HBRP | Healthy Balance Research Program

A community alliance for health research
on women's unpaid caregiving

Finding a Healthy Balance:
Research, policy and practice on women's unpaid caregiving in Nova Scotia

Forum Proceedings
May 2 & 3, 2006
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Foreword

On May 2 and 3, 2006, the Healthy Balance Research Program (HBRP) hosted *Finding a Healthy Balance: Research, policy and practice on women's unpaid caregiving in Nova Scotia.* The forum brought together over 100 participants from across the province and beyond including academic researchers, caregivers, policy-makers, research funders, students, union and labour leaders, employers and business leaders, and community-based organizations.

The objectives of the forum were to:

- bring forward Healthy Balance research findings for the consideration of policy makers, caregivers and community and business leaders;
- encourage dialogue among stakeholders about the future of caregiving in Nova Scotia and the development of strategies for action and change;
- profile Equity Reference Groups as a model for community/university health research alliances; and
- provide networking opportunities to stimulate collaboration between researchers, caregivers, policy makers and community and business leaders.

The 2-day forum presented five years of research on the impact of unpaid caregiving on the health and well-being of women in Nova Scotia. It marked the beginning of a year of sharing our findings and moving forward on strategic priorities for caregiving research, policy and practice.

Our opening panelists set the stage for us by sharing their personal experiences and strength, and caregivers' stories could be heard throughout the forum. Presenters also shared research results and expertise on a variety of topics related to unpaid caregiving. The forum concluded with a collaborative effort to identify strategic priority areas for policy recommendations from the Healthy Balance research.

This report highlights the key findings and outcomes from the Healthy Balance Forum, and outlines how the forum will impact the future activities of the HBRP. It includes summaries of each presentation along with copies of the presentation slides where available.

We encourage you to share this report with your friends, families and colleagues and to continue the discussions from the forum within your own communities.

We thank all the researchers, caregivers, policy makers, community and business leaders who participated in the forum, generously sharing their knowledge and experiences. The presentations and discussions that took place will inform activities of the Healthy Balance Research Program over the next year. As forum participants, you have showed us the most important areas of research, policy and practice to improve the situation of caregivers in this province and elsewhere.

This forum could not have taken place without the many people who have contributed to the Healthy Balance Research Program over the past five years; many thanks to the Equity Reference Group members, Research Teams and staff.

We would also like to thank the Canadian Institutes of Health Research Institute of Gender and Health, and Health Canada's Bureau of Women's Health and Gender Analysis for their continued financial support. Finally, we would like to thank our forum sponsors, our facilitator Colleen Cameron, speakers, moderators and other volunteers.

We look forward to continuing to work with everyone in the coming months.

Barbara Clow B Neumann Carol Amaratunga

Barbara Clow Brigitte Neumann Carol Amaratunga

Co-directors, Healthy Balance Research Program

Thank you to our forum sponsors:
Nova Scotia Health Research Foundation
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Nova Scotia Caregivers Recognized

The forum, which took place during National Caregivers' Awareness Week, represented a successful start to the dissemination of Healthy Balance research findings. Interest from television, radio and print media during the forum served to increase the profile of unpaid caregiving in the public eye. Politicians also took note just two days after the forum when two HBRP research publications were tabled in the Nova Scotia legislature. Elected members of the Conservative, Liberal and New Democratic Parties expressed their support for unpaid caregivers in this province. Honourable Judy Streatch, the Minister responsible for the *Advisory Council on the Status of Women Act* made the following comments:

"Most of us will become closely acquainted with caregiving and with care receiving as the oldest baby boomers turn, in their later years, to their daughters, sons, friends and neighbours for support with the activities of daily living. A recent survey completed through Healthy Balance shows that one-third of Nova Scotians provide unpaid care to someone who is experiencing an illness or health-related problem…
"This is Caregivers' Week in Nova Scotia, an opportunity to reflect on what can be done to support caregivers whose work is at the centre of many lives in the province. "

Ms. Marilyn More, MLA for Dartmouth South-Portland Valley, responded by stating that "the need for immediate action by this government to enhance the support of public policy and programs is very clear."

Ms. Diana Whalen, MLA for Halifax Clayton Park, closed the discussion by saying that "the role [caregivers] play has to be more integrated within government departments. Whether caregivers fall under the auspices of Community Services or whether they fall under the auspices of the Department of Health is immaterial. Their role needs to be supported and their value must be equally appreciated. Let us hope that the results from the Healthy Balance Research Program will be implemented so that this happens."

What's Next?

Over the coming months the Healthy Balance Research Program will be engaged in a number of projects designed to ensure that the findings of the Program do result in positive change in the lives of caregivers in Nova Scotia.

Policy recommendations based on the research findings are being developed for presentation to policy and community groups in the fall. These recommendations will reflect the strategic areas identified by forum participants and will be reviewed by the Healthy Balance Policy Advisory Committee that includes members of the public and private sectors as well as research organizations, community groups and HBRP Equity Reference Group members.

The HBRP will also be developing a Caregiver Resource to meet the need identified by many of the forum participants for improved access to the resources, information and tools that would allow them to improve their ability to care for themselves and others.

Additional HBRP publications are expected over the next year, and other activites are underway to disseminate the research findings and improve the lives of caregivers in Nova Scotia.

How can you help?

You can continue to support unpaid caregiving by talking to people in your community. You can also help us to work toward positive change by talking about unpaid caregiving with your Member of the Legislative Assembly (MLA) or Member of Parliament (MP). Tell your MLA or MP about your own experiences of caregiving and why you think it's important to support caregivers.

Contact information for your MLA is available at:
www.gov.ns.ca/legislature/members/directory/alpha.html.

Contact information for your MP is available at:
www.canada.gc.ca/directories/direct_e.html

Presentations

Summaries & Discussion

The Caregiver Experience

The forum opened with a panel of three women who shared their personal experiences of caregiving.

Marcie Shwery-Stanley

Marcie Shwery-Stanley has her BA in Political Science and Economics and her MBA in Community Economic Development. She has turned the challenge of being a person with a disability into rewarding experiences through her advocacy work in disability and women's issues and has held executive positions with various local, provincial and national organizations. Marcie is a member of the Persons with Disabilities Equity Reference Group on the Healthy Balance Research Program, and is both a caregiver and a care receiver.

Marcie is a caregiver for her mother, Eva, who is 82 years old. Marcie has been caring for Eva through breast cancer, knee replacement surgery, and most recently bone cancer. Marcie emphasizes the need for caregivers to do what works best for them. For her this means keeping a detailed list of things that need to be done, doctors' phone numbers and insurance companies, among other things.

Balancing her own needs with those of her mother's can be challenging, but it's something Marcie has been getting better at over the years. Her communication, coordinating, and multi-tasking skills, which she garnered as a Communications Officer with the Federal Government, have been an asset to her in coping with challenges and managing stress, and she has always taken a positive approach.

Marcie would like to see policy makers bring about change and action based on the existing research on caregiving. She stresses the importance of expanding accessible public transportation, having accessible, barrier-free and inclusive communities, advocating for positive change, and empathy. She urges policy makers to have an inclusive mindset, to be sensitive to the variety of caregiving situations that exist, and most importantly, to ensure that the delivery of services is **person-centred**.

Barbara Mulrooney

In 1991, Barbara's husband Edward was 53 years of age when he was diagnosed with Alzheimer's disease. Barbara was working full time and caregiving for her mother who lived in a seniors' apartment complex. Out of this caregiving experience, Barbara's entire life has changed in many ways as she is now very active in helping as many caregivers as she can through what she has learned and continues to learn about being a caregiver for a loved one with dementia.

Barbara compares becoming a caregiver with becoming a parent – there is no manual or preparation class. When Edward was diagnosed with Alzheimer's, Barbara sought as much information about the disease as possible. Edward's condition progressed from stuttering and forgetfulness to giving up driving after a series of accidents, difficulty shaving, reading, and doing crossword puzzles. He continued to enjoy walking and walked two marathons before he began to forget where he lived.

Meanwhile, Barbara was also caring for her mother who had moved from her seniors' complex into St. Vincent's. In 1997, Barbara's mother passed away. Edward's Alzheimer's continued to progress – medications were often not effective and sometimes caused aggression. Barbara was diagnosed with breast cancer in 1998 and described it as a 'pain in the butt' – she was just too busy for that. A year later, Edward was admitted to a care centre where he was well taken care of. He spent the last 10 days of his life in a hospital – Barbara described this part of the experience as awful.

Barbara encountered many challenges during her caregiving experience. It was difficult to find information about Alzheimer's at the time. The experience was isolating as friends stopped coming by to visit. Dealing with dementia is a very unique situation and Barbara sensed a general lack of awareness among friends, family, and health professionals about how to cope with the situation. In Edward's last days, Barbara described the hospital staff as unresponsive to his needs.

While she has learned much from these challenges, Barbara is also quick to point out the positive aspects of her caregiving experience, including a supportive family, the Forget-Me-Not Alzheimer's support group, the staff at care facilities who do not get the recognition they deserve, and the importance of maintaining a sense of humour (which Barbara has done admirably).

Barbara's advice to other caregivers is to take help when it's offered – it's invaluable and might just help to create a healthy balance. Barbara is now retired but continues to work as a member on the board of the Alzheimer's Society.

Glenda Robertson

Although Glenda was unable to share her wisdom at the forum because of her caregiving commitments, she was pleased to submit the following story.

My job is full time. Well, more than that I suppose - if a full time job is 40 (or a few more hours) weekly. I work around the clock seven days a week. There is no vacation time and so I give this position a new name - "perpetual unpaid caregiver." There are many similarities in my job as in most occupations and yet often times my job is viewed as not a job at all. But I know what I do and I know that at the end of my journey there is no Canada pension, no retirement income at all, no medical plan to address my inevitable aging, nothing to indicate that I have made a substantial contribution, that I have worked, and worked damn hard. I have been a woman that was to accept her "lot in life". Well, I did. I became the best damn caregiver I could be. My daughter, Arlene, is happy, well-adjusted, and as productive a member of society that society will allow. She loves life, loves herself and has a sense of humor second to none. She was born into a loving, caring and willing family. I thank a higher power everyday for the aid I received from a caring, never faltering husband and daughters, sons-in-law that embraced our lifestyle and grandchildren who grew knowing the wonder of a life like ours, and the blessing of an aunt like Arlene. She has taught them some of life's miracles, and an acceptance they will carry with them, as they become productive adults. Many families are struggling every day, many have ended the struggle in desperation, many are still faced with the fact that our government addresses corporate needs first and social needs like ours at a much slower pace.

LMBBS - the short form of the big issue - Laurence-Moon-Bardet-Beidyl Syndrome, was mentioned very little in Arlene's life. The traits were frightening - polydactylism, obesity, mental challenges, blindness, and sensory issues. This was the label... Arlene was the substance beneath the label. In her early beginnings it was evident that her blindness would be an ongoing obstacle, because sight was lost gradually. Many things had to be learned over and over again, sometimes with great frustration and tired tears. Then I would turn to my greatest teacher, Arlene, and she would patiently teach me again and again. Frustration, you see, for challenged mothers is very hard to overcome. But my happy, well-adjusted daughter, overcame hers much less painfully than her mother.

My caregiving is a legacy I pass on. The daughters I have raised will accept their sister into their adult lives as a special gift. We are a family. We are what life is all about... and we are caregivers. We need to be seen and heard and given the benefits of a life free of uncertainty and poverty. I try diligently to address the issues surrounding the plight of unpaid caregivers, without infringing on the rights of my daughter to feel the pride of being a productive member of society. After all, this issue of unpaid care is not her issue.

Sharon Reashore

Sharon Reashore, Executive Director of Caregivers Nova Scotia, highlighted some of the common themes emerging from caregivers' experiences. Balancing caregiving with health, work, and other aspects of life is challenging. How can policy address these issues? Caregivers are saying that policy must reflect the complexity of caregiving situations. There is no one-size-fits-all solution.

Healthy Balance Research Program: An Overview

Carol Amaratunga & Brigitte Neumann

The Healthy Balance Research Program (HBRP) was first conceived in 1998. The Nova Scotia Advisory Council on the Status of Women and the Atlantic Centre of Excellence for Women's Health wanted to develop a program that would make a difference in the lives of caregivers. With funding from the Canadian Institutes of Health Research in 2000, the HBRP was established to bring together a diverse group of community members, researchers, and policy advisors. The research projects were supported by Equity Reference Groups; networking among different sectors and within research communities across the country; database development (of existing research on unpaid caregiving); and a policy uptake/knowledge translation component.

To lead off the program, the HBRP commissioned the paper *Thinking it Through: Women, Work and Caring in the New Millennium.* This paper provides an analysis of caregiving in the lives of women, including the policy implications of changes in our approach to social and economic issues over the past decade. Most notably, the authors assert, "care needs to be understood as the objective, not the problem. It needs to be understood as a relationship, rather than simply as a task" (Armstrong & Armstrong, 2001, p. 4).

The HBRP includes four research teams:

Qualitative Research Team (*Team Q)*

Team Q conducted 18 focus groups including 98 women and 9 men ranging in age from 17 to 85 years. Focus group participants reflected a wide range of social, economic, cultural and ethnic backgrounds as well as a number of different types of caregiving relationships.

Caregiver Portraits Team *(Team P)*

Team P conducted in-depth case studies of 14 women actively engaged in unpaid caregiving in Nova Scotia. Participants were visited in their homes several times over many weeks at differing times of the day for a total of at least 24 hours.

Secondary Analysis Team

The Secondary Analysis Team has analyzed existing quantitative data to deepen our understanding of the health and well-being of women engaged in both paid and unpaid work in Atlantic Canada.

Survey Team

The Survey Team has completed a population-based survey of caregivers in Nova Scotia, providing evidence of the prevalence and scope of caregiving in the province for the first time.

The Healthy Balance Research Program has a commitment to include the perspective of historically disadvantaged and under-represented groups through its four **Equity Reference Groups**: African-Canadian women, Aboriginal women, women with disabilities and Immigrant women. The Equity Reference Groups have guided the research teams in developing projects that are sensitive to the needs and norms of different communities and have helped to interpret the resulting research findings. The Equity Reference Groups have also provided a link between researchers and communities to allow the findings to be broadly disseminated.

What are the next steps? How can we share the information, and how can we ensure that our research will help to shape future policy?
Public policy is shaped through evidence, public opinion, and perhaps a bit of public outrage. We need to:

- consider the economic needs of caregivers – what direct and indirect benefits do they need?
- ensure access for caregivers to the Canada Pension Plan;
- work with and encourage labour and unions to adopt more family-friendly structures; and
- implement improvements in caregiver support and respite.

Discussion – Key Points

- Although Acadian women were represented in the survey, they were not one of the Equity Reference Groups. Steps should be taken to ensure that HBRP findings are communicated to Acadian and Francophone communities in Nova Scotia and that future projects incorporate these communities in their design.

Caregiving in Nova Scotia: A selected profile

Janice Keefe

Amidst illness and disability, an aging population, and trends toward deinstitutionalization and centralization of services, the demand for care is rising. It is consequently important to examine caregiving in Nova Scotia.

Dr. Janice Keefe leads the HBRP's Survey Team, which recently published the first report in a series of documents which presents the Survey Team's initial research results. The report answers a number of questions: Who are Nova Scotia's caregivers? Who are they helping? What are they doing? What kinds of supports do they have? Who is receiving care, and why? The team surveyed almost 2000 Nova Scotians and revealed, for the first time, the prevalence of unpaid caregiving in the province.

Key findings from the report titled *A Portrait of Unpaid Care in Nova Scotia*, include:

- More than 1/3 of Nova Scotians are 'caregivers'*;
- 56% of caregivers are women, 44% are men;
- Gender differences exist in the provision of care;
- Most caregivers do not live with the individual who is receiving care;
- Caregivers feel high levels of stress; and
- Nova Scotians receiving care are not a homogeneous group.

The implications of these findings are significant, especially given the newly revealed prevalence of unpaid caregiving in Nova Scotia. Policy must reflect the diversity of care situations in Nova Scotia: by recognizing the importance of flexibility and choice in support options; and by assessing caregivers to understand their specific needs and how to best support them.

* In this study, caregivers are defined as those Nova Scotians aged 19 and over who gave care to someone because of a long term condition, mental illness, or temporary difficult time.

Click here to view the slides for this presentation.

Discussion – Key Points

- A broad question on life stress was used to measure level of stress in this report. However, a number of different indicators (employment, health, resiliency, personal competence, etc.), including stress, were measured in more detail and will be examined in two subsequent reports on caregiving and health, and caregiving and employment.
- If only 6% of Nova Scotians are receiving care, how can 33% of Nova Scotians be providing care? There are a few possible explanations for this:
    - With a telephone survey, it is possible that fewer individuals who received care were able to participate.
    - Multiple caregivers may provide care to one care receiver (e.g., Nine siblings may provide care to one parent)

- Given the current trend toward smaller families, what do we know about the future of caregiving? Fewer resources will be available for future generations – with fewer children, there may be an increase in care provided by siblings or other relatives. There will likely be a much greater need for paid caregivers.
- What about children who are caregivers? This is another important and interesting area in need of further research. A group in Niagara, Ontario, is currently focused on children as caregivers, and more information will become available at FICCDAT (Festival of International Conferences on Caregiving, Disability, Aging and Technology) in June 2007.

Balancing Health and Caregiving

(moderated by Colleen Cameron)

Shelley Phipps

Shelley Phipps leads the HBRP's Secondary Analysis Team. Her presentation focused on children with disabilities or chronic conditions and longer-term parental well-being.

What are the implications for the parents caring for a child with a disability? Are there differences for women and men? This study used nationally representative data from Statistics Canada to explore these questions, and drew the following key conclusions:

- Mothers of children with disabilities have lower health status than mothers of children who have never had a disability;
- The association of having a child with a disability and a mother's health is significant – it can be compared to 'smoking daily' and is particularly noticeable over the longer-term; and
- No negative association is apparent for fathers.

This study looked at health produced within the family context rather than health strictly produced by the individual and her/his choices or behaviours. It may not be surprising to observe the different health implications for women and men, given the existing traditional gender roles and responsibilities. The results presented stress the importance of respite care, particularly for mothers, and reveal the need for more research in this area.

Robin Stadnyk

Robin Stadnyk is a member of the HBRP's Caregiver Portraits Team. She discussed the implications of caregiving for women's health and well-being based on 14 in-depth interviews conducted by the Caregiver Portrait's Team.

Key issues raised by the women interviewed included:
- A lack of time for self (for activities outside of caregiving)
- Isolation (caregivers get ignored, are invisible)
- Exhaustion
- The need for balance
- Strain on relationships
- Effects on employment
- Financial strain

Each of these issues are directly related to the social determinants of health. Stress, support, exclusion & tenuous financial situations can all lead to negative health outcomes.

Click here to view the slides for this presentation.

Discussion – Key Points:
- In reference to the research by the Caregiver Portraits Team, the themes discussed above emerged from the interviews and were not identified prior to conducting the interviews.
- Although caregivers are experiencing stress and other health effects, many still wish to continue caregiving – how can this be addressed by policy? Policy should support all caregiving situations by ensuring the availability of a range of options. Support and provide resources that will be effective in helping with the wide range of existing caregiving situations.
- What is causing caregivers' stress? Is it the care receiver or the lack of supports for the caregiving? There are many possible causes of stress for caregivers, and they may be different for each caregiver. Suggested causes of stress include:
    - A lack of support
    - Liability issues
    - The complexity of rules and stipulations around homecare workers, government agencies, and what each of the people involved can/cannot will/will not do
    - Financial stress
    - Being an advocate
- One forum participant noted that policies and programs need to be diverse and flexible in how they support people and that we have to ask caregivers what the stresses are – they are the ones who know how they can best be helped. Caregivers need to be consulted in policy and program development, and unpaid caregiving needs to be made visible.

Partnering with communities:
Equity Reference Groups as a model for participatory research

(moderated by Linda Snyder)

Carol Amaratunga

Carol Amaratunga is a Co-Director for the HBRP and holds the Ontario Women's Health Council Chair in Women's Health Research at the Institute of Population Health, Faculty of Medicine, University of Ottawa.

Equity Reference Groups (ERGs) were pioneered by the HBRP in 2000. Recognized as an important research methodology, the ERGs transcend common research barriers such as culture, language and ethnicity.

The ERG model is necessary for building partnerships and conducting future research. It is an inclusive model that uses the 'community voice' to keep the research on track. It is essential that this voice is prominent throughout the research project, from research design and data collection to analysis and dissemination. This community alliance model helps to make the research findings relevant to diverse communities and contributes to the implementation of constructive policy, supports and programs.

We have learned a great deal, and while the ERG model has been excellent, there will always be room to improve the process. For example, in the future, an endeavour would be made to include the Acadian populations. The model will undergo an evaluation in the final year of the research program, which will help to identify and build on its strengths for future research. Thank you to all ERG members for their ongoing work and dedication to the project.

Nancy MacDonald

Nancy MacDonald is a member of the HBRP's Aboriginal Equity Reference Group, and a faculty member at Dalhousie University's School of Social Work.

She views the role of the Equity Reference Groups (ERGs) as contributing to further direction of HBRP projects. The ERGs have been actively engaged in the research process and have helped to enhance the cultural appropriateness of the research methods used, as well as the methods for sharing findings with their communities and with other relevant groups.

Nancy highlights the following benefits of the ERGs:

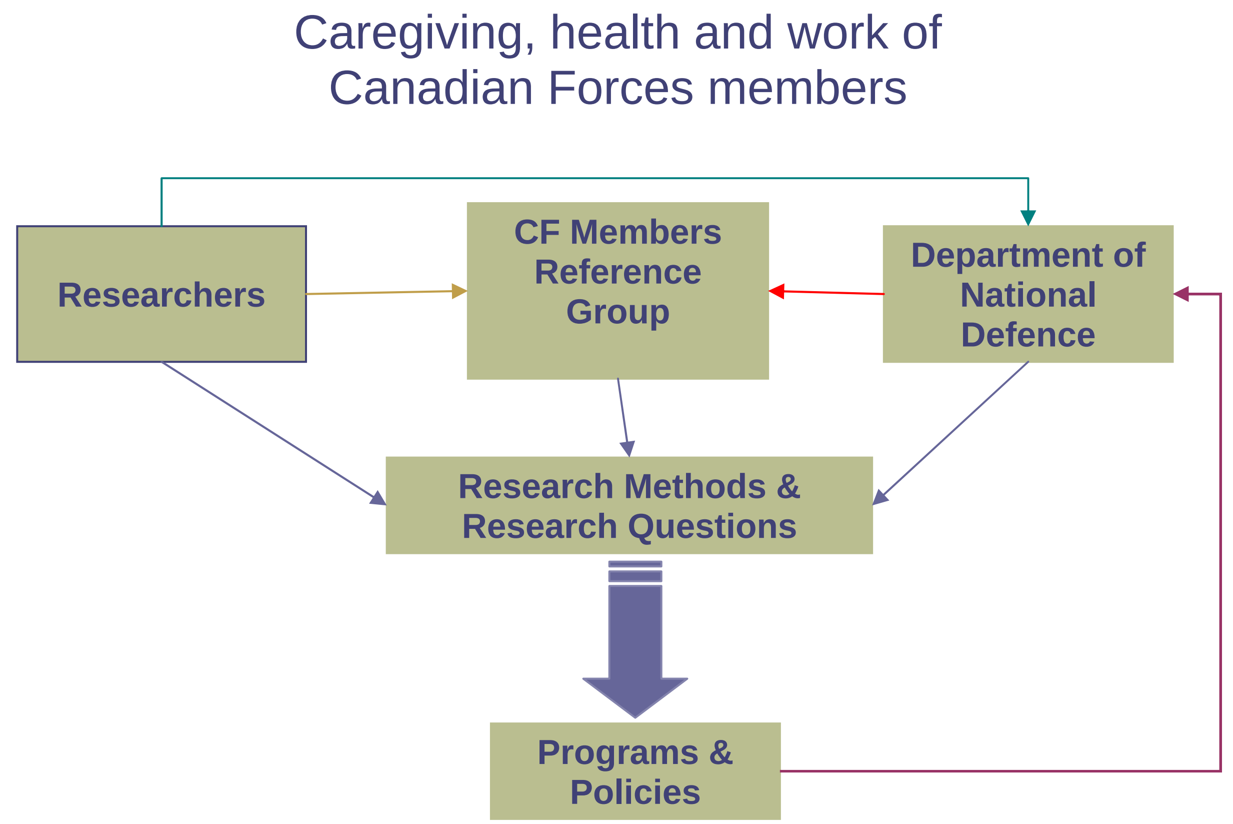
- Provided diverse perspectives from the inception of the project
- Offered a sample of the vast diversity of caregiving situations through their own experiences and communities
- Contributed to the research process, knowledge transfer, capacity-building and networking

The coming year will focus on the dissemination of HBRP findings and recommendations for further research, policy and practice. The ERGs will continue to collaborate on the project in an effort to make the process relevant and valuable for their communities.

Click here to view the slides for this presentation.

Kathy Petite

Kathy Petite is a Research Assistant with the HBRP and coordinates the Caregiving, Health and Work of Canadian Forces members project.



Brannen, C. (2006). Model for the Caregiving, health and work of Canadian Forces members research project.

Women in the military, although not a typical marginalized population, represent a unique group. The military has a distinct language and culture that must be understood in order to contextualize the research within the community. Women have traditionally been silenced in the Canadian Forces – only being fully integrated less than two decades ago. This project seeks to understand the reality of a gendered military and how caregiving responsibilities are balanced with the demands of service. In late 2004, a reference group of military members and researchers was formed. The first part of the project is a survey of work-life balance issues and will be piloted in Nova Scotia. The results of this survey are the foundation of a multi-methods project in this province, and will eventually lead to a national project. The goal of the research is to contribute to the development of policies that will support caregivers in the military.

Discussion – Key Points

- The Equity Reference Groups (ERGs) for the HBRP, which are the model for the Military Caregiver Reference Group (MCRG), meet at least twice each year for 2-day meetings. The MCRG meets three or four times per year for two to three hour meetings.
- It is important that ERGs are included in all aspects of the project, including the upcoming phase of analysis and dissemination.
- ERGs help to ensure that the research and subsequent projects are appropriate and meaningful for their communities.
- The ERGs help to emphasize the diversity of caregiving situations, and remind researchers and others to look at caregiving within the context of dynamic relationships and communities.

Common challenges, different needs: Diversity and caregiving

(moderated by Evie Tastsoglou)

Charlotte Loppie

Charlotte Loppie is a member of the HBRP's Caregiver Portraits and Qualitative Research Teams.

The caregiving experiences of Aboriginal women must be understood within their historical, social and cultural contexts. Indigenous peoples of North America comprise a diverse group geographically, socially, and otherwise. They also share common histories of colonization and colonialism, and have been marginalized economically, socially and politically.

Health is influenced by historical and socio-cultural contexts as evident in the relatively poor health profiles of Aboriginal peoples including a reduced life expectancy and increased rates of chronic illness. These health disparities also affect the experiences of Aboriginal caregivers.

Aboriginal peoples experience caregiving differently, not simply due to poorer health profiles, but also because of their perspectives on caregiving. In the Aboriginal community;

- caregiving roles are not subordinate;
- caregiving represents an essential role in the family/community;
- caregiver is an important element of identity;
- caregiving responsibilities encompass physical, emotional, spiritual, and social care; and
- caregiving is not seen as a separate component of relationships.

Aboriginal peoples view caregiving holistically, describe the caregiving relationship as reciprocal, and experience caregiving across the lifespan.

What are the implications for supporting Aboriginal caregivers? Supportive policies and programs must:

- consider the cultural context;
- respect holistic paradigms;
- support family/community networks; and
- support intergenerational care.

"The Creator ordained that people should live to an old age.
It is wrong to be unkind to our Grandmothers.
The Creator forbids unkindness to the Old.
An old woman shall be as a child again and her grandchildren shall care for her.
For only because she is, they care."
-Handsome Lake (Seneca) 1800

Click here to view the slides for this presentation.

Linda Carvery

Linda Carvery is a member of the HBRP's African Canadian Equity Reference Group and a Research Assistant for the Caregiver Portraits Team.

Linda refers to her role as a caregiver as "a position I didn't apply for." Unlike the decisions to get married, to become a mother, and to work as a counselor, Linda did not apply to raise a disabled child, but when her son was diagnosed with cerebral palsy at age 5, she accepted the new role of caregiver, and her family followed her lead. Although there was a difficult period of adjustment, Linda focused on the positive and her family grew stronger and closer as they encountered challenges along the way.

Another period of adjustment came when Linda's son moved into the youth wing of a nursing home – just as she hadn't been prepared for becoming a caregiver, she hadn't thought about what would happen when she was no longer his primary caregiver. Linda's son is happy in his new place, and Linda's caregiving experience continues. She would like to see future research that explores the impact of the caregiving experience on siblings of the care receiver, and emphasizes the importance of acknowledging diversity in all areas of research, policy and practice.

Maria José Yax Fraser

Maria José Yax Fraser is a member of the HBRP's Immigrant Equity Reference Group and a Research Assistant on the Caregiver Portraits Team.

Interweaving her own experience of long distance caregiving with the experiences of the immigrant women participants in the Caregiving Portraits study, Maria José highlights common issues faced by immigrant women caregivers. Maria José was born in Guatemala, Central America, and was raised in a culture where caregiving is a part of the circle of life. Like many immigrants, Maria José is involved in long-distance caregiving for her family members who live in her country of origin. This commitment can be a rewarding experience by maintaining relationships with distant family members as it provides a feeling of belonging, but it also presents a number of challenges including the financial cost of long distance telephone calls and travel. In some cases, a care receiver might move to Canada to join her/his caregiver, but Maria José points out that the joy of proximity is countered by the sadness of leaving one's country. "Losing one's community is like having nothing and being no one." Furthermore, the caregiver takes on the additional role of helping the care receiver adapt to a new country. The sense of isolation that is commonly reported by caregivers can be amplified for newcomers who are unfamiliar with a new social, political and economic system, who may be learning a new language, and who are a long distance from the support of friends and family.

More services are needed to support newcomers and immigrants in caregiving situations and to familiarize them with the services that are available.

Discussion – Key Points

- In many communities, caregiving is not seen as something distant from someone's role in a family or community. It is part of one's relationships and one's identity.
- Spirituality and holistic views were both prominent in these presentations – these may be areas for future research on caregiving.
- Navigating the system can be challenging for any caregiver, but especially for marginalized groups. There is a need for culturally appropriate services and resources.

Caring for others, caring for yourself: Balancing work and life

(moderated by Carolina Crewe)

Lynn Lethbridge

Lynn Lethbridge is a member of the HBRP's Secondary Analysis Team. Her presentation focused on parental labour force participation and child disability status.

The purpose of this study was to examine the effect of the disability status of a child on the labour force behaviour of the parents, and to identify differences for mothers and fathers. Previous research has revealed impacts on employment such as working fewer hours, or quitting paid employment, with greater impacts for mothers than for fathers.

Key results indicate that mothers of children with disabilities work fewer hours per week in paid employment and are less likely to be in the labour force at all, while fathers' participation in the labour force remained the same.

Click here to view the slides for this presentation.

Laurene Rehman

Laurene Rehman is a member of the HBRP's Qualitative Research Team. Her presentation was titled *Leisure… what leisure? Oh right, that!?*

Leisure can help to buffer stress, enhance well-being and contribute to positive health outcomes. Despite its many benefits, leisure has rarely been researched in the context of unpaid caregiving.

The Qualitative Research Team conducted 18 focus groups with a diverse population of caregivers from across Nova Scotia, and examined their experiences of leisure. Their key findings were that:

- Leisure provided a sense of enjoyment, fulfillment and relaxation
- Other factors could prevent release (e.g., fatigue, other responsibilities, limited financial resources, gender role expectations)

Participants expressed a need for 'time for self' and personal choice of how to engage in leisure. The results indicate a need for greater flexibility in the supports provided to caregivers including good alternative care, financial support for leisure, and accessible transportation.

Click here to view the slides for this presentation.

Barbara Corbett

Chief Petty Officer Barbara Corbett has been a member of the Canadian Forces for 29 years and is a member of the HBRP's Military Women's Reference Group.

As a woman in the military, duty comes first – family and children take a back seat. This can be a difficult concept for people outside of the military to understand, and it can make caregiving a complex issue.

Barbara was a caregiver for her mother, and learned to balance her caregiving role with her role as a woman in the military, overcoming challenges along the way. She is excited about the current research underway and hopes that it will lead to the development of policies and programs that support caregivers in the military.

Discussion – Key Points

- Leisure can add a whole new dimension to homecare. Many caregivers expressed a desire to share leisure time with their care receiver(s).
- Caregivers at the forum expressed the challenge of finding both time and money for leisure. This could be an area of focus for future research and recommendations for supportive policies and programs.

New directions in research on caregiving

(moderated by Colleen Cameron)

Robin Stadnyk

Robin Stadnyk is a member of the HBRP's Caregiver Portraits Team. Her presentation was titled, *Assumptions we make in providing supportive choices: The experience of family caregivers.*

The data from the 14 interviews conducted by the Caregiver Portraits Team reveals two main types of assumptions made in the provision of support services. Familism refers to the concept of 'the perfect caregiver' – assuming that all caregivers have supportive families and static lifestyles, and never have bad days. Any deviation from being 'the perfect caregiver' can have a negative effect on one's ability to access services.

Residualism refers to the assumption that 'any service is good service,' ignoring issues of the availability of care, the challenges of coordinating care, and the quality of care. The illusion of choice and control actually translate into "trust and obey" – implying that caregivers should trust and obey services when they are offered. Three key issues are apparent for caregivers accessing services:

- Caregivers are often not recognized as experts, and are instead expected to listen to other 'experts';
- Coordinating care is a major challenge – if services are offered, they must be available at appropriate times to be useful for the caregiver and care receiver; and
- The quality and type of respite care is not always appropriate – services should be sensitive to family diversity and social context.

Click here to view the slides for this presentation.

Carol Amaratunga

Carol Amaratunga is a Co-Director for the HBRP and holds the Ontario Women's Health Council Chair in Women's Health Research at the Institute of Population Health, Faculty of Medicine, University of Ottawa.

In 2003, the SARS epidemic in Canada resulted in burned out health care workers and institutions, stigmatization and racism, a travel ban and decline in tourism, and negative economic implications. Using this example, a research project has been designed to address front line health care worker response, preparedness and resilience for coping with disaster scenarios. The project is titled: *Caring About Healthcare Workers as First Responders: Enhancing Capacity for Gender-Based Support Mechanisms in Emergency Preparedness Planning.*

It is important to examine gender in this area of research as it has not been considered in past research, and it helps to ensure that the needs of front line healthcare workers, most of whom are women, are considered in emergency planning. This research also asks the question, do disasters affect men and women differently?

The project's aim is to reduce the impacts of future disasters by providing appropriate support mechanisms. It consists of the following four components:

- a substantive review of existing literature;
- a survey of public healthcare workers;
- identification, risk assessment, and analysis of hospital employee support mechanisms during an infectious disease outbreak; and
- dissemination and knowledge transfer to policy audiences.

Deborah Norris

Deborah Norris is a researcher on the current research project *Caregiving, Health and Work (CHAW)*, which will examine the relationship of caregiving and health for women who are members of the Canadian Forces.

How do women balance the responsibilities of the role of mother with a career in the Canadian military, particularly when experiencing work-related family separation?

Forces members are required to be separated from their families for extended periods during deployment and, in recent years, the number of women in the Canadian military has declined.

Women in the military share the stresses of their domestic counterparts and also have some additional stresses. There are number of things to consider including:

- the length, pace and nature of the deployment
- the potential for conflict between military and gender ideologies (ie. the idea that the military must come first in contrast to the socialization that family must come first).

How can women negotiate these conflicting ideologies? We know little about how this is experienced both by the women and by military institutions. This current research project will focus on how caregiving relates to the health of women in the Canadian

Forces, and the goal of the project is to contribute to improving policies, programs and services.

Click here to view the slides for this presentation.

Discussion – Key Points

- Focus groups for the First Responder research were based in major population centres to look at larger institutions and their capacities – a good next step might be to look at rural areas.
- Rural communities face many challenges including: the trend toward centralization of services, compromised access to services, fewer resources, and less comprehensive networks of services. This may be an indicator that further research is required on rural communities.
- Another area for future research might be to consider family violence and its relation to military deployment. It might also be useful to look into education initiatives regarding the impacts of deployment. There is an emerging awareness of the possible problems that occur during the adjustment phase when a military member returns from deployment as well.
- Military policy can be difficult to change because of rigid, institutionalized ideology, but they do have some good family programs and are getting better about providing pro-active support to families.
- Literacy can be a challenge when disseminating information and should be considered during the knowledge transfer stage of the Healthy Balance Research Project. These challenges reveal the need for novel strategies like the performance of *Balancing Act*- an original play about unpaid caregiving created and performed at the forum by the Irondale Ensemble Project.
- It is important to keep a feminist perspective and to prevent unpaid caregiving from becoming invisible (and/or to make it more visible). Gender-based analysis is important for everyone, not just for women.

Caring at all costs: The economic implications of caregiving

(moderated by Maureen O'Connell)

Brigitte Neumann

Brigitte Neumann is a Co-Director of the HBRP and Executive Director of the Nova Scotia Advisory Council on the Status of Women. Her presentation was titled: *Retirement, women and caregiving.*

Retirement is a social institution originally developed for men. The first retirement policies were designed for male industrial workers who worked at a single job for the duration of their working lives, provided for large families, and had much shorter life expectancies than we do today.

Today, retirement lasts as long as a generation. Decreased birth rates and increased retirement are contributing to labour shortages, and employment patterns have changed. Concern is growing about the sustainability of pension plans and there is an increasing emphasis on private planning for retirement income. In addition, women have entered the workforce in unprecedented numbers, but still have quite different work patterns than men do.

How do assumptions about retirement based on traditional family structures and labour force participation affect women? Women's workforce participation is much more likely to be interrupted, or to be part-time. Consequently, women's lower average lifetime earnings result in lower public pension payouts.

Women transition into retirement differently than men. Men are more likely to continue with some part-time paid work, while women are twice as likely to retire into caregiving. It is essential that caregiving is recognized and integrated into retirement income systems.

Click here to view the slides for this presentation.

Janice Keefe

Dr. Janice Keefe leads the HBRP's Survey Team. Her presentation addressed some of the issues faced by caregivers and potential ways to support unpaid caregiving.

Current trends in health care include a shift away from hospital care to community care. This has placed stress on family and friend caregivers who are now providing more care. Given the changing demographics, and the slow process of developing policy in Canada, we must prepare now for the increased caregiving demands which will inevitably occur as the population ages.

There are many consequences associated with providing unpaid care, including increased expenses, poorer health, decreased social activities, decreased holiday plans, and less sleep. Many caregivers also experience employment consequences such as a reduction in work hours, or changed work patterns. Given these issues, how can we sustain caregiving?

One possibility is to learn from other countries. Although it may not be as simple as introducing policies that are working in other countries, examining their policies may provide insight and direction for successful policy development in Canada. Possible methods for supporting Canadian caregivers include the following:

- Enhance respite/home care
- Education
- Direct compensation (caregiver payment/allowance)
- Employment policy (e.g., Compassionate Care Leave)
- Pension schemes
- Taxation system

We know a great deal about the situation of caregivers in Canada. It is time we take this opportunity to build on existing knowledge to focus on developing a strategy to meet the needs of caregivers. Maximizing choice and flexibility are key to the development of effective policies.

Click here to view the slides for this presentation.

Discussion – Key Points

- It seems possible that the separation between the provincial Department of Health and Department of Community Services may impede progress on issues such as unpaid caregiving. There is a need for better collaboration and cooperation in these areas.
- Women contribute differently to pension and retirement, and they transition differently. Policy in this area needs to move forward and this forum is providing some of the momentum to make that happen.

Building Better Policies for Caregivers

Carolyn Nicholson

Carolyn Nicholson is a retired, ordained minister in the United Church of Canada, and a trained hospital chaplain in Halifax. She was a caregiver for her late husband for 4 ½ years and she now operates a home-based business with her sister, which allows them both to provide care to their mother.

At age 39, Carolyn's husband David received an alarming phone call – he was told that he may have ALS. The diagnosis was later confirmed by a specialist who also informed the family that no treatment existed, and that David could be expected to live no more than five years.

Overwhelmed by the diagnosis, Carolyn and David contacted the ALS Society for information and support. This proved to be helpful in the long run, but was initially distressing as they read the detailed guide about the disease which offered guidance for making difficult decisions about medical interventions like tracheotomies and feeding tubes and whether to withhold treatment for infections or intubate for breathing difficulties.

David attended ALS support groups which were helpful, but it was difficult to attend the many funerals of the other members. As the disease progressed, Carolyn experienced many caregiving challenges. When David could no longer drive, transportation became very difficult. Friends stopped calling or dropping in and Carolyn found it increasingly difficult to balance the demands of caregiving with work. It was also difficult to judge when David was no longer able to make decisions about his care. David fell regularly and could be hurt and had to lie on the floor until someone could help him up. Lifeline was helpful for a short while.

David received about 1 ½ hours of home care each day, and although it was helpful, it meant that Carolyn provided care during the other 22 ½ hours each day. She was sleep deprived, frustrated and anxious about the type and complexity of the care that she was providing.

At the end of his life, David never went to the hospital. He died at home. When people die at home, their caregivers can be suspected of killing them. Carolyn experienced a range of emotions and eventually was self-diagnosed with complicated mourning* – she compares it to Post-Traumatic Stress Disorder. She did not find any source of treatment for this condition. She did attend a grief support group and this was helpful.

Carolyn's caregiving continued and she and her sister now care for their mother, with some help from a home care program. Carolyn's experiences have highlighted some of the current issues in caregiving, including:

- a shortage of hospital beds;
- a lack of compassion and empathy, especially from healthcare workers;
- a need for information and support for caregiver related distress; and
- barriers to accessing private nursing care (e.g., need for referral from a medical specialist).

Carolyn stresses the importance of developing supports for care receivers who stay at home, and for the people who provide their care.

*"Complicated mourning – given the amount of time since the death, there is some compromise, distortion, or failure of one or more of the 6 "R" processes of mourning. Even when the mourner successfully engages in only select sub-processes or only some elements of a given sub-process, (e.g. Expresses certain psychological reactions but not all of them.), the "R" process as an entity is said to be compromised. All elements of each component of an "R" process must be completed successfully to avoid the designation of complicated mourning.

"In all forms of complicated mourning, the mourner attempts to do two things; a) deny, repress, or avoid aspects of the loss, its pain, and the full realization of its implications for the mourner; and b) hold onto and avoid relinquishing the lost loved one. These attempts, or some variation, are what underlie and cause complications in the "R" processes of mourning. No matter what type of treatment is employed, it will need to address these two issues. Complicated mourning always must be interpreted within time constraints. Incompletion of an "R" process due to insufficient time having passes since the death to permit the mourner to work through the process does not indicate complicated mourning, only that it is too soon to have addressed that specific "R" process."

- Therese A. Rando, *Treatment of Complicated Mourning*

Sandra Harder

Sandra Harder is Acting Director of the Families and Caregivers Unit at Human Resources and Social Development Canada. Her presentation offered an overview of the federal policy landscape in the context of unpaid caregiving.

Caregiving is not a new policy issue. Caregivers relieve pressure on the formal health care and social service systems. In the struggle to balance their caregiving with employment, childcare, and other demands, many caregivers will experience negative impacts. The objective of policy is to develop initiatives to help ensure the well-being of caregivers and care receivers.

Policy work on caregiving in the Government of Canada has focused on three streams: consultations (with experts, stakeholders and caregivers); research; and discussions with interdepartmental and provincial/territorial counterparts.
Based on our research, most caregivers do not want to hand off their caregiving responsibilities, but want to receive better support to continue in their role. Supports

should recognize the diversity of caregivers' circumstances and needs. Priority areas for support include: awareness and recognition; information and navigation; economic security; employment and workplace supports; respite and homecare services; and strengthened community organizations.

The following challenges play a role in policy development:

- Caregivers' situations are dynamic;
- Funds are limited;
- Caregiving is a complex policy issue; and
- Limited data is available that covers the spectrum of caregiving across Canada.

As policy development proceeds, the following questions need to be kept in mind:

- How can we best work with the many partners that have a role to play in supporting caregivers?
- What is the degree to which caregivers are able to exercise choice about whether to take on a caregiving role?
- What do families see as their obligation to provide care, and is there a limit to what they are willing to do?
- What supports are currently provided by governments and/or the voluntary sector and how well are these supporting caregivers?
- What is the optimal balance amongst different types of supports?
- What are the costs and benefits of policy options?

Click here to view the slides for this presentation.

Brigitte Neumann

Brigitte Neumann is a Co-Director of the HBRP and Executive Director of the Nova Scotia Advisory Council on the Status of Women. Her presentation was titled *Financial repercussions of caregiving: Support through tax and transfer systems.*

Women's role as caregivers is a central barrier to women's economic equality. It is also being increasingly recognized as essential for sustaining economies, social values, and a desirable quality of life. In the HBRP report *Policy options to support dependent care: The tax/transfer system*, Richard Shillington has identified three policy paradigms:

- Social Support
- Social Insurance
- Tax Measures

Each system has a different set of assumptions underlying it. Social support (income assistance) is intended to target those "most in need," who have no other resources. There are stringent eligibility criteria and benefits are drastically reduced if income increases. In contrast, Social Insurance (e.g., EI and CPP) is contribution dependent and varies according to the level and consistency of an individual's contribution over time. EI, under which maternity, parental and compassionate care leave is provided, is not helpful to people who are self-employed or who have little or no paid work participation. CPP is limited for people whose life course includes frequent career interruptions. Non-refundable tax credits benefit only those with sufficient income to benefit from a decrease in income tax owed.

The first step in the quest for solutions must be to obtain a better grasp of the scope and distribution of caregiving in relation to the various benefit systems, with particular attention to the interaction among them. Too often, small earned income gains can result not only in loss of one particular benefit, but reduce other benefits as well. Financial support measures need to be complemented by effective home care programs, housing and transportation. Supportive policies and programs must recognize the diversity of caregivers and caregiving circumstances. Policy makers should be careful in their analysis of international experiences, pointing out the difficulties found in other approaches as well as the promising outcomes.

Click here to view the slides for this presentation.

Next Generation: The future of caregiving research, policy and practice

Robin Stadnyk

Robin Stadnyk is a member of the HBRP's Caregiver Portraits Team. Her presentation posed the questions: *What do we know about the next generation of caregivers, and what will they need?*

Who are the caregivers of the future? As the baby boomer generation ages and the trend toward smaller families continues, the caregiving landscape is changing. Families are more broadly defined and include diverse networks of friends and family members. Not surprisingly, caregiving situations are also extremely diverse.

How can we support a healthy balance for caregivers? We need to start by asking people what they need. It is not acceptable to assume that people don't need help simply because they haven't asked for it. We also need to help the larger society to understand caregiving, and make this important work more visible.

How will we deal with violence? There are many examples of violence in the Caregiver Portraits Team research. We must not continue to deny services or ignore the problem.

How must supportive services evolve? Care should be person-centred, empathetic, and not based on tasks. Respite services must be consistent and integrated with the needs of the family. The financial implications of caregiving must also be recognized.

Click here to view the slides for this presentation.

Maggie MacDonald

Maggie MacDonald is a Policy Analyst for the Halifax Chamber of Commerce, where she coordinates the Chamber's policy development and government relations by working with policy, advocacy and government relations committees.

The Halifax Chamber of Commerce has approximately 1700 members, most of which are small businesses. The Chamber provides support to its members through member services, advocacy and lobbying for a better business environment, and leadership.

The Chamber became involved in workplace wellness following the wrap up of its 2001 Health Care Task Force. The Task Force looked at health and health care in Nova Scotia and concluded, among other things, that illness prevention and healthy living would have to be a major component of any successful health care strategy for the province. The Chamber started advocating to its own members on the importance of workplace wellness, citing the $1.138 billion loss in productivity to Nova Scotia due to illness each year and roughly proportional compared costs to individual businesses.

Another factor that makes a healthy workforce increasingly important is the changing demographic in Canada, especially, Nova Scotia. Many are predicting a shortage of skilled workers – this will contribute to a heavier reliance on the existing workforce. E.g. businesses will try and entice workers to stay past current normal retirement age and businesses will seek to keep employees happy. Interestingly for Generation X employees this is less likely to mean simply financial compensation – for this generation flexibility, and company values and attitude (including such things as healthy workplace) are also important. Another potential source of labour to meet the future need is immigrants.

With respect to healthy workplace, several factors should be considered, including the physical environment, social environment & health practices at the workplace. While the social environment can be the hardest to change, it can also have the greatest impact on employees. A care-giving policy may be one element of a healthy workplace. We know that care giving can be physically and emotionally draining and that many caregivers are also employed full time in paid work.

Another important question is how can businesses offer flexible options for their employees that will support care giving? Some businesses offer Leave of Absence programs, or flexible work schedules. Others may offer counseling or health care services. The question of flexibility and policies is particularly challenging for small businesses who may operate on very narrow profit margins, don't have the number of employees to be able to cover shifts and would find it difficult to invest both time and money into making special arrangements for employees. Eighty-five percent of the Chamber's members are small businesses and it can be difficult for them to compete with large companies in terms of benefits for employees.

Further investigation is required to determine the most effective workplace policies for supporting caregivers.

Joanne Hussey

Joanne Hussey is the Coordinator of the HBRP. At the age of 27, Joanne is most happy when she finds balance between her roles as mother, wife and professional. Looking ahead to the future, she shared her thoughts on the evolving roles of women and the supports they will need to achieve balance in the next generation.

Joanne's first look at caregiving came when her great grandfather passed away and her great grandmother moved in with her grandmother. Her grandmother dutifully accepted and committed herself to the role of caregiver.

The experience provided Joanne with some insight into caregiving. She observed that her grandmother did not have a choice of whether to become a caregiver; she was not recognized by her family or community for her role as a caregiver; and she did not have support for her caregiving.

Joanne would like to see more recognition and better supports for the next generation of caregivers, and recommends that we:

- cultivate a culture wherein the work of caregiving is acknowledged, recognized, and supported. There is no work that doesn't count;

- recognize the need to be supported not only as a caregiver, but as an individual with needs and desires beyond the caregiving role;
- develop policies and programs that reflect the diversity of needs and offer a range of options to all people; and
- acknowledge and respect the value of caregiving for individuals, families, communities, and for society as a whole.

Discussion – Key Points

- It is difficult for small businesses to compete. Small businesses generally prefer to see incentives from government rather than regulation.
- How can we get agencies and supports to be more effective and targeted to the needs of caregivers and care receivers? We need to start by treating people like people. A more collaborative approach is also necessary. One solution for business is to empower workers and managers to take initiative, and to give them the flexibility to accommodate employees.
- Can caregivers come together to express ideas through the churches and other faith communities? Some action and support groups already exist. Caregivers NS does support local initiatives for support groups and voices. There is a need to focus on change in addition to providing support. The faith community is a good way to spread awareness to the general public. The Wolfville area is already doing this through Interchurch Council, but resources are limited.

Research to Action: Strategic directions for caregiving research, policy and practice

How can we bridge the divide between caregiving research, policy and practice? During a session of table-talk discussions, forum participants talked about what is needed to connect these areas and to promote change.

Participants emphasized the uniqueness of the caregiving landscape in Nova Scotia.
The higher prevalence of caregiving in Nova Scotia compared to the rest of Canada is significant, and reinforces the importance of providing caregivers with adequate supports. When asked about the needs of caregivers in Nova Scotia, forum participants clearly agreed that the following are priority areas:

- transportation support;
- consistent service delivery, availability and coordination;
- improved sensitivity/empathy of service providers; and
- ready and convenient access to information about existing programs, services, supports and resources for caregiving.

Participants also noted the need for diversity considerations in unpaid caregiving policy. Research Team reports from the HBRP have included recommendations to design programs, supports and policies in consideration of diverse identities, situations and needs of caregivers, with special consideration for the Equity Reference Groups (African Canadian women, women with disabilities, immigrant women, and Aboriginal women). In addition, forum participants noted the need to include Acadian communities in future activities, and to provide access to caregiving information that is relevant to francophone communities.

Participants indicated the need for policies to adequately and flexibly support caregiving. In her presentation on policy supports for caregivers, Sandra Harder from Human Resources and Social Development Canada (HRSDC) highlighted the fact that caregivers relieve pressure on formal health care and social service systems. Participants agreed that unpaid caregiving does not receive the recognition it deserves, and added that policies that address caregiving must include financial supports. Additionally, a suite of policy options would ensure that all Nova Scotians have choices in providing care to their family and friends.

Participants called for caregiving policy to address the gendered context of caregiving. Healthy Balance research has revealed that the majority of caregivers in Nova Scotia are women, and that differences exist in the ways that men and women provide and receive care (Keefe et al., 2006). Forum participants responded to this information by suggesting that empowering women as policy makers and ensuring that women are represented in the legislature may improve the capacity of legislation, policy and programs to reflect the realities of women's lives.

Participants identified the need for policy to address information and service gaps. Existing gaps are often the result of inflexible programs and services. Participants noted the need for flexible options for replacement care and called for improved communication and coordination among community organizations and other service providers.

Participants specifically noted the need for employment-related policy considerations. In recognizing the impact of unpaid caregiving on employment, participants recommended that employers be empowered to provide flexibility to employees, allowing for a healthy balance between unpaid caregiving and paid employment.

Appendices

APPENDIX A – Forum Program At-A-Glance

TIME	LOCATION	ACTIVITY
DAY ONE - TUESDAY, MAY 2, 2006		
9:00-9:15	Lake City Ballroom	Welcome and Opening Remarks
9:15-10:15	Lake City Ballroom	*The Caregiver Experience*
10:15-10:30	City Terrace	Nutrition Break
10:30-11:15	Lake City Ballroom	*Healthy Balance Research Program: An Overview*
11:15-12:00	Lake City Ballroom	*Caregiving in Nova Scotia: A selected profile*
12:00-1:15	City Terrace	Lunch
1:15-2:45	Alderney Room	*Balancing health and caregiving*
	Sullivan Room	*Partnering with communities: Equity Reference Groups as a model for participatory research*
	Hawthorne Room	*Common challenges, different needs: Diversity and caregiving*
2:45-3:00	City Terrace	Nutrition Break
3:00-4:30	Alderney Room	*Caring for others, caring for yourself: Balancing work and life*
	Sullivan Room	*New directions in research on caregiving*
	Hawthorne Room	*Caring at all costs: The economic implications of caregiving*
5:00-7:30	Harbourside Terrace	Networking Reception & Dinner Reception beginning at 5 p.m. Dinner served at 6 p.m.
DAY TWO - WEDNESDAY, MAY 3, 2006		
8:00-9:00	City Terrace	Next Generation Networking Breakfast
9:00-10:00	Lake City Ballroom	Theatre Performance by The Irondale Ensemble Project
10:00-10:30	City Terrace	Nutrition Break and Information Fair
10:30-12:00	Lake City Ballroom	*Building better policies for caregivers*
12:00-1:00	City Terrace	Lunch
1:00-2:00	Lake City Ballroom	*Next Generation: The future of caregiving research, policy and practice*
2:00-3:00	Lake City Ballroom	*Research to Action: Table talk discussions*
3:00-3:30	City Terrace	Nutrition Break and Information Fair
3:30-4:30	Lake City Ballroom	*Looking Ahead: Strategic directions for caregiving research, policy and practice*

APPENDIX B – Speaker Biographies

AMARATUNGA, Carol
Carol Amaratunga is a Co-Director of the Healthy Balance Research Program. She holds the Ontario Women’s Health Council Chair in Women’s Health Research, at the Institute of Population Health, Faculty of Medicine, University of Ottawa. Prior to joining the University of Ottawa in 2003, Carol was the Executive Director of the Atlantic Centre of Excellence for Women’s Health.

CAMERON, Colleen
Colleen Cameron has over 30 years experience in the area of community health and development, adult education and social justice. She has practiced and taught in nursing and community health in Canada and Africa, and currently teaches at the Coady International Institute and at St. Francis Xavier University. Ms. Cameron's teaching areas are Health and Development, Gender and Development, Gender and Health, Adult Education, and Nursing.

CARVERY, Linda
Linda Carvery, of Halifax, is an accomplished performer, singer and entrepreneur with interests in the community, economic and social development. Ms. Carvery has spent many years working in the community, particularly with persons with disabilities and families in crisis. She received an Honorary Doctorate of Letters from Saint Mary's University in 1998.

CLOW, Barbara
Barbara Clow is a co-Director on the Healthy Balance Research Program. She is the Executive Director of the Atlantic Centre of Excellence for Women’s Health and Associate Professor Research in the Faculty of Health Professions at Dalhousie University. Barbara has a PhD in the history of medicine from the University of Toronto and is the author of the only monograph on the history of cancer in Canada, “Negotiating Disease: Power and Cancer Care, 1900-1950" with McGill-Queen’s University Press (2001).

CORBETT, Barbara
Chief Petty Officer Barbara Corbett has been a member of the Canadian Forces for the past 29 years and participated in a focus group addressing caregiving needs for service families in Nova Scotia. She currently volunteers with the Halifax/Shearwater Military Family Resource Centre.

HARDER, Sandra

Sandra Harder is a sociologist by training and is currently Acting Director of the Families and Caregivers Unit at Human Resources and Social Development Canada. She has more than 15 years of policy and research experience in the federal government and has worked on a broad range of social policy issues including gender equality, women's health, child development, aging and immigration.

HUSSEY, Joanne

Joanne Hussey is the Coordinator of the Healthy Balance Research Program. She recieved a Master's degree in Gender Studies and Social Policy from the University of Leeds in 2001. In the past she has been employed as a policy analyst and researcher. She and her husband are parents of the smartest three year old ever and live in Halifax.

KEEFE, Janice

Dr. Janice Keefe is a Team Leader on the Healthy Balance Research Program. Dr. Keefe is a Professor and a Canada Research Chair in Aging and Caregiving Policy, Department of Family Studies and Gerontology, Mount Saint Vincent University. She is the Director of the Nova Scotia Centre on Aging and holds the Lena Isabel Jodrey Chair in Gerontology.

LETHBRIDGE, Lynn

Lynn Lethbridge has been a researcher in the Department of Economics at Dalhousie University for 13 years. Her research interests include child health and well-being, poverty and inequality and gender-related issues. For the past year and a half she has also worked at the Department of Medicine where she works on research surrounding quality care for breast cancer patients.

LOPPIE, Charlotte

Dr. Charlotte Loppie is an Assistant Professor in Dalhousie's School of Health and Human Performance. Charlotte is currently a member of the Mi'kmaq Health Research Group and a Board member of the Atlantic Aboriginal Health Research Program. Her research interests include women's sexual and reproductive health across the lifespan and the cultural determinants of health but her research is primarily in the area of health issues facing Aboriginal peoples.

MACDONALD, Maggie

Maggie MacDonald is a Policy Analyst for the Halifax Chamber of Commerce, where she coordinates the Chamber's policy development and government relations by working with policy, advocacy and government relations committees. Prior to joining the Chamber in 2004, Maggie worked in Cornwallis, NS at the Pearson Peacekeeping

Centre and in Ottawa at Environment Canada. Maggie holds a BA in Economics from Dalhousie University and an MA in Public Policy and Public Administration from Concordia University.

MACDONALD, Nancy
Nancy MacDonald is a Mi'kmaq person and a member of the Aboriginal Equity Reference Group. She is a faculty member at Dalhousie University's School of Social Work and is currently working on her coursework for the PhD Interdisplinary Studies of Health Professions.

MULROONEY, Barbara
In 1991 my husband was 53 years of age when he was diagnosed with Alzheimer disease. I was working full time and also caregiving for my mother who lived in a seniors' apartment complex. How one's life can change in a very short time! Out of this caregiving experience my entire life has changed in many ways as I am now very active in helping as many caregivers as I can through what I learned and continue to learn about being a caregiver for a loved one with dementia.

NEUMANN, Brigitte
Brigitte Neumann is the Executive Director of the NS Advisory Council on the Status of Women and a Co-Director of the Healthy Balance Research Program. She began as a sociologist, and has finished her 3rd decade in the public service of Nova Scotia. Ms. Neumann is active in promoting women's participation in electoral politics, and in promoting the principles of gender equity, cultural diversity and social inclusion in the legislation, policies and programs of the Province of Nova Scotia.

NICHOLSON, Carolyn
Carolyn Nicholson is a chaplain in Halifax. She was a caregiver for her late husband who had Lou Gehrig's disease. She and her sister now operate a home-based business, which allows them to provide care to their mother.

NORRIS, Deborah
Dr. Deborah Norris has a PhD in Education and undergraduate and Masters degrees in Family Studies. As a feminist qualitative researcher, Dr. Norris has studied the deployment cycle as experienced by female military partners. Feminist frameworks also inform her ongoing research within the military community. Dr. Norris teaches undergraduate courses in family relations, family life education, family and social theories, and family violence. At the graduate level, she teaches courses on critical theories and research methods.

PETITE, Kathy

Kathy Petite is the Healthy Balance Research Program scholarhip award winner for 2005-2006. Kathy is conducting her studies from Mount Saint Vincent University where she is completing her Masters Degree in Family Studies and Gerontology. Her project is entitled *"Tinker, Tailor! Soldier, Sailor! Mother?: Making sense of the competing institutions of motherhood and the military."* Prior to joining the Healthy Balance Research program, Kathy worked in the non-profit sector, including 6 years with the Military Family Resource Centre

PHIPPS, Shelley

Shelley Phipps is a Professor in the Department of Economics at Dalhousie University and holder of the Maxwell Chair in Economics since 2000. Phipps received a BA (Honours) in Economics from the University of Victoria in 1981, an MA (1981) and then her PhD from the University of British Columbia in 1997. She is the "team leader" for the secondary data analysis component of the Healthy Balance Research Program.

REASHORE, Sharon

Sharon is the Executive Director of Caregivers Nova Scotia Association, which is a non-profit organization dedicated to providing practical supports and recognition to family and friend caregivers. She is also a board member of the Canadian Caregiver Coalition.

REHMAN, Laurene

Laurene Rehman, Ph.D. is the Acting Associate Director (Graduate Studies) in the School of Health and Human Performance. She was a member of the Qualitative Research Team in the Healthy Balance Research Program. Her research interests are in the area of understanding access to recreation/leisure by marginalized groups.

ROBERTSON, Glenda

I am Glenda Robertson – wife, mother of three, grandmother of five, and a stay-at-home-forever Mom. I am a full time advocate and (unpaid) caregiver for our youngest daughter. I am a board member for Caregivers Nova Scotia and most recently a writer for the Glace Bay Gleaner, a community paper. I am consistently challenged while living with the happiest, fun-filled, wonderful gift of twenty-two year old Arlene. Arlene was born with Laurence-Moon-Bardet-Beidyl Syndrome, a condition that will never go away....and so....life goes on.

SHWERY-STANLEY, Marcie

Marcie Shwery-Stanley has her BA in Political Science and Economics and her MBA in Community Economic Development. She has turned the challenge of being a person with a disability into rewarding experiences through her advocacy work in disability and women's issues and has held executive positions with various local, provincial and national organizations. Marcie is a member of the Persons with Disabilities Equity Reference Group on the Healthy Balance Research Program, and is both a caregiver and a care receiver.

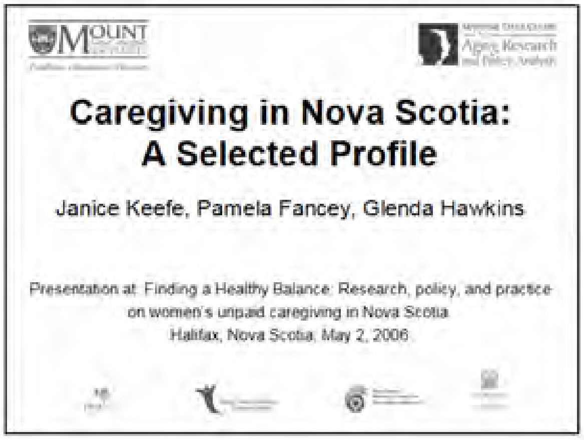
STADNYK, Robin
Robin Stadnyk is a postdoctoral fellow with the Hidden Costs/ Invisible Contributions Research Program (SSHRC), working at the University of Alberta. She is on leave from her position with the School of Occupational Therapy at Dalhousie University, where she is a member of Team P (Caregiver Portraits) of the Healthy Balance Research Program.

YAX FRASER, Maria José
Maria José was born in Guatemala, Central America. After settling in Halifax in 1991, she first began working as a spiritual leader supporting Latin American newcomers in their settlement process. Working as a cultural health interpreter at the North End Community Health Centre, she helped develop the program that is now known as the Cultural Health Information and Interpretation Services (CHI-IS). Currently, Maria José is a Master's candidate at Dalhousie University in the Women's Studies Program. Her research interests are in gender and migration, international development and social justice issues. Her greatest love is her husband and their three young children who support her work and her involvement in local and global initiatives.

APPENDIX C – PowerPoint Presentations

Caregiving in Nova Scotia: A Selected Profile

Janice Keefe



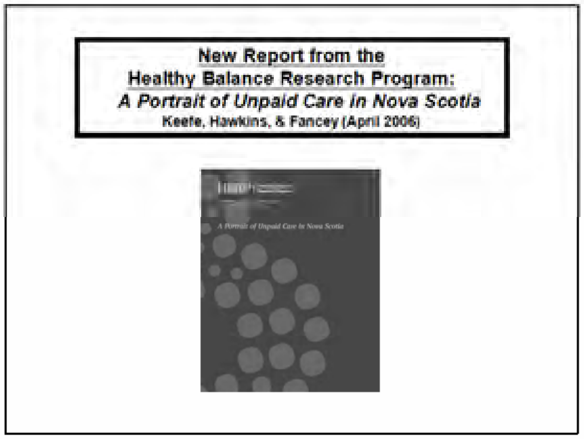
Caregiving in Nova Scotia: A Selected Profile

Janice Keefe, Pamela Fancey, Glenda Hawkins

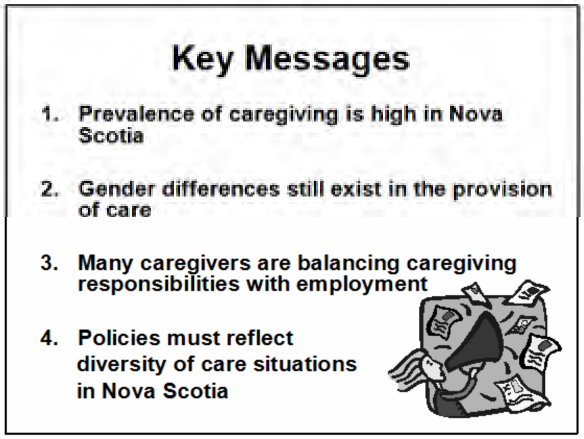
Presentation at: Finding a Healthy Balance: Research, policy, and practice
on women's unpaid caregiving in Nova Scotia
Halifax, Nova Scotia, May 2, 2006

Why Examine Caregiving in Nova Scotia?

- The demand for care is rising.
  - High rates of illness and disability
  - Population aging
  - Deinstitutionalization (e.g. early hospital discharge)
  - Issues in rural areas (migration, service avail.)

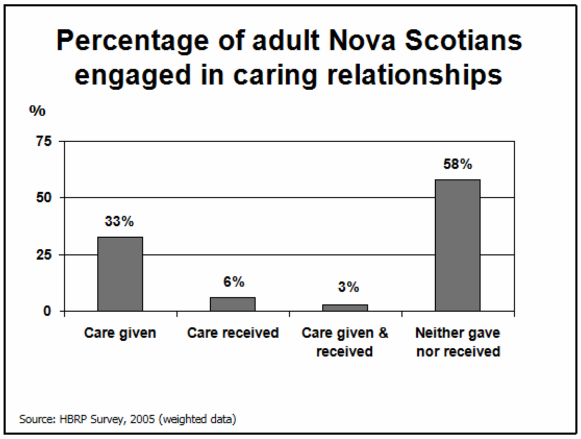


New Report from the
Healthy Balance Research Program:
A Portrait of Unpaid Care in Nova Scotia
Keefe, Hawkins, & Fancey (April 2006)



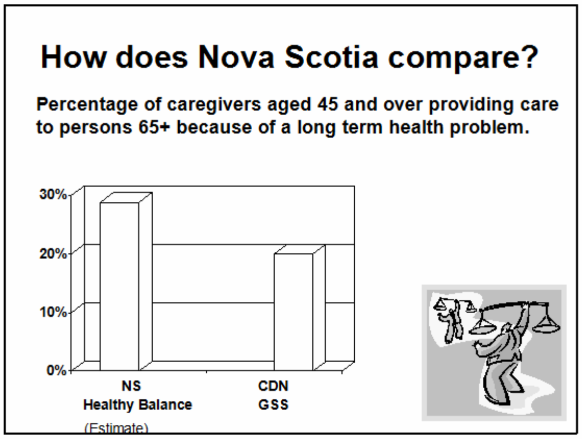
Key Messages

1. **Prevalence of caregiving is high in Nova Scotia**
2. **Gender differences still exist in the provision of care**
3. **Many caregivers are balancing caregiving responsibilities with employment**
4. **Policies must reflect diversity of care situations in Nova Scotia**



Percentage of adult Nova Scotians engaged in caring relationships

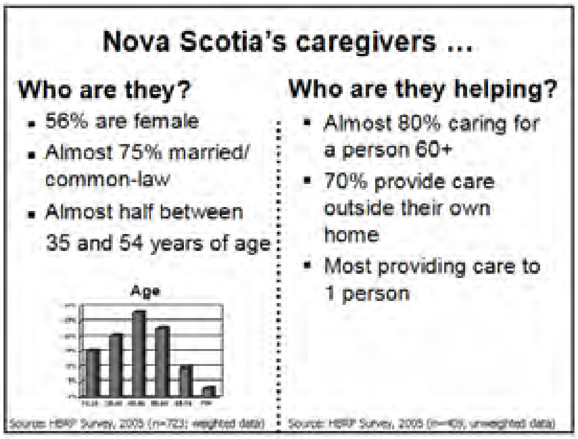
Source: HBRP Survey, 2005 (weighted data)



How does Nova Scotia compare?

Percentage of caregivers aged 45 and over providing care to persons 65+ because of a long term health problem.

A Portrait of Caregivers in Nova Scotia



Nova Scotia's caregivers …

Who are they?

- 56% are female
- Almost 75% married/ common-law
- Almost half between 35 and 54 years of age

Source: HBRP Survey, 2005 (n=723; weighted data)

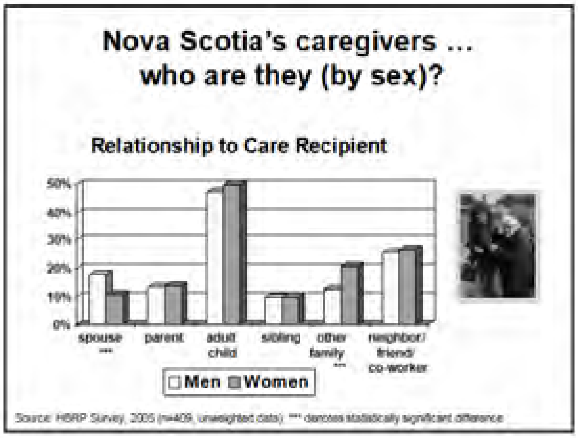
Who are they helping?

- Almost 80% caring for a person 60+
- 70% provide care outside their own home
- Most providing care to 1 person

Source: HBRP Survey, 2005 (n=409, unweighted data)

Gender Differences Still Exist

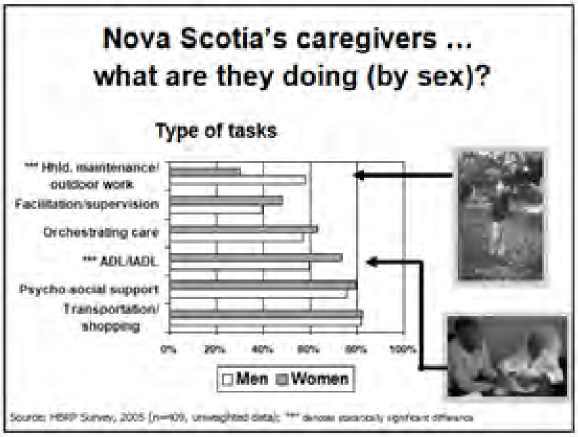
- Involvement in caregiving
- Relationship to care recipient
- Activities provided
- Frequency of care provision



Nova Scotia's caregivers … who are they (by sex)?

Relationship to Care Recipient

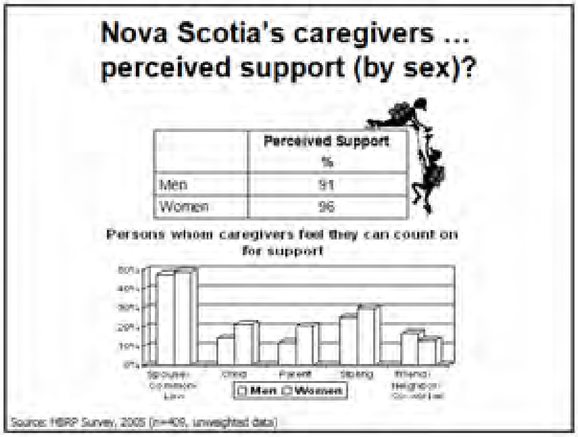
Source: HBRP Survey, 2005 (n=409, unweighted data) *** denotes statistically significant difference



Nova Scotia's caregivers … what are they doing (by sex)?

Type of tasks

Source: HBRP Survey, 2005 (n=409, unweighted data); *** denotes statistically significant difference

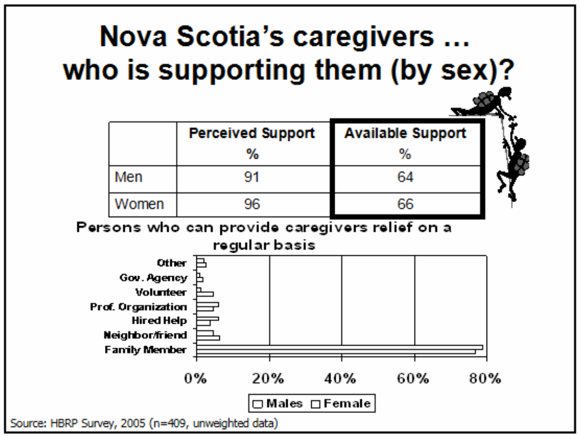


Nova Scotia's caregivers … perceived support (by sex)?

	Perceived Support %
Men	91
Women	96

Persons whom caregivers feel they can count on for support

Source: HBRP Survey, 2005 (n=409, unweighted data)

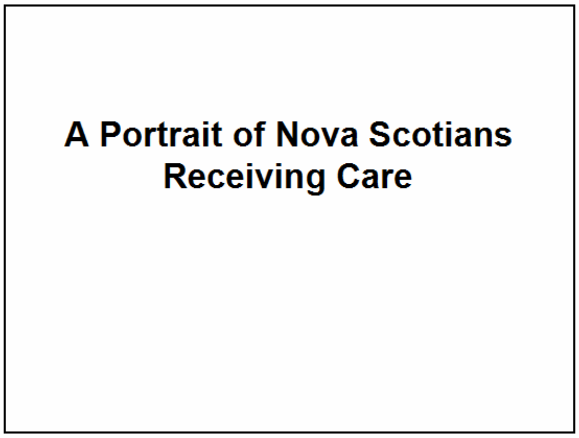


Nova Scotia's caregivers … who is supporting them (by sex)?

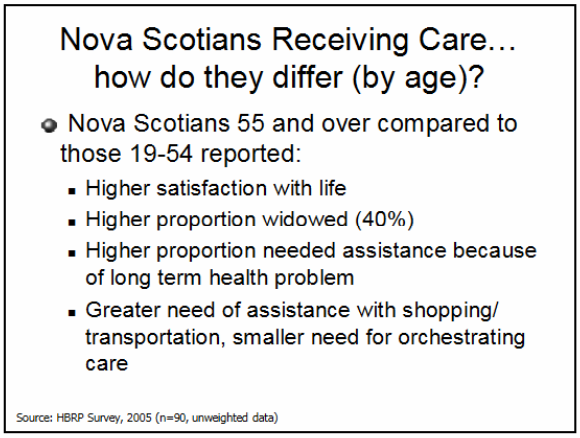
	Perceived Support %	Available Support %
Men	91	64
Women	96	66

Persons who can provide caregivers relief on a regular basis

Source: HBRP Survey, 2005 (n=409, unweighted data)



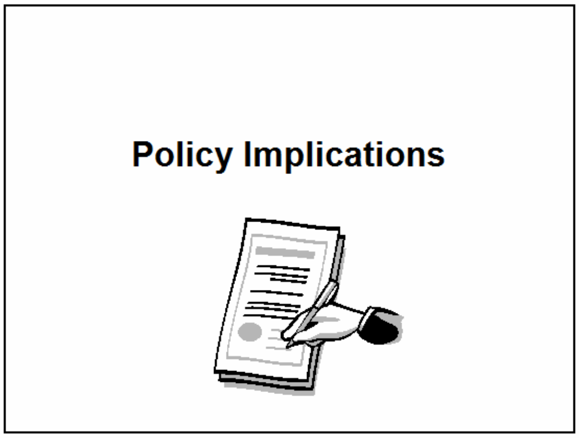
A Portrait of Nova Scotians Receiving Care



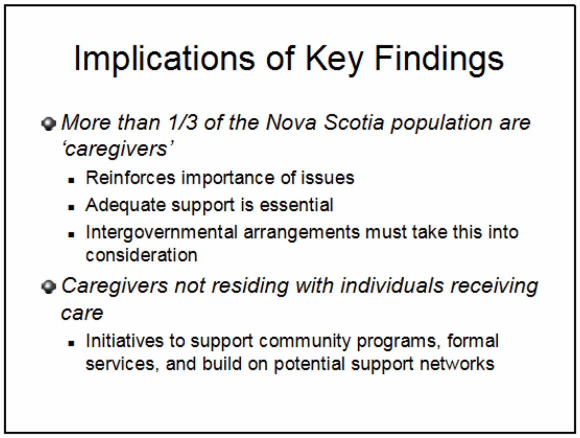
Nova Scotians Receiving Care… how do they differ (by age)?

- Nova Scotians 55 and over compared to those 19-54 reported:
  - Higher satisfaction with life
  - Higher proportion widowed (40%)
  - Higher proportion needed assistance because of long term health problem
  - Greater need of assistance with shopping/ transportation, smaller need for orchestrating care

Source: HBRP Survey, 2005 (n=90, unweighted data)

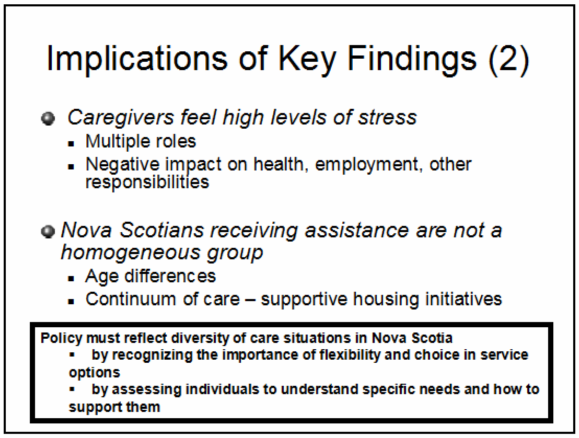


Policy Implications



Implications of Key Findings

- *More than 1/3 of the Nova Scotia population are 'caregivers'*
  - Reinforces importance of issues
  - Adequate support is essential
  - Intergovernmental arrangements must take this into consideration
- *Caregivers not residing with individuals receiving care*
  - Initiatives to support community programs, formal services, and build on potential support networks



Implications of Key Findings (2)

- *Caregivers feel high levels of stress*
  - Multiple roles
  - Negative impact on health, employment, other responsibilities
- *Nova Scotians receiving assistance are not a homogeneous group*
  - Age differences
  - Continuum of care – supportive housing initiatives

Policy must reflect diversity of care situations in Nova Scotia
- **by recognizing the importance of flexibility and choice in service options**
- **by assessing individuals to understand specific needs and how to support them**

Acknowledgements

- **Funder** – Canadian Institutes of Health Research
- **Co- Principal investigators** – Carol Amaratunga, Brigitte Neumann, Barbara Clow
- **HBRP Phase II Research Group** – Janice Keefe, Susan Kirkland, Shelley Phipps, Cyndi Brannen, Victor Thiessen, Sheva Medjuck, Jennifer Jarman, Jacqueline Gahagan
- **MSVU Phase II Research Team** – Janice Keefe, Pamela Fancey, Glenda Hawkins, Tasha Ellis, Nadine Brun

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or visit
www.healthyb.dal.ca or www.msvu.ca/mdcaging

Balancing Health and Caregiving

Robin Stadnyk

Caring in diverse contexts: Implications for women's health and well-being

Brenda L. Beagan
Dalhousie University, Halifax, NS
May, 2006

Sample

- 14 women: urban, rural, women w/ disabilities, African NS, First Nations, immigrant, lesbian
- Caring for mother (4), father (1), mother-in-law (2); child (3); adult child (2); grandchild (1); spouse (2)
- Most caring at home; all but 4 care recipients need full time care

Methods

- ~24 hrs observation, 3 interviews w/ caregiver, where possible 1 w/ care recipient, 1 w/ 'other' caregiver
- Research assistants were from reference groups
- Each woman's story summarized as a 'caregiver portrait'

Time for Self

I can't even fathom a day that I could just basically get up in the morning and do what [I want]. . . For me, it's "Okay, how much time do I have to do this? How much time do I have to do that? Okay, do I have fifteen minutes to sit down and read the newspaper?"

--Melissa caring for mother with Parkinsons

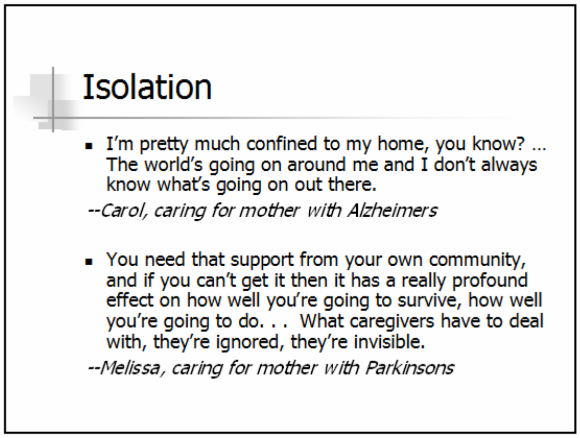
Time for Self

- I don't have 'other parts' of my life. There are no other parts.

  --*Karla, caring for a 9 yr old son with cerebral palsy*

- You know, like extras. Like, I couldn't fit my exercise in. And that was bothering me. . .

  --*Leanne, caring for ex-mother-in-law who needs kidney dialysis*



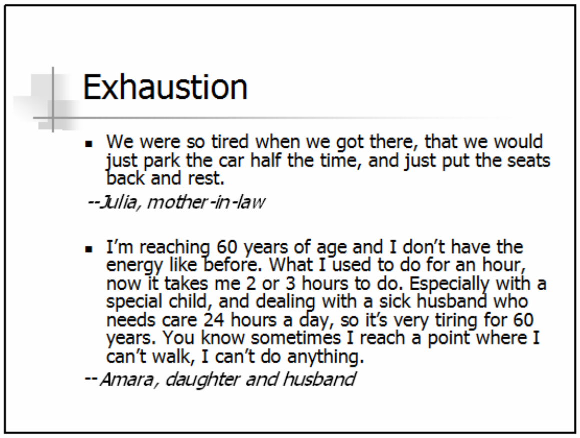
Isolation

- I'm pretty much confined to my home, you know? … The world's going on around me and I don't always know what's going on out there.

--Carol, caring for mother with Alzheimers

- You need that support from your own community, and if you can't get it then it has a really profound effect on how well you're going to survive, how well you're going to do. . . What caregivers have to deal with, they're ignored, they're invisible.

--Melissa, caring for mother with Parkinsons



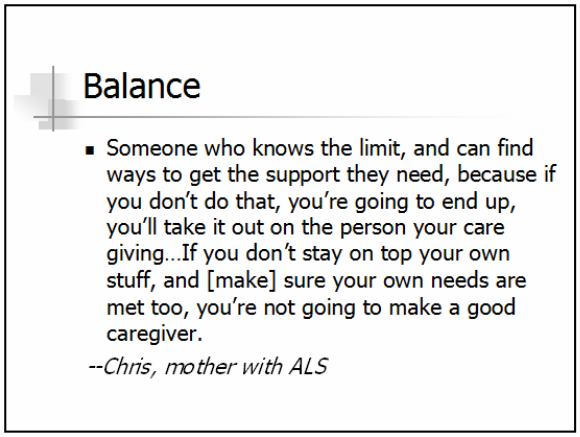
Exhaustion

- We were so tired when we got there, that we would just park the car half the time, and just put the seats back and rest.

--Julia, mother-in-law

- I'm reaching 60 years of age and I don't have the energy like before. What I used to do for an hour, now it takes me 2 or 3 hours to do. Especially with a special child, and dealing with a sick husband who needs care 24 hours a day, so it's very tiring for 60 years. You know sometimes I reach a point where I can't walk, I can't do anything.

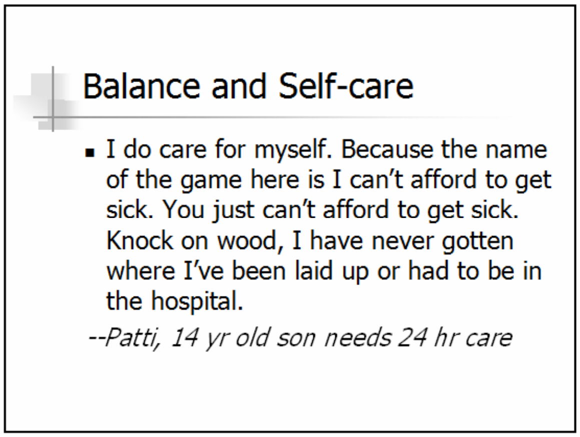
--Amara, daughter and husband



Balance

- Someone who knows the limit, and can find ways to get the support they need, because if you don't do that, you're going to end up, you'll take it out on the person your care giving…If you don't stay on top your own stuff, and [make] sure your own needs are met too, you're not going to make a good caregiver.

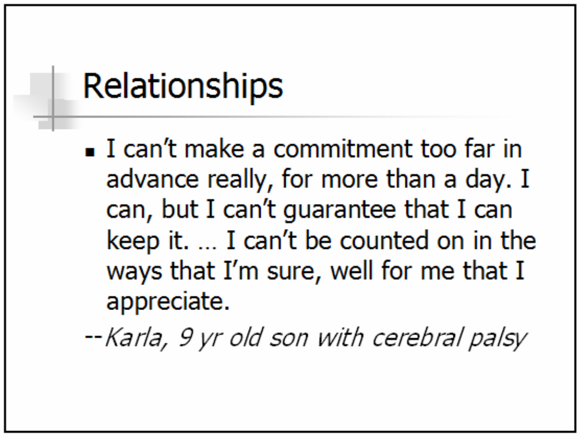
--Chris, mother with ALS



Balance and Self-care

- I do care for myself. Because the name of the game here is I can't afford to get sick. You just can't afford to get sick. Knock on wood, I have never gotten where I've been laid up or had to be in the hospital.

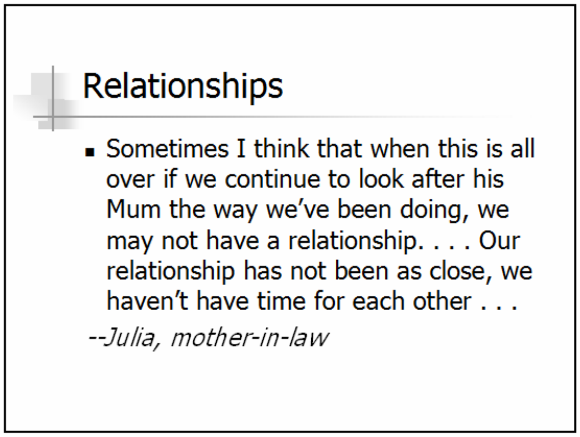
--Patti, 14 yr old son needs 24 hr care



Relationships

- I can't make a commitment too far in advance really, for more than a day. I can, but I can't guarantee that I can keep it. … I can't be counted on in the ways that I'm sure, well for me that I appreciate.

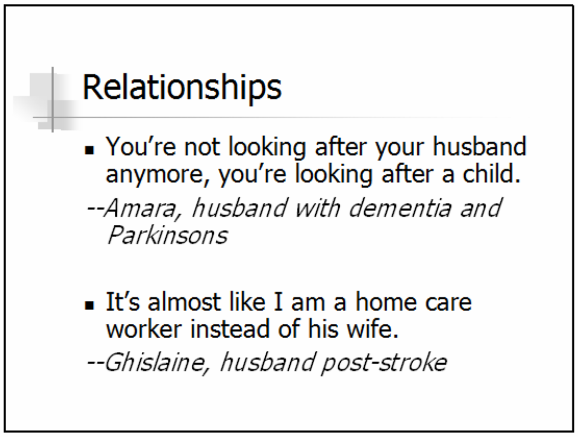
--Karla, 9 yr old son with cerebral palsy



Relationships

- Sometimes I think that when this is all over if we continue to look after his Mum the way we've been doing, we may not have a relationship. . . . Our relationship has not been as close, we haven't have time for each other . . .

--Julia, mother-in-law



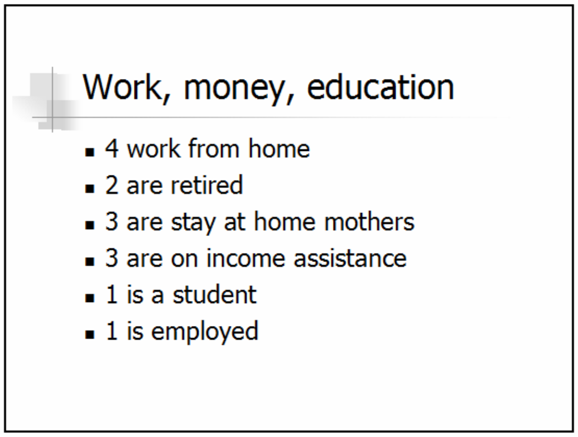
Relationships

- You're not looking after your husband anymore, you're looking after a child.

--Amara, husband with dementia and Parkinsons

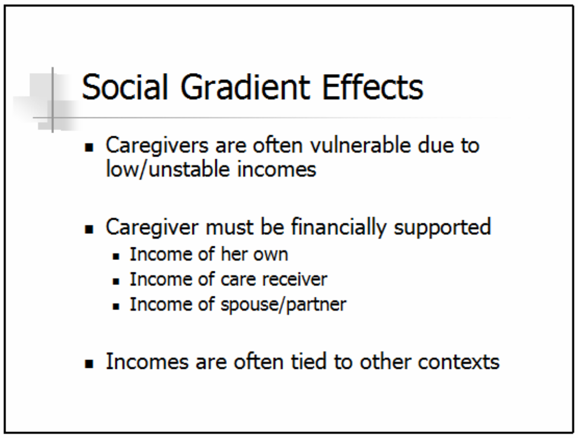
- It's almost like I am a home care worker instead of his wife.

--Ghislaine, husband post-stroke



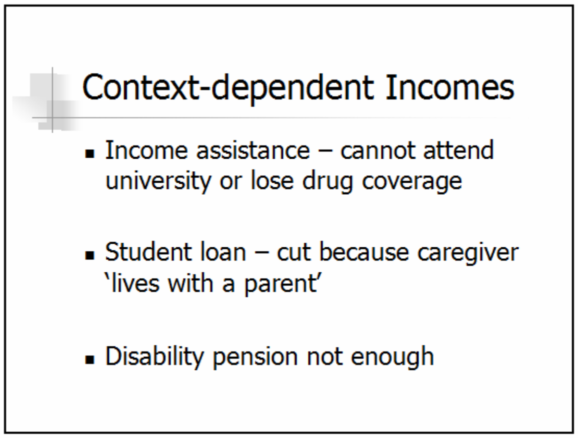
Work, money, education

- 4 work from home
- 2 are retired
- 3 are stay at home mothers
- 3 are on income assistance
- 1 is a student
- 1 is employed



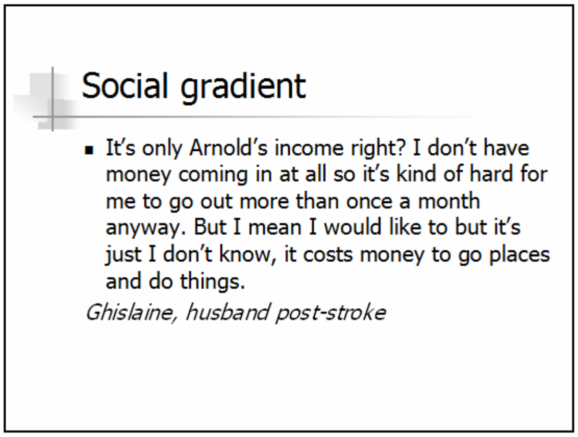
Social Gradient Effects

- Caregivers are often vulnerable due to low/unstable incomes
- Caregiver must be financially supported
  - Income of her own
  - Income of care receiver
  - Income of spouse/partner
- Incomes are often tied to other contexts



Context-dependent Incomes

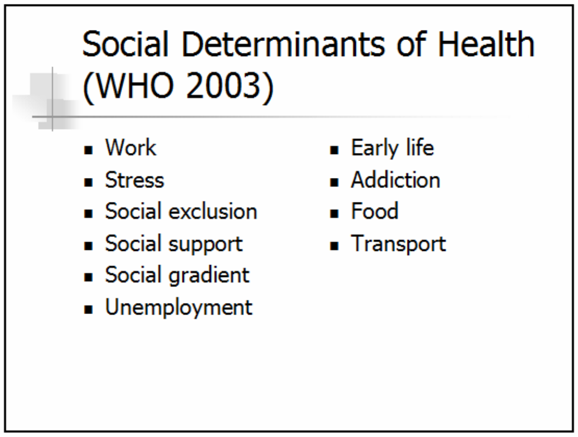
- Income assistance – cannot attend university or lose drug coverage
- Student loan – cut because caregiver 'lives with a parent'
- Disability pension not enough



Social gradient

- It's only Arnold's income right? I don't have money coming in at all so it's kind of hard for me to go out more than once a month anyway. But I mean I would like to but it's just I don't know, it costs money to go places and do things.

Ghislaine, husband post-stroke



Social Determinants of Health (WHO 2003)

- Work
- Stress
- Social exclusion
- Social support
- Social gradient
- Unemployment
- Early life
- Addiction
- Food
- Transport

Relationships of Health Determinants for Caregivers in Diverse Contexts

Work

Stress, Support, Exclusion

Exhaustion and isolation
Balance and self-care needs
Relationship changes

Nature of Caregiving Work

Potential for Health Problems

Low, context specific incomes
Difficulty arranging employment
No meaningful financial compensation for caregiving work

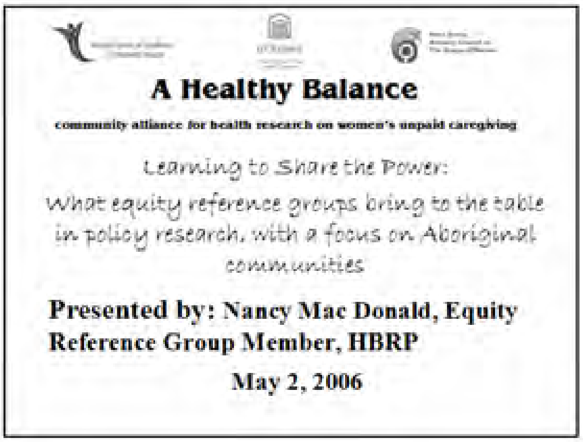
Social Gradient

Acknowledgements

- Research assistants: Linda Carvery; Jen Davis; Maria Yax-Fraser; Hiroko Fujimoto; Toni Thompson; Juliana Weins
- Research team: Brenda Beagan, Barb Hamilton-Hinch, Charlotte Loppie, Judy MacDonald, Nancy MacDonald, Robin Stadnyk

Partnering with communities:
Equity Reference Groups as a model for participatory research

Nancy MacDonald



A Healthy Balance

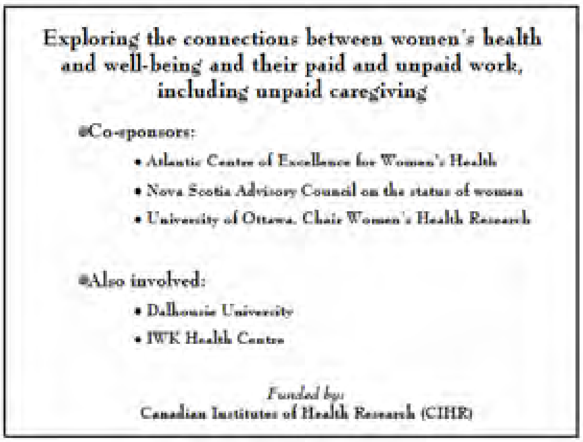
community alliance for health research on women's unpaid caregiving

Learning to Share the Power:

What equity reference groups bring to the table in policy research, with a focus on Aboriginal communities

Presented by: Nancy Mac Donald, Equity Reference Group Member, HBRP

May 2, 2006

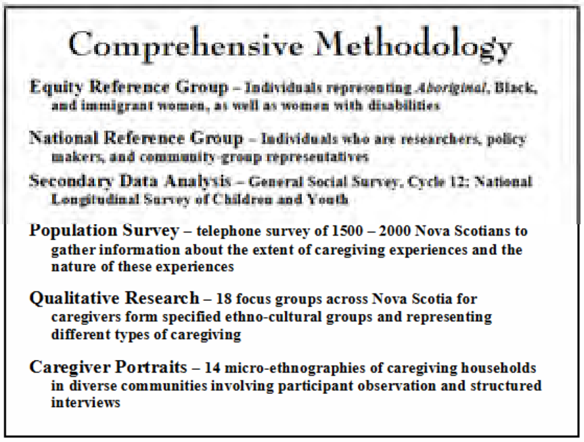


Exploring the connections between women's health and well-being and their paid and unpaid work, including unpaid caregiving

Co-sponsors:
- Atlantic Centre of Excellence for Women's Health
- Nova Scotia Advisory Council on the status of women
- University of Ottawa, Chair Women's Health Research

Also involved:
- Dalhousie University
- IWK Health Centre

Funded by:
Canadian Institutes of Health Research (CIHR)



Comprehensive Methodology

Equity Reference Group – Individuals representing *Aboriginal*, Black, and immigrant women, as well as women with disabilities

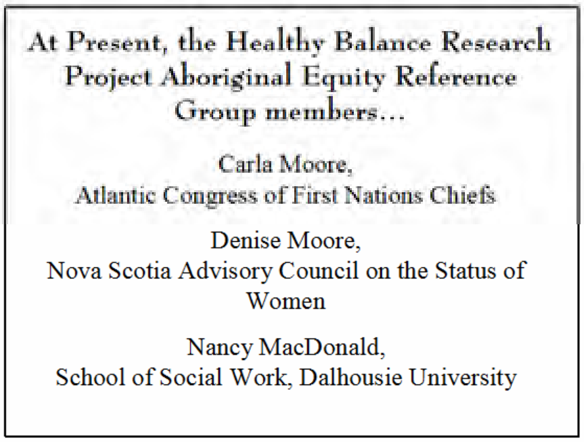
National Reference Group – Individuals who are researchers, policy makers, and community-group representatives

Secondary Data Analysis – General Social Survey, Cycle 12; National Longitudinal Survey of Children and Youth

Population Survey – telephone survey of 1500 – 2000 Nova Scotians to gather information about the extent of caregiving experiences and the nature of these experiences

Qualitative Research – 18 focus groups across Nova Scotia for caregivers form specified ethno-cultural groups and representing different types of caregiving

Caregiver Portraits – 14 micro-ethnographies of caregiving households in diverse communities involving participant observation and structured interviews

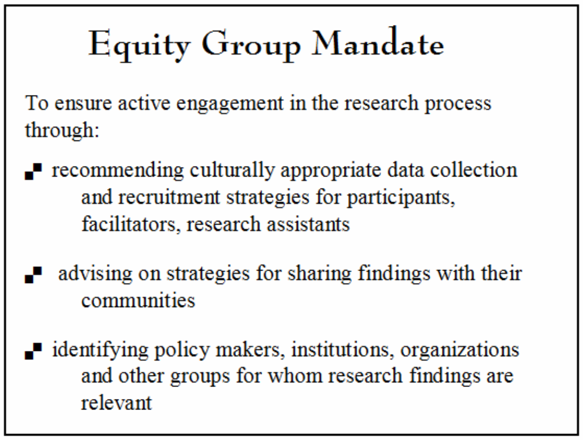


At Present, the Healthy Balance Research Project Aboriginal Equity Reference Group members…

Carla Moore,
Atlantic Congress of First Nations Chiefs

Denise Moore,
Nova Scotia Advisory Council on the Status of Women

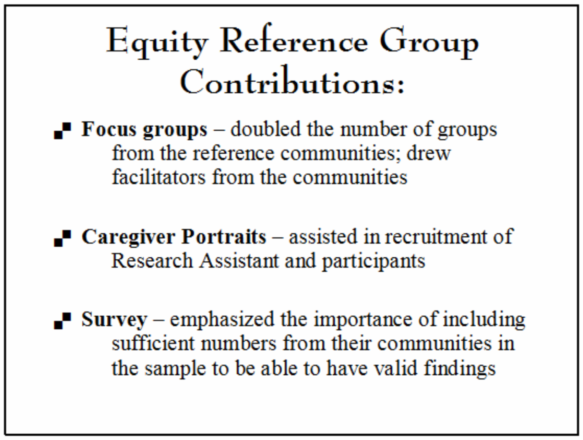
Nancy MacDonald,
School of Social Work, Dalhousie University



Equity Group Mandate

To ensure active engagement in the research process through:

- recommending culturally appropriate data collection and recruitment strategies for participants, facilitators, research assistants
- advising on strategies for sharing findings with their communities
- identifying policy makers, institutions, organizations and other groups for whom research findings are relevant



Equity Reference Group Contributions:

- **Focus groups** – doubled the number of groups from the reference communities; drew facilitators from the communities
- **Caregiver Portraits** – assisted in recruitment of Research Assistant and participants
- **Survey** – emphasized the importance of including sufficient numbers from their communities in the sample to be able to have valid findings

Role of Equity Reference Group

- Provide advice on how to proceed in a culturally relevant manner in all aspects of the research study
- Facilitating the translation of research into better policy and practice

Decision Making Process of the Equity Reference Group

- provide recommendations on the focus group process
- provide recommendations on the development and use of culturally appropriate and respectful data collection methods
- provide feedback on recruitment issues and potential focus group facilitators
- contribute information on sharing strategies in their communities

Challenges that the Equity Reference Group presented for the Researchers…

- To forge a productive, respectful relationship with the ERG so that research methodologies collect data in a way acceptable to the communities and that it reflects the realities of life there
- To recognize the importance of the ERG as playing an active role in the discussion and in the determination of the ways to present the findings in their communities

Benefits of the Equity Reference Groups…

June, 2003, mid-way point;
what have the ERG's brought to the study?

- Included perspectives from diverse groups, from the beginning and throughout the study
- Taking unique views of some fairly established issues – e.g. secondary analysis, taking a new look at work, stress, health gender
- Recognition of women's diversity, health, power, opportunities and challenges

Benefits of the Equity Reference Groups… continued…

- Bringing together people with diverse experience and expertise which enabled researchers to look at the issues through a very broad lens
- Including the ERG's as a major component of the research has provided 'validity' to the study
- Emphasis from the ERG's on continued involvement and on knowledge transfer

Where can Equity Reference Groups contribute…

- Knowledge generation
- Knowledge transfer, transformation , and uptake
- Strengthening research capacity in Atlantic Canada
- Fostering relationships and networks among academics, policy makers, community and clinical researchers

Equity Reference Groups can broaden the discussion…

- What findings would we like to discuss with other Equity Reference Group members?
- What findings would we like to share with your community?
- What are our ideas for further research?
- What have we learned about partnering with communities such as ours to do research that is meaningful and relevant?
- Which findings surprised us the most?
- Which findings most strongly reinforced something that we already knew about caregiving?

Equity Reference Group's; making a voice for community in research

2 members of this ERG are also members of the Mi'kmaq Health Research Group, located at Dalhousie University;

http://aahrp.socialwork.dal.ca/aahrp_3994.html

As members of the Mi'kmaq community and as researchers at the University, they are also guided by the principles of OCAP and by Mi'kmaq Ethics review procedures.

For Example – Mi'kmaq Ethics Watch…

In 1999, the Grand Council of Mi'kmaq appointed a group of Mi'kmaw leaders, elders, educators and other professionals to study the issues of cultural and intellectual protection of Mi'kmaw people.

The MEW developed the 'Principles and Guidelines for Researchers Conducting Research with and/or Among Mi'kmaq People

Mi'kmaq Ethics Watch has defined AHRG in Mi'kmaq communities…

Aboriginal Health Research Governance includes the processes for Mi'kmaq research ethics reviews, and research agreements, such as has been made with the MHRG to ensure the research that is conducted on and for Mi'kmaq peoples is directed by and accountable to Mi'kmaq communities.

The work of ERG's continues…

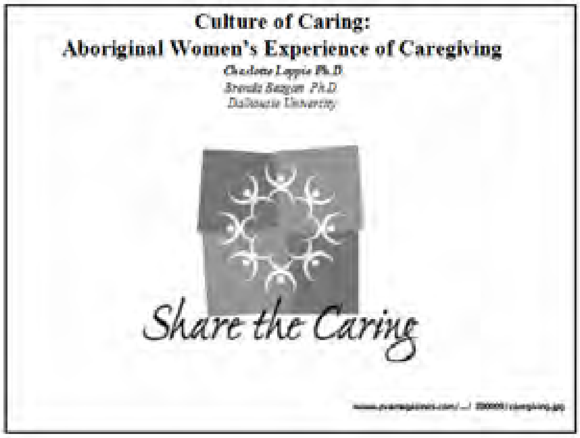
- Through on-going collaborative efforts, we need to disseminate our findings on exploring the connections between women's health and well-being and their paid and unpaid work, including unpaid caregiving.
- It is important to include representatives of the ERG members in the analysis and writing processes that now needs to be done with this research study.

The End…

Your feedback is welcome on your experiences and thoughts on next steps.

Common challenges, different needs: Diversity and caregiving

Charlotte Loppie

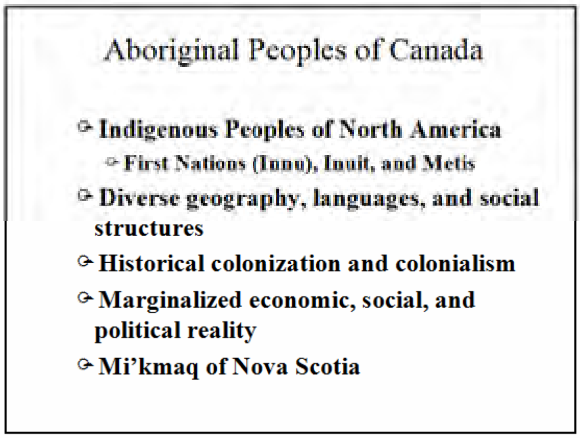


Culture of Caring: Aboriginal Women's Experience of Caregiving

Charlotte Loppie Ph.D
Brenda Beagan Ph.D
Dalhousie University

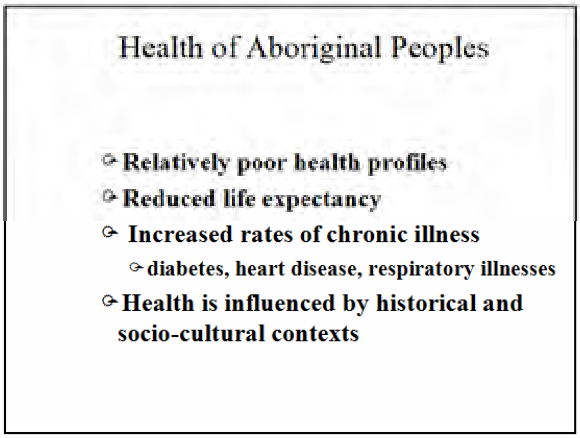
Overview

- Historical and social contexts of Aboriginal caregivers
- Cultural context of Aboriginal caring
- Intergenerational caring
- Reciprocal caring
- Including Indigenous caregiving perspectives
- Implications for caregiver support



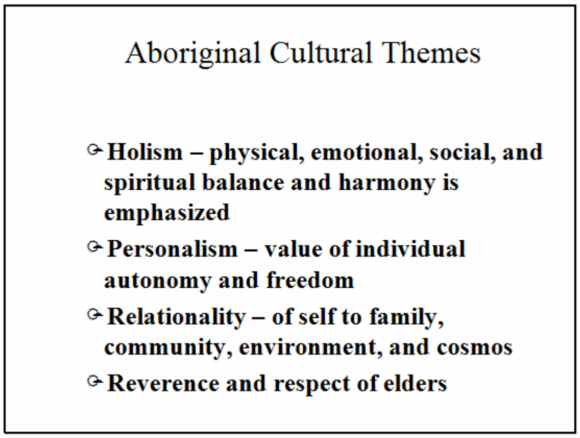
Aboriginal Peoples of Canada

- **Indigenous Peoples of North America**
  - **First Nations (Innu), Inuit, and Metis**
- **Diverse geography, languages, and social structures**
- **Historical colonization and colonialism**
- **Marginalized economic, social, and political reality**
- **Mi'kmaq of Nova Scotia**



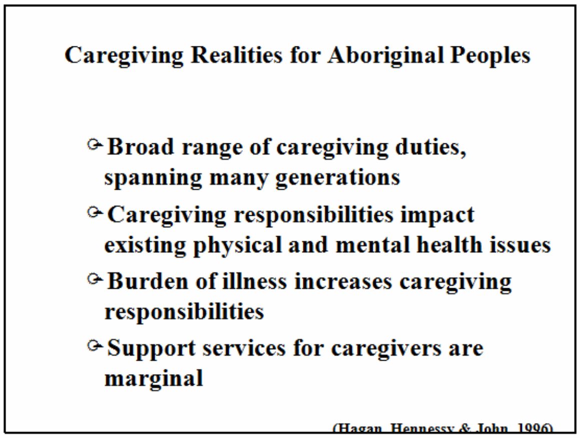
Health of Aboriginal Peoples

- **Relatively poor health profiles**
- **Reduced life expectancy**
- **Increased rates of chronic illness**
  - **diabetes, heart disease, respiratory illnesses**
- **Health is influenced by historical and socio-cultural contexts**



Aboriginal Cultural Themes

- **Holism – physical, emotional, social, and spiritual balance and harmony is emphasized**
- **Personalism – value of individual autonomy and freedom**
- **Relationality – of self to family, community, environment, and cosmos**
- **Reverence and respect of elders**



Caregiving Realities for Aboriginal Peoples

- **Broad range of caregiving duties, spanning many generations**
- **Caregiving responsibilities impact existing physical and mental health issues**
- **Burden of illness increases caregiving responsibilities**
- **Support services for caregivers are marginal**

(Hagan, Hennessy & John, 1996)

Aboriginal Perspectives on Caregiving

- Caregiving roles are not subordinate
- Caregiving represents an essential role in the family/community
- Caregiver is an important element of identity
- Caregiving responsibilities encompass physical, emotional, spiritual, and social care
- Caregiving is not seen as a separate component of relationships

---

Aboriginal Caregivers' Voice

"In our culture, it's inherent. You look after your own folks, you look after kids, and whatever caregiving comes with that."

"You're obligated because they're your family or your friends, and that's our culture."

"As a Native person, we feed everybody that comes to the door. You come in, you sit down, we feed you. You don't have to ask."

Aboriginal Caregivers' Voice

"When [someone] is coming into and leaving the world, you have to be holistic."

"It's important to remember those words, 'holistic', and 'emotional care', 'spiritual care'."

"You are also a spiritual support person too".

Reciprocal Care

- Everyone is a care giver and care receiver
- Large kinship and community networks create expansive reciprocal relationships
- Caregiving is not the exclusive domain of women
- Children are viewed as contributors to the family/community, rather than a burden
- Each individual is valued for their unique contribution to caring

---

Aboriginal Caregivers' Voices

"Some of the cultural things…the grandmother raises the grandchildren and then down the road, you look after her when she's dying, so you could be a caregiver very young."

"But they [elders] won't go to a home. We take care of them right at home."

Aboriginal Caregivers' Voices

"With me doing that for her [caring for her mother], she also helped me too. I helped her in one way and she helped me in another way. We helped each other. I took care of her for a while so she could get back on her feet and then she was able to help me. Basically, to me, it's pretty much what caregiving really is."

Intergenerational Care

- Caregiving is experienced across the lifespan
- Does not become a responsibility during adulthood – particularly for mid-life women
- Children and elders represent caregivers

Aboriginal Caregivers' Voices

"I started raising my sisters, then my children, and then my aunt when she was sick and they had no doctors then…most of the time she was at my home."

It's a cultural thing…We have elders who come in and talk to you…you get counseling; they tell you stories about a long time ago…they're kind of caregivers too; they're giving you the comfort and the emotional support you need."

Aboriginal Caregivers' Voices

"Our caregiving seems to start really young with Aboriginal women. I've heard of people starting at 12 raising sisters and when they are done raising sisters, they started raising their kids, and then after the kids, raising their grandchildren, so we're looking at three generations of caregiving by the time we're 40."

"Some of us lost our mothers at a young age and we had to take over."

Defining Caregiving from an Aboriginal Perspective

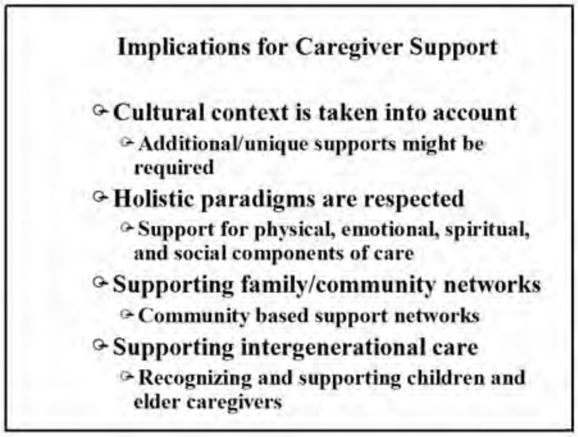
- Care of elders is viewed as an honour, rather than a burden
- Respect for elders is universal among Aboriginal peoples
- Grandparents play a critical role in family/community life as:
  - teachers, story tellers, spiritual leaders, healers, historians, cultural conduits

Diversity in Caregiving

- Caregiving is linked to self-concept
- Holistic conceptualization of health and caring enhances supports as well as responsibilities
- Caregiving responsibilities increase with social, economic, and political marginalization

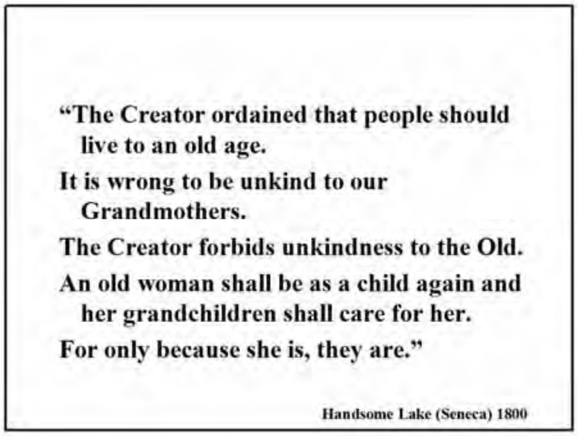
The Role of Kinship Networks in Caregiving

- Extended kinship networks create unique caregiving arrangements
- Involve many community and family members
- Span several generations and life years
- Kinship ties are reflected in caregiving activities and identity
- Community networks linked to kinship ties



Implications for Caregiver Support

- Cultural context is taken into account
  - Additional/unique supports might be required
- Holistic paradigms are respected
  - Support for physical, emotional, spiritual, and social components of care
- Supporting family/community networks
  - Community based support networks
- Supporting intergenerational care
  - Recognizing and supporting children and elder caregivers



"The Creator ordained that people should live to an old age.

It is wrong to be unkind to our Grandmothers.

The Creator forbids unkindness to the Old.

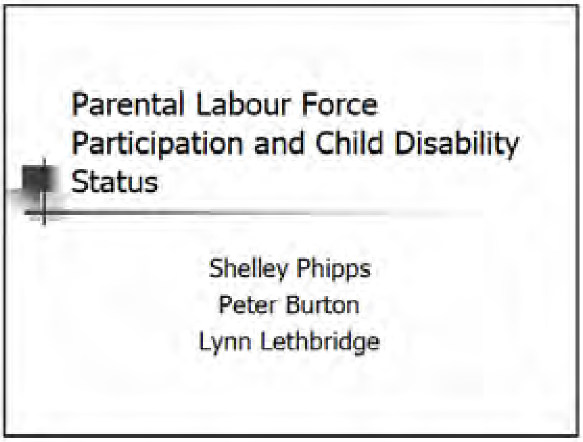
An old woman shall be as a child again and her grandchildren shall care for her.

For only because she is, they are."

Handsome Lake (Seneca) 1800

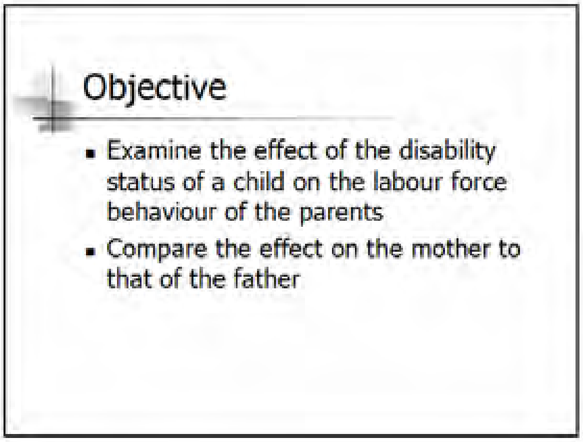
Caring for others, caring for yourself: Balancing work and life

Lynn Lethbridge



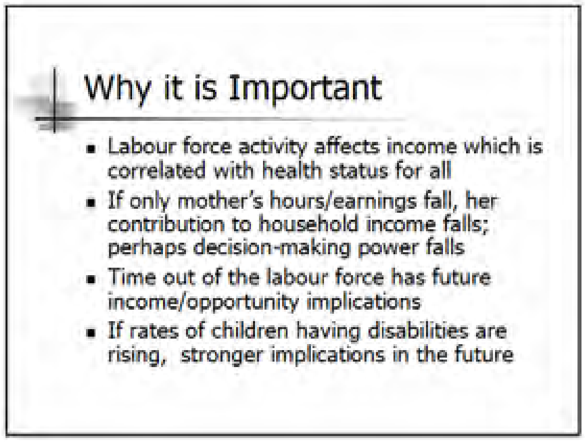
Parental Labour Force Participation and Child Disability Status

Shelley Phipps
Peter Burton
Lynn Lethbridge



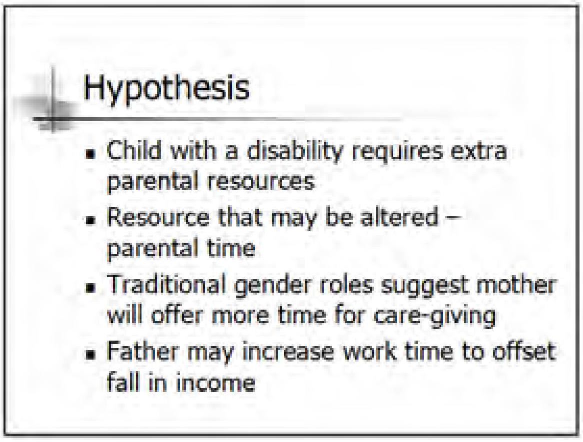
Objective

- Examine the effect of the disability status of a child on the labour force behaviour of the parents
- Compare the effect on the mother to that of the father



Why it is Important

- Labour force activity affects income which is correlated with health status for all
- If only mother's hours/earnings fall, her contribution to household income falls; perhaps decision-making power falls
- Time out of the labour force has future income/opportunity implications
- If rates of children having disabilities are rising, stronger implications in the future



Hypothesis

- Child with a disability requires extra parental resources
- Resource that may be altered – parental time
- Traditional gender roles suggest mother will offer more time for care-giving
- Father may increase work time to offset fall in income

Previous Research

- PALS (Participation and Activity Limitations Survey) 2001
- Governmentt of Canada report based on PALS
    - 54.1% of children < 5 with mild/moderate have at least 1 parent's employment affected
    - 72.3% of children < 5 with severe or very severe

Previous Research

- Employment Impacts
    - 38.2% turned down promotion or better job
    - 31.3% worked fewer hours
    - 31.2% not taking a job
    - 22.8% changing work hours
    - 18.6% quitting paid employment

(not mutually exclusive)

Previous Research

- A large number of papers from the (early 1970's – 2003) showing reduced labour force participation of mothers with children in ill-health
- Powers (2003) varys the definition of disability - multiple definition show effects on LFP of mothers
- Many studies in the US, but not Canada

Method of Analysis

- Simple means comparing married mothers/fathers
  - All households
  - Households with a child with disability in 2000
  - Household without a child with disability in 2000
- Multivariate analysis to control for other factors
  - Currently in the labour force (y/n)
  - Total hours currently working (continuous)

Data

- National Longitudinal Survey of Children and Youth (NLSCY)
- Cycles 3 and 4 (1998 and 2000)
- Children ages 2-15 in 2000
- Married couple households (both years)
- Sample 13,719 households

Definition of Disability

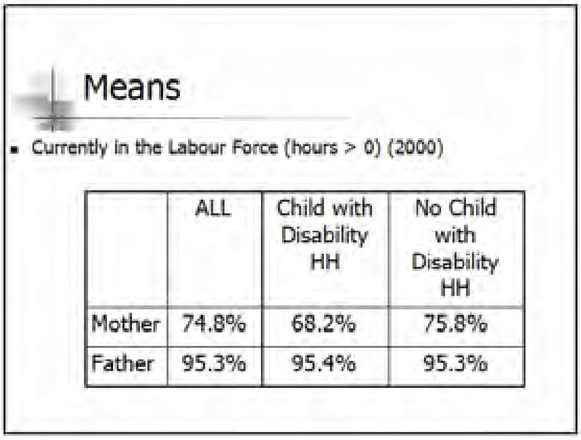
- Child described by PMK (96.8% mom) as having any one or more of:
  - Activity limitation, limited due to asthma, bronchitis, heart condition, mental condition, epilepsy, cerebral palsy, kidney condition, mental condition, cannot see with glasses, cannot hear without aid, cannot walk without mechanical assistance, *has fair/poor health*

Child With Disability in Household

- For the year 2000, 13.4% of married couple households had a child with a disability by our definition

Labour Force Hours

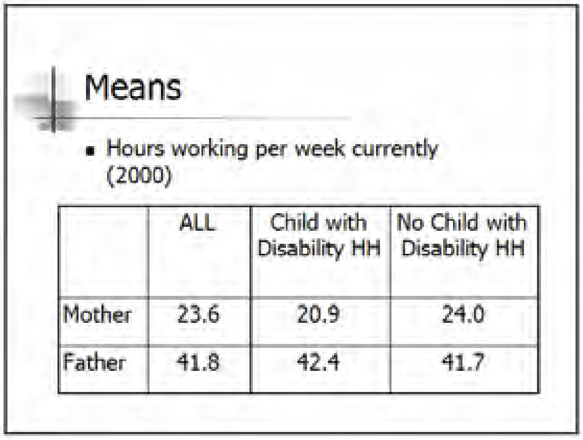
- PMK answers for both
- Hours are a fairly objective measure
- PMK likely to have good knowledge of work hours for spouse



Means

- Currently in the Labour Force (hours > 0) (2000)

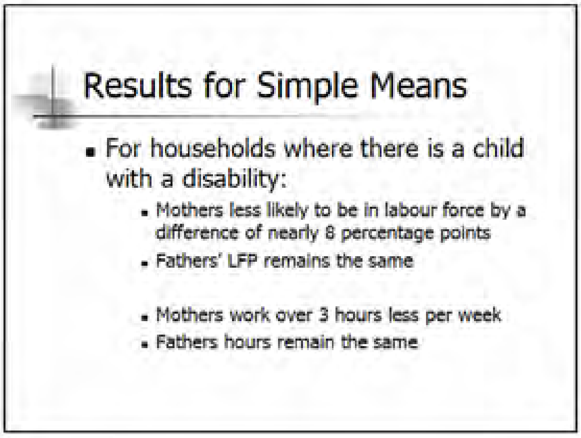
	ALL	Child with Disability HH	No Child with Disability HH
Mother	74.8%	68.2%	75.8%
Father	95.3%	95.4%	95.3%



Means

- Hours working per week currently (2000)

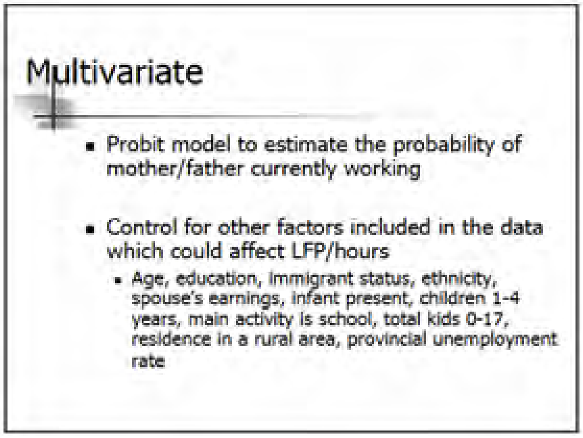
	ALL	Child with Disability HH	No Child with Disability HH
Mother	23.6	20.9	24.0
Father	41.8	42.4	41.7



Results for Simple Means

- For households where there is a child with a disability:
  - Mothers less likely to be in labour force by a difference of nearly 8 percentage points
  - Fathers' LFP remains the same

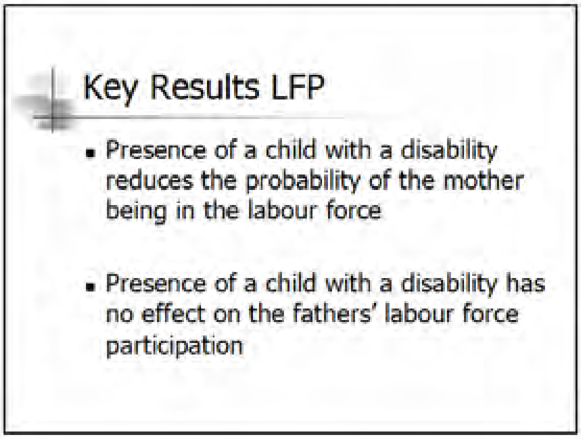
  - Mothers work over 3 hours less per week
  - Fathers hours remain the same



Multivariate

- Probit model to estimate the probability of mother/father currently working

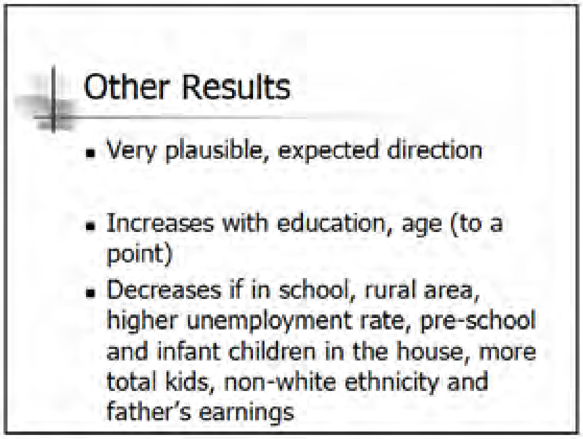
- Control for other factors included in the data which could affect LFP/hours
  - Age, education, immigrant status, ethnicity, spouse's earnings, infant present, children 1-4 years, main activity is school, total kids 0-17, residence in a rural area, provincial unemployment rate



Key Results LFP

- Presence of a child with a disability reduces the probability of the mother being in the labour force

- Presence of a child with a disability has no effect on the fathers' labour force participation



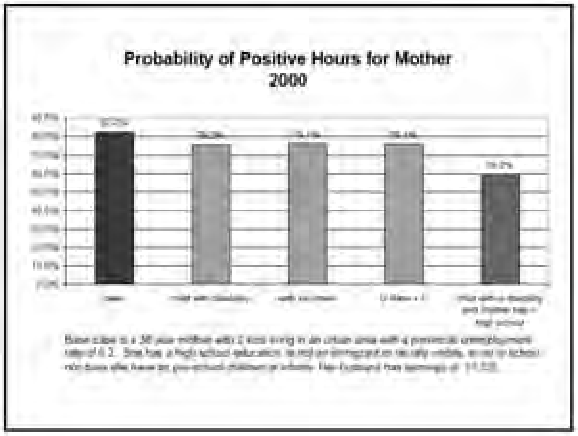
Other Results

- Very plausible, expected direction

- Increases with education, age (to a point)
- Decreases if in school, rural area, higher unemployment rate, pre-school and infant children in the house, more total kids, non-white ethnicity and father's earnings

Size of Probability Change

- Coefficients are not intuitive
- Probability simulations to show marginal effects
- Take a base case scenario and make changes



Probability of Positive Hours for Mother 2000

Multivariate for Hours

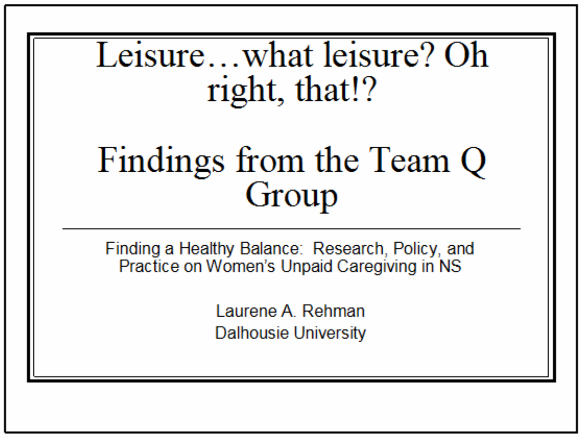
- Very preliminary
- Tobit Model to account for censoring
- Results similar to LF models
- Households with a child with a disability
  - Mother works about 4 hours less per week
  - Fathers hours stay the same

Conclusions Thus Far

- Having a child with a disability reduces the probability of LFP of mothers but not fathers
- Initial work suggests mothers work about 4 less per week; fathers hours are not reduced

Caring for others, caring for yourself: Balancing work and life

Laurene Rehman

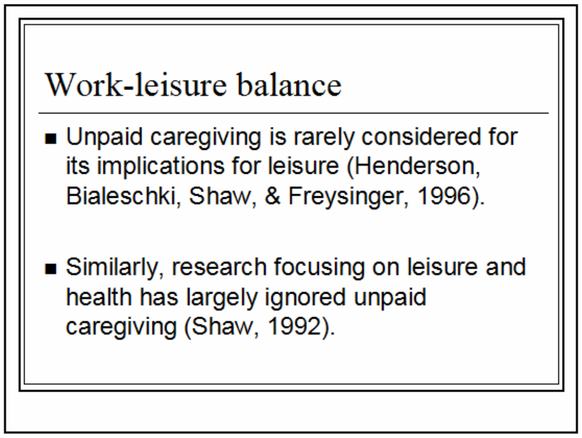


Leisure…what leisure? Oh right, that!?

Findings from the Team Q Group

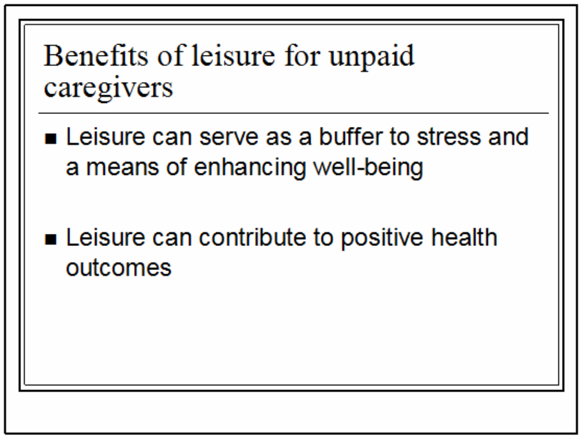
Finding a Healthy Balance: Research, Policy, and Practice on Women's Unpaid Caregiving in NS

Laurene A. Rehman
Dalhousie University



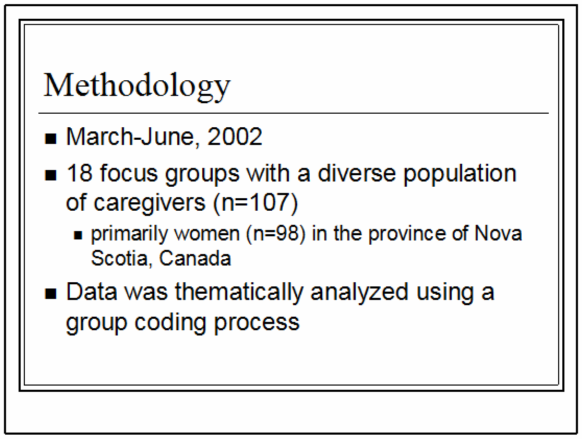
Work-leisure balance

- Unpaid caregiving is rarely considered for its implications for leisure (Henderson, Bialeschki, Shaw, & Freysinger, 1996).
- Similarly, research focusing on leisure and health has largely ignored unpaid caregiving (Shaw, 1992).



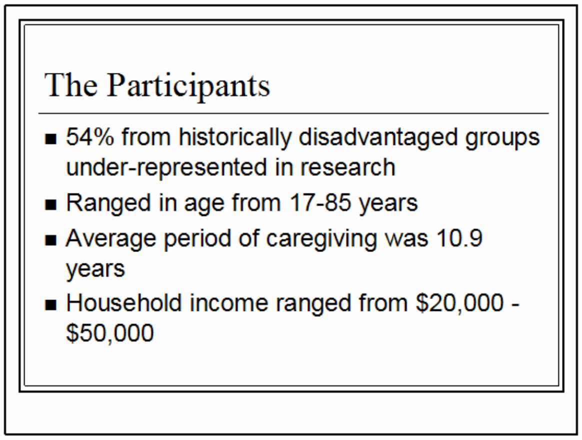
Benefits of leisure for unpaid caregivers

- Leisure can serve as a buffer to stress and a means of enhancing well-being
- Leisure can contribute to positive health outcomes



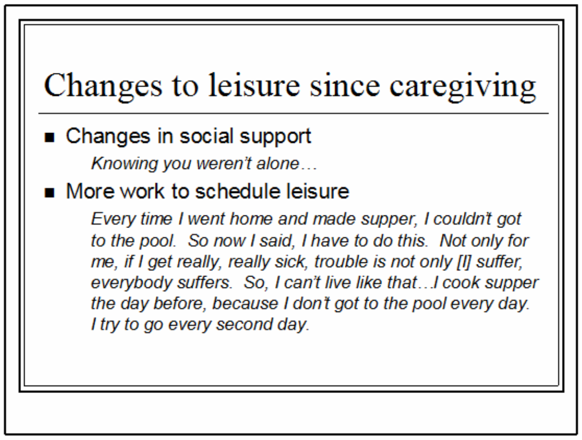
Methodology

- March-June, 2002
- 18 focus groups with a diverse population of caregivers (n=107)
  - primarily women (n=98) in the province of Nova Scotia, Canada
- Data was thematically analyzed using a group coding process



The Participants

- 54% from historically disadvantaged groups under-represented in research
- Ranged in age from 17-85 years
- Average period of caregiving was 10.9 years
- Household income ranged from $20,000 - $50,000



Changes to leisure since caregiving

- Changes in social support

  Knowing you weren't alone…

- More work to schedule leisure

  Every time I went home and made supper, I couldn't got to the pool. So now I said, I have to do this. Not only for me, if I get really, really sick, trouble is not only [I] suffer, everybody suffers. So, I can't live like that…I cook supper the day before, because I don't got to the pool every day. I try to go every second day.

Changes to leisure (cont.)

- Emotional exhaustion meant forgoing leisure

  [It is] challenging scheduling time for self when caregiving is not a 9 to 5 type of work. I know when Mom was really sick, there was nothing. It was 24 hours a day, 7 days a week.
- Unique definitions of leisure
  - *When my mothers calls me*
  - *Walking around the mall*
  - *The clothesline!*

Leisure as a mediating effect on caregiving

- Both positive and negative effects
- The Positive Side
  - Leisure provided a sense of enjoyment, fulfillment, and relaxation

    For one hour a week, let me have a little bit of normalcy in my life. Just sitting in the back yard in the summer having a cup of coffee. So I don't think I realized at the time that I was stressed or that that was a way of dealing with the stress, but I think that's exactly what it was.

Leisure as a mediating effect – the negative

- The Negative Side
  - Leisure didn't always provide a sense of reprieve
  - other factors could prevent release (e.g., fatigue, additional responsibilities of managing social support, limited financial resources, gender role expectations)

    So, we have worry and terror, we have stress, [it is] mentally draining, we have time management, we have loving comfort, we have sleepless nights, change of priorities, cost both financial and emotional, responsibility, sacrifice; we have the issues of being a full caregiver, we have bargaining, we have change of role, both for the parent and the "child" and I have "child" in quote because it could be an adult child.

What does this mean?

- The importance of leisure as "personal space" and "time for self" or relaxation with care recipient
- The chance for stress relief or reprieve from leisure
- Greater need for flexibility in the supports provided to caregivers
  - Need for good alternative care
  - Need for financial support that recognizes leisure
  - Need for transportation

For more information, please contact:

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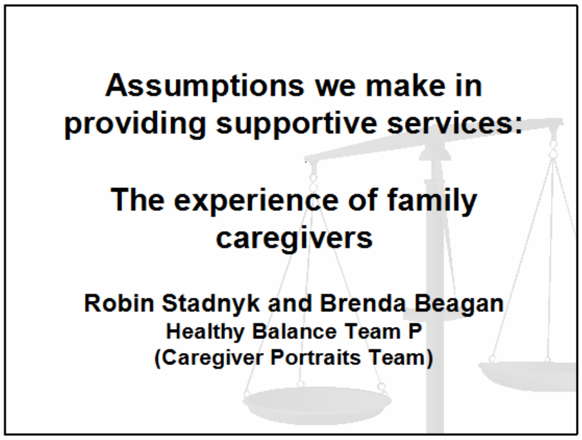
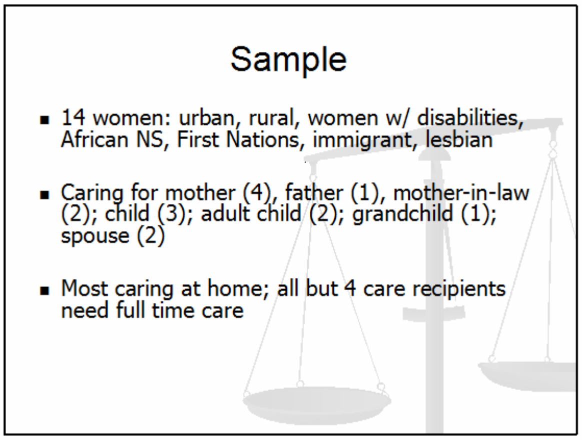
New directions in research on caregiving
Robin Stadnyk



Assumptions we make in providing supportive services:

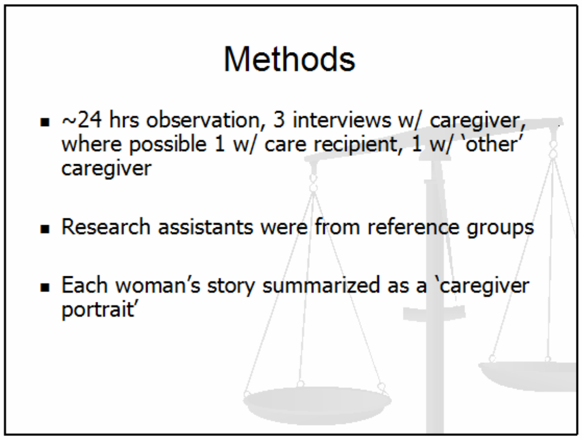
The experience of family caregivers

Robin Stadnyk and Brenda Beagan
Healthy Balance Team P
(Caregiver Portraits Team)



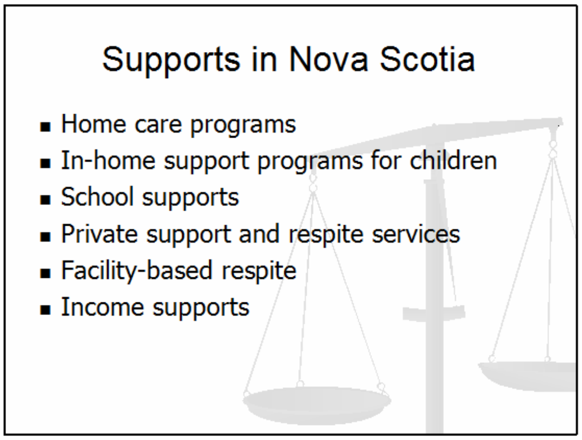
Sample

- 14 women: urban, rural, women w/ disabilities, African NS, First Nations, immigrant, lesbian
- Caring for mother (4), father (1), mother-in-law (2); child (3); adult child (2); grandchild (1); spouse (2)
- Most caring at home; all but 4 care recipients need full time care



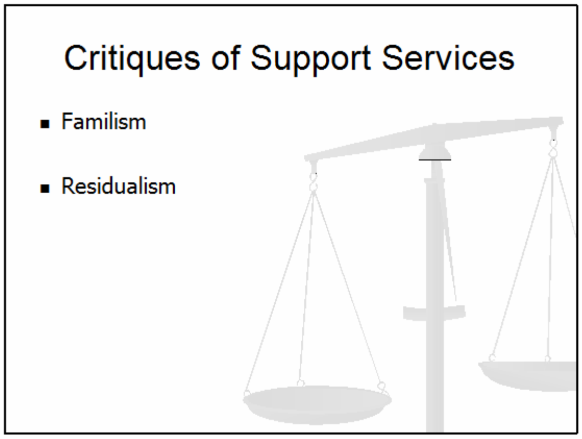
Methods

- ~24 hrs observation, 3 interviews w/ caregiver, where possible 1 w/ care recipient, 1 w/ 'other' caregiver
- Research assistants were from reference groups
- Each woman's story summarized as a 'caregiver portrait'



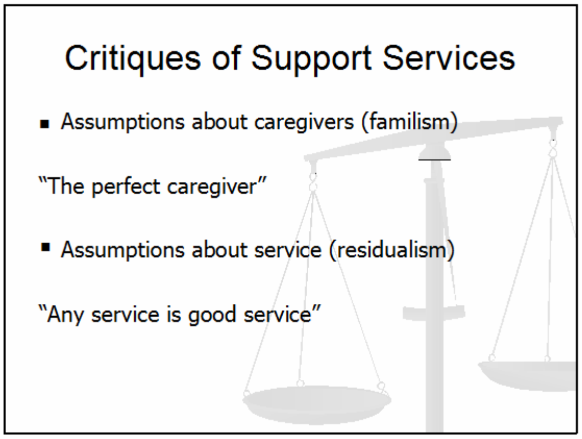
Supports in Nova Scotia

- Home care programs
- In-home support programs for children
- School supports
- Private support and respite services
- Facility-based respite
- Income supports



Critiques of Support Services

- Familism
- Residualism



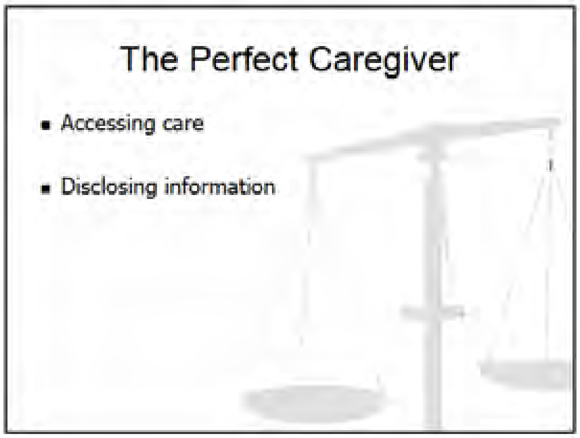
Critiques of Support Services

- Assumptions about caregivers (familism)

"The perfect caregiver"

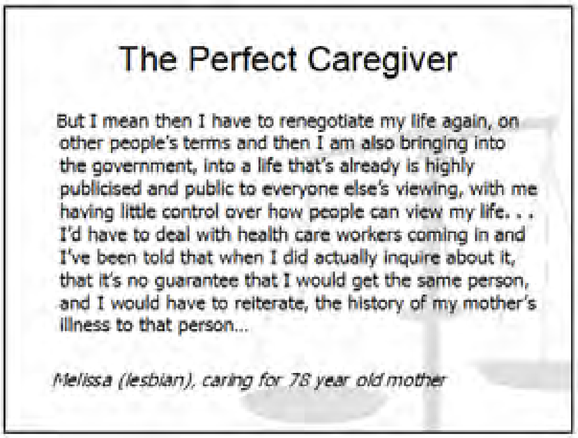
- Assumptions about service (residualism)

"Any service is good service"



The Perfect Caregiver

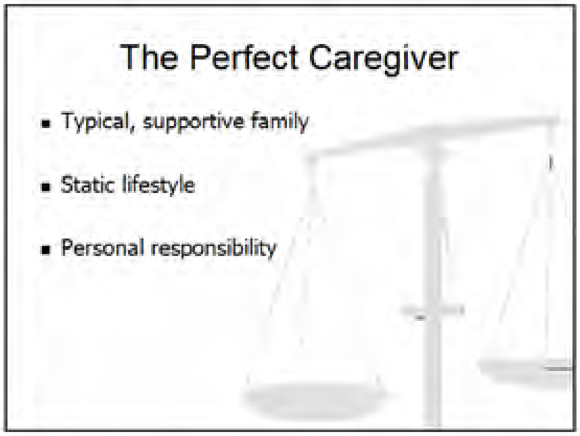
- Accessing care
- Disclosing information



The Perfect Caregiver

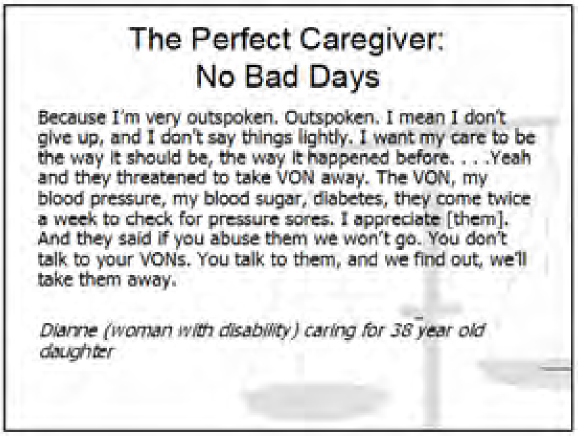
But I mean then I have to renegotiate my life again, on other people's terms and then I am also bringing into the government, into a life that's already is highly publicised and public to everyone else's viewing, with me having little control over how people can view my life. . . I'd have to deal with health care workers coming in and I've been told that when I did actually inquire about it, that it's no guarantee that I would get the same person, and I would have to reiterate, the history of my mother's illness to that person...

Melissa (lesbian), caring for 78 year old mother



The Perfect Caregiver

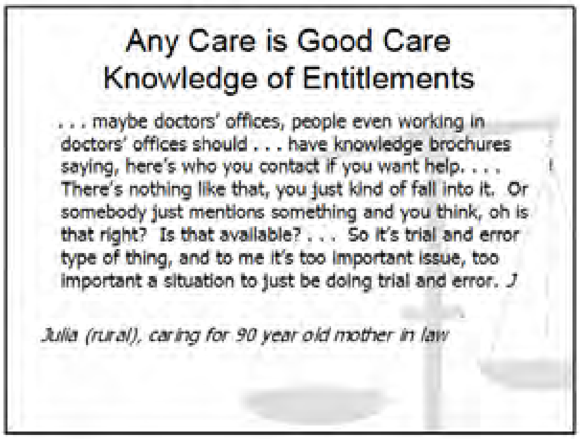
- Typical, supportive family
- Static lifestyle
- Personal responsibility



The Perfect Caregiver: No Bad Days

Because I'm very outspoken. Outspoken. I mean I don't give up, and I don't say things lightly. I want my care to be the way it should be, the way it happened before. . . .Yeah and they threatened to take VON away. The VON, my blood pressure, my blood sugar, diabetes, they come twice a week to check for pressure sores. I appreciate [them]. And they said if you abuse them we won't go. You don't talk to your VONs. You talk to them, and we find out, we'll take them away.

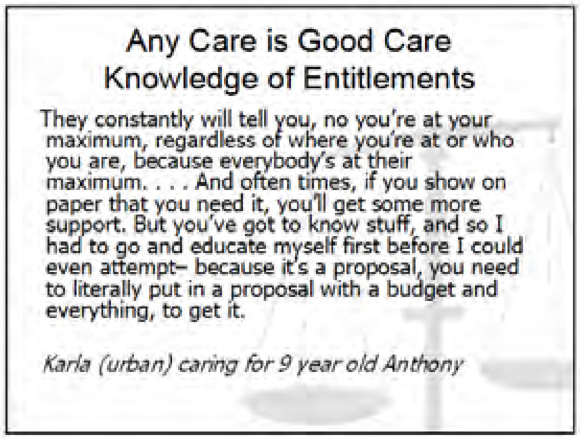
Dianne (woman with disability) caring for 38 year old daughter



Any Care is Good Care Knowledge of Entitlements

. . . maybe doctors' offices, people even working in doctors' offices should . . . have knowledge brochures saying, here's who you contact if you want help. . . . There's nothing like that, you just kind of fall into it. Or somebody just mentions something and you think, oh is that right? Is that available? . . . So it's trial and error type of thing, and to me it's too important issue, too important a situation to just be doing trial and error. J

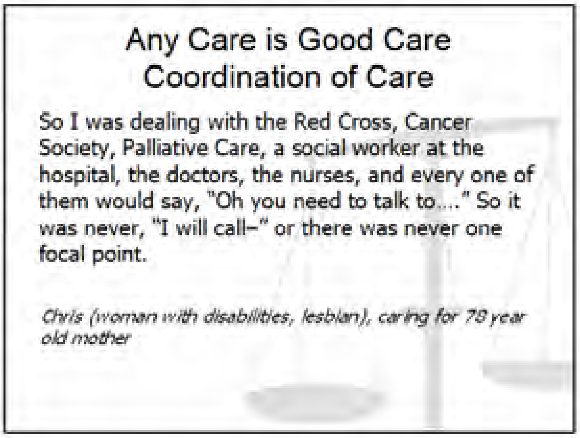
Julia (rural), caring for 90 year old mother in law



Any Care is Good Care Knowledge of Entitlements

They constantly will tell you, no you're at your maximum, regardless of where you're at or who you are, because everybody's at their maximum. . . . And often times, if you show on paper that you need it, you'll get some more support. But you've got to know stuff, and so I had to go and educate myself first before I could even attempt– because it's a proposal, you need to literally put in a proposal with a budget and everything, to get it.

Karla (urban) caring for 9 year old Anthony



Any Care is Good Care
Coordination of Care

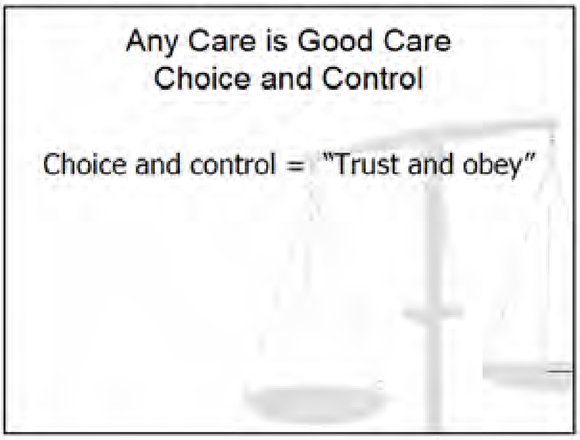
So I was dealing with the Red Cross, Cancer Society, Palliative Care, a social worker at the hospital, the doctors, the nurses, and every one of them would say, "Oh you need to talk to...." So it was never, "I will call–" or there was never one focal point.

Chris (woman with disabilities, lesbian), caring for 78 year old mother

Any Care is Good Care
Availability of Care

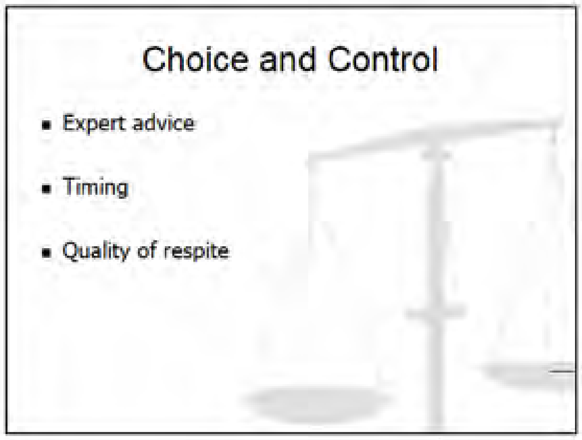
They authorized [a home support service increase] in May but we didn't get it until December. Now I didn't push for it all summer. I didn't push for it at all. . . . And they finally said, "You know, we just can't anybody to take those additional hours on. We can't get [agency] to take those additional hours on."

Carol (urban), caring for 87 year old mother



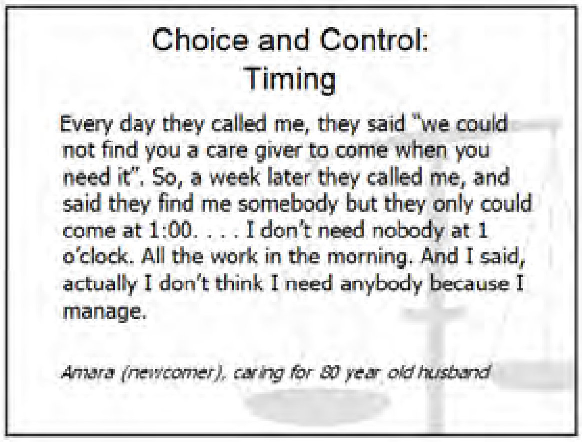
Any Care is Good Care
Choice and Control

Choice and control = "Trust and obey"



Choice and Control

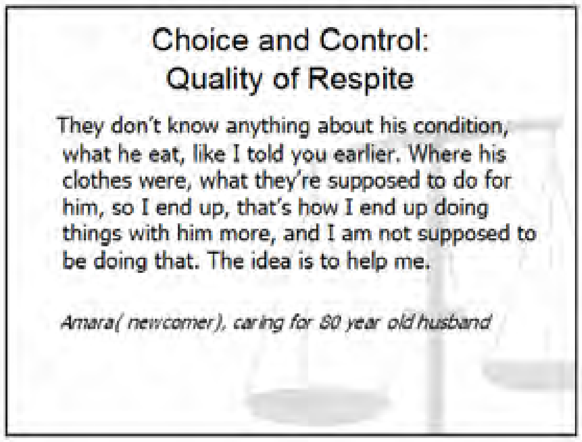
- Expert advice
- Timing
- Quality of respite



Choice and Control:
Timing

Every day they called me, they said "we could not find you a care giver to come when you need it". So, a week later they called me, and said they find me somebody but they only could come at 1:00. . . . I don't need nobody at 1 o'clock. All the work in the morning. And I said, actually I don't think I need anybody because I manage.

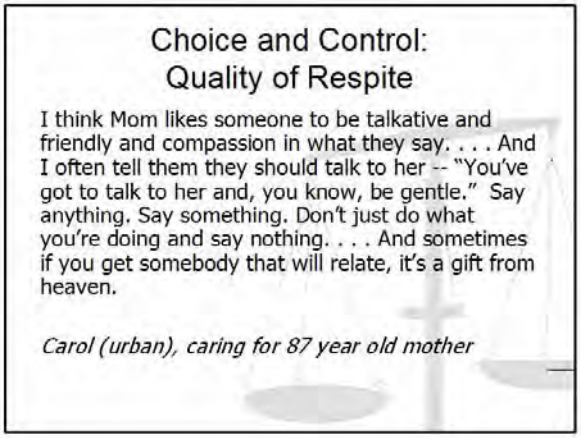
Amara (newcomer), caring for 80 year old husband



Choice and Control:
Quality of Respite

They don't know anything about his condition, what he eat, like I told you earlier. Where his clothes were, what they're supposed to do for him, so I end up, that's how I end up doing things with him more, and I am not supposed to be doing that. The idea is to help me.

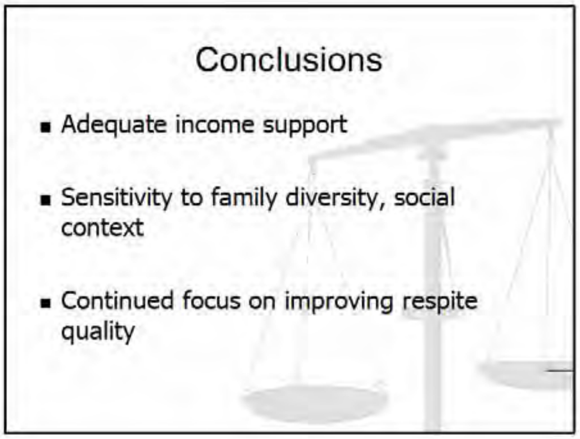
Amara(newcomer), caring for 80 year old husband



Choice and Control: Quality of Respite

I think Mom likes someone to be talkative and friendly and compassion in what they say. . . . And I often tell them they should talk to her -- "You've got to talk to her and, you know, be gentle." Say anything. Say something. Don't just do what you're doing and say nothing. . . . And sometimes if you get somebody that will relate, it's a gift from heaven.

Carol (urban), caring for 87 year old mother



Conclusions

- Adequate income support
- Sensitivity to family diversity, social context
- Continued focus on improving respite quality

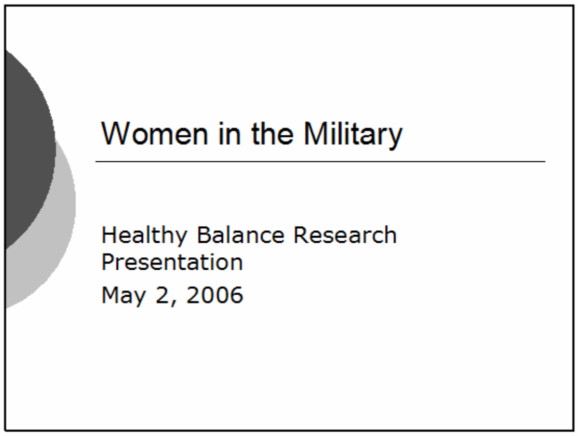
Acknowledgements

- Data coding: Jen Davis
- Research assistants: Linda Carvery; Jen Davis; Maria Yax-Fraser; Hiroko Fujimoto; Toni Thompson; Juliana Weins
- Team members: Brenda Beagan, Barb Hamilton-Hinch, Charlotte Loppie, Judy MacDonald, Nancy MacDonald, Robin Stadnyk

- The Canadian Institutes for Health Research
- The Atlantic Centre of Excellence for Women's Health & The Nova Scotia Advisory Council on the Status of Women
- Hidden Costs/ Invisible Contributions, Department of Human Ecology, University of Alberta

New directions in research on caregiving

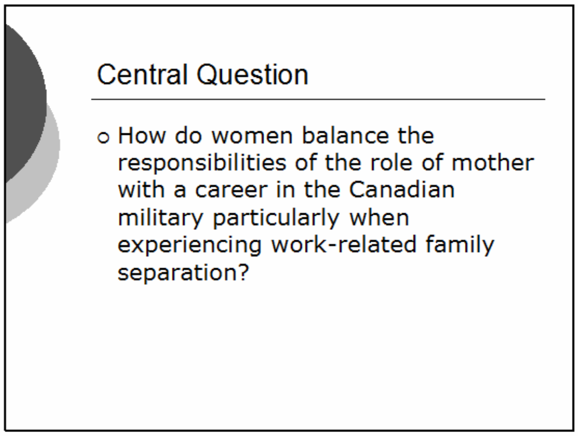
Deborah Norris



Women in the Military

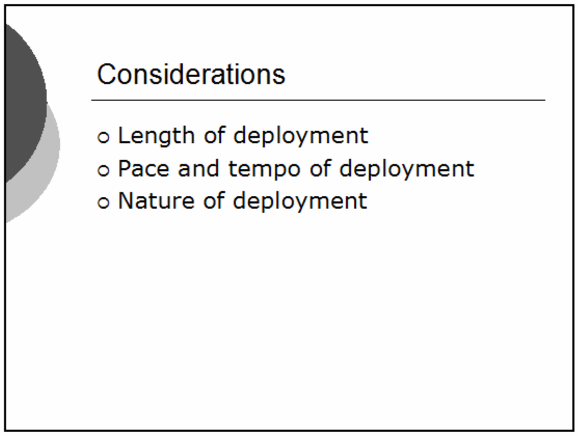
Healthy Balance Research Presentation

May 2, 2006



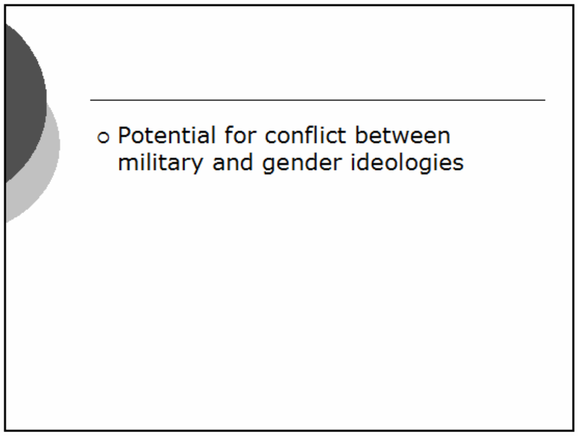
Central Question

- How do women balance the responsibilities of the role of mother with a career in the Canadian military particularly when experiencing work-related family separation?

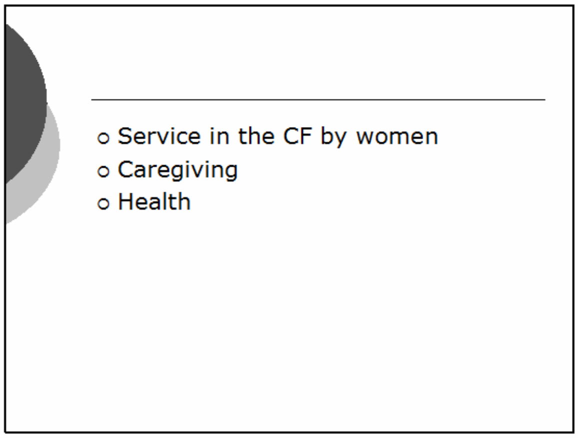


Considerations

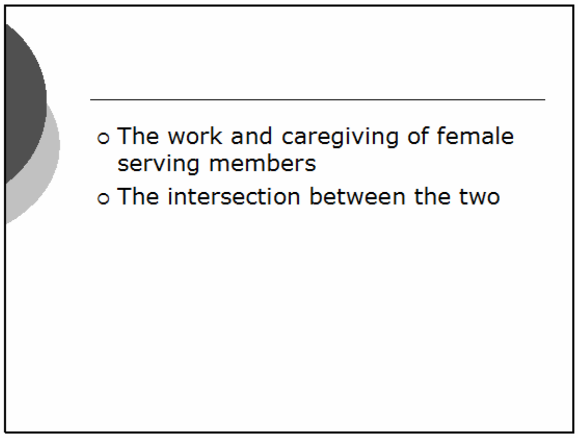
- Length of deployment
- Pace and tempo of deployment
- Nature of deployment



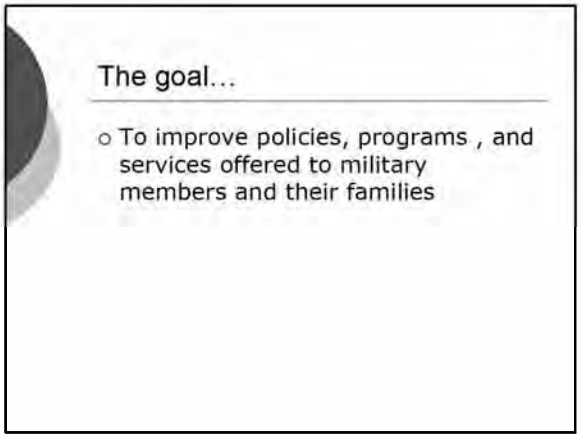
- Potential for conflict between military and gender ideologies



- Service in the CF by women
- Caregiving
- Health

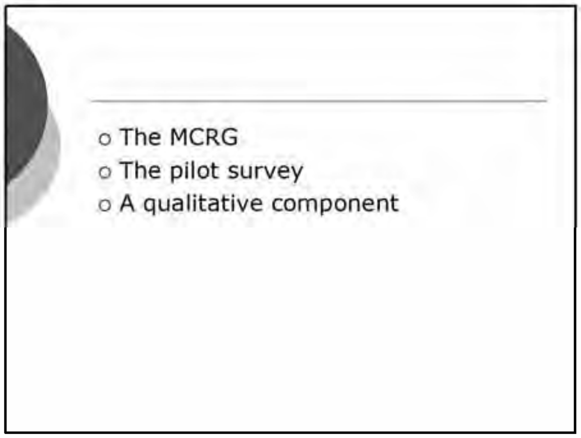


- The work and caregiving of female serving members
- The intersection between the two



The goal…

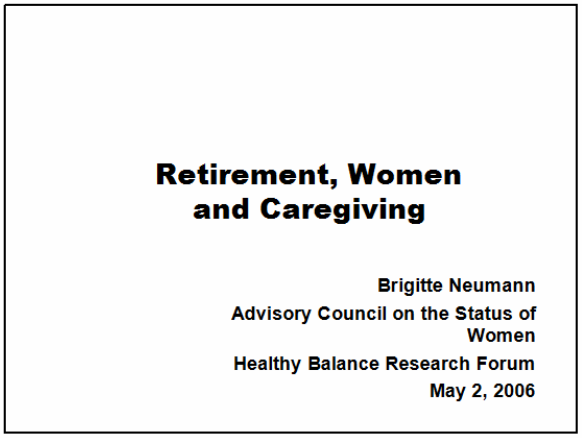
- To improve policies, programs , and services offered to military members and their families



- The MCRG
- The pilot survey
- A qualitative component

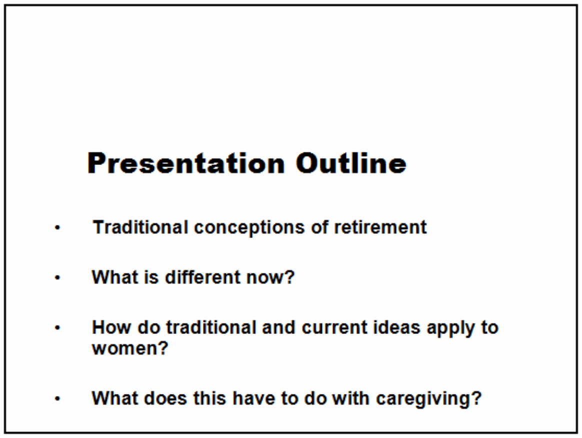
Caring at all costs: The economic implications of caregiving

Brigitte Neumann



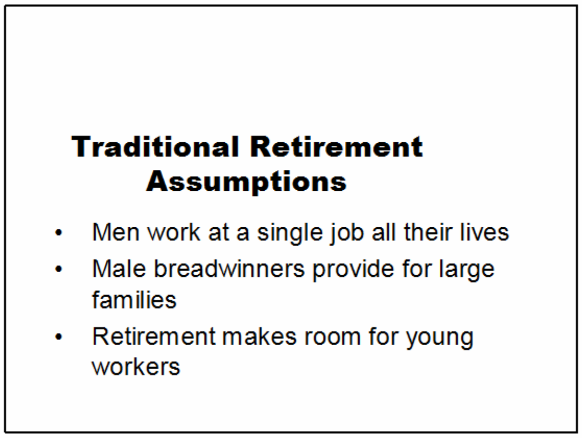
Retirement, Women and Caregiving

Brigitte Neumann
Advisory Council on the Status of Women
Healthy Balance Research Forum
May 2, 2006



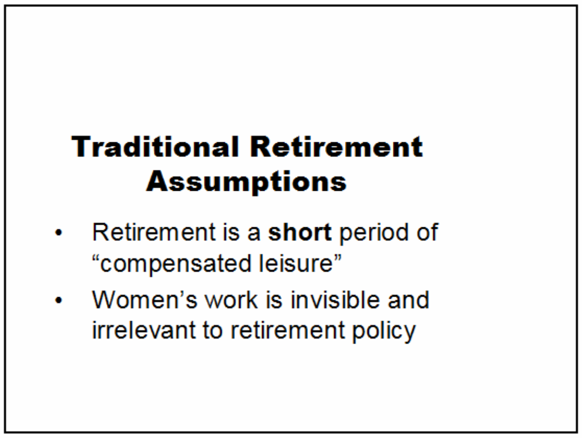
Presentation Outline

- **Traditional conceptions of retirement**
- **What is different now?**
- **How do traditional and current ideas apply to women?**
- **What does this have to do with caregiving?**



Traditional Retirement Assumptions

- Men work at a single job all their lives
- Male breadwinners provide for large families
- Retirement makes room for young workers

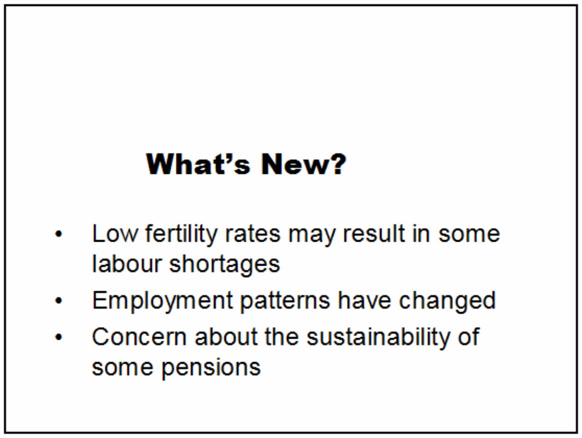


Traditional Retirement Assumptions

- Retirement is a **short** period of “compensated leisure”
- Women’s work is invisible and irrelevant to retirement policy

What’s New?

- Retirement lasts as long as a generation
- Emergence of “The Third Age”
- Trends to early retirement are reversing



What’s New?

- Low fertility rates may result in some labour shortages
- Employment patterns have changed
- Concern about the sustainability of some pensions

What’s New?

- Increased emphasis on private planning for retirement income
- Increased concern with intergenerational equity
- Women have entered the workforce

Women and Retirement

- Women’s workforce participation is much more likely to be interrupted, part-time, “casual”, etc.
- Women are less likely to have an employer pension

Women and Retirement

- Lower average lifetime earnings lead to lower public pension payouts
- 2005 CPP payouts:

– Maximum	$828.75
– Women	$333.76
– Men	$527.04

Women and Retirement

- Women’s transition to retirement differs from men’s
- Men are more likely to continue some paid work for longer
- Women are twice as likely to retire into caregiving

Women and Retirement

- More women than in the past will retire with good pensions
- But many will find themselves in financial hardship—divorced women, racialized women, immigrant women, women with irregular work histories

Women and Caregiving

- A first in human history: many seniors have living parents
- Women have children at later ages
- Therefore: more care needed, for longer

Women and Caregiving

- More variety in caregiving situations and in retirement possibilities
- Risk of increased polarization of haves and have-nots

Conclusions

- Recognition of caregiving is vital in retirement income systems
- Policies and programs must be designed with flexibility, in order to address the wide variety of needs

Conclusions

- We have to find a way to do retirement planning that isn't just for the well-off!
- Retirement and Caregiving Plans need to be integrated

- Source:

  Stone, L. (ed.) (2006) *New Frontiers of Research on Retirement.* Ottawa: Statistics Canada, Cat. # 75-511-XIE

Caring at all costs: The economic implications of caregiving

Janice Keefe

Supporting Caregivers in Canada

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Finding a Healthy Balance Forum
Halifax, NS, May 2, 2006
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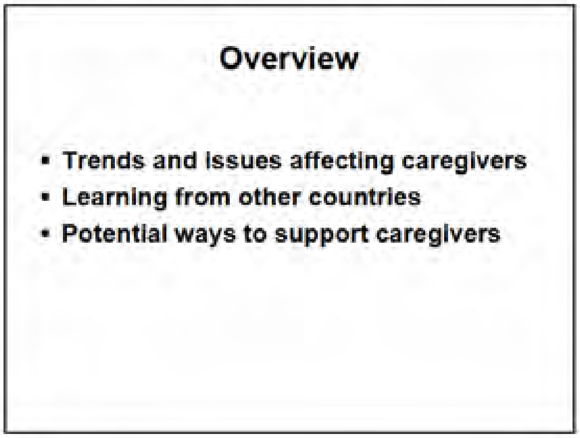
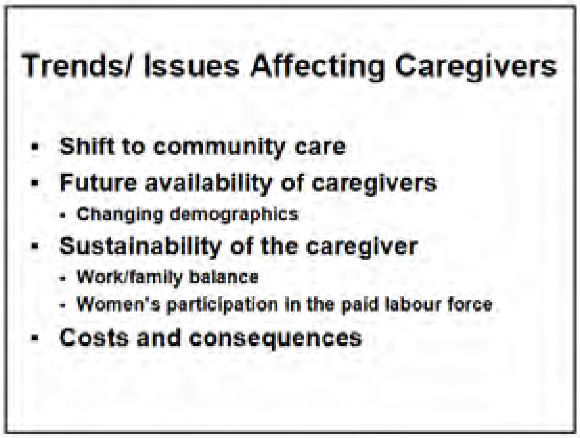


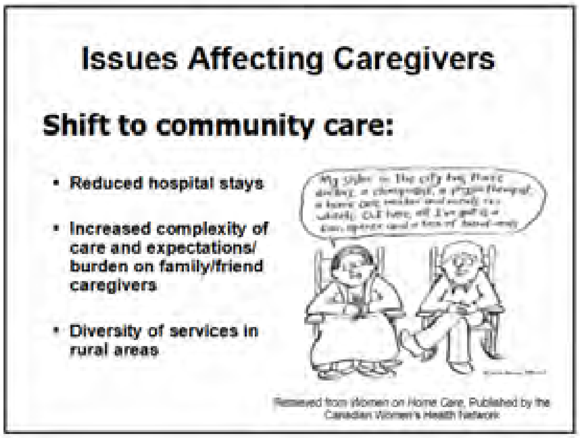
Overview

- Trends and issues affecting caregivers
- Learning from other countries
- Potential ways to support caregivers



Trends/ Issues Affecting Caregivers

- Shift to community care
- Future availability of caregivers
  - Changing demographics
- Sustainability of the caregiver
  - Work/family balance
  - Women's participation in the paid labour force
- Costs and consequences



Issues Affecting Caregivers

Shift to community care:

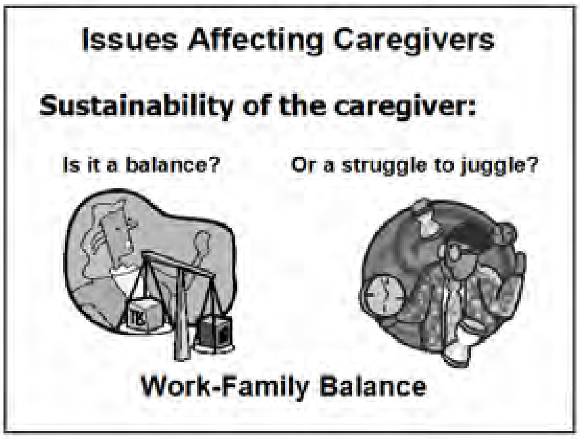
- Reduced hospital stays
- Increased complexity of care and expectations/ burden on family/friend caregivers
- Diversity of services in rural areas

Retrieved from Women on Home Care, Published by the Canadian Women's Health Network

Issues Affecting Caregivers

Future Availability:

- Baby boomers aging
- Birth rate decreasing
- Divorce rate increasing
- Common-law partnerships increasing
- Geographic mobility increasing
- Ethnic diversity increasing



Issues Affecting Caregivers

Sustainability of the caregiver:

Is it a balance? Or a struggle to juggle?

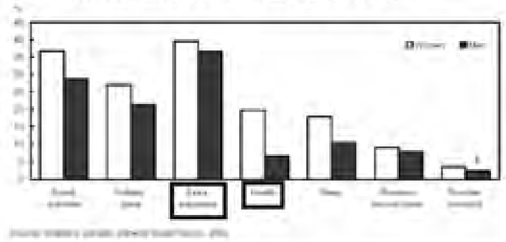
Work-Family Balance

Costs & Consequences

Issues Affecting Canadian Caregivers

Consequences - all caregivers:

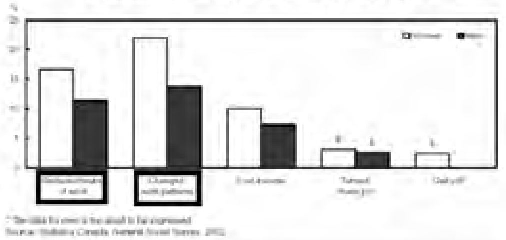
Percentage of caregivers 45 years and over who experienced consequences due to caregiving, 2002 GSS



Issues Affecting Canadian Caregivers

Consequences - employed caregivers:

Percentage of Canadian caregivers 45 years and over who experienced employment consequences, 2002



What can we learn from other countries?

Caregiving is a global issue

Countries have "carer" strategies or comprehensive programs

- **Australia**
  - Home and Community Care Program HCAA (1992)
  - National Respite for Carers Program (1996)
- **Germany**
  - Long Term Care Insurance Program
- **United States**
  - Amendment to Older Americans Act (2000) established the National Family Caregiver Support Program (NFCSP)
- **United Kingdom**
  - National Strategy for Carers (1999)

Profile of Financial Compensation Initiatives by Country

	Australia	**Germany**
Population	20 million	82 million
% 65+	12%	18%
% person w. disability	20%	Not available
Caregiver Policy Context	• Caregivers recognized as clients. • National respite program. • $461 M Carers Package announced 2004.	• Long-Term Care Insurance Program. • Registration of caregivers.
Direct	Cash payment to CG. Cash supplement. Cash payment to Veteran CR.	Cash payment to CR.
Indirect	CG tax deduction.	Pension insurance. CG tax deduction.

*See **http://www.msvu.ca/mdcaging/policyprofiles.asp** for more information on international caregiver financial compensation policies.

Australia

Carer Allowance

- Payment of $90 CAD every two weeks
- Available to all caregivers – eligibility recently expanded
- Not taxable
- "Recognition" rather than income replacement
- *Also has Carer Payment

Germany

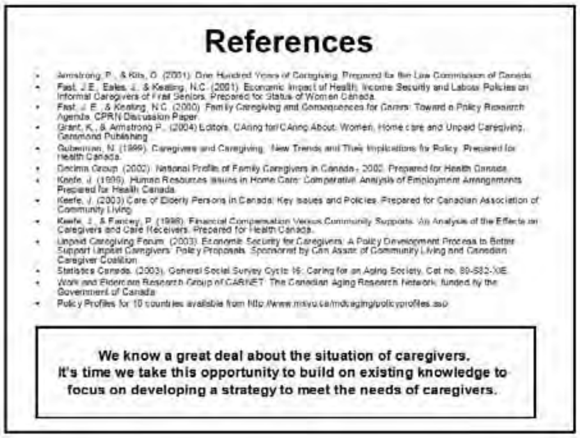
Home Care/ Domiciliary Care Benefit

- Eligible clients choose money or services
- 3 payment levels based on CR needs
- $318 to $1033 per month
- Paid to CR to pay CG – but no evidence of how it is used
- Additional payment available for Stand-In Care

Ways to Support Canadian Caregivers

- Direct Services
  - Enhanced Respite/Home Care
  - Education/Information/Support
- Direct Compensation : Caregiver payment/allowance
- Employment Policy (Employment Insurance)
  - Compassionate Care Leave: Extension to care for chronically ill family member
- Pension Schemes
  - CPP dropout (similar to childcare)
  - Caregiver pension credits
- Taxation System
  - Inclusion of care expenses
  - Expansion of Tax Credits

- **Caregivers are diverse - "One Size" policy does not fit all.**
- **Understanding caregiver needs can best occur through a comprehensive assessment process.**
- **Maximizing choice and flexibility are key.**



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- Work and Eldercare Research Group of CARNET: The Canadian Aging Research Network, funded by the Government of Canada.
- Policy Profiles for 10 countries available from http://www.msvu.ca/mdcaging/policyprofiles.asp

We know a great deal about the situation of caregivers.
It's time we take this opportunity to build on existing knowledge to focus on developing a strategy to meet the needs of caregivers.

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Building Better Policies for Caregivers

Sandra Harder

Human Resources and Social Development

Federal Policy Landscape: Caregivers

Presentation at Healthy Balance Research Program

May 3, 2006

Outline

- Context of federal involvement
- Starting point for policy development
- Policy challenges and considerations
- Current status

Why focus on caregiving?

- Caregiving is a complex and emerging policy challenge. Many players including the Government of Canada, see the importance of working to better support caregivers.
  - Caregivers relieve pressure on formal health care and social services systems.
  - As the population ages and home care becomes more important, face decreasing capacity to provide informal care. Most OECD countries are facing similar challenges.
  - Many families and friends today provide care for loved ones, while at the same time facing employment and/or childcare demands (sandwich generation).
  - For some, caregiving involves only a few hours a week, while for others it may involve daily assistance over a long period of time.
- While caregiving has its rewards, caregiving responsibilities may negatively impact the quality of life of caregivers and those they are caring for.
  - Policy objective is to develop initiatives to help ensure the well-being of caregivers and care receivers.

Policy work focused on three streams

- In 2005, the former Social Development Canada became the focal point for caregiving in the Government of Canada. Policy work has focused on three streams:
  - Consultations
    - Five roundtable discussions with experts and stakeholders from disability, seniors and caregiver organizations held in Atlantic Canada, Prairies, Ontario, BC and one in Ottawa with national organizations.
    - Online consultation with Canadians active between May and July 2005. Heard from Canadians on their personal caregiving experiences and ideas on how to improve supports.
  - Research
    - Taking stock of existing research to help construct caregiver and care receiver profiles, understand the health, social and financial burdens of caregiving, and scope out best practices in supporting caregivers.
  - Discussions with interdepartmental and provincial/territorial counterparts
    - Caregiving is a cross-cutting issue. Many key tools to assist caregivers rest with other levels of government, and many of the Government of Canada's existing initiatives are delivered by other federal departments (e.g., Health Canada, Veterans Affairs, Finance).

Starting points for policy development

- Quick facts:
  - Close to 3 million Canadians provide unpaid care/support to a family member or friend;
  - Caregivers are a heterogeneous population, the majority are women, but there is a growing number of men;
  - Tasks can range from personal care to emotional care and case management, and
  - Costs can be economic as well as social and health related.
- What we consistently heard:
  - Rather than handing off their caregiving responsibilities, most caregivers want better supports to help them continue in their role, and
  - Supports should recognize the diversity of caregivers' circumstances and needs.
- Six areas where caregivers require support most:
  - Awareness and recognition;
  - Information and navigation;
  - Economic security;
  - Employment and workplace supports;
  - Respite and homecare services, and
  - Strengthened community organizations.

Policy challenges

- Context:
  - Situation is dynamic, need to be aware of, and able to adapt to changes in other key areas such as health and tax agenda.
  - Funds are limited.
- Caregiving is a complex policy issue:
  - Shared jurisdiction with provinces-territories, and involves other sectors (healthcare providers, voluntary sector, employers, and individuals/citizens);
  - Due to its private nature, often does not become public until families face a crisis and caregiver burden is high;
  - Interlinked with supports to care receivers;
  - Extensive variation in supports provided across and within jurisdictions, and among types of care receivers (elderly, disabled, adult, child);
  - Horizontal issue, drawing on research and best practices from aging, disability, health, gender communities; and
  - Need to assess and focus on greatest needs, but also need to provide assistance prior to crisis.
- Fragmented data sources: there is no recent survey that covers the spectrum of caregivers across Canada.
  - Most surveys focus on a segment of caregivers, making it difficult to provide a comprehensive picture of caregivers.
  - Most stressed caregivers will not have the time to participate in surveys, so data will not reflect their situation.

Policy considerations

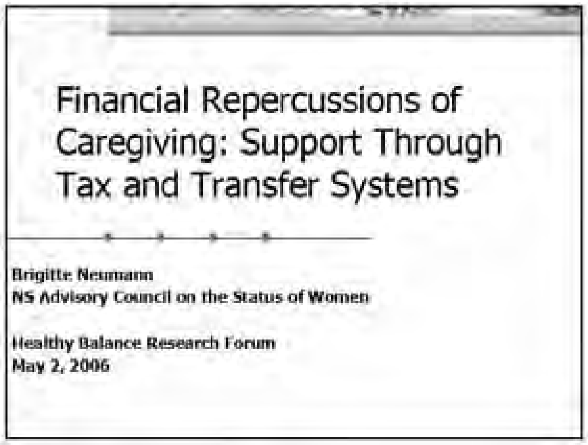
- As policy development proceeds, a number of questions need to be kept in mind:
  - How can we best work with the many partners that have a role to play in supporting caregivers?
    - Who are all of the partners, where are they, are they representative of the different sub-populations, are they in agreement with what we are proposing?
  - What is the degree to which caregivers are able to exercise choice about whether to take on a caregiving role?
  - What do families see as their obligation to provide care, and is there a limit to what they are willing to do?
  - What supports are currently provided by governments and/or the voluntary sector and how well are these supporting caregivers?
  - What is the optimal balance amongst different types of supports?
- Evidence based policy making is required, so need to be able to demonstrate things such as:
  - Economic costs facing caregivers, as well as the indirect costs of caregiving to employers and the healthcare system;
  - Benefits of different types of supports;
  - Replacement costs of providing formal over informal care; and
  - Which caregivers are most vulnerable to negative consequences.

Canada 7

Current status

- Social Development and Human Resources and Skills Development have been merged into Human Resources and Social Development:
  - Will better integrate social and labour market issues in one department, and enhance linkages between the two.
  - Positive development for horizontal files such as caregiving.
- In addition to Minister Finley, MP Lynne Yelich has been appointed Parliamentary Secretary, and will have specific responsibility for the caregiving file.
- New government has signaled a strong interest in families, including persons with disabilities and seniors.
- Policy work is continuing on the file.

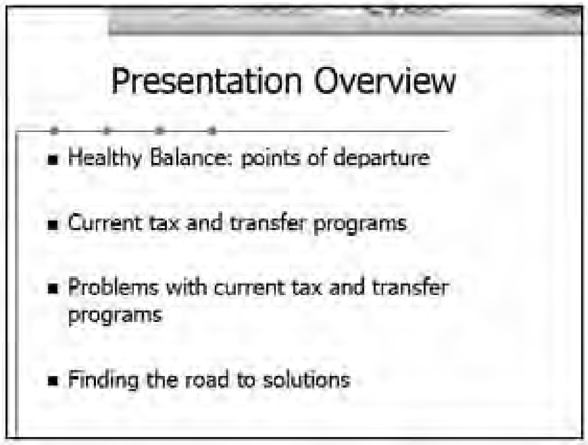
Canada 8



Financial Repercussions of Caregiving: Support Through Tax and Transfer Systems

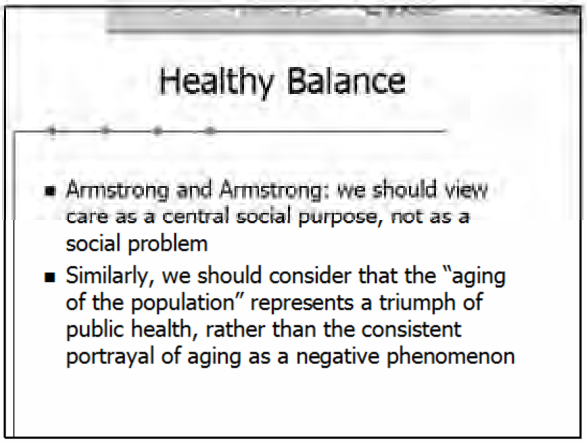
Brigitte Neumann
NS Advisory Council on the Status of Women

Healthy Balance Research Forum
May 2, 2006



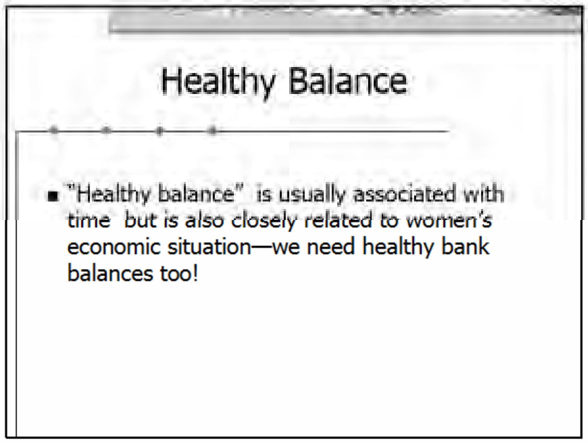
Presentation Overview

- Healthy Balance: points of departure
- Current tax and transfer programs
- Problems with current tax and transfer programs
- Finding the road to solutions



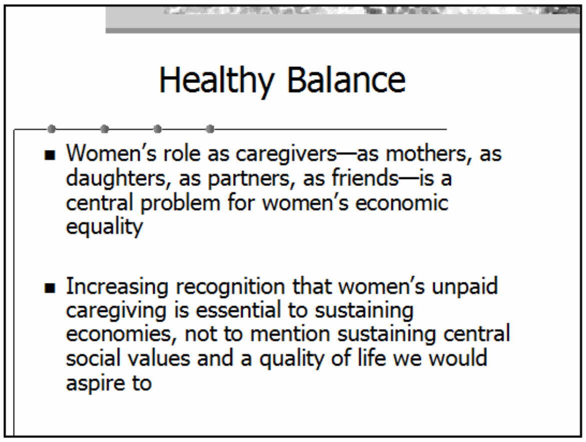
Healthy Balance

- Armstrong and Armstrong: we should view care as a central social purpose, not as a social problem
- Similarly, we should consider that the "aging of the population" represents a triumph of public health, rather than the consistent portrayal of aging as a negative phenomenon



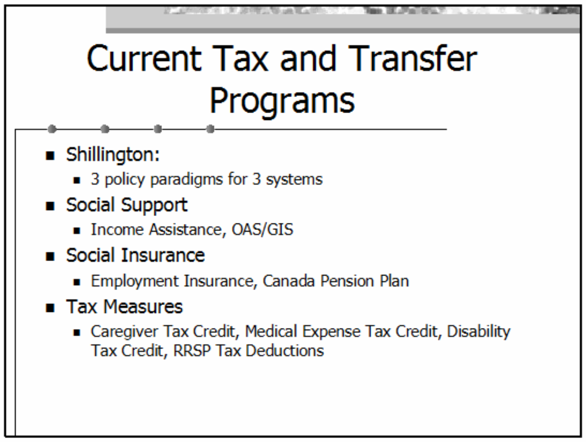
Healthy Balance

- "Healthy balance" is usually associated with time *but is also closely related to women's* economic situation—we need healthy bank balances too!



Healthy Balance

- Women's role as caregivers—as mothers, as daughters, as partners, as friends—is a central problem for women's economic equality
- Increasing recognition that women's unpaid caregiving is essential to sustaining economies, not to mention sustaining central social values and a quality of life we would aspire to

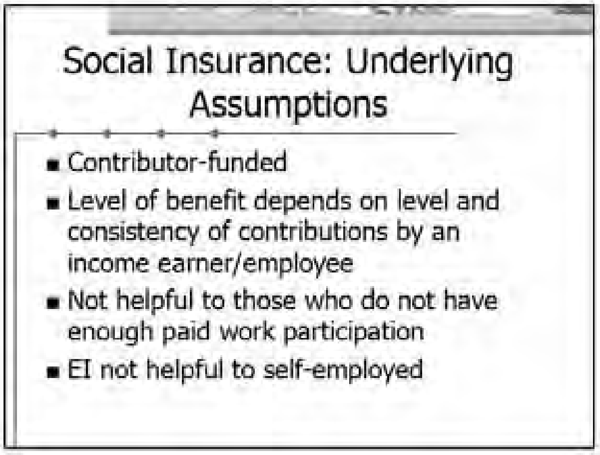


Current Tax and Transfer Programs

- Shillington:
  - 3 policy paradigms for 3 systems
- Social Support
  - Income Assistance, OAS/GIS
- Social Insurance
  - Employment Insurance, Canada Pension Plan
- Tax Measures
  - Caregiver Tax Credit, Medical Expense Tax Credit, Disability Tax Credit, RRSP Tax Deductions

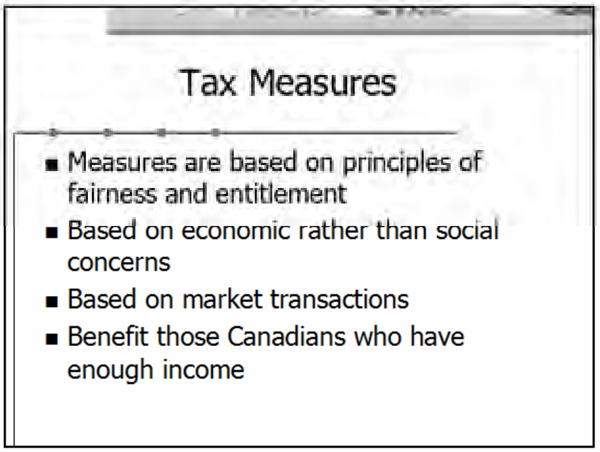
Social Support: Underlying Assumptions

- Target those "most in need"
- Direct expenditure for those with no other resources
- Stringent eligibility criteria, concern with prevention of fraudulent claims
- Rapid reduction of benefits if income increases



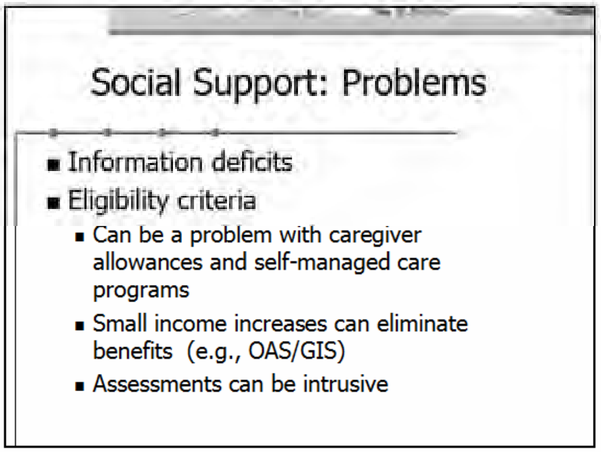
Social Insurance: Underlying Assumptions

- Contributor-funded
- Level of benefit depends on level and consistency of contributions by an income earner/employee
- Not helpful to those who do not have enough paid work participation
- EI not helpful to self-employed



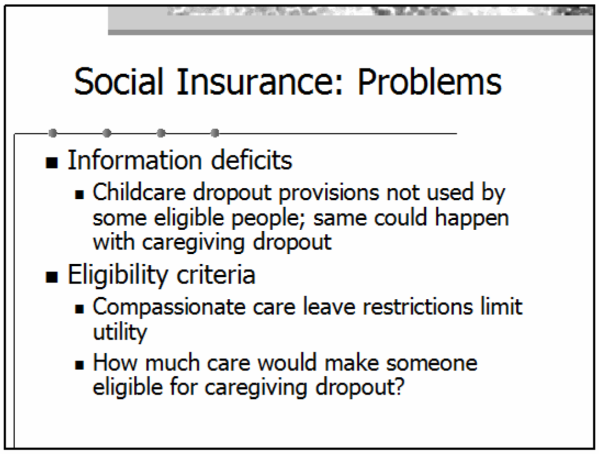
Tax Measures

- Measures are based on principles of fairness and entitlement
- Based on economic rather than social concerns
- Based on market transactions
- Benefit those Canadians who have enough income



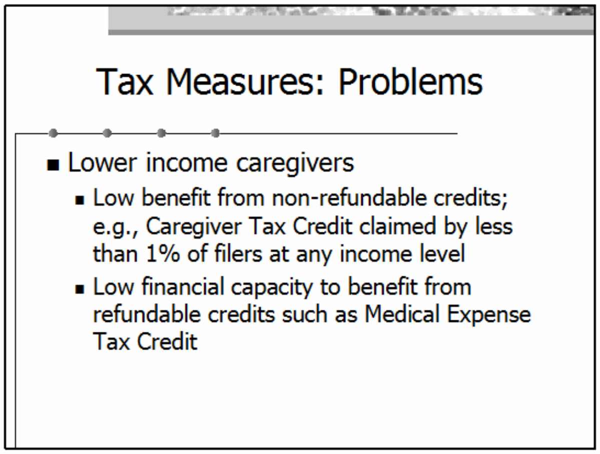
Social Support: Problems

- Information deficits
- Eligibility criteria
    - Can be a problem with caregiver allowances and self-managed care programs
    - Small income increases can eliminate benefits (e.g., OAS/GIS)
    - Assessments can be intrusive



Social Insurance: Problems

- Information deficits
    - Childcare dropout provisions not used by some eligible people; same could happen with caregiving dropout
- Eligibility criteria
    - Compassionate care leave restrictions limit utility
    - How much care would make someone eligible for caregiving dropout?



Tax Measures: Problems

- Lower income caregivers
    - Low benefit from non-refundable credits; e.g., Caregiver Tax Credit claimed by less than 1% of filers at any income level
    - Low financial capacity to benefit from refundable credits such as Medical Expense Tax Credit

Tax Measures: Problems

- Eligibility rules complex
- Information deficits hard to remedy
- Non-market transactions not eligible

Finding Solutions

- Better grasp of the scope and distribution of caregiving is imperative
  - Perception of caregiving as long-term only may be incorrect
  - Impact on caregivers of episodic caregiving needs to be better understood

Finding Solutions

- Financial support measures need to be complemented by effective home care programs as well as innovative approaches to housing and transportation, for example
- Helping those who don't claim benefits for which they are eligible—would automated solutions help? E.g., GIS; Childrearing dropout provision

Finding Solutions

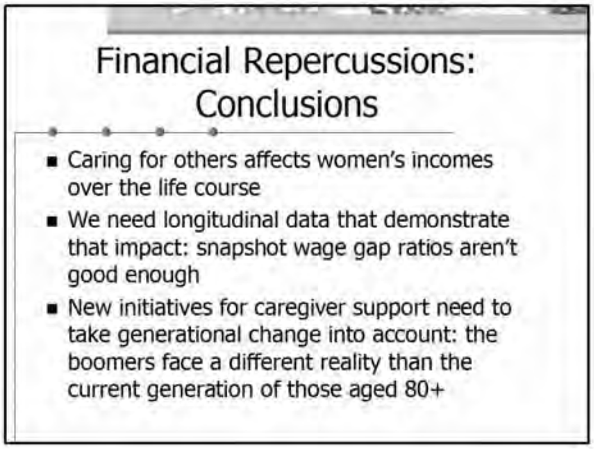
- Recognizing the diversity of caregivers
  - The impact of gender must be analyzed in conjunction with other sources of disadvantage
  - Aboriginal status
  - Newcomers
  - African Nova Scotians
  - Persons with disabilities
  - Rural versus Urban location (transportation issues)

Finding Solutions

- Analysis of international experience
  - "The devil is in the details"
  - E.g., German caregivers experience great difficulty in getting eligibility assessors to recognize high levels of care
- Interaction of various support measures
  - Addressing the marginal tax rate problem

Finding Solutions

- Building income supports within the tax system
  - Taxes: main purpose is to raise government revenue
  - What issues does delivery of social programs through tax system raise?
  - Child Tax Benefit adapted to become a Caregiver Tax Benefit?



Financial Repercussions: Conclusions

- Caring for others affects women's incomes over the life course
- We need longitudinal data that demonstrate that impact: snapshot wage gap ratios aren't good enough
- New initiatives for caregiver support need to take generational change into account: the boomers face a different reality than the current generation of those aged 80+

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Next Generation: The future of caregiving research, policy and practice

Robin Stadnyk

The next generation of caregivers: What do we know about them?

What will they need?

Robin Stadnyk and Brenda Beagan
Healthy Balance Team P
(Caregiver Portraits Team)

Sample

- 14 women: urban, rural, women w/ disabilities, African NS, First Nations, immigrant, lesbian
- Caring for mother (4), father (1), mother-in-law (2); child (3); adult child (2); grandchild (1); spouse (2)
- Most caring at home; all but 4 care recipients need full time care

Four questions we need to answer

- Who are the caregivers of the future?
- How can we support a healthy balance?
- How will we deal with violence?
- How must supportive services evolve?

Who are the caregivers of the future?

- Population projections
- Diverse family/friend situations
  - Cultural diversity
  - Diversity in families, friends and care networks
  - Diversity in care obligations/ expectations
- Caregiver health and disability

How can we support a healthy balance?

- “Squeeky wheel” and “Judge Judy” problems
- Who and what is respite for?
- How do we get information to people who need it?
- How do we ensure flexibility and client-centred services?

How will we deal with violence?

- Our typical responses to violence
  - denial of service
  - ignoring the problem
- Violent behaviour of care receivers
- Violence toward caregivers
- Violence experiences of care receivers

How must supportive services evolve?

- Person-centred, empathetic care, not care based on tasks
- Respite care that actually offers respite
- Recognition that income is an issue for many caregivers

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- Hidden Costs/ Invisible Contributions, Department of Human Ecology, University of Alberta

APPENDIX D – Healthy Balance Research Program
List of Publications

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