

The *mission* of the CCC-CCAN is to join with caregivers, service providers, and other stakeholders to identify and respond to the needs of caregivers in Canada.

La Coalition a pour *mission* de s'associer aux aidantes et aidants, aux fournisseurs de services et autres acteurs du milieu dans le but de cerner les besoins des aidantes et aidants naturels au Canada et d'apporter des réponses.

**CANADIAN CAREGIVER COALITION
ROUNDTABLE ON THE ROLE OF MEN IN CAREGIVING
OTTAWA, ONTARIO
FRIDAY, MAY 2, 2003**

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The views expressed herein do not necessarily represent the official policies of Health Canada.

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CANADIAN CAREGIVER COALITION
ROUNDTABLE ON THE ROLE OF MEN IN CAREGIVING
OTTAWA, ONTARIO
FRIDAY, MAY 2, 2003

EXECUTIVE SUMMARY

A priority issue for the Canadian Caregiver Coalition is a national caregiving strategy and policy as a key element of home and community care¹. According to Statistics Canada, there are 2.85 million caregivers in Canada. In fact, 10% of all men in Canada are caregivers, approximately 1.5 million men. Caregivers are family members or friends who provide ongoing care and assistance, without pay, to those in need of support due to physical, cognitive or mental health conditions.

On May 2, 2003 in Ottawa, the Canadian Caregiver Coalition hosted the Roundtable on the Role of Men in Caregiving with generous funding from Health Canada. The Roundtable gathered policy analysts, researchers, Coalition partners, and other stakeholders for a one-day meeting

- To identify policy questions and research gaps as they relate to men and caregiving
- To establish recommendations for further study and action on this issue

In plenary, the participants focused their discussion on the following five themes:

- Profile of men who care and their needs
- Caregiving Relationships – family and system and the impact of care
- Broad Societal and Dominant Culture Perspectives on Men and Caregiving
- Service Access and Utilization – the interface with the health care system
- Policies - What policies would respond to the needs of men who are caregivers?

In keeping with the Coalition's priority for a national caregiving policy and strategy as a key element to home and community care and the discussion at the Roundtable, the Canadian Caregiver Coalition recommends the following pillars to support research, policy development, and service delivery that recognizes the contribution of both men and women as caregivers:

1. To identify the potential knowledge gaps on the role and experience of men as caregivers taking into consideration the ethno-cultural attitudes towards men as caregivers.
2. To advance a research agenda to support and fund quality research that explores the role and experience of men as caregivers.

¹ CCC-CCAN. (2002). *Calling for a national caregiving policy: A prerequisite for home and community care.*

3. To build awareness and open a policy dialogue on the role of men as caregivers including the definition of the ‘family’, and the collective social responsibility to care.
4. To work with Federal/Provincial/Territorial policy makers to ensure that assessment of the needs of caregivers is a key component of the core basket of services under home and community care.
5. To promote the suggested policy framework (page 8) that engages caregivers (both men and women) in a process to identify policy options under three broad policy domains – home and community care, financial, and workplace - that would benefit caregivers and respect the diversity among caregivers and between groups of caregivers.

The Coalition is prepared to work with its partners and federal, provincial, territorial, and municipal governments to support the implementation of these recommendations.

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SUMMARY REPORT

INTRODUCTION

A priority issue for the Canadian Caregiver Coalition is a national caregiving strategy and policy as a key element of home and community care². According to Statistics Canada, there are 2.85 million caregivers in Canada. In fact, 10% of all men in Canada are caregivers, approximately 1.5 million men. Caregivers are family members or friends who provide ongoing care and assistance, without pay, to those in need of support due to physical, cognitive or mental health conditions.

Since our inception in November 2000, the Coalition has been engaged in a variety of activities to build awareness and educate the public on the needs of caregivers. This report summarizes the proceedings of the Roundtable on the Role of Men in Caregiving hosted by the Canadian Caregiver Coalition on May 2, 2003 in Ottawa with generous funding from Health Canada. The Roundtable gathered policy analysts, researchers, Coalition partners, and other stakeholders (See Appendix A for a list of participants) for a one-day meeting

- To identify policy questions and research gaps as they relate to men and caregiving
- To establish recommendations for further study and action on this issue

The Roundtable on the Role of Men in Caregiving was grounded with the presentation of early research results from a study being conducted by Dr. Lori Campbell of McMaster University (See Appendix B for the Slide Presentation).

In plenary discussion, the participants reviewed an initial list of possible themes for the day. The list was adopted with one addition and these five themes became the framework for the discussions:

- Profile of men who care and their needs
- Caregiving Relationships – family and system and the impact of care
- Broad Societal and Dominant Culture Perspectives on Men and Caregiving
- Service Access and Utilization – the interface with the health care system
- Policies - What policies would respond to the needs of men who are caregivers?

The first task for the group was to create a list of possible research questions and policy issues for each theme area. This was accomplished with the use of small groups, each one spending about 10 minutes on each theme, brainstorming ideas for the list of questions and issues.

² CCC-CCAN. (2002). *Calling for a national caregiving policy: A prerequisite for home and community care.*

The second task was to create some structure and make some selections for possible priorities from the wealth of ideas generated in the brainstorming exercise. Participants self-selected into working groups based on the theme areas. They consolidated the ideas, created logical sequence patterns, identified short and long-term priorities, or developed frameworks for moving ahead in this area (See Appendix C for the Roundtable Agenda).

At the end of the day, the groups reported back and had a brief discussion on possible overall priorities. The Summary Report was distributed to participants with an opportunity for feedback. Finally, the CCC-CCAN Board of Directors made recommendations to Health Canada based on the results of the Roundtable. The recommendations include strategies for moving forward (See Appendix D for the Theme Discussion Notes).

BACKGROUND

Historically, women have played a critical role in providing care to dependent persons both in health care facilities and in the community. However, the context of care in Canada and other industrialized countries has changed considerably in recent decades. In Canada, more and more individuals are requiring care in the community, due both to the aging of the population and the shift in the provision of services from institutions to the community. The increasing labour force participation rates of women, increasing geographic mobility, and changing family networks are also impacting on the capacity of families to provide care.³ While women continue to provide the bulk of care to dependent adults (including seniors and others) living with health-related problems in the community, men also play an important role. In 1996, an estimated 39% of caregivers to seniors were men.⁴ Although men tend to be more involved in the provision of financial support, transportation, home repairs and maintenance, etc., these are all critical components in terms of maintaining people in their homes.

In the policy environment, federal, provincial and territorial governments have recently introduced initiatives from which some caregivers may benefit, including men who are caregivers. For example, the 2003 First Ministers Accord on Health Care Renewal includes a commitment to the creation of a five-year \$16 billion Health Reform Fund targeted to primary health care, home care and catastrophic drug coverage, and the improvement of the basket of services offered for short-term acute home care. As confirmed in the federal budget of March 2003, other initiatives will include a compassionate leave benefit under the Employment Insurance program. At the provincial level, the governments of Ontario and Nova Scotia made 2003-2004 budgetary commitments to enhance tax support for family caregivers. The Quebec government's February 2003 changes to its labour standards include an extension of the reasons for family leave e.g. to include the health of a partner, parent, sibling, or grandparent.

³ Janet Fast and Norah Keating, *Family Caregiving and Consequences for Carers: Toward a Policy Research Agenda*, CPRN Discussion Paper No. F/10, 2000, p. 5.

⁴ Janet Fast and Norah Keating. (2000).

To determine how governments could be more effectively support caregivers, we need to understand the impact of federal, provincial and territorial policies on men who are caregivers. We also need a clearer picture of the impact of private-sector policies (e.g. workplace) on men who are caregivers.

There are several policy areas that could be considered in a policy impact analysis, such as the following: home and community care, housing, transportation, financial compensation (direct and indirect), and workplace supports. It is worth noting that the program of *Research on Aging, Policies and Practice*, co-led by Dr. Norah Keating and Dr. Janet Fast, will provide important insights into the kinds of supports that are available for male (and female) caregivers in these broad areas, and how the eligibility criteria of existing policies in these areas influences access.

Any evaluation of the impact of public policy on men who are caregivers must take into account the diversity of this group. Male caregivers are not a homogeneous group, and no single policy option will meet their diverse needs. The availability of services for men who are caregivers may differ depending on place of residence (e.g. rural/remote). Ethno-cultural considerations must also be taken into account (e.g. ethno-cultural attitudes towards men as caregivers, availability of culturally-sensitive community supports for men who are caregivers, inclination of men from different ethnic backgrounds to access caregiver services, etc). Consideration might also be given to the potential role of technology, such as the Internet and tele-health to help ease the caregiving consequences experienced by men.

ROUNDTABLE THEMES, RESEARCH QUESTIONS, AND POLICY ISSUES

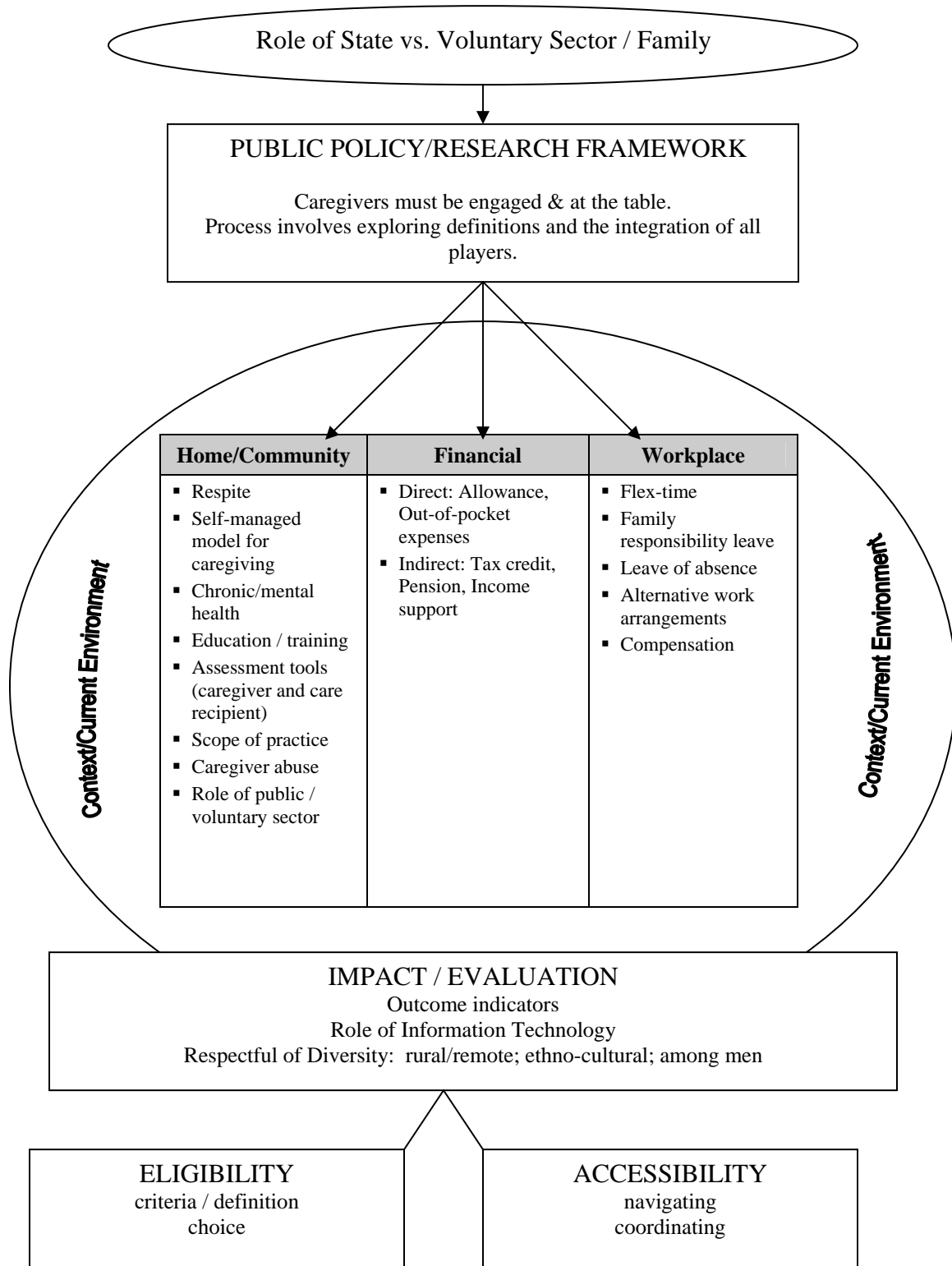
Themes	Research Questions	Policy Issues	Potential Partners, Opportunities, Funding Agencies
<p>Profile of men who care and their needs</p>	<ol style="list-style-type: none"> 1. Who are men who are caregivers? Methods: Meta analysis, Literature, Databases. Canadian content is needed. 2. Characteristics of men who are caregivers as they vary by: Type of care, Relationship, or Role as secondary caregiver (Other characteristics can be found in the theme discussion notes See App D)* 3. Comparison with women - Similarities and Differences 4. Why do some men become caregivers and others not? Issue of legitimate excuses and reasons and motivations 5. Do men experience caregiving differently? By gender, within and by type of care and stage of life? Gender differences in perception/ responsibility re. Pain / suffering / illness? And HOW? If there are gender differences, how are responses / involvement different? 6. What do they do about it? How do men problem solving, accessing social support, and use formal respite? In recognition of the diversity, how do characteristics “come together” to create “high risk” situations? What are the unique and positive attributes/responses that men bring to caregiving role? What are the needs of men who are caregivers and how are they being assessed? 	<ol style="list-style-type: none"> 1. Societal support for men doing care (i.e., work place) 2. What is particularly relevant in the current environment? <ul style="list-style-type: none"> - Problem: policy makers are men and don't see caregiving as a men's issue. Therefore not high on the agenda. - Answers to profile research may help shift importance of role of men e.g., highlighting amount and type of caregiving work men do and including groups not previously identified will help define caregiving as a men's issue as well as a women's issue. 	<p>* It was noted that the 2002 General Social Survey would have this information. Expected to be released June 2003 by Statistics Canada</p> <p>Investigators: Veterans Affairs Canada, Campbell, Keefe, Chappell, Keating/Fast, Canadian Association for Community Care, Health Canada, Matthews (siblings), and Harris</p> <p>Funders: Veterans Affairs Canada, Health Canada, Canadian Institutes for Health Research, SSHRC, Health groups, such as Alzheimer Society, MS Society, and McConnell Foundation</p> <p>Community Representatives: VAC, CCC-CCAN, CACC, Health groups, Health Canada, HRDC, CAG</p>

Themes	Research Questions	Policy Issues	Potential Partners, Opportunities, Funding Agencies
<p>Caregiving Relationships – family and system and the impact of care</p>	<ol style="list-style-type: none"> 1. What are the possible relationships? <ul style="list-style-type: none"> - Situations where/when male caregiver preferred - Role (individual and network) - Quality of interaction - Perception of caregiver and recipient of “what is care” - Determinants leading to caregiver role (including life stages, generational modelling) - Primary and secondary caregiver - Long distance vs. “present” caregiver 2. Relationship with the health, community, social services system? <ul style="list-style-type: none"> - Does the system respond differently to men who are caregivers? More or less assistance, different skills, emotions? - Does the system recognize the caregiver relationship? During care and after care? 3. Impact of care on relationship (with care receiver) <ul style="list-style-type: none"> - How do men cope? - What is the impact of being an active part in caring for someone who is suffering/afflicted with the same/similar illness or condition? 	<ol style="list-style-type: none"> 1. Recognition of caregivers as clients and partners in primary health care 2. Caregivers be recognized as part of system (federal, provincial/territorial, regional) to promote the creation of services that would legitimize role 3. Extend notion of what is “family?” 	

Themes	Research Questions	Policy Issues	Potential Partners, Opportunities, Funding Agencies
Broad Societal and Dominant Culture Perspectives on Men and Caregiving	<ol style="list-style-type: none"> 1. Has societal (and men's) expectations of their role changed? 2. What are the differences in perspectives re: urban/rural, ethno-cultural and geographic regions? 3. How do expectations transfer into actual behaviour? 4. What is the impact of economic factors that influence men in caring roles, given the lack of value of caregivers (paid / unpaid)? 7. Changing demographic trends upon men to take on the care giving role, such as <ul style="list-style-type: none"> - Labour force participation - Mobility - Divorce rate - Family type, composition, size - Early retirement 9. How does society's attitude toward the illness of the care receiver impact men becoming caregivers and/or their experience of care giving? 	<ol style="list-style-type: none"> 4. What is the impact of economic factors that influence men in caring roles, given the lack of value of caregivers (paid / unpaid)? 5. What is a "family"? 6. Societal biases that affect expectations, for example: <ul style="list-style-type: none"> - Under what conditions men who are caregivers can say 'no' - The provision of intimate care to female care receivers 8. How does access to services/policies break down barriers to male care giving? 10. Is care a social responsibility? The obvious priority 	<p>Investigators: Jean – Pierre Lavoie, Nancy Guberman, SANT</p> <p>Funders: CIHR, Institute of Gender and Health, Status of Women in Canada</p> <p>Participant or Community Representative: CCC-CCAN, Vanier Institute for the Family</p>

Themes	Research Questions	Policy Issues	Potential Partners, Opportunities, Funding Agencies
<p>Service Access and Utilization – the interface with the health care system</p>	<p>1. Research on underlying assumptions about men and caregiving</p> <p>2. Barriers</p> <ul style="list-style-type: none"> - Gender Stereotyping - Ethno-cultural - Literacy / language - Stigma of disease - Rural / remote - Relationship with providers - Gender of providers (Choice) <p>3. What are the needs of men who are caregivers, among groups of men, and between men and women?</p>	<p>1. Policy Regarding Assessment: Needs to be an initial and ongoing assessment that includes a caregiver assessment to support decreasing multiple assessments and easier access and coordination of services. Services must follow the assessment. Common standards for assessment</p> <p>2. Research to inform policy</p> <ul style="list-style-type: none"> - Do providers approach men differently? - What questions need to be asked to uncover needs of men as caregivers? - Who keeps the information? - Who can access the information? - What assumptions do we have about access/use of services by men who are caregivers? - Who does the assessment? (Competency, sensitivity, and training) 	<p>Investigators: Guberman, Keefe</p> <p>Funders: CIHR, Health Canada, Alzheimer Society, Pharmaceutical Companies, Foundations including the McConnell Foundation</p> <p>Opportunities:</p> <ul style="list-style-type: none"> - Health Care Accord and the core basket of services for acute home care, palliative care, acute community mental health, - Researchers interested in service access and use, - Provincial / federal elections, - Opportunities to collect information/network - Re-organization of Primary Health Care Division at Health Canada - Senator Carstairs as a champion of palliative care - Palliative Care secretariat in Health Canada
<p>Policies - What policies would respond to the needs of men who are caregivers?</p>		<p>See Diagram on Page 7</p>	

POLICIES: What policies would respond to the needs of men who are caregivers?



LINKAGES, OVERLAPS, AND OBVIOUS PRIORITIES

There are obvious linkages, overlaps and priorities. The following were the reflection of participants at the end of the Roundtable including:

Linkages:

- Common aspects for both men and women
- Responsibility for care

Overlaps between Theme Areas:

- Who – what men are caregivers?
- Types of care?
- Definition of “family”
- Rural/remote
- Diversity – multi-faceted
- Public / private responsibility for care
- Assess what are the needs of men who are caregivers

Any Obvious Priorities:

- Profile of men who provide care and types of care
- Assumptions we make and how the system interacts with men who are caregivers
- Data collection
- Argument for services
- Evaluation of programs and services
- Impact of different policies on men

RECOMMENDATIONS

In keeping with the Coalition’s priority for a national caregiving policy and strategy as a key element to home and community care and the discussion at the Roundtable, the Canadian Caregiver Coalition recommends the following pillars to support research, policy development, and service delivery that recognizes the contribution of both men and women as caregivers:

1. To identify the potential knowledge gaps on the role and experience of men as caregivers taking into consideration the ethno-cultural attitudes towards men as caregivers.
2. To advance a research agenda to support and fund quality research that explores the role and experience of men as caregivers.
3. To build awareness and open a policy dialogue on the role of men as caregivers including the definition of the ‘family’, and the collective social responsibility to care.
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The Coalition is prepared to work with its partners and federal, provincial, territorial, and municipal governments to support the implementation of these recommendations.

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**ROUNDTABLE ON THE ROLE OF MEN IN CAREGIVING
OTTAWA, ONTARIO
FRIDAY, MAY 2, 2003**

**APPENDIX B: SLIDE PRESENTATION
BY DR. LORI CAMPBELL**