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**Policy Challenges:  
The Caregiver/Care Receiver Relationship**

*by*

**Sherri Torjman**

**June 2011**

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This paper is the text of a presentation delivered at the International Conference on Caregiving held in Toronto on June 8, 2011, as part of the Festival of International Conferences on Caregiving, Disability, Aging and Technology. While this paper focused on the policy implications of the caregiving/care receiver relationship, the other panelists explored this issue from service and research perspectives.

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ISBN 1-55382-537-3

Published by:

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## ***Introduction***

Caregiving is concerned with individuals who provide care to the infirm elderly or to persons with disabilities. There are both positive and challenging developments on the caregiving front. The good news is that caregiving is finally being recognized as a significant issue on the public policy agenda. Never before has such direct attention been paid explicitly to this policy domain.

The challenges relate to the fact that caregiving is a complex policy area. Its solutions must respond to highly individualized needs and diverse circumstances. While the caregiving agenda is concerned primarily with caregivers, it is clear that interventions directed toward care receivers can provide significant relief from caregiving pressures.

The purpose of this discussion paper is to explore the policy challenges and opportunities embedded in the caregiver/care receiver relationship. The paper is divided into three main sections.

Section 1 sets out the context for caregiving as a public policy issue. It points to several core drivers that have helped make caregiving a more prominent policy issue in recent years.

Section 2 examines the unique challenges and opportunities rooted in the caregiver/care receiver relationship. These are discussed with respect to the major components of the policy process: key issues, desired objectives, identified targets, selected interventions, financing, and monitoring and assessment.

Section 3 considers potential strategies to enhance these advantages and address the myriad challenges.

### ***#1 Caregiving as a Public Policy Issue***

Caregiving has garnered significant public attention in recent years. The major factors driving this agenda include consumer voice, an aging population and rising costs.

#### ***a. Consumer voice***

Caregiver voice was largely silent until the mid-1990s. A significant turning point came in November 2000 when more than 50 participants from across Canada, including caregivers, professionals, researchers, government officials and voluntary organizations gathered at the founding meeting of the Canadian Caregiver Coalition. The consumer voice has been bolstered by a number of significant academic studies over the years that have helped build the empirical evidence base of the caregiving field [e.g., Hollander, Lui and Chappell 2009; Fast, Williamson and Keating 1999; Keefe and Fancey 1999].

There is also a growing movement in the health field around patient- and family-centred care. This movement seeks to ensure that professionals in the health care field listen actively and *genuinely* to the voice of patients and their caregivers.

### ***b. Aging population***

Canada's aging population is helping to cast a spotlight on caregiving. The average Canadian is now expected to live to age 81. By 2036, the number of seniors is projected to reach between 9.9 million and 10.9 million, more than double the level of 4.7 million in 2009 [Statistics Canada 2009].

Canada will also have more old elderly people. In 2009, there were an estimated 1.3 million individuals aged 80 or over. According to a medium-growth population scenario, this figure could increase to 3.3 million by 2036 [Statistics Canada 2009]. There clearly will be a greater demand for caregivers in future.

Caregiving has assumed more prominence on the public agenda as policy-makers grapple with the anticipated costs of an aging society. According to the International Monetary Fund, the toll of aging on G20 nations will be 10 times more than that of the recent financial crisis – and will be even higher in Canada.

### ***c. Rising costs***

While the cost of health care in particular is a major concern, some clarification is required. A recent national study points out that multiple chronic conditions – not age – drive health costs [CIHI 2010]. The number of health care services used by seniors is determined more by the number of chronic conditions than by age.

Seniors age 85 and over with no chronic conditions made less than half the number of health care visits compared to younger seniors (ages 65 to 74) with three or more chronic conditions such as diabetes, hypertension and heart disease. Seniors with three or more chronic conditions reported using three times as many health care services as Canadians age 65 and older with no chronic conditions [CIHI 2010].

Rising health costs have become a high-profile issue, especially in light of the pending expiry of the Canada Health Transfer in 2014. Health care spending could comprise almost 19 percent of the Canadian economy within 20 years, up from about 12 percent today [Dodge and Dion 2011]. That rise represents a per capita increase from about \$5,000 in 2011 to \$10,700 by 2031 in constant dollars. Home-based options are being viewed increasingly as a key part of health care reform – effectively pushing caregiving to the heart of the public policy agenda.

## ***#2 Policy Challenges and Opportunities***

The first step in the policy process – ensuring that caregivers and the caregiving relationship find a place on the public radar screen – is succeeding well. The tough policy challenges embedded in the complex caregiver/care receiver relationship must now be articulated and addressed.

The purpose of public policy in any realm is to achieve a goal considered to be in the best interest of society. Policy development basically scopes out the dimensions of a given issue. It then sets in motion a decision-making process that identifies a desired objective (or set of objectives) and various means to achieve that end.

The target of the intervention is next identified – the entire population or a subset based on selected features such as age, gender, marital status, Aboriginal status, geography or presence of a health- or disability-related condition.

The formulation of policy measures then involves the analysis of actions that might respond to the identified goal. Possible interventions are weighed against a number of factors, including cost and financing considerations. Monitoring and assessment are other core elements of the policy process.

These core elements are laid out in Figure 1. Of course, the policy process does not follow a neat, linear trajectory as this diagram implies. However, for the purposes of this discussion, it is a helpful conceptualization in that it includes the primary considerations addressed in the policy process.

There are major questions related to the caregiver/care receiver relationship that arise at every stage of the policy development process. The following discussion briefly explores each step and the associated challenges and opportunities.

### ***a. Key issues***

The first action in the policy process is to articulate key issues. In the case of caregiving, there are several major challenges and opportunities related to boundaries, innate tensions, and depth and duration of the caregiving relationship.

The *boundaries* of the caregiving relationship – i.e., the point at which formal caregiving begins – need to be better understood. The presence of an elderly parent/friend or family member with a disability does not necessarily equate with caregiving. In any relationship, there may be light caring responsibilities but these are no different from regular family/friend connections.

A caring relationship that occasionally involves assistance with shopping or transportation, for example, is part of everyday life. A *caregiving* relationship, by contrast, typically requires some form of intimate personal care or intervention outside the realm of the ordinary –

e.g., administering medication; assisting with toileting or personal grooming; or assuming the legal competence or financial responsibility of the care receiver. A formal study of caregiving costs noted this distinction.

It is recognized that some caregiving may be for short periods of time or may entail matters better described as ‘help’ or ‘assistance,’ such as providing transportation. However, we use *caregiving* to cover the full range of unpaid care provided from some basic help to personal care [Hollander, Liu and Chappell 2009: 42].

The boundaries issue is important in terms of eligibility determination. Take, for example, a measure such as the infirm dependant tax credit. At what point is an aging parent considered ‘infirm’? When does a concerned daughter or son who makes regular phone calls or visits become a ‘caregiver’ to an aging parent?

Another policy complexity embedded in scoping the caregiving relationship relates to its *innate tensions*. These can arise from the fact that some adults with disabilities react negatively to the ‘care receiver’ label. Many believe it inadvertently can relegate them to the status of dependent patient within a medical model rather than independent citizen within a human rights framework of disability. As a result, some argue that the concerns of caregivers and of so-called ‘care receivers’ should be considered at separate policy tables.

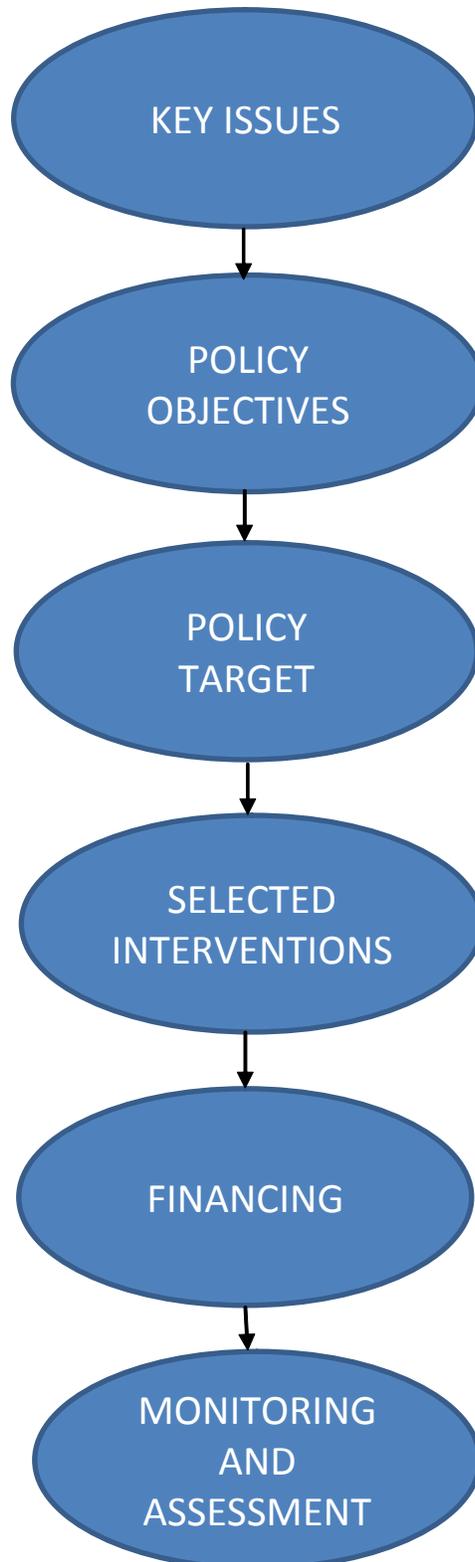
Finally, most policy challenges are rooted in the specific circumstances of individuals, groups or place. In the case of caregivers/care receivers, by contrast, policy challenges are defined by the *depth and duration of the caregiving relationship*. This relationship is a function of the condition of the care receiver, including age as well the type and expected duration of the frailty or disability.

Age of the care receiver makes a significant difference to the caregiving relationship. A caregiver’s life trajectory can be profoundly altered, for example, by the birth of a child with a severe disability. The need for supports for the care receiver may be more significant and the duration of care is certainly longer. The employment status of the caregiver is also likely to be affected if the caregiving period is expected to be intense or of long duration.

By contrast, caring for a spouse who has acquired a disabling condition fairly late in life, such as Alzheimer’s, may mean an intensive but relatively short period of caregiving. The needs of the caregivers of frail seniors may be quite different from those caring for persons who require palliative care. In the latter case, the caring requirements may be significant but they are usually time limited. The duration of caregiving does not typically extend beyond several weeks or months.

The needs of the elderly may be distinct from those of persons with severe disabilities. In the case of the elderly, a significant question is whether the care receiver is experiencing the normal process of aging or whether he or she is living with some form of disabling condition. In the latter instance, the nature of the caregiving relationship is shaped by several additional factors related to type of disability.

**FIGURE 1**  
**The Policy Development Process**



There may be unique pressures involved in caring for persons with some form of mental or emotional disability. The behaviour may be less predictable and more stressful for the caregiver. It may be hard to communicate with the care receiver or to understand his or her unique needs if speech problems are associated with the disabling condition.

Progressive mental deterioration also means that caregivers must make more decisions on behalf of care receivers. It is often difficult to know when to deem care receivers as mentally incompetent.

In short, the caregiving relationship defines the diverse and highly individualized nature of the caregiving tasks. The depth and duration of the caregiving relationship are among the key factors to consider when scoping out the issues in this policy domain.

### ***b. Policy objectives***

Once the nature of the caregiving relationship is clarified, the next step is to identify the policy objectives that subsequent interventions should seek to achieve. In terms of caregiving, the policy challenges and opportunities involve goal selection, needs assessment and caregiving voice.

Wide-ranging recommendations have been made over the years with respect to the caregiving agenda. Despite the scope of the various proposals, they effectively can be grouped into two major streams of desirable actions, which help narrow the process of *goal selection*.

The first core policy objective of the caregiving agenda is to enable caregivers to carry out more effectively their caregiving role. The second core policy objective involves easing the pressure on caregivers by providing some relief from their ongoing caregiving responsibilities.

It appears at first glance that these two objectives are discrete and distinct, almost on parallel tracks. The first objective focuses on more effective achievement of caregiving tasks while the second objective involves temporary removal from the caregiving role.

One might argue, however, that the opposite is true – that the two objectives are intrinsically linked. Caregivers experience relief when care receivers receive good care whether delivered by themselves or a professional service. Because of the unique nature of the caregiver/care receiver relationship, the attainment of the second objective actually may be made possible by achieving the first – a significant advantage.

A second challenge with respect to policy objectives involves the *assessment of caregiver needs*. On the one hand, it is clear that these are determined largely by the age and condition of the care receiver.

But caregivers themselves have their own distinct needs. These are often overlooked because of the primary focus on the care receiver. Caregivers can experience isolation and depression, which are not treated in a timely fashion.

In order to highlight the separate and distinct social and emotional needs of the caregiver, the VON Canada Caregiver Best Practice Team has supported the use of the CARE Tool and Caregiver Risk Screen. This psychosocial assessment tool treats caregiver needs as equally significant to those of the care receiver [Keefe et al. 2008]. It allows the needs of both parties to the relationship to be assessed with equal weight.

Finally, *caregiver voice* is a crucial dimension in setting policy objectives. Voice refers to the fact that caregivers themselves want to be actively involved in identifying their unique needs and in developing the policies and programs that affect them. In fact, it is one of several principles that caregivers have highlighted – along with choice, empowerment and recognition.<sup>1</sup>

In summary, the policy process involves the articulation of core objectives. Perhaps the most important factor is to ensure the inclusion of caregiver needs and voice in the selection of these objectives.

### *c. Policy target*

The policy development process requires a clear statement of target. The caregiving relationship raises a number of policy challenges and opportunities related to the identification of primary target, prioritization and target differentiation.

Public policies typically focus upon individuals, families, groups or places. Employment Insurance and the Canada Pension Plan, for example, are social insurances that are concerned with protecting income due to temporary or permanent absence from the workforce. The Canada Child Tax Benefit is a policy measure that seeks to bolster the income security of Canadian families with children. Policies that focus on immigrants, First Nations and persons with disabilities are concerned with the well-being of members of these groups. Finally, economic development strategies are examples of policies that focus on place.

Caregiving is a policy domain that is somewhat different from these other discrete areas. It is far more difficult to identify the *primary target*.

Caregiving is concerned with individuals who provide care to the infirm elderly or to persons with disabilities. But as noted, the health, well-being and capabilities of the care receiver directly affect the well-being of the caregiver. Indirect interventions directed toward care receivers can provide significant relief from caregiving pressures.

Because of this intrinsic link, interventions that assist care receivers in terms of income security, services and supports typically result in direct or indirect relief for caregivers. Simi-

larly, supports provided to ease the responsibilities of caregivers generally have a positive, albeit indirect, impact on care receivers.

This mutually interactive dimension means that caregivers can benefit both directly from interventions designed for them and indirectly from measures intended for care receivers. On the one hand, this interaction is positive. It means that there are multiple routes to providing caregiver relief. Many of the investments made on behalf of care receivers will have a more powerful impact because they will also be felt by caregivers.

At the same time, this positive dimension gives rise to several policy challenges. With scarce resources, for example, is it better to invest in supports for care receivers, such as home care or attendant care? Or is it preferable to allocate scarce resources toward supports for caregivers, such as respite services that provide some direct (though limited) relief?

Clearly, choices must be made around *prioritization* – whose interests take priority in a relationship in which the needs of both parties are intrinsically linked. Because the concerns of both caregivers and care receivers are relevant, questions can also arise as to whose voice takes precedence if differences arise in such areas as course of treatment or legal competence.

The fact that the target of any subsequent interventions is not as clear as other policy areas highlights the need for *target differentiation*. It is important to identify which measures best meet the needs of which party to the caregiving equation. If a focus on care receivers effectively affords respite to caregivers, then questions can arise as to whether it is necessary to address caregiver needs at all. Both practice and the research evidence would say that the answer is yes – for two reasons.

The first is that certain interventions are *best* targeted toward caregivers. These measures include emotional support as well as training and information about how to handle certain problems pertaining to the condition, legal questions or financial matters.

Second, certain interventions are intended *only* for caregivers. These have to do with employment circumstances including flexible work arrangements, job security, income and pensions, and respite services.

Target differentiation enables policy-makers to select the precise interventions that can best meet the *unique needs* of care receivers and caregivers. It can also identify the specific actions that best meet the *needs of both parties* to this relationship. Disability supports, for example, are of chief interest to care receivers while employment-related leave is of primary concern to caregivers. Information about services and the availability of home care and long-term care, by contrast, are of value to both parties.

In summary, the process of selecting a primary target is complex when the relationship is of primary concern. It is clear from this discussion, however, that the needs of both parties must be given equal consideration.

#### *d. Selected interventions*

The fact that there are interventions unique to each party and common to both parties to the caregiving relationship creates challenges and opportunities in selecting appropriate interventions, especially in a context of relatively scarce resources. Concerns at this stage of the policy process relate to outcome, breadth of intervention and the substitution effect.

Respite is an intervention of particular concern to caregivers. The complexity related to this area arises from the fact that, in recent years, it has become understood not as a single service but more as an *outcome*.

Respite effectively is a break or relief for the caregiver that derives from a number of possible interventions delivered in the home or at another site. These include, for example, a temporary break, personal emergency system, information on care receiver needs, adult day care, housekeeping, outdoor home maintenance, counselling and peer support.<sup>2</sup>

But there are also challenges associated with this *breadth of intervention*. Governments typically are not set up to address needs through wide-ranging responses. Interventions that embody the notion of respite as outcome can be conceptualized as a ‘buffet’ – or broad array of measures that can be selected according to the preferences of the caregiver. But governments generally fund the individual plates on the buffet (i.e., single services) rather than the wide spectrum of choices.

Finally, the potential *substitution effect* is a policy red flag raised by the breadth of intervention factor. Here is how one policy-maker described the problem in a study that was undertaken several years ago on the concept of respite as outcome [Torjman 2003: 7].

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.

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.

The policy development process involves the selection of appropriate interventions. This task can be challenging when many possible interventions can lead to a similar outcome.

### *e. Financing*

The question of financing is a core element of any policy process. Three challenges relate to financing on the caregiving front: projected cost, designated payer and future uncertainties.

Not surprisingly, a major issue in any policy domain involves the *projected cost* of a given initiative. Estimating the cost of supports – whether directed toward the care receiver, the caregiver or both – is a tough issue because the demand for supports is almost infinite. There is no amount that would ever be considered sufficient to meet the needs of both care receivers and caregivers. There are always more investments that might be made in terms of equipment upgrades, increased benefits or additional supports.

As a result of this potentially infinite demand, the typical policy response is to set a maximum lump-sum amount or number of service hours to which a given household is eligible. An outside ballpark figure is then determined by calculating the potential demand for the service times the maximum possible number of hours. Of course, fiscal constraints mean that the levels of available service generally are less than what ideally would be required.

But projected cost is not the only policy challenge within the financing domain. A second, equally important, component relates to the *designated payer*. Governments often make policy decisions on the basis of who will pay for a given measure.

Caregivers and care receivers face both direct and hidden costs with respect to health- and disability-related supports. Direct costs are readily itemizable. They include, for example, technical aids and equipment to enable independent living outside of a hospital or residential care facility, or modification of a primary residence such as the addition of an elevator or ramp. Governments provide these supports or recognize these costs as an income tax deduction.

Hidden costs, by contrast, cannot be easily measured though they are very real – the out-of-the-way trip to the accessible store or the wear-and-tear on clothing. In recognition of the additional hidden costs of caregiving and other financial pressures, the federal government provides some relief through two income tax measures – the caregiver credit and the infirm dependent credit.

These measures are intended to help caregivers by reducing their federal income taxes. But these measures do not provide a lot of money and they are not available to all caregivers – so government offsets only a modest portion of the costs borne primarily by private households.

Other interventions that assist both care receivers and caregivers are somewhat more complex in terms of responsibility for payment. Take, for example, the issue of accommodation. This term refers to changes to the environment to enable active participation in society. It may be in the form of a ramp, sign language interpretation or volume controls on telephones.

To assist with financing, governments can provide tax credits to individuals to offset the costs of accommodation, which benefits both care receivers and caregivers. Alternatively, governments can pay grants to municipalities or to employers to make their respective environments more accessible. The first policy measure places the cost burden primarily upon the individual household with tax-assisted support. The second option makes municipalities and employers the primary payers of the measure – again with tax-assisted support.

Accommodation is positive for both care receivers and caregivers. It assists care receivers directly by making their environments more livable. It helps caregivers indirectly by easing their pressures because the barriers on care receivers are reduced or removed. While both parties benefit from the intended measure, the actual payer in the above examples is different. Policy-makers need to think carefully about which party or parties ideally should bear the burden of the costs – and what proportion of the entire caregiving package they are being asked to carry.

Finally, there are financing challenges related to *future uncertainties*. A major unknown in the caregiving field has to do with the extent to which technological solutions will be employed for caregiving purposes. There are a wide range of technologies that are useful for different types of treatment and stages of care. They include but are by no means limited to:

- new rehabilitation equipment – e.g., for spinal cord injuries
- new drugs and technological interventions for cancer treatment
- Bliss symbol boards and other sophisticated communication aids
- electronic and remote sensing devices to monitor the health and safety of seniors living on their own
- virtual social networks.

These technologies will affect the caregiving relationship in profound ways. They offer improved treatments and quality of life for care receivers. They provide crucial supports for caregivers. But they may also have inadvertent negative consequences in that some care receivers may be left alone more frequently with monitoring devices used increasingly as a ‘replacement’ for personal visits.

The policy challenge goes beyond the fact that many of these technologies are costly. A related problem derives from the unknown – i.e., their price tag. Many treatment and care-related technologies are in their design stages or are being tested. It is difficult to calculate the costs of the technology of the future. But because of potentially high costs, user pay or co-financing may be essential.

Financing is central to every policy process. In the case of caregiving, in particular, there are some unresolved questions related to both who pays and how much.

*f. Monitoring and assessment*

As in financing, monitoring and assessment are core components of the policy process in any field. In the case of the caregiving relationship, the challenges and opportunities related to responsiveness, adequacy and attribution must be addressed.

All public policy initiatives must be assessed at some phase of their design or implementation. Ideally, policies and programs in all areas monitor and correct their course on an ongoing basis. The need for continuing feedback within the policy process is based on the assumption that evaluation is important not just for accountability purposes. There is also a vital learning component implicit in this work, which leads to better quality practice when lessons are widely shared.

Ongoing assessment is especially relevant to the caregiving policy area as caregiving needs typically shift over time, often with greater, not fewer, demands for care. The changing nature of the caregiving relationship means that *responsiveness* to both the needs of caregivers and care receivers is crucial. This is a very significant opportunity to respond more effectively to caregiver needs.

The responsiveness principle translates into practice in various ways – e.g., through information, eligibility and ease of access to services. Direct cash payments in the form of individualized funding, for example, could be made to allow greater choice and flexibility in the purchase of various supports and services.

Responsiveness is also important because of the changeability factor inherent in the caregiving relationship. Disabling conditions with symptoms that recur and remit (i.e., episodic conditions) are typically unpredictable, creating difficulties around appropriate supports for care receivers and around employment and current/future income security for caregivers. Similarly, supports and services must be responsive to the sudden and unexpected onset of disability resulting from an accident or injury.

In addition to responsiveness, *adequacy* is a common benchmark used for evaluative purposes. In the caregiving area, the notion of adequacy presents its own unique problems.

It is difficult to assess adequacy in the absence of designated standards. Evaluating the adequacy of service provision is unlike an assessment in other policy areas such as poverty reduction, for example, in which there are commonly used benchmarks – i.e., the low income cut-off or Low Income Measure.

In the case of caregiving relationship, the primary evidence of adequacy effectively derives from consumer voice. For years, both care receivers and caregivers have identified lack of supports as a major impediment to their care.

In Ontario, for instance, households are eligible for a maximum 15 hours of personal support/homemaking services a week (the limit doubles for adults with physical disabilities) [Canadian Home Care Association 2008: 87]. This ceiling translates into a daily maximum of just over two hours. Clearly, this allocation is insufficient for many households – especially for those in which care receivers require around-the-clock care.

At the same time, however, it is important to acknowledge that home care is one service for which there likely will never be ample supply. Households that provide caregiving can always use additional supports and more help at home. The demand for this type of assistance is almost endless. Supply will never be sufficient relative to demand.

For evaluation purposes, it may be necessary to shift the question from adequacy to sufficiency. The quantity and quality of supports in place for a given caregiving relationship may never be adequate – but they may be good enough. Determining the point of sufficiency is important.

*Attribution* is the third major policy challenge related to monitoring and assessment. Caregivers have sought to ensure the availability of a package of policy interventions in response to their needs. As noted, interventions that help care receivers are also of value to caregivers.

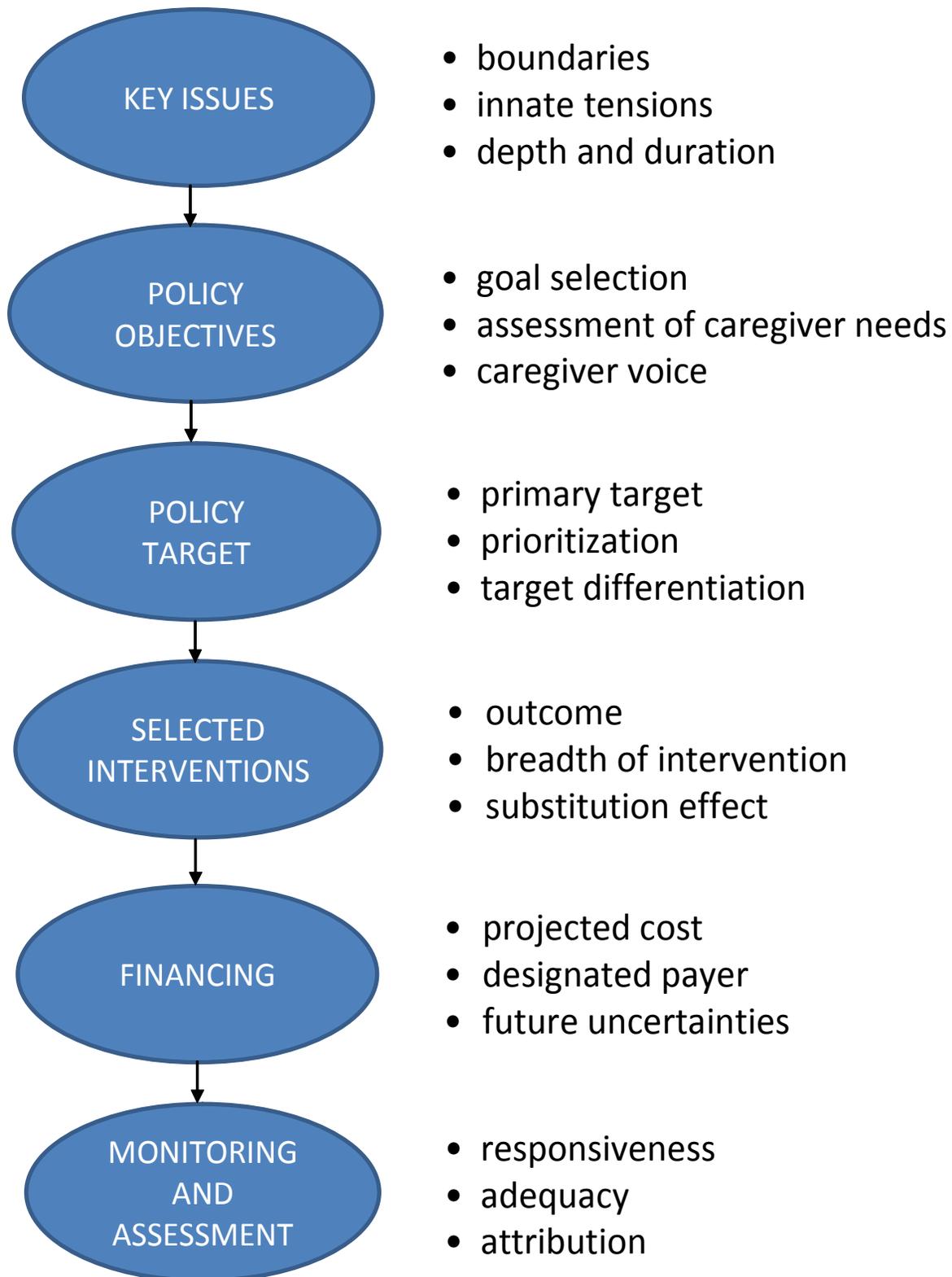
Both the breadth of interventions and the mutually interactive dimension of the caregiving equation make it difficult to attribute changes in the quality of life to a given policy measure. It is hard to pinpoint the precise relationship between a specific intervention and its associated impact.

Indeed, the only way to infer a cause/effect relationship is to ask caregivers and care receivers directly about the influence of a given measure upon their lives. In order to determine the relative effectiveness of various actions, it may be necessary to carry out some form of qualitative assessment through, for example, personal interviews or focus groups involving caregivers and/or care receivers. While these may be slow and costly methods, they are likely the best way to gather rich and comprehensive information. They also provide an opportunity to give expression to caregiver voice.

The policy process necessarily involves plans for ongoing monitoring and assessment. It is clear that caregiver feedback must be sought in order to evaluate effectively the impact of various caregiving policies and practices.

The core elements of the policy process and the associated challenges and opportunities embedded in the caregiver/care receiver relationship are summarized in Figure 2.

**FIGURE 2**  
**Caregiving and the Policy Development Process**



### ***#3 Potential Strategies***

It is clear that the caregiver/care receiver relationship gives rise to significant challenges and opportunities at every step of the policy development process. While there are no magic bullet solutions, there are several strategies that can help tackle these challenges and enhance these opportunities. These strategies relate primarily to the *alignment* of interventions that support the caregiving relationship.

There are three components to this alignment: at the intra-jurisdictional, inter-jurisdictional and multisectoral levels.

#### ***a. Intra-jurisdictional alignment***

Alignment of supports and services at the intra-jurisdictional level is vital to ensure that investments in respect of both care receivers and caregivers are ‘seamless.’ Disability-related goods and services, for example, typically are made available in disaggregated pieces that fall under the auspices of various departments. Within a single level of government, the measures for care receivers and/or for caregivers need to be designed in a more integrated way.

Australia provides a good example of intra-jurisdictional alignment. Its Commonwealth Respite and Carelink Centres comprise a network of 54 centres in 65 storefront locations, typically near shopping centres. The Carelink Centres serve as a single point of contact for care receivers, caregivers, general practitioners, employers and health professionals on all issues related to aging/disability and carer support.

Each centre includes a national hotline and can provide information on services, government programs and eligibility criteria/applications/assessment for financial assistance. Information is available in 16 languages and can accommodate Indigenous clients and persons with visual impairment. Short-term counselling is available at the centres through the National Carers Counselling Program delivered in partnership with Carers Australia. The centres also enable access to the national respite database.

Here at home, the Supportive Care Program introduced by Nova Scotia in 2010 is an example of intra-jurisdictional alignment. It provides \$500 per month to eligible seniors with cognitive impairment to help them purchase home support services such as personal care, respite, meal preparation and essential housekeeping. Clients may also be eligible for up to \$495 a year for reimbursement for snow removal services. Another new measure pays up to \$480 per year to enable eligible seniors to purchase a personal alert assistance device. The Caregiver Benefit Program for eligible caregivers was expanded to assist more than 1,000 caregivers.

The Aging at Home Strategy brought in by the Government of Ontario in August 2007 is another example of intra-jurisdictional alignment. While the Ministry of Health and Long-Term Care assumes primary responsibility for this strategy, other ministries are involved as well.

Under the Aging at Home Strategy, the province expanded community-based options for seniors, providing a wider range of home care and support services to enable independent living at home. These options include home care, assistive devices, assisted living services and supportive housing, long-term care beds and end-of-life care. Ontario announced an expansion of the Strategy in August 2010.

Because of Constitutional responsibilities in Canada, intra-jurisdictional alignment is not sufficient. Supports and services for both caregivers and care receivers are divided between the federal and provincial/territorial governments. For this reason, it is essential to ensure that various interventions in respect of the caregiving relationship line up between jurisdictions as well.

### ***b. Inter-jurisdictional alignment***

There is a significant policy precedent in Canada that provides a model for this crucial inter-jurisdictional alignment. The National Child Benefit was introduced in 1998 under a clear negotiated agreement in which the federal government assumed responsibility for the income payments to households in the form of the Canada Child Tax Benefit and the National Child Benefit Supplement.

Provinces and territories were required to use their windfall cash from social assistance (or welfare) savings to reinvest in services and supports for families. The type of investment was open and could take the form of early childhood development, child care, and recreational or other programs. However, the target of the intervention – low-income households with children – was not negotiable.

A similar inter-jurisdictional alignment, modelled on the National Child Benefit, has been proposed in the disability policy sphere. The proposal for improved alignment derives from the fact that more than 40 percent of Canadians with disabilities are not in the labour force, forcing many of them to rely on social assistance. These benefits are very low and do not bring individuals even close to the poverty line in most jurisdictions throughout the country.

Welfare was designed as a last-resort safety net. It never was intended as a lifetime guarantee. A possible option for reform is a *Basic Income Plan for Canadians with severe disabilities* that would reconfigure both income support and services [Mendelson, Battle, Torjman and Lightman 2010]. The proposal consists of three parts: a new federal Basic Income, a refundable disability tax credit, and essential supports and services.

The foundation of the plan is a new federal Basic Income that would replace provincial/territorial social assistance for most working-age persons with severe disabilities. The Basic Income program would be modelled on the long-established Guaranteed Income Supplement for low-income seniors.

The second proposed reform is to convert the existing non-refundable disability tax credit into a *refundable disability tax credit* that would extend financial compensation for the extra costs of disability to the lowest-income people with disabilities. The refundable credit would pay \$2,000 through the income tax system to every person eligible for the disability tax credit.

The third component of the broader reform focuses on the *essential supports and services* that enable persons with disabilities to function on a daily basis. The two federal income security initiatives described above would free up funding for the provinces and territories to set up a coherent, comprehensive system of supports and services for both care receivers and caregivers.

But while inter-jurisdictional alignment is a necessary strategy, it is not sufficient. Governments are not the only players in the caregiving arena. The business sector and voluntary sector play equally important roles.

### *c. Multisectoral alignment*

A third promising strategy involves the coherence of actions among all sectors in the form of *multisectoral alignment*. The UK is likely the best example in the world of a joined-up strategy that seeks to create alignment among sectors. The government, private and voluntary or ‘third’ sectors are all actively involved in the comprehensive strategy for carers.

In 1999, the Department of Health introduced the National Strategy for Carers which represents a wide-ranging caring for carers approach. It set out three core components: information for carers, support for carers and care for carers. The Strategy includes measures related to income security, respite and other supportive services, and employment arrangements.

On the financial front, an Invalid Care Allowance was introduced as a taxable, non-contributory benefit for people of working age (16-65) caring at least 35 hours a week for an individual receiving a qualifying disability benefit. Its purpose was to help caregivers maintain their income when they must give up their employment because of caregiving responsibilities.

Since 2001, the measure was streamlined into a Carer’s Allowance – worth £55.55 a week as of April 2011. It allows earnings of up to £100 a week or less after deductions and removed age 65 as the upper limit for qualifying. There are no restrictions on caregiver/care receiver relatedness or living arrangements. Lower-income beneficiaries of the Carer’s Allowance may be eligible for extra amounts in the form of a carer premium.

A new Carer’s Credit was introduced in April 2010. It is a National Insurance credit which will enable carers to build up qualifying years for the basic State Pension and State Second Pension.<sup>3</sup>

The National Caregiver Strategy also brought in several initiatives related to the provision of supports at home. From 1999 to 2002, the UK government allocated £140 million for local authorities to offer respite, which can include short-term sitting services or longer-term holidays.

The initial efforts were followed in 2008 by a Supplementary Carers' Strategy. It embraced the recommendations put forward in a "New Deal for Carers," developed by four task forces comprising the Standing Commission for Carers in 2007. In 2008, £150 million was designated for Carers Grants administered on a personalized basis through local authorities. It introduced a Caring with Confidence training and rights education program and has enabled voluntary efforts through its support of Carers UK, the national voice for caregivers.

On March 30, 2010, the former government put forth a white paper entitled *Building the National Care Service*, which proposed system-wide reforms to restructure the delivery of health care to the UK's aging population. The paper sought to integrate all the stakeholders involved in caregiving and included important measures for carers. As of April 2010, as noted, home-based informal carers became eligible for full state pensions. Access to medical information has improved through the National Health Service helpline.

Wide-ranging measures have been introduced around employment. In 2007, for example, the *Work and Families Act* was amended to allow caregivers the right to request flexible working arrangements. Requests can involve changing the hours, times or place of work through provisions such as job sharing, home working, annualized hours and shift swapping.

Carers are eligible to make a request once every 12 months after working 26 weeks with their employer. Employers, in turn, have a duty to consider the request and cannot terminate an employee on the basis of submitting an application. They do have the right, however, to refuse if the business cannot accommodate caregiver needs. Employees who feel that their request was wrongfully rejected may launch an appeal that can result in an employment tribunal.

In short, the UK Caregiver Strategy has many component parts that engage all major sectors of society involved in caregiving.

## ***Conclusion***

Caregiving has finally taken its place on the public policy agenda. It must now be viewed through a policy development lens, which typically involves a number of steps and a unique process of analysis. Unlike other policy areas that are defined by person, group or place, caregiving is the function of an evolving relationship.

This reality gives rise to both challenges and opportunities at every step along the policy development spectrum. The core challenges arise from the fact that caregiver needs are determined largely by the needs of the care receiver. However, caregivers also have their own unique needs, which must be taken into account in the policy process.

Despite the wide-ranging questions to be addressed, there are several core strategies that can help reduce the associated challenges and enhance the possible opportunities. These strategies involve the alignment of agendas at the intra-jurisdictional, inter-jurisdictional and

multisectoral levels. The principle of alignment would help ensure that various actions undertaken in support of caregivers and care receivers are effective, coherent and mutually reinforcing.

## Endnotes

1. Caregiver choice means that caregivers have access to a range of options to meet their identified needs. Caregiver empowerment refers to ways that caregivers can participate in and influence decisions that affect the caregiving relationship. Caregiver recognition involves helping the public, community health and social service providers, and government officials acknowledge that caregivers' unpaid work plays a crucial role in society.

Persons with disabilities have set out a similar set of principles that they believe should guide the reform of disability supports. *Comprehensiveness* means that supports should be available within a coherent system, assuring a wide range of goods and services. *Accessibility* means that personal supports would be available to all Canadians who need them. *Portability* seeks to ensure that persons with disabilities have access to the forms and levels of support they require wherever they need them. *Self-determination* means that all services would be self-directed and self-managed in order to meet individual requirements. The *responsiveness* principle means that all supports and services need to be highly individualized [Torjman 2007].

2. For some caregivers, respite or a sense of relief derives from information from a qualified provider that helps better meet the needs of the care receiver. It is possible that the individual wanders at night or inadvertently risks causing a fire through unsupervised use of the stove. Advice on how to minimize the likelihood of these potentially difficult behaviours can provide significant relief. Other caregivers experience relief when they are able to have a free night, weekend or even a week. A 24-hour break allows many to get badly needed rest. A weekend or week enables caregivers to take a break or brief holiday if they are able to afford the time and cost. The physical rest helps them “recharge their batteries” in order to carry on with their caregiving responsibilities [Torjman and Makhoul 2008].
3. The State Pension is composed of two parts: a flat-rate basic pension and an earnings-related additional pension, also called the State Second Pension. Entitlement to State Pension is based on the number of qualifying years – i.e., tax years in which caregivers have paid, are treated as having paid or are credited with National Insurance Contributions. Those who cannot work or do not earn enough to pay National Insurance Contributions because they are caring for someone may still be credited for these contributions.

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