengths and weaknesses, and the links to related policy areas.

Links to Related Policy Areas

An issue that was raised in several discussions is the fact that policy development has not made the links between respite and related areas, like housing and transportation. It was suggested, for example, that closer ties be developed with the Canada Mortgage and Housing Corporation to promote integrated design for housing, home care and respite.

Housing affordability is another policy issue related to respite. Families that are squeezed to pay the rent usually cannot afford to purchase suitable respite. The caregiving burden can be especially heavy for employed caregivers who must leave their job in order to provide at-home care. But many caregivers must continue to work because of concerns regarding their future income security.

The ability to pay for respite was raised as another issue that needs policy attention. When a service is considered to be ‘medically required,’ then it is covered by medicare. But when a service is delivered as ‘extended health care,’ then user fees may apply. Care at home often means that the family ends up paying all or part of the cost of service that used to be available in hospital and therefore covered under medicare.

Several respondents suggested that the affordability recommendations in the Romanow Report on health care are crucial. The inclusion of home care within medicare is intended not only to expand the availability of this service but also to ensure its affordability. Romanow recommended a two-year transitional fund to establish the infrastructure for home care and palliative care under an amended Canada Health Act. (Some respondents noted that the weakness of the report is that it cast its net fairly narrowly in terms of palliative and end-of-life care.)

Generally speaking, respondents pointed to the need for provincial and territorial involvement to ensure the presence of a wide range of supports and services that potentially could provide respite. Home care is considered provincial responsibility, aside from the federal authority for Aboriginal Canadians and veterans.

Most key informants felt that provinces would not take well to the federal government attaching conditions to their spending. The federal government effectively is in no position to tell the provinces directly that they must spend money for respite. In their view, the direct federal role in respite was fairly limited.

According to these respondents, the most appropriate role for the federal government is to generate national information and research, and to support evaluative work to help create the evidence base for good practice. Provinces and territories, in turn, are responsible for putting in place the actual supports.

Key informants generally had not considered this larger role that the federal government potentially could play. They were asked whether they thought, from a policy perspective, that the issue of respite as outcome could be linked to other multidimensional policy areas. Early childhood development and disability supports are cases in point. The Early Childhood Development Agreement, signed in September 2000, enables Ottawa to direct funds to provinces and territories in respect of a wide range of broadly defined early childhood development programs.

What Are Policy-Makers Saying about Respite?

Disability supports is a complex field that seeks a menu of solutions based on individual needs. Proposals have been put forward for a national disability supports initiative in which the federal government would allocate a designated amount of funds to provinces and territories to enhance the supply of disability supports, which include a wide range of equipment and services.

While respondents themselves did not make these links, most found it helpful to be able to refer to actual policy precedents or other active policy proposals. The politicians, in particular, saw these examples as valuable in that they themselves have been struggling with the policy dimensions of both early childhood development and disability supports.

These policy analogies helped make the links to respite. While the federal government may appear to have only tangential responsibility in this area, it actually can play an active role in bolstering the supply of supports and services through its spending power. As noted, the unanswered question is whether the provinces and territories will buy into a deal that sets conditions or ‘strings’ on any federal dollars.

On another dimension of the federal role, two key informants made reference to the current tax provisions – the caregiver credit and the infirm dependent credit – related to caregiving. Both felt strongly that these measures are “useless to families,” many of whom are unaware of their existence. Their value is so low that they barely provide any assistance. Moreover, because the two credits are nonrefundable, they are of no use to households too poor to pay income tax. These key informants believed that governments should be investing in the *supply* of supports and services. In their view, there is no point having extra cash, however modest, if there is nothing appropriate to purchase.

Window of Opportunity

Most respondents felt that it was a good time to be putting respite on the public policy agenda. As noted, the 2003 federal Budget announced the compassionate care leave provision intended explicitly for caregivers. The Budget also introduced a new Child Disability Tax Benefit to recognize the additional costs (including respite) incurred by parents caring at home for children with severe and prolonged disabilities.

The federal Budget allocated funds toward health care in respect of the recently signed First Ministers’ Accord on Health Care Renewal. The Accord identified home care as a major pillar in the basket of health care services in which investment is required. First Ministers agreed to provide first dollar coverage for this basket of services for short-term acute home care, including acute mental health care and end-of-life care. The Accord states that: “First Ministers agree that access to these services will be based on assessed need and that, by 2006, available services could include nursing/professional services, pharmaceuticals and medical equipment/supplies, support for essential personal care needs and assessment of client needs and case management.”

But there is no explicit reference to respite *per se* in the Accord on Health Care Renewal. This omission is surprising; at the Annual Premiers' Conference held in August 2002, Premiers committed themselves to developing a coordinated long-term care approach. Within this overall commitment, they identified five discrete but related strategies, the *first of which was support for caregivers*.

The commitment in the Accord on Health Care Renewal embraced several of the recommendations on community care in the Romanow Report. The Kirby Senate Committee is slated to follow up its initial report on health care with a focus on community care.

Federal Health Minister Anne McLellan has identified home care as one of her top priorities and Senator Sharon Carstairs is an active champion of palliative care. The Secretariat on Palliative and End-of-Life Care, which reports to both Minister McLellan and Senator Carstairs, is developing a long-term strategic plan. As noted, Health Canada currently is conducting a survey of provincial and territorial respite services in recognition of the need for more information in this area.

Several respondents pointed out that in addition to important policy developments, pressing social and economic needs should help raise the profile of respite. One key informant noted that the demographic profile of the population increasingly will create a demand for care at home and respite for caregivers. Both home care and respite should be positioned far more strongly within the context of population aging in order to make it an issue that both policy-makers and the public understand.

The discussion led another respondent to suggest that respite be framed within a demographic context that looks not only at population aging but other relevant factors, such as the labour force participation of women, marital status and the geographic dispersion of families. There is a tendency to assume that all seniors live in a concentrated core region when, in fact, they are widely dispersed in inner cities, suburbs and rural areas.

One respondent pointed out that while the window of opportunity may now be slightly open, it is fairly late in the game relative to identified needs. Her concern was widely shared: The policy and practice related to respite are well "out of sync" with the realities of most families.

Recommendations

The recommendations presented here reflect both the direct comments of key informants and an interpretation of these comments. In some cases, respondents actually suggested explicitly that the McConnell Foundation carry out certain actions. In other instances, they made proposals as to what should be done in the field, not necessarily by or even through McConnell to help advance the respite agenda. But the range of issues is included so as to relay the full scope of the discussions.

What Are Policy-Makers Saying about Respite?

Perhaps the first and basic conclusion is that there is a need for a *knowledge home* for respite. There is actually a need for a core policy presence in all fields – including respite – in order to capture the basic concepts and research that comprise the elements of a given policy area. But respite, in particular, appears to require a home to house its core knowledge base. This finding speaks to the importance of the work of the Canadian Association for Community Care and the Canadian Caregiver Coalition.

While substantial research on various aspects of respite has been carried out or is under way, most policy-makers are unaware of this work. Because the research is being conducted in a piecemeal fashion by various government departments as well as different branches within single departments, universities and voluntary organizations, it is difficult for any policy-maker to have a sense of the available and forthcoming evidentiary base. Even those actively working within this field are unaware of the full scope of current work.

There is a need for *knowledge transfer with respect to research on respite*. There appears to be no effective system of disseminating available research findings. There is no strategic approach to knowledge dissemination; if one exists, policy-makers are not aware of it.

There is a need for *knowledge transfer with respect to effective practice models*. The evaluation results of tested models should be more broadly shared. In fact, one respondent asked whether the evaluation results of the pilot projects supported by McConnell as part of and subsequent to the National Respite Care Project could be made available. He felt that these results could help shape future community work.

It is clear that respite also needs a *policy home*. This requirement highlights once again the importance of the Canadian Association for Community Care and the Canadian Caregiver Coalition. There must be a strong and stable voice outside of government which can speak to the diverse dimensions of respite and the range of supports that potentially can provide respite. There is a need for an organization that keeps this issue alive in the face of changing governments and policy-makers.

A policy home is required for other reasons as well. Current policy work with respect to respite not only is embedded in other ‘primary’ policy areas but also is scattered among various departments and branches within the same department. There is also a lack of policy coherence in this area. Most of the work under way in the country falls within the purview of Health Canada because respite is linked intrinsically to primary health care reform and home care. Other than the recently announced compassionate care leave provision within Employment Insurance, respite effectively is treated as a policy residual that is subsumed within other areas.

There is a need for *policy development* that involves rigorous analysis of the various dimensions of respite. The analysis should address the questions raised by one respondent regarding the requirements for building a policy case. On the one hand, respite often gets embedded within other issues and does not get the attention it deserves. It is seen as a subsidiary to home care, just like the needs of caregivers generally are considered secondary to those of care receivers.

There is a need to *translate the broad concept into policy terms*. It is essential to explain far more clearly to policy-makers the notion of respite as outcome. One way to do this is through a short commentary that succinctly describes the concept.

It also would be helpful to *articulate policy analogies of relevance to respite*. Examples of these policy analogies – the Early Childhood Development Agreement and proposals on disability supports – could help explain various dimensions of the federal role in ensuring the availability of a menu of services and supports.

It is important to find ways to *relay these ideas to the general public*. While most caregivers understand all too well the need for respite, they rarely use that term to describe their need for relief. There is a disconnect between the research community and the general public in terms of their understanding of and language around respite.

Finally, a note about the interviews themselves is in order. In the meetings which several staff attended together, respondents mentioned that holding a discussion in which their colleagues were engaged with an ‘outsider’ actually was very helpful. It gave them some time to reflect on and debate some of the policy issues related to respite in particular. Few of them actually had focused on this dimension of the community care continuum – primarily because respite typically is lumped together with other areas but never really explored as an entity in itself.

Another unanticipated consequence of this discussion is that it encouraged reflection and debate among those working together in the same unit or in the same department. While it is often assumed that colleagues engaged in similar issues share the same perspectives, in some cases their views were divergent or had not even been articulated before. Most felt that they had learned something new as a result of these discussions. Several indicated their interest in participating in future conversations.

Finally, most respondents were pleased to participate in these interviews. They recognize the need and welcomed the opportunity for informed and clear discussion, which serves in turn as the foundation for well-designed and effective public policy.