The Objective Is Care:

Proceedings Of The National Think Tank On Gender And Unpaid Caregiving

November 8 - 10, 2001

Charlottetown, PEI

Prepared by Ann Pederson, British Columbia Centre of Excellence for Women's Health and Patsy-Beattie Huggan, The Quaich Inc.

The *National Think Tank on Gender and Caregiving* was funded in part by the Government of Canada. The views expressed in the *Proceedings* do not necessarily represent the views of the Government of Canada or any of Canada's provincial or territorial governments

ORGANIZERS FOR THE NATIONAL THINK TANK ON GENDER AND UNPAID CAREGIVING

Logistics for the Think Tank were undertaken by the Maritime Centre of Excellence for Women's Health (now the Atlantic Centre of Excellence for Women's Health), the PEI Health Research Institute of the University of Prince Edward Island, the Province of PEI, Veteran's Affairs Canada and The Quaich Inc. The program was the responsibility of the National Coordinating Group on Health Care Reform and Women of the Centres of Excellence for Women's Health program of Health Canada. The Think Tank Co-Chairs were Dr. Carol Amaratunga, Executive Director of the Maritime Centre of Excellence for Women's Health (now the Atlantic Centre of Excellence for Women's Health) and Dr. Pat Armstrong, Chair of the National Coordinating Group on Health Care Reform and Women and Professor, York University.

ACKNOWLEDGMENTS

The Coordinating and Planning Committees for the National Think Tank on Gender and Unpaid Caregiving wish to thank all those who assisted with the preparations for the conference and those who worked at the conference. In addition they would like to thank:

Sponsors (in alphabetical order)
Centres of Excellence for Women's Health Program, Health Canada
Institute of Gender and Health, Canadian Institutes of Health Research (CIHR)
Interministerial Women's Secretariat, Government of PEI
Maritime Centre of Excellence for Women's Health
National Coordinating Group on Health Care Reform and Women
PEI Health Research Institute
Status of Women, Canada
The Quaich Inc.
Women's Health Bureau, Health Canada

Helping Partner
Veterans Affairs Canada

TABLE OF CONTENTS

Appendices

INTRODUCTION

The National Think Tank on Gender and Unpaid Caregiving was organized to bring together researchers, care providers and policy makers to consider care giving in relation to gender. The objectives were to share what we knew about the current state of knowledge on gender and unpaid caregiving, to identify gaps in that knowledge, to establish research priorities, create a network to share information and move toward action.

Initiated by the National Coordinating Group on Health Care Reform and Women, a group that crosses the Centres of Excellence for Women's Health, the Think Tank was hosted in Charlottetown by the Maritime Centre of Excellence for Women's Health (now the Atlantic Centre of Excellence for Women's Health) based in Halifax, and the PEI Health Research Institute, an institute of the University of Prince Edward Island.

The Think Tank was initially about unpaid caregiving but early discussions among participants stressed the inseparability of paid and unpaid caregiving. Thus, despite the title, these proceedings reflect presentations and discussions that tried to consider the entire range of home care activities, from those provided by state-funded workers to those provided by family members and friends. Throughout the discussions and these Proceedings, we also tried to consider the perspectives and needs of care recipients, who range from children through seniors, from persons with short-term acute health care needs to those with chronic illnesses or disabilities to those requiring palliative care.

We are pleased to present this report on the proceedings of the Think Tank. The event was an inclusive, dynamic workshop that engaged 55 people from academia, community agencies and government who also are, have been or will be care givers and possibly care recipients. The personal experiences of caregiving combined with our various understandings based upon research, practice or policy-making made our discussions compelling, rigorous and practical.

Care giving is overwhelmingly an activity of women – though it is not necessarily presented as such in either research or policy analyses. We devoted a lot of energy to discussing gender differences in caring and what the implications of those patterns of caring mean for families, policy developers and health care. We also learned that women are the majority of those receiving home care. We debated what these patterns mean for women over the course of their lifetimes and what could be done to maximize women's choices with respect to how and when they provide care and from whom they receive care.

This Think Tank began as a discussion about the current state of knowledge on unpaid caregiving but quickly expanded to encompass paid caregiving. Participants recognized that what care is provided by family, friends and neighbours is integrally related to what care is available from other sources.

The Think Tank began with an overview of research that approached the study of caregiving from a gendered perspective. From there, Think Tank participants identified gaps in research that need to be addressed. For example, we need greater clarification of the variations in caring and receiving care in different regions, among different populations, and by different types of care providers. We need to understand more about the different kinds of caring provided by women and men, boys and girls, on both a paid and voluntary basis. We need to conduct research into the costs of providing care in the home—for both the providers of care and the recipients of care. And we need to translate the findings of research in ways that people not trained in research are able to understand and use for their own planning, advocacy and policy-making.

We agreed that, while there remain critical gaps in research, there is enough research to provide a basis for action. From the opening session of the Think Tank, there was a sense among us that part of what had to happen over the course of our meeting was to find a way to articulate the urgent need for action, action that would improve the conditions for paid and unpaid caregiving, for both care providers and those who receive care. Based on our deliberations, we developed *The Charlottetown Declaration on the Right to Care.* This Declaration sets out the principles for a national health care system that is organized around care as the objective and expands upon the present physician- and hospital-based system to include home health care.

These proceedings include verbatim transcripts from keynote speakers based on tape recordings of their presentations, as well as summaries of plenary and small group discussions. As this was a working meeting, there were relatively few formal presentations and most of the work occurred in plenary or small groups. The format and organization changed continually in response to developments in both small group and plenary sessions. We hope that our notes capture some of the dynamism and passion of the dialogue.

Discussions were lively and animated. As the organizers of the event, we made every effort to be responsive to participants' requests for modifications to the agenda. This meant, for example, that the topics for the second set of small group discussions were generated among the participants, based on priorities that emerged during the plenary and initial small group sessions. We believe that this flexibility was key to the success of the event and thank the participants for their willingness to take risks in telling us their preferences and challenging our initial program of activities to better meet their needs for learning, debate and networking.

It is our hope that these Proceedings enable those who were not in attendance to experience some of the highlights of our three days together. We also hope that for those who participated in the Think Tank, these Proceedings serve as an accurate reflection of an important event. Overall, we hope that our deliberations help to inform current debates on the future shape of the health care system in Canada.

Pat Armstrong, PhD
Chair, National Coordinating Group on Health Care Reform and Women Health
Co-chair, National Think Tank

Carol Amaratunga, PhD
Executive Director
Atlantic Centre of Excellence for Women's

Co-chair, National Think Tank

DAY ONE November 8, 2001

Opening Session

The opening large group discussion reviewed the goals of the Think Tank:

1. To identify gaps in knowledge regarding providing care in the home
2. To work toward expanding the range of knowledge recognized as contributing to our understanding of the provision of home health care
3. To establish a network of academic and community researchers, service providers, unpaid caregivers, and policy makers who share a commitment to improving the provision of care in the home to Canadians
4. To apply a gender lens to research and policy making with respect to home health care in order to illuminate the potential differences for women and men as care providers and those who receive care
5. To develop policy advice from these perspectives

To help orient the participants, Marika Morris presented a summary of a paper she had prepared as a background document to the Think Tank on Gender-sensitive Home and Community Care and Caregiving Research.[1]

Opening Address: Marika Morris

Summary of Themes, Gaps, Issues and Policy Questions Identified in 'Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper'[2]

It's very exciting to be here, as some of the most prominent home care studies I reviewed for the paper are written by people in this room.

The draft paper you received is a work-in-progress. I hope that you will feel free to speak to me about how the paper could better meet its goals and be of use to you.

Some of the major themes running through the gender-sensitive home care literature are not news to anyone here. Unbelievably, they are still not a part of mainstream research or policy consciousness. Simple things—like the fact that women are the majority of unpaid caregivers, the majority of care recipients, and as such are greatly affected by home and community care policies and practices—are not yet commonly discussed. Because women and men experience different socioeconomic contexts and gender role expectations, women give more hours of unpaid care than men. Women perform more demanding forms of care than men, such as more personal and intimate care, and care for persons with dementia and cognitive disabilities. Women travel further and more often to

[1] The final version of this paper, Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper is available in English and French from Health Canada's Women's Health Bureau.

[2] Verbatim transcript of presentation.

provide unpaid care. More women have responsibility for more than one care recipient than men.

Not surprisingly, given the greater average load and increased expectations, women's health is more negatively affected by caregiving than men. Research also shows that caregiving interferes with women's ordinary lives, plans, and paid work much more so than men's. Although caregiving involves financial costs for men and women, there are more and deeper longer-term costs for women.

There's some research emerging on rural women and care. Rural women provide more hours of unpaid care than either their urban or male counterparts and there are fewer support systems in place to aid them.

Caregiving is not necessarily a horrible experience for everyone. Research is important to identify the factors that lead to positive and supported caregiving experiences. The issue is that caregiving is a gendered experience, one that needs to be taken into account in research and policy.

Another gendered experience is the receiving of care. The literature shows that women receive fewer hours of care than men, whether they need care because of chronic functional limitations, or short-term care following surgery. The theory is that when women are assessed for care, they are assumed to be more capable than men of performing household and personal care tasks because these are in keeping with female gender roles.

A significant theme is that health care restructuring has particularly hurt women. Shorter hospital stays, deinstitutionalization and the shift toward community care increase the burden of women's unpaid work. It has also hurt women as the majority of care recipients, many of whom are living in poverty and cannot afford to buy private services to supplement or replace disappearing publicly-funded services.

Some studies raise issues of citizenship engagement: Caregivers, who are predominantly women, and care recipients, who are predominantly older women and women with disabilities, are left out of the policy-making process about issues that affect them. Umbrella organizations that represent retired persons, people with disabilities, or persons interested in home care, do not necessarily use any gender analysis in their publications or representations to government.

Research gaps

I looked at well over 2,000 home and community care studies, and only 177 were gender-sensitive. Some of the studies that are not gender-sensitive are major, well-known studies that are used as a basis for policy-making. Gender is a gap in home care literature at large.

But there are also research gaps within the gender-sensitive research. For example, population group gaps:

- There's research on Aboriginal women and health care in general, which shows that Aboriginal women are poorly served by the health care system. We also know that more Aboriginal women are single parents and tend to have more family responsibilities. There's research on Aboriginal home care in general, which highlights jurisdictional and funding problems. But there's no research on gender and Aboriginal home care. Aboriginal women are dealing with such a mountain of health-related concerns that home care is not at the top of the priority list. We need to fund visionary research by Aboriginal women to flesh out what a good quality, culturally-sensitive, accessible home care program would look like for First Nations, Inuit and Métis peoples.

- There's rather sparse Canadian-based gendered literature on immigrant, refugee and visible minority populations and home care. We know that caregivers and care recipients in immigrant, refugee and/or visible minority communities face racism, and language and cultural barriers. Some studies lump together women from very diverse communities, expecting that they will have had the same kinds of experiences. Most studies just ignore them altogether.

- There's no real quantitative research on lesbians and gay men in caregiving, but a number of interesting leads to follow up on. The qualitative research suggests that some lesbians in need of care may have fewer family resources to draw on because of rejection. Because they may also face hostility and discrimination from health care providers, some lesbians have the added responsibility of caring for lesbian friends, as well as partners and family members.

There are regional, provincial and territorial gaps in gender-sensitive research: There's nothing based in Alberta, PEI, Yukon, Northwest Territories or Nunavut.

There needs to be more links made in research, as some the research tends to be fragmented. For example:

- research that includes all people with functional limitations, not just seniors alone or persons with disabilities under 65 alone;
- information about caregiving and care-receiving of women and men with short-term functional limitations, such as those in home-based post-operative recovery and early maternity discharge;
- research that recognizes the fact that caregivers can also be care recipients or in need of care, such as women over 65 who tend to be caregivers to spouses or to adult offspring with disabilities, and such as women with disabilities in general who may be caring for children and in need of support for functional limitations at the same time. The literature often creates a dichotomy between caregiver and care recipient;
- research that draws the links between all forms of caregiving, including paid and unpaid caregiving which are both dominated by women, and caregiving of children as well as of people with functional limitations. There's a reason why women take on

paid and unpaid caregiving of all kinds and these forms of caregiving interact with each other.

More research is needed on the economic fallout of caregiving. For example,

- I would like to know the average life-long financial impact on individual women and men of care-related absenteeism, reduced work hours, unpaid leave, missed educational opportunities and other hidden costs;
- We need research about options for financial compensation programs for caregivers, including an up-to-date comparative analysis of home and community care and caregiver support mechanisms between Canada and other industrialized countries.

Other gaps include long-term visions and views: Research that goes beyond developing short-term recommendations designed to help women cope with their caregiving role, to long-term recommendations about how to challenge the gendered nature of the caregiving role.

What would also be useful is:

- research on the different effects on mental and physical health among those who choose caregiving and those who are forced into it because of a lack of alternatives; and
- research on men who take on the female role of caregiving, why a few men do provide many hours of care contrary to cultural expectations.

We know that women and men care recipients are subject to violence and physical safety risks, but women caregivers may be at greater risk than men. We need more research sensitive to issues of violence.

Policy implications

There were many policy options identified in the literature. Most involved improving services. Others dealt with more drastic policy changes aimed at valuing the caregiving role and the experiences of recipients. A very few others were broader policy changes aimed at transforming the root causes of gender inequality in caregiving and home and community care.
Instead of running down the entire list of policy recommendations, which you can find documented in the paper and condensed in the Executive Summary, I'll instead say a few words about the policy implications of gender-sensitive research. How do the recommendations of gender-sensitive research differ from recommendations of research that do not take gender into account?

One way that gender-sensitive research might be different is that if you are lumping women and men caregivers in one study, you may find that the burden of caregiving is not that great. You may find that caregivers' health is more or less okay, and that caregivers are not severely financially or personally impacted by caregiving. If you separate the statistics for men and women, a different picture emerges. You find one

group doing less caregiving and on whom caregiving has less of an impact, and one group doing more caregiving and experiencing greater effects from these activities.

So research that is not gender-sensitive underestimates caregiving burden and health, personal and financial costs, because the third of caregivers who are men don't tend to give as many hours of care, and give up less in terms of their career and personal life.

Because gender-sensitive research tends to be done by researchers with a grasp of socioeconomic gender differences, it tends to pay more attention to income and poverty issues. These studies ask questions about financial implications, which are reflected in recommendations such as providing a travel allowance/transportation assistance; reviewing income support, disability-related programs, and tax programs to alleviate poverty; establishing workplace policies that take caregiving into account; compensating caregiving work through tax relief, pension benefits, a wage, or some form of financial compensation; timely, appropriate and low-cost respite care; including counselling services for caregivers and recipients as part of free and available services. This is a perspective that is missing in the mainstream health care debates about user fees. That debate centres around how the government can afford care. What is missing is the gendered perspective of how women afford to continue giving more and more unpaid care.

Gender-sensitive research brings out how men and women are treated differently as care recipients, something completely lost in research that ignores gender. This has policy implications for the home care assessment process.

Sometimes what is valuable about gender-sensitive research is the perspective of researchers, which tends to be more feminist or social-justice oriented. These researchers bring up issues such as the citizenship rights of caregivers and recipients. In most of the literature, care recipients in particular tend to be viewed as objects of care, rather than human beings with social and political rights. The majority of care recipients are women seniors and women with disabilities, and another common view is that they are sexless, which leads to an underestimation of how they suffer from violence against women. These studies stress the importance of involving caregivers and recipients in decision-making at local, provincial and federal levels.

Gender-sensitive research doesn't just provide answers, it also asks the tricky questions, such as a series of questions developed by Pat Armstrong and Olga Kitts[3] to apply to all policy, legislation and regulations: Is caregiving and receiving voluntary? Can caregiving be equally shared among women and men? Can caregiving be culturally sensitive without making inappropriate assumptions about cultural groups and without contravening other equity principles? Can the assumptions made about personal relationships related to caregiving be justified? Is there recognition of the different interests that need to be balanced in caregiving? Is need defined in ways that exclude some groups while

---

[3]Armstrong. P. & Kits, O. (2001) *One Hundred Years of Caregiving.* Prepared for the Law Commission of Canada, April.

privileging or stigmatizing others? What are the long-term consequences? Are the objectives reinforced or undermined by other legislation, regulations or policy? Are the contributions of care recipients recognized and the skills required for giving care acknowledged? Are current patterns themselves constructs of policy or does policy reflect actual preferences and practices?

It is important to remember that not all of the recommendations of gender-sensitive research are gender-specific, but they are developed using research that was gender-sensitive and consultative of the needs of women and men. As most of these recommendations are geared to building a better home and community care system and alleviating the burden on caregivers, they will naturally have a greater impact on women as the majority of caregivers and recipients. However, they will also benefit men who have taken on the traditionally female gender role of caregiving, and men who find themselves in similar economic situations to the majority of women with functional limitations. Even though statistically not as many men perform the caregiving role, and statistically fewer men give a lot of their sweat and blood for caregiving, there are some men who are deeply involved in unpaid caregiving, and they will benefit equally from the recommendations of gender-sensitive research.

The purpose of gender-based analysis is to develop good, evidence-based policy that is based on a complete picture of how women and men are affected.

Over the next few days I hope we can discuss how we can take action in our own ways to ensure that home care research and policy-makers are gender-sensitive, whether it means strategies for educating colleagues, ways of promoting gender-sensitive research, or perhaps taking advantage of some of the ongoing reviews, such as the Romanow Commission. I hope we can also discuss how the identified research gaps can be addressed, and come out of this meeting with a concrete plan of action.

LARGE GROUP DISCUSSION

Moderator's Comments[4]

Participants were invited to the Think Tank because of their knowledge and experiences in caregiving as policy makers, practitioners or researchers. Pat Armstrong suggested that "It is time now to build on what we know to move forward to fill the research gaps that remain and change both policy and practices." She challenged the group to explore and define care as the objective, and consider the following questions:

- What does good care look like?
- What kinds of care are good for women?

---

[4] Pat set the tone, indicating that participants need to feel that the Think Tank should be a safe place to raise any ideas, with respectful discussion; a think tank that goes beyond what each participant knows from their research and practices; a time for challenging thinking; a time to dare to dream.

- How can care take women's different locations into account?
- Which women should or can provide what kinds of care?
- What kinds of care are good for families?
- How can care take into account different kinds of families?
- What kinds of care are good for communities? Which communities?
- What kinds of care are good for which regions?
- What kinds of care are good for the country?
- What kinds of care are good for those who need it?
- How can we build and support care as a relationship, a relationship that respects the needs and skills of everyone involved?
- What would our dream care world look like in terms of both paid and unpaid care, in terms of conditions, resources, decision-making and participation?

Summary of the Large Group Discussion

Some of the comments made in response to Pat's questions include the following:

Divesting the myths

"The challenge to divest myths such as the myth that costs of health care are increasing because of the increase in the number of elderly...cost drivers are prescription drugs and high tech equipment."

Definition of care

"Theorization of care is imperative. Often hospital logic is transferred to the home and there is a need to recognize the logic of the home. This is more of an issue now as more high tech care is now being provided in the home than ever before."

Models of care

"What are some of the creative models of caregiving? What is the interface between paid and unpaid care?"

"There is a need to 'ungender' caring; with a model that is not necessarily hooked to women, and in which caregiving is viewed as paid and unpaid."

"There is a need to personalize care so that the person is always the locus of agency and power within a public system which becomes more intimate and acknowledges the importance of relationships."

"The caregiver/care receiver unit should be central and valued."

"A more holistic model of care that does not follow the industrial model is required. The present system of care is fragmented with a lot of money paying for a system that doesn't work for anyone."

"Home care was designed to replace hospital care, not to promote integration, engagement, independence and interdependence, which are "dream characteristics" of good care."

Requirements for effective care

"Language, a sense of community, and adequate funding and other resources are important."

"There is need for possible action through the Human Rights Commission."

Pat Armstrong summarized the discussion, highlighting the fundamental question surrounding the question of "What is care?" as that of values. She also identified the power of language in framing discussions about home and community care and asked, "Why do we call it giving?"
She suggested that the initial discussion outlined a vision of care that begins with notions of entitlements, recognizes difference, is based on respect, addresses issues of language and cultural appropriateness, and challenges the assumption that people are all alike. The system of care needs to recognize the integration and continuity of services and policies. We also need to accept and manage both dependence and interdependence and the tension between the two. To achieve this vision, we need to define our underlying values, question the meaning of "productivity" that does not recognize care work as work; provide information and training (for paid and unpaid providers) which is culturally sensitive and accessible; provide meaningful choices that include the right to decide and participate; address barriers posed by jurisdictional issues; overcome inequity in access; and openly consider questions such as "What is community?"[5]

Public Forum and Panel Presentation

Designing Home and Community Care for the Future: Who Needs to Care?

A public forum was held in the evening of November 8 to enable local community members to hear from some of the participants to the Think Tank regarding home care. One hundred people attended. The forum included two panel presentations then reflections by a discussant followed by an open discussion.

Panel Presentation: Jane Aronson, Professor, School of Social Work, McMaster University, Hamilton, Ontario

To stir our thinking about designing home care for the future, I will focus particularly on:

- **long-term care** directed to elderly people (mostly women) who live at home with a range of chronic conditions and disabilities and who need largely social care, i.e., personal care, assistance with the daily domestic round. (This population made up the majority of home care recipients before acute and sub-acute medical care was transferred out of the hospital and institutional sector with health care restructuring).

- **the recipient's view** ... turning up the volume on the voices of those most affected by the design of home care, whose knowledge is least tapped and invited.

---

[5] Given that many of the elements of a framework of care were outlined through the discussion, a smaller group was given the challenge of constructing a visual of this framework that could be posted on the wall and added to by others during the Think Tank. The framework was created and initially circulated to the large group in the morning of November 9 before a larger version was posted on the wall.

To this end, I will draw on research I'm just completing: a longitudinal study of women receiving home care in Ontario involving a sample of 27 women, interviewed two or three times a year for the last three years.[6] The study is Ontario-based so in some ways particular, but broad policy trends and political-economic configurations are to be found elsewhere.

I will organize my remarks as follows:
1) Describe the experiences of one study participant, Mrs. M, over the last three years. Her experience provides us with a window for understanding the current design of home care.
2) Consider the present policy "design" that frames and shapes Mrs. M's story.
3) Consider the implications for designing good, or at least better, home care.
4) Close with some puzzles about how to move toward such improvements.

1) Mrs. M

Mrs. M is 81, widowed and lives alone. She has a number of chronic health problems including a progressive neurological condition that impairs her mobility severely.

When we first met 3 years ago, a home support worker came to her three times a week for two hours and assisted her with bathing, laundry, food preparation and light housekeeping. Mrs. M's mobility was deteriorating and she was spending more and more time in her wheelchair. Her case manager at the Community Care Access Centre (CCAC) assured her that they would do whatever was needed to enable her to stay at home, her dearest wish.

Some months later, the CCAC experienced budget cuts. Mrs. M was cut from 3 to 2 visits from a support worker. Previously very consistent, the support workers changed and came from new agencies. This upset Mrs. M greatly; she found "successions of strangers" in her home very difficult. She was told that they would no longer provide any housekeeping at all, just personal care: "you can pay if you like, services are reserved for people who are really ill." She felt fearful about the future: "I don't know what to count on any more."

Mrs. M decided to pay for help with cooking, as she had always valued a good diet. She also began paying privately for house cleaning but gave up because of the cost and because the cleaner was unreliable. She "felt sorry" for her case manager who had to explain and implement the cuts: "I know it's not her fault."

In an interview a year after the cuts began, Mrs. M expressed mounting anxiety and said she realized that her friends (themselves getting older) and her niece (her closest relative whom she couldn't keep burdening) "could not help her more and I hate to ask." She was

---

[6] Jane Aronson (forthcoming). Frail and Disabled Users of Home Care: Confident Consumers or Disentitled Citizens? *Canadian Journal on Aging.*
Jane Aronson and Sheila M. Neysmith (2001). Manufacturing Social Exclusion in the Home Care Market. *Canadian Public Policy*, XXVII (2): 151-165.

embarrassed at being unkempt, no longer having her hair permed, felt she couldn't invite friends in. She'd given up leaving her apartment except for medical appointments.

Soon after, she fell and twisted her ankle. She didn't seek medical attention because she feared hospital, the pressure to leave her home, the intrusion. She didn't call her case manager despite the increased difficulty of managing day to day: "I saw no point, she said last time that they couldn't afford to give more. It was kind of scary to stand up to clean my teeth or just to wash my hands because this foot would turn under me. And if I go down again, it's curtains for me."

At a later interview: "I get depressed but I don't tell my niece or my friends because what's the point? You mustn't complain. I'd be mortified if they knew. My mistake was not having a daughter...I know now I'm on my own with this."

In summary, Mrs. M found herself at the end of her resources and her expectations of home care support had been depleted. She felt diminished and managed day to day by dint of her own hard work and inventiveness and with stoicism.

2) The policy backdrop framing Mrs. M's experience

Mrs. M is a single instance or case but her experience provides a window into understanding the wider context – a snapshot that illuminates the reverberations of home care reorganization, cuts and rationing in individuals' everyday lives.

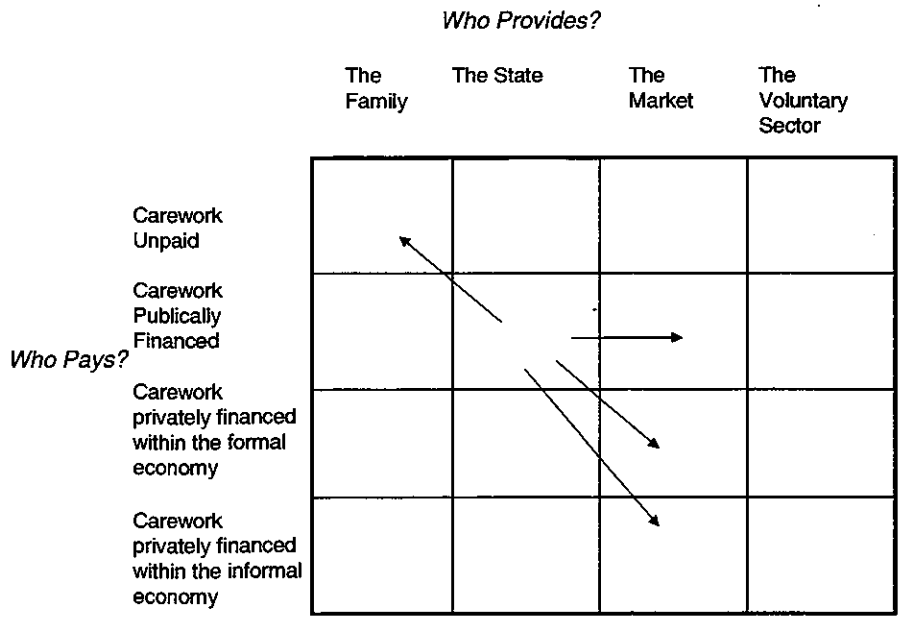
That Mrs. M feels "on her own with this" is the consequence of federal and provincial policies that structure home care and day-to-day allocation decisions at its front line. To speak of home care's current "design" implies that it has been intentional, thoughtful and debated. It is, more accurately, the product of non-decisions and non-debate:

- the federal government chose not to act on the recommendation of the National Forum on Health (1997) to integrate a national home care programme into health care with comparable standards etc...
- the provincial government in Ontario has, with particular ideological vigour, pursued a quest to cut costs and frame social and health issues as individual, not collective, problems requiring individual, not collective/ public, solutions. Without consultation or debate, "managed competition" was rapidly introduced in home care, confining the public sector role to assessment of eligibility and contracting out of service delivery. In successive years, the CCACs have had tight and unpredictable budgets and been charged with administering tighter and tighter rationing criteria that give priority to medically-defined needs. The kind of supportive/ preventive care required by Mrs. M is not a priority.

By implicit design, care is being ejected from the public sphere...slipping off the map of public policy...offloaded as a matter of private/individual responsibility. This offloading

- medically-defined needs. The kind of supportive/ preventive care required by Mrs. M is not a priority.

By implicit design, care is being ejected from the public sphere...slipping off the map of public policy...offloaded as a matter of private/individual responsibility. This offloading is graphically captured in Szebehly's depiction of the privatization of care, i.e., its transfer to the informal sphere and to the private market: [1]



(From Marta Szebehely. 'Concepts and trends in home care for frail elderly people in France and Sweden.' Conference presentation, *Comparing social welfare systems in Nordic countries and France.* Paris, 1998

In Mrs. M's experience, we see how responsibility for providing and paying for care was pushed from the public domain, pressing her to pay privately, to make do/go without help and to live at some risk to herself. Like many older people and people with disabilities in her situation, she did not have available family to help her (the assumption of a retreating state) and she could not afford to pay privately to compensate for insufficient public services.

Other participants' experiences revealed other repercussions of offloading: for example, some were pressed by service cuts to ask neighbours and others (informal ties) for help; some relied on the discretionary help of paid home care workers who did "extras", over and above their paid work. Many participants recognized the fragility of such support and voiced "humiliation" at their diminishment and lack of entitlement.

[1] Marta Szebehely (1998). "Concepts and trends in home care for frail elderly people in France and Sweden." Conference presentation, *Comparing Social Welfare in Nordic Countries and France.* Paris.

3) Key ingredients for the design of good, inclusive home care

From this quick picture of the present design of home care from elderly recipients' perspectives, we can identify some key elements/ areas for change in the future. For example:

- clarity of entitlement: minimum levels of service assured, national standards, assured access to social/ supportive care.

- stability: consistent providers that minimize recipients' exposure, foster their dignity/ individuality and ensure that care is provided in the context of stable relationships.

- voluntary, not coerced care receiving and giving.

- conditions of care that are rewarding and supported for both recipients and providers.

- policy-making processes that are transparent and that engage the participation of those who use home care services and have front line knowledge of their design.

4) Puzzling our way forward

We have seen much energy devoted to making these public issues. For example:

- In terms of research and evidence gathering, we have seen a huge amount of work and analysis in recent years,not least, the contributions of many of those gathered here in PEI.
- Numerically, more people are aware of home care's shortcomings (recipients, their families, informal and community ties).
- Advocates and activists are taking up the issues e.g. seniors and disability rights groups like those who have supported my research (Older Women's Network, Care Watch Toronto, Canadian Pensioners Concerned); and labour groups concerned with privatization and the degradation of working conditions in home care.

Yet, we still do not have a national home care programme and see little evidence of significant change. Rather:

- at every level of government, administration and service delivery - allocation decisions are made continually, obscured as managerial matters or as self-evident inevitabilities.
- and the implications of offloading are borne out of view, in people's homes and private worlds. Witness Mrs. M.

---

[8] Nancy Pollak (2000). "Cutting Home Support: From 'Closer to Home' to 'All Alone.'" In *Without Foundation: How Medicare is Undermined by Gaps and Privatization in Community and Continuing Care.* Vancouver: Centre for Policy Alternatives, p.93.

How then to engage strategically?

Many of us gathered here are researchers and have an investment in thinking that research has something to contribute, that knowledge will "transfer" into government response or activity. A recent editorial in the *British Medical Journal* cautions against assuming so simple a transfer. Writing about preventive health services for old people, Clark observes:

> The real issue, however, may have nothing to do with research at all. A recent review of health visiting services in Wales found that home visits by health visitors to older people had almost disappeared - not as a result of any demonstration of their effectiveness or otherwise, nor even as a result of a deliberate policy decision, but simply by default, because older people were not seen as a priority.[9]

If the withdrawal of public support of people who are old , frail or disabled may have little to do with research at all, we will need to think at this meeting about other strategies and actions for working toward progressive change in home care in Canada.

Panel Presentation: Nancy Guberman, EQUAM, Montréal, Québec

Before answering the second part of the question posed by the organizers of this conference, that is, "who needs to care?" I would like to look at the first half: "designing home and community care". Indeed examining the concepts of home and community care will lead me to my answer to the question of who needs to care.

As stated, the words "designing home and community care," imply that we are talking about two realities: home care and community care. But, in fact, in current policy, practice and the lived experience of most people, these two realities are too often collapsed into one reality, and that reality is home care.

Indeed, more often than not, when we talk about community care, we are talking about home care, supplemented occasionally by day centres. And when we talk about home care, more often than not we are talking about care provided mainly by family and friends, supplemented by some homemaking, personnel care or nursing support and perhaps Meals-on-Wheels or volunteer transportation services. And among family and friends we are most often talking about women. So, more often than not, what is called community care is, in fact, care by women in the family with little or no support from the community. Today, most people with disabilities are being cared for in the community, but not by the community.

---

[9] J. Clark (2001). "Preventive Home Visits to Elderly People: Their Effectiveness Cannot be Judged by Randomized Control Trials." *British Medical Journal* 323, p.708.

Community care does not mean institutional care

What would care by the community look like? Faced with the challenge of trying to envisage genuine community care, we are immediately confronted with the current dichotomous vision of care as being either home care or institutional care. They are the only two viable options that people are currently offered and only one of those options is considered really viable, and that is care in the home.

As they exist today, care in the home or care in an alternative setting are presented almost as dichotomously as good and bad.

Dichotomous Visions of Care

INSTITUIONS	FAMILIES
cold, unfeeling	warmth, emotional bonds
Professionals	lay
Wages	love
technical interventions	spontaneous/ simple
lack of freedom	freedom
Regimentation	absence of schedules

Given these images, the choice is simple. Institutionalisation is seen by most people with disabilities and by most caregivers as a last resort and it is so socially depreciated as an option that it is more like a non-choice, not to mention the current severely restricted access to institutional beds. The home appears to be the only and the best option. Therefore, despite the numerous documented difficulties of caring and being cared for at home, this appears to be the only real choice available.

In this situation, in my opinion, family care is a non-choice because there are not viable, socially acceptable alternatives. It is a non-choice because choice has been dichotomised as one between warm, loving, caring families and cold, bureaucratic uncaring institutions.

But there are many indications that people might choose different solutions if they had different options available to them. For example, it is clear that people with sufficient means generally buy the services and hire the people required to meet their needs as they grow frailer or develop disabilities, rather than choosing to be cared for by family and friends. Family members and friends continue to offer emotional and social support, but they do not do most of the hands-on activities required unless they and the person with disabilities choose this option. It is considered not only acceptable, but often desirable, for a wealthy senior to move into a senior's village or private residence with adapted facilities

and meal, laundry, housekeeping and on-site medical services. However, what makes these options appealing is the fact that people maintain control over their own lives, they have their own private spaces and they have options available to them with regard to services and programs.

We should also consider, that based on many research studies, it would appear that the first choice of most disabled people is not to be dependent on or a burden to their families. Rather, they want to maintain intimacy at a distance A Norwegian researcher, in addressing the issue of preferences with regard to family or public care, states:

> The contrast between what responsibility an adult child will accept for old parents, and the responsibility the elderly are willing to impose on their own children, may go to the core of the issue. Parents are afraid of overloading their children, and use alternatives when they have a reasonably good choice. Like all persons, young and old alike, they find it easier to give than to receive; easier to be the independent provider than the dependent receiver. One-sided dependency has probably never been productive for good family relations.

Younger persons with physical, mental or intellectual disabilities, those in their twenties, thirties or forties, generally want a chance to strike out on their own. They don't feel it is normal to still be living with or dependent on their parents.

And yet, based on current practices where, in the face of non-choice, people with disabilities are being cared for at home by family and friends for as long as possible, we are told by policy makers that family care is the most natural and moral option and the choice of Canadians.

I would like to propose to you that home care as it exists today is neither the most natural nor the most moral option and I am far from sure that it is indeed the first choice of most Canadians. We have to shift paradigms and start asking questions like how can we as a society provide people needing support or care options which offer them as much independence, choice and autonomy as possible given their individual situations, options which enable them to participate, to the extent possible, as active integrated citizens, while offering the safety and security and support they need?

What would genuine community care look like?

I would now like to present what has been called a social model of community care. It is a model which is more of a framework, than a blueprint for policy makers and program designers – that is, it provides the framework for community care policies and programs, but it has to be fleshed out and adapted by the people most concerned – people with disabilities, caregivers, feminists and professionals. This is not an original model, it takes much inspiration from work by Sheila Neysmith and her collaborators in Canada and Nancy Hooyman and Judith Gonyea in the U.S.

This model conflicts with current dominant assumptions about the role and responsibilities of families and government for providing care for disabled people. It also

may appear unrealistic given the prevailing economic and political climate. However, given the nature and the level of disabilities of people being maintained at home and their care requirements, given the fact that an increasing number of care givers are elderly themselves and have their own health problems, given the economic necessity for younger caregivers to be in the labour force, given the evolution of family structures and the complexity of many new family relationships, given the inequitable sharing of caregiving between women and men, We have to ask if the current model where families and women in families assume the lion's share of the care is viable? Is this really the best option for all people with disabilities? Do caregivers have the concrete conditions to assure quality care to disabled kin without undue negative consequences to themselves, and possibly the care recipient, which may in the long run be more costly to the state? But beyond economic concerns, it is issues of justice and equity that should push us in this direction.

Central principle: Care needs are seen as a social issue and a social responsibility

With this approach, responsibility for caregiving does not rest primarily on families and caregivers, i.e., women, but on the community as a whole, that is, all sectors of the community in a partnership orchestrated by the public sector and where the public sector plays a major role. This is because the public sector represents the collectivity and social responsibility. By public sector, I am of course referring to health and social services, but also housing, employment, recreation, urban development services, etc. The care needs of people with disabilities are considered a social issue requiring a collective solution. They cannot be reduced to a family or an individual responsibility.

Orientations

1. Genuine Choice To Assume Caregiving

This is an approach that fosters social messages and a social organisation that does not oblige families to assume the major responsibility for care. To really have the possibility of choice, we have to find a balance between people's individual values, conditions, capacities, and skill at making choices, and concrete viable options from which to choose. As we have seen, these options must be of equal social value to be real choices.

Choice and the quality of care are dependent upon the existence of an array of support resources in sufficient quantity, including sufficient residential alternatives when the choice is not to be cared for at home. By residential alternatives I am not referring to long-term care facilities as we know them today, but rather to a variety of small-scale residences with services integrated into the community: things like group homes, sheltered housing, supervised apartments, satellite homes around long-term care facilities, etc.

When people with disabilities and a family member or friend do agree to caregiving at home, they must be supported by a comprehensive range of accessible, integrated and culturally appropriate services. Given the diversity of caregivers and caregiving situations, services, measures and supports must be wide-ranged and varied.

To promote empowerment and genuine choice, a social care model must ensure that all the measures, programs and services offered be they at home or in alternative settings, are characterised by flexibility, adaptability, variety, continuity, coordination and the organized input of disabled people and caregivers. The essential core of a model of social community care is the organization of a continuum of community-based services, financed mainly by the State, which are accessible, adapted, and flexible with a single point of entry and a single assessment. Within this organisation, we would find third party advocates whose role is to help caregivers and care recipients negotiate through the system and to defend their rights.

Current home care services must be substantially increased, particularly housekeeping and psychosocial services, and an array of new innovative services should be added aimed at maximizing the autonomy and assuring the highest possible level of integration of people with disabilities into all aspects of society.

2. Care As A Right Of Citizenship

When caring is seen as a social responsibility, access to services becomes a right of citizenship. Each individual is entitled to these services no matter what his or her family situation. A minimum floor of adequate support should be assured to all disabled individuals. This means guaranteeing sufficient funding of community-based services. Universal access to a guaranteed minimum of services assures equity among people and will work against the development of a two-tiered system wherein solely those with sufficient financial resources are able to access a variety of supports in the for-profit sector. It also counters the current situation where the quality and quantity of care that a person receives is mainly determined by the competency, availability, resourcefulness and circumstances of his or her family. It may also prevent the fracturing of family ties and bitter conflicts among family members that are currently the outcome of caregiving in some families.

3. Building Communities For The Integration Of People With Disabilities

Building community for the genuine integration of people with disabilities implies developing a partnership between all concerned stakeholders: people with disabilities, caregivers, the private-not-for-profit, the private-for-profit sector, the voluntary sector and the community, a partnership orchestrated by the state and organised around a strong public presence. Each of the various stakeholders is mobilised around their specific areas of expertise. Building community means designing geographically and architecturally accessible neighbourhoods and towns, including efficient adapted transportation, particularly in rural communities. It means adapted recreation facilities, etc. It can also mean undertaking media campaigns to change attitudes and behaviours with regard to the disabled, the ill, and the elderly or stronger incentives to integrate people with disabilities into the work force.

4. Promotion Of Global Vision Of Health, Prevention And Management Of Disease

Another aspect of the model, as stated by Hooyman and Gonyea, is that it promotes "a redefinition of health that integrates social and health services, physical and mental health care, and prevention as well as treatment". It also takes into account the reality that caregiving is often long-term. As well, this model is not disease-specific and does not dichotomize between chronic and acute care.

Researchers and practitioners have advanced a number of strategies for minimizing the impact of functional limitations on people's daily lives. First among these is increased access to rehabilitation programs for disabled people without prejudice as to their age, their place of residency or their type of disability. While rehabilitation is not a panacea, it can reduce incapacities or develop compensatory skills. The adaptation of houses and of communities to the realities of the disabled and all other actions aimed at reducing barriers to the self-accomplishment of their daily activities should be promoted, as should access to technical aids, prostheses and other equipment which enable disabled people to make-up for certain functional deficits due to their condition

5. Input From People With Disabilities And Caregivers

The input from people with disabilities and caregivers at all levels of the health care system, from conception to evaluation, is a major aspect of this model. This involvement would ensure that their situations are truly recognized, appreciated and taken into consideration in all decisions. People with disabilities and caregiver participation should involve delegation from consumer advocacy groups so that representatives represent a constituency. The capacity of these delegates to represent their group and participate in decisions concerning policy, planning and implementation will be enhanced by the existence of consumer rights groups working from an empowerment approach. These groups must be supported with long-term statutory funding.

Would care in the home continue to be the preferred choice of people with disabilities and family and friends, if genuine community care were available?

After all, caring by families and friends does not end because a person is in some form of alternative residential setting. Keating found that 30% of direct services of institutionalised older people was being provided by family members. While this is surely a reflection of the under-funding and lack of resources in today's institutions it is also a sign of family involvement with kin no matter where they are housed.

So let's look now at the second half of the question posed to us tonight: who needs to care? Well, obviously, many of us already do care. We know that family and friends provide between 80-90% of all care to disabled people at home and that over 2/3 of them are women. Women already care as the vast majority of paid carers – homemakers, nurses, social workers, rehab personnel, etc. But we are currently caring as if care were an individual or family affair.

So I believe we have to switch our thinking and start asking how we can best promote independent living and quality of care for people with disabilities. How can we make care a social issue?

I believe we have to start thinking about equity and justice for all people with disabilities and about gender equity and justice for women who care as paid and unpaid caregivers. But most of all, I believe our governments, politicians and policy makers need to care. Despite short-term economic setbacks we are a rich society. We have the means to offer genuine social community care. We have always believed in free and universal health care, in equity and social justice. To design home and community care which reflect these values, we must work to protect, reaffirm and reinforce them and make the type of model I am proposing a political priority. Then we will *all* care.

RESPONSE TO THE PANEL

Evelyn Shapiro, Senior Researcher, Manitoba Centre for Health Policy and Evaluation and Professor, Department of Community Health Sciences, University of Manitoba, Winnipeg, Manitoba

Evelyn Shapiro is an expert on the factors that determine the health of elderly people. She has conducted studies on the elderly and is a recipient of a 2001 Canadian Medical Association Medal of Honour.

Evelyn opened her remarks by saying that her role in responding to the panel was to provide a reality check. The main issue for her was, therefore, not with the views on the individual's experience as expressed by Jane Aronson or with the vision of society and the model of care proposed by Nancy Guberman with which she agreed. The issue for her was: What do we need to be able to achieve what they envision or, at the very least, to move closer to their vision?

She stated that the reality is that we are not starting from scratch and we should not pretend that we can. Home care programs have now been around for a relatively long time. Evelyn, therefore, believes that, in order to achieve the goal of more adequately and fairly meeting the needs of caregivers, we have to begin by ensuring that Canada has the kind of home care policies, models and practices that will help us meet those needs. Making this goal our highest priority will make it possible to achieve the ends proposed by Aronson and Guberman.

Evelyn next identified the main problems we currently face that need to be addressed:

- Current continuing care policies in too many parts of Canada do not support a social model of home care. For example, the imposition of user fees for support services that are the mainstay and primary need of care recipients and their caregivers by some provinces, especially in those provinces that do not even have a cap on total charges, deny the day-to-day reality that confronts the majority of caregivers.

- Policies that prescribe services limits regardless of need mean that only those who are wealthy enough to be able to purchase additional services from private companies can meet their assessed needs.

- Insufficient financial resources allocated to home care have led some home care programs in regional authorities within the same province to reduce or totally eliminate the support they provide to home care recipients who need minimal services even though a recent B.C. study shows that those who take this step incur higher costs within three years because these clients land up in hospital or nursing homes as a result.

- The quality of care delivered by formal care providers is important, not only in itself but because it makes it possible for informal caregivers to provide quality care. However, the quality of care depends on:

    a. Training and a continuing process of staff development

    b. Adequate pay scales and the availability of full-time employment (if desired) to increase staff retention rates instead of the current situation in which private companies reduce work hours to avoid paying fringe benefits.

    c. The assumption of some responsibility for training those who will provide services to clients who elect to participate in self-managed programs in which clients elect to purchase their own service with monies based on their assessed need for service. (There seems to be less enthusiasm for this choice amongst elders as compared to younger disabled individuals who may prefer to have personal control over their service providers.) The question is: "Are we abdicating our responsibility to provide trained quality personnel for these persons?"

Conclusion

Evelyn concluded with a story. She recounted her experiences with a six-week strike by unionized personal care workers in Manitoba in response to government announcement that it was going to privatize 20% of services in Winnipeg on the grounds that privatization would save money. She was struck by how quickly a coalition of care recipients, caregivers, churches and community residents rallied to support home care workers and also with how much importance home care users and their caregivers attached to having continuity in their service providers. The story illustrates the power of political action when people are mobilized by a cause and the results of the strike refute the myth that the private sector is cheaper and better. Evelyn herself became concerned about consumer protection issues as private caregivers were soliciting new business for which they said they would be paid a commission. The strike ended with an agreement to privatize only 10% of the services and to have an outside evaluation after a year of the experiment. The provincial government did not announce the results of the evaluation but

the experiment ended and all clients were returned to the public service workers, most probably because the experiment did not save money or provide services of adequate quality.

Her closing statements stressed the need to ensure that Canada has a national policy that assures that the assessed needs of clients and caregivers for health and social care are met without discriminating between health and social supports by levying charges for the latter. She indicated that we have some good and useful models of home care in Canada that could serve as examples. Since we are not in a position to start from scratch, she emphasized the importance of advocating for the necessary policy changes in home care.

"While it is true that such advocacy may not create a perfect system immediately, it will certainly improve the current situation and ensure that we have the capacity and the capability to achieve such a system within the near future. Finally, we must keep the intimate relationship between home care recipients and their caregivers in mind. We must, therefore, remember that caregivers need a solid home care program on which they can depend for the help they need even if we want to advocate for further steps to improve their lot."

DAY TWO November 9, 2001

Moderator's Comments

Pat Armstrong introduced the day's discussion by asking: "Why is this a woman's issue, and how do we translate this in ways others can understand?" "What are the gaps in research, how can we fill them and what kind of research still needs to be done?"

Round Table Discussion

Participants responded to Pat's questions with many comments, including the following:

- An acknowledgement that pressure from stakeholder groups gets the attention of policy makers and politicians, and therefore there must be a strategy that is evidence-based, with pressure from care providers and recipients.
- Need to focus on people providing care – easier to focus on people delivering care.
- Must keep the vision beyond home care – to imagining the kind of nation we want
- Need research for the purpose of action; need to gear research to activism on a broader perspective - caregiving being one.
- Need more research re women's health and women's needs.
- The Kirby and Romanow commissions are opportunities for input on government policy.
- We need economic information on both short- and long-term costs.
- We are "shooting ourselves in the foot" by naming home care a women's issue by implying it is only of interest to women.
- Need to approach this as an issue of social capital/social cohesion as these are areas of focus for policy makers; using the language of policy makers helps one participate.

- Need to put our energy into arguing that caregiving is a value important to all society.
- Need action such as a Caregivers Bill of Rights; a Home and Community Care Act
- Need action at two levels: politicians need to hear from constituents and policy advisors need evidence.

Summary

Pat Armstrong summarized the discussion, indicating that she heard a call for making the "business case" for caregiving by documenting both the long-term and short-term costs, and contextualizing home care in relation to other issues such as caring for children, and balancing work and family responsibilities in the new economy. A key question from the discussion was: How do we make care more visible to policy makers? The group called for different kinds of action and activism. It was also stressed that traditional studies of economic costs are not necessarily sufficient but need to also encompass an analysis of social, psychological, spiritual costs and benefits.

Small Group Discussions

Participants broke up into four small groups to discuss the issues raised in the morning's plenary, including areas in which they thought research was missing and needed. Comments from the discussions are pooled and summarized below, based on notes taken in each group.

It was proposed that what is needed is a paradigm shift with regard to home care which recognizes care as entitlement, a human right, does not denigrate dependence, and recognizes people's interdependence.

Some participants concluded that the Think Tank should not make the assumption that *homecare* is necessarily the ultimate goal; rather, there is a need to seek alternatives. The present system is untenable, as it places an unequal burden on women.

It needs to be recognized that caring is at the very heart of women's lives and that the women's equality agenda cannot move forward without addressing caring; on the other side of the argument, positioning care as a women's issue is difficult and some men do engage in caregiving.

Other questions that were posed include: How do we sustain care in an environment of rationing? What are implications of caring for the workplace and employee benefits? The language of policymaking and service delivery can be a barrier to participation in discussions because it excludes those not familiar with it.

The creation of a national homecare policy is difficult in the context of federal/provincial relations, but it also lacks visible public support. How do we broaden awareness and bring together and engage policy makers and researchers, *and* place this issue on the public agenda? There have been related shifts in policy that suggest possible approaches.

Witness the changes in parental leave policies; these serve as models of the process of legitimation of issues of caring.

It was suggested that there is a need for a national committee to provide leadership, a clear communication plan, and a watershed event such as a Women's Summit to raise awareness and political action. A tool box was developed to represent some of these "tools".[10] A Declaration – a principled statement around changing the culture of care was discussed as something that would be useful as set of principles for future action on this issue.

Research gaps identified by this group were related to the impact of different models of care; assessment of current values on caring; social location of carers; when/how do people identify as carers?; what are the rewards/joys of caring?; narratives of care; how to shift relations/unit of care outwards?; and the use of better questions in existing instruments that capture the nature of change in caregiving

Other suggestions for research included the following:

1. Explore economic and human resource policies to support care giving, e.g., drop clauses for CPP; pensions, income replacement, and extending labour protection for caregivers.
2. Adopt a multi-departmental approach - not view homecare as only a health issue; need a communication plan targeted at employers and employees to get the word out.
3. Collect information on the costs and burdens of homecare.
4. Adopt a social model as per N. Guberman's presentation.
5. Research on needs/opportunities regarding care work across the life cycle.
6. More research, and policy development, on jurisdictional boundaries, especially among professional groups, regions and the life span.
7. Study the costs of *not* caring, especially over the long-term, in ways that are inclusive of social, individual and collective consequences.
8. Recognize in policy and research the changing contexts of families and work.
9. Explore alternative models to caring communities, listen to other voices and recognize the variety in needs and response.
10. Recognize that gender matters.
11. Study homes as workplaces.

While there are still important gaps in the literature, such as the need to study those who work in the labour force as care providers, and also do the same thing without pay at home, participants also felt it was time to develop a long-term care policy that is based on the recognition that care is required 24/7/365 and that is inclusive, involving institutions, communities and homes.

---

[10] A visual representation of the tool box can be found in the activity report of the Think Tank. Contact the ACEWH for further information.

A small group began to identify founding principles for homecare. These included: equitable entitlement to homecare based upon standards of care – both medical and social care; caregiver recognition; more resources for the present system to ensure training, quality and adequate amount of services; caregivers as part of the assessment process; dollars for family members who provide care; more workplace flexibility; respite programs; an appropriate needs assessment that include(s)social and functional needs; provision of information regarding services available and how to access them; closer examination of the implications of policy options e.g., impact of tax breaks, etc.

Changes that are needed were articulated: Information and education for caregivers; access to services; respect; support for choices; responsive, quality services including mental health, palliative care, support for caregivers; inclusivity – culturally and geographically. A stable, well-paid homecare workforce that is well-trained, enjoys good working conditions, and for which there are standards of care.

Barriers to change were identified: Women's issues/caregiving are not high priorities; current environment – focus on money yields uncertainty and insecurity; several governmental levels and jurisdictions, therefore responsibilities cross several government departments; senior decision-makers and organizations are male dominated.

The question of how to frame the issues of home care were debated. Options include framing the issues as one of: Social justice? Economic? Women's issue? Societal issue (elders, parents, disabled)? Human rights? Determinants of health? Social cohesion? Welfare state? Work/family balance?

Numerous action strategies were proposed: Short and long term strategies are required; with a focus on values. Timing is important – need to build on what already exists, e.g. coalitions, caregivers' organizations, allies with government and researchers. Need to mobilize public support, share success stories, and influence the F/P/T agenda and policy. One participant suggested that it was time to launch a Charter challenge based on the argument that the lack of a coherent program unequally discriminates and impacts women

In each of the small groups, participants expressed a strong desire for action to address the problems identified through research and caregiving experience. In response to the group's readiness to develop action strategies, the Coordinating Committee proposed a restructuring of the small groups for the next day's discussions. These new groups were organized to: write a Declaration on the Right to Care; explore legislative changes; outline a research agenda; discuss network building and a Women's Summit; and address human resource issues of paid and unpaid care providers.

DAY THREE November 10, 2001

Small group discussions were conducted in the morning on research, human resource issues, a possible declaration, networking and summit, and legislative issues. Reports were given following the luncheon video presentation by Dr. Miriam Stewart.

Brief Summary of Address – *Future Directions in Research on Home Care*[11]

Dr. Miriam Stewart is Professor in the Faculty of Nursing and in Public Health Sciences, Faculty of Medicine (University of Alberta). She is a Health Senior Scholar, Alberta Heritage Foundation for Medical Research and a former Medical Research Council of Canada and National Health Research Development Program (MRC/NHRDP) Scholar. Dr. Stewart was appointed as the first Scientific Director of the Canadian Institutes of Health Research, Institute of Gender and Health.

Miriam reviewed the mandate of the Institute of Gender and Health as that of generating evidence about the health of females and males across the lifespan, and the influence of gender and sex on health and interactions with other determinants; providing evidence to inform the design of programs, policies and practices that enhance the health of women, men, girls, and boys in Canada; and to exert international impact. The Institute's priorities as they relate to gender are identified as: Access and equity for marginalized populations; promoting health in context of chronic conditions; gender and health across the life span, promoting positive health behaviours; and gender and the environment. For each priority there are strategies to advance work by offering grants and awards, and building capacity through funding training. She stressed that all of these initiatives are relevant to caregiving, and that much has been learned and will continue to be learned through this research about the necessity of providing support for caregivers, who are predominantly women. The research should make a difference in influencing the development of programs that will support the health, competence and confidence of caregivers over time.

Reports on Small Group Discussions

Each group offered a summary of their discussions as part of the final plenary session.

Focus One: Human Resource Issues in Caregiving

Group's statement for possible inclusion in the Declaration:

> *"In research, policy and practice related to home care, the interdependence between paid and unpaid care and the subsequent cause and effect relationships must be recognized and acted upon."*

Policies related to human resources in home care should be screened according to the following principles:

- Policies should promote equity (across genders, locations, sites of care)
- Long-term consequences of carework should be evaluated (e.g. impacts on health and lifelong earnings)

[11] Dr. Stewart was unable to attend the Think Tank in person so presented her address via videotape. This summary only captures a brief portion of her remarks.

- Impacts on both paid and unpaid care work should be evaluated.

Concrete Recommendation for Action:

Assess the existing research on the pros and cons of direct and indirect compensation policies, examine the policy implications and develop policy recommendations based on that research, and undertake a pilot study of selected policy option(s).

Brainstormed List of Human Resources Issues:

- Keeping both paid and unpaid careworkers' issues together
- Inequities across regions, provinces
- Financial compensation, wages, benefits, pensions
- Access to services – availability, means tests, entitlement to formal services
- Single entry point to system
- Access to training
- Work/family balance issues, flextime, paid leaves, on the books but not used
- Scheduling, assignments, problems re: deployment of paid careworkers
- Relationship between paid and unpaid care providers – conflicts, privacy, good relationships seen as problematic.
- Care recipient's right to choose who will provide personal care.
- Compulsory or "voluntary" caregiving work by family and friends.
- Safety issues in the place of work
- Standards of care, safety of recipient, transfer of care tasks to whom?
- Working conditions, heavy workloads, length of workday.
- Hospital procedures done in the home, under what conditions?

In conclusion, this group created both a national framework entitled a "Perennial Perspective on Care" and a "Caregiving and Human Resource Policy Issues Framework" as mechanisms to present their information to the larger group. The policy issues framework is reproduced below.

Caregiving And Human Resources Policy Issues Framework

Issues	Paid Carework	Unpaid Carework
Compensation Issues Need to evaluate long-term consequences, impact on lifelong earnings, and identify which women will benefit, e.g only those in paid labour force, or eligible for tax credits.	Adequate compensation for the value of the services provided. Equitable compensation across sites and locations – in different jurisdictions, homes and institutions.	Direct payment to "family" caregivers (pros and cons) Direct payment to care recipients (pros and cons) Income support and paid leave for some forms of unpaid care. Pension coverage for unpaid caregiving
Conditions of Work Issues	Need to provide safe work environment Workers Compensation Training and Certification	Need to provide safe work environment Workers Compensation Appropriate Training Assessments for formal services need to include, not assume, caregivers' capacity to provide unpaid care.

Focus Two: Research

This group identified numerous issues and priorites for research:

1. Knowing what is being done and who to contact
The group determined that there was a need to know what research is presently underway, to connect with those who engaged in research in this field, and to collaborate with known expertise in writing future proposals. They recommended that participants provide information on their areas of expertise for future proposal writing, and that a list serve be established.

2. Research Agenda
The group recommended the anchoring of a research agenda in relation to a policy agenda designed to:

-reduce the burden of care and mitigate its consequences;
-value care, caregivers, and care recipients;
-build a caring community; and
-ensure that the gendered dimensions of care/caring are fully integrated into the research program(s).

3. Methodology
The group felt there exists a need to link qualitative and quantitative research, especially in the economic sphere, where there needs to be work done to recognize costs, yet at the

same time there needs to be a way of addressing those areas not appropriate for quantitative data collection. There is a need for indicators, development of which could be done based on existing research. There needs to be a link between methodological issues and analysis of existing data.

4. Public Policy Agenda
Research and information need to be developed for a variety of purposes, one of those being the public policy agenda. There is a need to look at the meso level and macro level of systems, e.g. to research the complexity of care, such as mediation work involved in caregiving, regional disparity, etc.

5. Research Gaps
The group generated a list of research gaps. It was brought to the attention of the participants that some of the gaps are being addressed by Québec research. This raised the issue of translation and dissemination. It was recommended that the list of gaps be reviewed in light of research which may be available in other languages, and ways found to disseminate the information and collaborate.

6. Research Realities
It was recognized that some of the realities of conducting and overcoming barriers in research with caregivers could be informed by the experience of participants. This sharing of experience and tools, etc. and was referred to the list serve recommended by this group.

Much of the discussion that followed this presentation had to do with the problems in completing application for research funding.

Research Gaps

The research discussion group focused on research gaps, and felt that it would be useful to develop a listserv of participants, as well as a database including all participants' areas of expertise. Their discussion focused on anchoring the research agenda in relation to a policy agenda designed to:

- reduce the burden of care and mitigate its consequences;
- value care, caregivers, and care recipients;
- build a caring community; and
- ensure that the gendered dimensions of care/caring are fully integrated into the research program(s).

Discussions considered the gaps in terms of a variety of lenses:

- basic/applied/policy research
- intersectoral research (not just in health)
- focusing on uptake of findings, and research for action by individuals and those in the policy sector
- the need for relevant training in connection with the research agenda.

Research gaps identified were numerous, as follows:

Caregivers

- youth in the caregiving role
- the stigma of caring
- the role of non-family carers -the interaction between institutions and carers
- dual caregivers (i.e., those who perform both paid and unpaid care work)
- research on the processes by which people come to be carers, and studying the background and pressures that surround the decision/reality of caring (i.e., structural constraints on carers)
- the "caring community" -men who care -demographic changes and their impacts on care/caring (e.g., migration, fertility, contingent work force and other labour force issues)

Variations in caring and receiving care

- regional and cultural variations in caring
- urban/rural differences in caring
- Northern/Arctic research and research with First Nations communities
- international comparisons
- research on specific populations, kinds of care, and locations of care
- research on care recipients is needed so as to humanize them rather than objectify them
- research on the complexity of mediation work (between recipients, carers, and hospitals/doctors, etc.)
- the disconnect between assessments and what can be provided by the home care system

Costs

- the economic costs of caring across the life cycle
- costing research (i.e., may find out that good care costs more, not less) -- this type of research is especially important because the costs extend to individuals, employers and governments -- this type of research can help to mobilize carers who are mostly women, and for public education; it can be useful to employers who presently do not know the extent of the problem or its impacts on individuals' well-being and productivity; it may be important in terms of the development/ enhancement of Employee Assistance Programs as well; need to look at both economic and non-economic indicators, short- and long-term costs (e.g., it would be useful to do a study on women in poverty to see how they deal with care work, and how they deal with circumstances in which someone is released without home care -- what are the effects? what are their options? etc.); a major problem in costing research is trying to quantify that which is not quantifiable; need also to get the different perspectives (of recipients and care providers) in cost/benefit research

Policy process

- the impact of policy change on carers and those receiving care (i.e., research on the policy process)
- link home care to other policy areas, e.g., voluntarism, disabilities, children, etc.

Information – access, management, and dissemination

- the under-analysis of existing data (need for gender-based analysis of existing data; this is also related to the need for training in the conduct of secondary data analysis)
- improvements in the Stats Canada data on care work -linking qualitative and quantitative data
- need for the development of new methods for studying such topics as palliative care
- harmonization of information systems
- what Canadians need to know -- meaningful indicators of quality care that are valid -- needed to enhance current accountability systems in health care -research on policy, "best practices" -the issue of "choice" -the most burdened -the full spectrum of caring (i.e., child/infant care through eldercare)

Focus Three: Legislative Change

This group determined that there is a need for strong federal legislation and leadership to establish publicly funded, long-term home and community care programs. They envisioned a program that would establish standards and entitlement, and a system that would not assume that unpaid work be performed by the family. It would provide health and social services as well as provide supports and resources for associated costs of equipment and respite care.

Discussion focused on how to make this happen, and initially explored modifications to existing legislation, questioning whether it may be too limited in its scope. Discussion then moved to exploring models of loss-of-autonomy, disability insurance and flexibility within public resources. A desired outcome determined by the group is that women who are absent from paid employment because of caregiving should not live in poverty now or later. There was an expressed need to identify the best way to achieve this and to seek best practice.

Recommendations:

1. To ensure that unpaid caregivers are not penalized action must be taken now to:
    a. Adapt CPP/QPP to allow contributions by unpaid caregivers and a "drop-out" policy developed so that there is no penalty for time away from employment and contributions.
    b. Workplace compensation legislation should include injury while providing care.
    c. Income protection and job protection should be assured while on caregiving leave.
    d. Home care regulations and policies should allow payment and benefits to a family member if that person is the most appropriate to give care.

2. Unpaid caregivers need to have brought to their attention those services which are designated protected services such as those identified in nursing and medical legislation.

3. The present system needs to be challenged through human rights complaints and possible Charter challenges to provide adequate resources and supports. Leadership is required.

Focus Four: Declaration

In taking on the development of *The Charlottetown Declaration on the Right to Care*, the Framework of Care from Day 1 was revisited as well as the *Canada Health Act* and the *Ottawa Charter for Health Promotion.* Once written, the group prepared overheads, and prepared handouts in English and French to begin discussion and editing in the large group. There was not sufficient time to reach consensus during the think tank, but the sentiment was supported by all. There were several recommendations to continue to refine the Declaration and disseminate it. The amended Declaration follows as the summary of the final plenary session.

Focus Five: Network-Building and Summit

In reporting on their discussions, the group determined that access to information should be addressed as a priority. Major barriers to engaging in discussions of home care policy include not being aware and not having access to information. For Arctic women, and other minorities, translation and access to technologies are also barriers. Challenges to communication include in Canada multiple languages, cultural diversity, access to technology, the need for plain language materials and the absence of alternate formats. They recommended that core documents be identified and translated, and that in future, projects should ensure that translation costs are built into project budgets. They also recommended that reporting research back to communities and participants is critical as is involvement of communities in the design and implementation of research, through participatory, feminist, community-based research practice. Rural health and caregiving needs to be formalized as a specific area of research and action.

As an immediate issue they raised the question of how the results from the think tank would be shared and offered several suggestions:

- Include champions on list of receivers of the think tank report
- A working document should be sent to participants and those who could not attend
- Another document should be sent to politicians and ministers of health
- Communication should take place at F/P/T meetings
- Presentations should be made at the international homecare conference in Toronto in the spring

Who should do this work?

- Each participant should commit to sharing this information within their organization and share it with colleagues, but it must also be shared with caregivers themselves.

We need to build a network of concern people that includes:

- Former caregivers are resources, as are caregivers with family members in long term facilities
- Unions, professional organizations and social justice & labour groups working to organize marginalized paid workers.

When the group considered those who government listens to on policy and legislative changes, they were aware that grassroots caregivers have the least opportunity and the fewest resources to engage with policy makers. They identified a continued need to create opportunities for grassroots participants and organizations to make a contribution to agenda setting, advocacy, research and legislative change, and these groups need support wherever possible.

This thinking led to the following recommendations to encourage and support networking:

1. Craft consistent national messages that go out from established network channels. Post these messages on all organizations websites.
2. Create a national database of organizations that support caregiving; every province should be responsible for its own database of provincial organizations
3. Establish a clearing house for information
4. Create public awareness events e.g. caregiver month
5. Apply for international year of the caregiver

The group concluded with a recommendation that a Woman's Summit, inspired by the International March of Women, should be pursued. It could be a landmark event that could follow and build on the momentum of this think tank, and serve as a way to combine mobilization, networking and public education.

Plenary Round Table Response – Where do we go from here?

During the last session of the Think Tank, discussion was animated as participants crafted a Declaration on the Right to Care. The National Coordinating Group was directed to complete the wording of the Declaration and oversee its dissemination.

THE CHARLOTTETOWN DECLARATION ON THE RIGHT TO CARE[12]

The Right to Care

Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life without discrimination as to gender, ability, age, physical location, sexual orientation, socioeconomic and family status or ethno-cultural origin. The right to care is a fundamental human right.

The Right To Care requires: access to a continuum of appropriate, culturally sensitive services and supports; appropriate conditions; the choice to receive or not receive, or to provide or not provide unpaid care; that there is no assumption of unpaid care; and access to reasonable alternatives and sufficient information.

Care is: essential; an interdependent relationship; skilled work; multidimensional; and diverse.

Care should be: equitable; available; accessible; continuous; responsive and transparent. Care should incorporate diversity and be participatory; enforceable; standards-based; be publicly administered; and respectful.

These rights to care must be viewed through the lense that recognize the importance of gender analysis, diversity, interdependence between paid and unpaid care, and linkages among social, medical and economic programs.

Origins:

In Charlottetown in November 2001, 55 experts from the academic, policy and caregiver communities gathered to discuss research and policy on women and home care. Based on their experiences and the existing research literature on gender in relation to home and community care, these experts concluded that women's experiences and needs are often different from those of men.

---

[12] This document is revised from the one draft during a "National Think Tank on Gender and Unpaid Caregiving"organized by the National Coordinating Group on Health Care Reform and Women and the Maritime (now Atlantic) Centre for Excellence in Women's Health, November 8 - 10, 2001 in Charlottetowne, PEI. Forty- six of the fifty five participants signed the Declaration. Some participants were not in the position to commit their organization or government department. See http://www.cewh-cesaf.ca/healthreform

- Women are the majority of those who receive care
- Women are the majority of those who give care
- Women are more often expected to provide care
- Women have fewer financial resources to provide care
- Women provide more demanding care, work longer hours, and have more responsibility
- Women's lives and plans are more disrupted by caregiving
- Women have more extensive and supportive networks, however these networks may also be a source of conflict
- Women with care needs receive fewer hours of paid care

Existing conditions for caregiving mean that,

- Women providing care often end up in poor health
- Women are rewarded by caregiving, although inadequate resources limit rewards and make it harder to care
- First Nations, Inuit and Métis women face persistent and pervasive obstacles in giving and receiving care
- Women from immigrant, refugee, and visible minority communities may face racism, language and cultural barriers in giving and receiving care
- Women receiving and giving care are often subject to violence and other physical risks
- Women are facing deteriorating working conditions, low wages and lack of security in providing care

The workshops and plenary discussions led to a consensus on the fundamental principles for a national home care strategy that ensures equity for both women and men. These were codified into the Charlottetown Declaration on the Right to Care, which recognizes that home care needs to be an integral part of a publicly administered health care system.

Understanding the Declaration

The right to care is a fundamental human right.[13] This means that, **Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life.** Such care must be provided **without discrimination as to gender, ability, age, physical location, sexual orientation, socio-economic and family status or ethno-cultural origin.** Care is thus understood as a public good rather than as a private one to bought individually for a price. Furthermore, access to care should not depend on a person's ability to pay.

[13] Statements in bold are direct excerpts from the Charlottetown Declaration.

The right to care requires access to a continuum of services and supports. Our public health care system began initially by financing hospitals and then moved on to pay for physicians. But the Hall Royal Commission that led to medicare clearly understood an effective and efficient public system had to provide a full range of co-ordinated services and supports, including public home care. Indeed, the Commission saw the financing of hospitals and doctors as merely the first step, because only with a continuum of services would people receive care at the most appropriate level, move easily from one service to another and avoid costly duplication. Such a continuum in public care does not currently exist. In addition to services, care givers and those receiving care need supports such as training, care leave, job security and income programs. **Taking into account the particular preferences of those in the care relationship into account, such services and supports must be culturally sensitive.**

The right to care requires appropriate conditions. Whether care is provided at home or in a facility, it is necessary to provide conditions that meet the needs of care recipients and care providers. We know that health is determined by culture, physical and social environments, social support, security, gender, economic and educational resources, and coping skills, as well as by biology, genetic makeup and health services. These all count in the provision of care, and some are even more important given the fragility of people who are ill or have a disability. Homes are not necessarily havens and hospitals can be dangerous to the health of patients and providers if conditions do not meet their particular needs or ignore the determinants of health.

The right to care requires the choice to receive or not receive, or to provide or not to provide unpaid care. Care involves both the person who gives care and the person who receives care. Both need choices about who provides care and about what care is provided. As the Prime Minister's National Forum on Health was told, women "conscripted" into care end up in poor health and may be unable to provide adequate care. Women who need care may not want to receive such care from relatives conscripted into service. At the same time, many want to provide care or to receive assistance from relatives but need help to do so. Public care should provide alternatives in ways that offer a genuine choice for those involved in the care relationship.

The right to care requires that there is no assumption of unpaid care. Care is not a choice if it is assumed families in general and women in particular, are willing and able to provide care. Many lack the skills, other resources or desire to give or receive unpaid care. This is particularly the case as the majority of women must rely on having income from paid work and as more of the work sent home requires complex treatment. At the same time, unpaid care may not be possible without necessary supports.

The right to care requires access to reasonable alternatives and sufficient information. The right to care requires not only a choice about providing or receiving care but also a choice about how and where care is provided. For many but not all, the home may be the best place for care. For some, but not many, facilities may best serve their needs. Such alternatives must be available to ensure appropriate and culturally sensitive care. Moreover, reliable, accessible information on the benefits of and problems

with alternatives and on how to access them, as well as on how to give and receive care, is a necessary component of a public care system.
To ensure the right to care, **care must be understood as essential**, something we must provide as a country. While we have choices about how, when and where to provide care, we do not have a choice about whether to provide care to those who need it. We cannot leave people without necessary care. Care must also be understood as **an interdependent relationship**. It is not simply about what one person does to or for another but also involves reciprocity. It frequently involves paid and unpaid care providers, extended family and friends, as well as the person receiving care.

Care is **skilled work**, requiring education, training and experience. It is not something women do naturally by virtue of being women. Care is at the same time **multidimensional**, involving all aspects of those involved in the relationship. It includes everything from feeding, injecting and hugging to bandaging, chatting and intubating. And finally, care is by definition **diverse**. People are different. Their cultures and experiences shape their needs and how those needs aught to be addressed.

Care should be:

Equitable. Equitable care does not mean the same care for everyone. Rather, it means a fair distribution of care based on appropriately assessed needs, and a fair distribution of care work. The *Canada Health Act* defines equitable as care provided under "uniform terms and conditions," and this principle should apply to homecare.

Available. Available care means public services provided within a reasonable distance without unreasonable delays. The *Canada Health Act* recognizes that care must be there to be accessible, and this principle should also apply to homecare.

Accessible. The *Canada Health Act* says that necessary services must be provided in a manner that "does not impede or preclude, either directly or indirectly" access to care. This includes user fees or other charges that can undermine the right to care. The accessibility principle from the *Canada Health Act* should apply to homecare

Continuous. Care does not only require that there be a smooth transition among services and a range of services to provide appropriate care. It also requires continuity in care providers and services.

Responsive and transparent. Care should respond to the particular needs of those giving and receiving care. People need to know how to access services that respond to their needs and how decisions about services are made. This includes decisions about what care is publicly provided and what is not.

Incorporate diversity. Responsive care recognizes cultural, regional, age and gender diversity, as well as differences related to sexual orientation, and socio-economic and family status. Particular attention must be paid to traditional practices and activities of First Nations, Inuit and Métis peoples.

Participatory. Both those providing and those receiving care should be involved in decisions about how, when, where and by whom care is provided. And, the public should be part of the process in determining how the system is organized and how care is delivered.

Enforceable. It is not enough to set out the principles for the right to care. It is also necessary to put mechanisms in place to ensure that these rights are protected through the provision of services and supports that protect this right.

Standards-based. It is important to respond to individual needs and to allow individuals to participate in decisions about care. It is also necessary to have standards for care based on evidence about the effectiveness and the appropriateness of care. Evidence should provide guidelines for providers and standards against which care can be compared.

Publicly administered. There are clear benefits to a publicly administered health care system in terms of cost savings and co-ordination. It is also easier to hold a publicly administered system accountable to citizens.

Respectful. Those providing both paid and unpaid care, as well as those receiving care must be treated with respect. Respectful care recognizes that individuals have preferences, abilities, feelings, experiences, and histories.

The Right to Care must **recognize the importance of gender analysis, diversity, interdependence between paid and unpaid care, and linkages among social, medical and economic programmes.**

A Call to Action:

The *Charlottetown Declaration* was a product of deliberations on existing research, practice and experience. It provides the principles for further action on developing a comprehensive public system that includes home care and works for both women and men.

The *National Think Tank on Gender and Caregiving* was funded in part by the Government of Canada. The views expressed in the *Charlottetown Declaration* do not necessarily represent the views of the Government of Canada or any of Canada's provincial or territorial governments.

Appendix A

PROGRAM COORDINATING COMMITTEE

Members of the National Coordinating Group
and Health Canada Women's Health Bureau

Pat Armstrong (National Think Tank Co - Chair)
Department of Sociology
York University

Carol Amaratunga (National Think Tank Co -Chair)
Executive Director
Maritime (now Atlantic) Centre of Excellence for Women's Health

Madeline Boscoe
Executive Coordinator
Canadian Women's Health Network

Lynne Dee Sproule
A/Director Women's Health Bureau
Health Policy and Communications Branch, Health Canada

Karen Grant
Department of Sociology
University of Manitoba

Ann Pederson
Manager of Research and Policy
BC Centre of Excellence for Women's Health

Jean Kammermayer
Women's Health Bureau
Health Canada

Kay Willson
Prairie Women's Health Centre of Excellence
Saskatoon Program Coordinator

Catherine Kulisek
Acting Manager
Centres of Excellence for Women's Health Program

EVENT PLANNING COMMITTEE

Carol Amaratunga (Co - Host)
Executive Director
Maritime Centre of Excellence for Women's Health

Donna Murnaghan (Co –Host)
University of PEI
PEI Health Research Institute

Sandy Bentley
Interministerial Women's Secretariat
Province of PEI

Jeannita Bernard
Veteran's Affairs Canada
Health Promotion and Education Directorate

Patsy Beattie-Huggan
Consultant, The Quaich Inc.

EVALUATION SUMMARY

Evaluation forms (above) were circulated to the group on the final day of the think tank and later circulated by e-mail for those who may have missed the opportunity of completing an evaluation at the time of the event. In the end, 45% (25/55) of participants completed the evaluation form.

Information Presented: In relation to ratings for information presented, 96% (23/24) agreed or strongly agreed that the information was helpful; 79% (19/24) agreed or strongly agreed that the preparatory reading was helpful, with two comments indicating that there was too much material sent in advance.

Participation: In response to questions regarding their level of participation 96% (23/24) agreed or strongly agreed that they felt comfortable speaking out, had time for reflection, had input into the outcomes of discussion, and adequate opportunity for networking. Two comments reflected the need for more caregiver voices.

Organization: In response to questions regarding organization, 100% (25/25) of participants agreed or strongly agreed that the think tank was well organized; 95% (21/22) agreed or strongly agreed that the facilitation was effective and that there was a good mix of speakers, small and large group activities. Comments included:

- "Extremely well organized – I felt almost pampered"
- "Pat Armstrong set a good tone by her skills for clarifying and synthesizing and good humor"
- Félicitations aux organisatrices! Ça été une experience agreeable et enrichissante et, j'espère productive.

A high percentage 88% (21/24) rated the physical space as supportive to the work. Of those who did not find the space supportive, 3 comments related to problems with air temperature, and lighting, and 3 comments regarding the setup of the large room. Although 86% (19/22) felt that conditions were positive for consensus building there was a concern expressed by three people that there was insufficient time to reach consensus.

- "pas assez de temps pour arriver à un reèl consensus. Le Samedi après-midi était trops ambilieux"

Work accomplished: In terms of work accomplished, 91% (20/22) agreed or strongly agreed that objectives were relevant and achieved, and 90% (18/20) agreed or strongly agreed that they were satisfied with the outcomes of the Think Tank.

- "I was pleased with the outcomes. I think we have our work ahead of us to build the network to support caregivers."
- "I very much appreciated strong minds and hearts working together in feminist processes. Thank you coordinating committee for bringing us back to feminist participatory process which contributes to sound deliverables!"
- "la rencontre rèpond à mes attentes"

Four people offered comments related to the desire for more discussion on action.

- "Would have liked more time for discussion of actions. The group suffered from the fewer number of community activists/consumer groups"

And for two of those who missed the opening of the Think Tank, there was an expression of confusion regarding the objectives.

- " I found the event to lack focus – I continue to wonder what the objectives were; therefore it is difficult to judge whether the outcomes were satisfactory. I found that the events which transpired to be far removed from the stated objectives in ThinkTank correspondence"
- "les objectifs de qui? Seulement le comite de coordination? ça a rencontré mes objectifs. A la fin, nous avons voté un peu trop rapidement sur les dernier.

The remaining sections of the evaluation provided room for participants to comment. Respondents indicated that what they liked best about the Think Tank was meeting and learning from others (12 comments); the process (5 comments); potential for action (3 comments). The most useful thing they learned was working together is productive (3 comments); meeting others of similar interests (5 comments); sharing of information and interests (4 comments) and developing new insights (3 comments).

When asked how the think tank could have been improved, the responses were reflective of concerns identified throughout the evaluation: No improvement required (1 comment); clearer objectives (3 comments); including others (5 comments); improved physical environment (2 comments); more time on action (2 comments); more information on research interests (1 comment).

When asked about next steps, respondents were keen to offer ideas, ranging from forming a network, to taking action, to transferring the process to other areas of research/policy:

Forming a Network

- "Formation of (formal or informal) consortia for future research and advocacy"
- "linking Centres of Excellence with Canadian Coalition for Home care groups e.g. VON, provincial caregivers associations"
- "circulate research/policy/advocacy interests of all participants on list serve"
- "Need to follow-up with a concrete plan of action and keep in touch through a list serve"
- "Network with existing groups/organizations e.g. CCC. The time is right to move on this issue"

Taking Action

- "Send women with declaration to policy makers; public education; stay with it, don't let it drop"
- "Use the final report as a marketing /awareness tool for advancing the issue on the policy front"

- "Clearer articulation of 'hand off' - draft of recommendations circulated in advance"
- "Make sure information gets widely distributed"
- "Following through on small group recommendations – opportunity to meet again while there is momentum around the issue"
- " Publish & publicize the Charlottetown Declaration
- Commission research on: a) potential human rights & charter challenges (based on discrimination against women); b) economic analysis of the costs of unpaid caregiving"

Transfer to other areas

- "Should be repeated in other areas of research/policy"

Follow-up suggestions

- "Please send a copy of the final report to the Canadian Caregiving Coalition and Family Caregiver Network Society"
- "élarger le comité de coordination"

Participants closed the evaluations with many expressions of thanks to the organizers, and for the opportunity to have participated in such a worthwhile and productive event.

Appendix D

Reference Material Circulated to Participants

Preparatory Documents

Morris, M. (2001). *Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper* (Second Draft). Ottawa: Health Canada Women's Health Bureau, October. [The final version of this paper is available from the Women's Health Bureau of Health Canada, see http://]

Armstrong, P. & Kits, O. (2001) *One Hundred Years of Caregiving.* Prepared for the Law Commission of Canada, April.

Circulated at the Think Tank

Armstrong, P., Amaratunga, C., Bernier, J., Grant, K., Pederson, A., Willson, K. (Eds.) (2001) *Exposing Privatization: Women and Health Care Reform in Canada.* Aurora, ON: Garamond Press.

Follow-up Documents

Fast, J., Eales, J. & Keating, N. (2001). *Economic Impact of Health, Income Security and Labour Policies on Informal Caregivers of Frail Seniors.* Ottawa: Status of Women Canada.

Fast, J. & Keating, N. (2000). *Family Caregiving and Consequences for Carers: Toward a Policy Research Agenda*, CPRN Discussion Paper No. F/10, Canadian Policy Research Networks, Ottawa.

Guberman, N. (1999) *Caregivers and Caregiving: New Trends and Their Implications for Policy* (Final Report), Health Canada, March.

Keefe, J. & Fancey, P. (1998) *Financial Compensation Versus Community Supports: An Analysis of the Effects on Caregivers and Care Receivers* (Final Report), Health Canada, March.

Appendix E

Lessons Learned

We were fortunate in this Think Tank to have the opportunity to bring together a dynamic, committed group of researchers, policy makers and care providers. Together, we identified many opportunities for research that will help inform planners and advocates. In addition, we were able to outline the principles for health care system that is designed with care as the objective.

We think that there were a number of processes that facilitated the success of our Think Tank including:

Preparation for the Think Tank

- A background paper was commissioned and distributed to all Think Tank participants in advance of the workshop. This paper provided a common basis for discussion and reflection prior to and during the Think Tank.
- The National Coordinating Group met prior to design the format for each session to maximize participation, discussion and the flow of information.
- We had the luxury of planning the Think Tank program whilst not being responsible for operational details, enabling us to pay attention to details of how each session of the workshop would flow.
- We built in time for informal networking and fun as well as structured discussions and prepared speakers.

Responsiveness to Issues and Participants

- Throughout the Think Tank, we remained open to adjusting the format and the direction of discussions in order to suit the concerns, interests and needs of participants. We met throughout the workshop to reflect upon how things were progressing and to bring forward input from the delegates regarding the process.

Resources

- The Think Tank received support from a number of sponsors. The level of support was critical to our ability to be able to meet the needs of some delegates who required additional support to participate in the Think Tank.

Facilitation Skills and Training

- All group facilitators were trained in facilitation and group processes. This high level of skill meant that small groups were supported to operate optimally.

Limited Didactic Sessions

- This was not a Think Tank of detached expert "talking heads" but one in which everyone's expertise was recognized and valued. We limited formal presentations in order to maximize opportunities for discussion and exchange.