

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 Highlights May 2 & 3, 2006



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About the Healthy Balance Research Program...

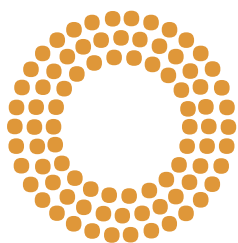
The Healthy Balance Research Program (HBRP) is funded by the Canadian Institutes of Health Research, coordinated by the Atlantic Centre of Excellence for Women's Health, the Nova Scotia Advisory Council on the Status of Women, and the Institute of Population Health at the University of Ottawa, and is supported by Dalhousie University, the IWK Health Centre and Health Canada's Bureau of Women's Health and Gender Analysis.

Over the past five years the HBRP, through partnerships with researchers, community-based organizations and caregivers, has shed new light on women's unpaid caregiving, health and work / life balance. The Program has deepened our understanding of the challenges facing women in Nova Scotia as they care for family, friends,

neighbours, and others in their communities while attending to their own health and well-being.

The HBRP includes four Research Teams: Qualitative Research (Team Q); Caregiver Portraits (Team P); the Secondary Analysis Team; and the Survey Team. Research undertaken by these four teams has helped to identify both the prevalence of caregiving and the scope of activities performed by unpaid caregivers. It has also examined the impact of caregiving on the employment, health, and finances of unpaid caregivers, and has critically examined existing policies and programs such as the Caregiver Tax Credit, Compassionate Care Benefit, and respite services.

For more information on the HBRP, visit www.healthyb.dal.ca to download research reports and other resource materials.



In 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.



Equity Reference Group member Patricia LeBlanc, HBRP Co-Director Brigitte Neumann, and Jen Powley from the Nova Scotia League for Equal Opportunities

The forum featured personal stories of caregiving, key findings from the research, and discussions on the methodology and policy implications of the research. Topics included:

- A selected profile of caregiving in Nova Scotia
- Balancing health and caregiving
- Equity Reference Groups as a model for participatory research
- Diversity and caregiving
- Balancing work and life
- New directions in research on caregiving
- The economic implications of caregiving
- Building better policies for caregivers

For a FULL REPORT of the forum proceedings, including summaries of each presentation and copies of presentation slides where available, please visit www.healthyb.dal.ca.

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.

Participants noted the need for diversity considerations in unpaid caregiving policy.

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
- ready and convenient access to information about existing programs, services, supports and resources for caregiving

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 and other policy 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.

Glenda's Story

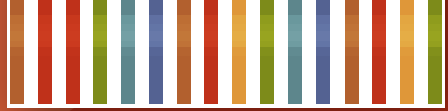


Although Glenda Robertson was unable to share her wisdom at the forum because of her caregiving commitments, she was pleased to submit the following story.

My job is full time. Well, more than that I suppose - I work around-the-clock seven days a week with no vacation time. I have given this position the 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, 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 humour second to none. She was born into a loving, caring and willing family.

LMBBS - the short form of the big issue - Laurence-Moon-Bardet-Beidyl Syndrome, was mentioned very little in



“We need to be seen and heard and given the benefits of a life free of uncertainty and poverty.”

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.

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.

Caregivers Susan Bethune and Linda Swim

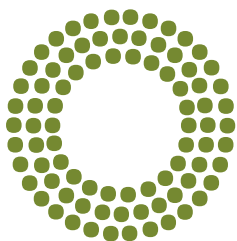


After Balancing Act, participants were asked to share their reactions to the performance in a creative 'clothesline exercise.'





The Irondale Ensemble Project shines the spotlight on caregivers



In the morning of May 3, 2006, forum participants gathered to watch *Balancing Act* – a play created and performed by the Irondale Ensemble Project.

Balancing Act tells the story of Tara, whose aging mother has just moved in after being released from medical care. Thrust into the caregiving role, Tara struggles to balance her

own needs with those of her son – a university student who still lives at home on weekends – and the needs of her mother.

The audience could clearly relate to the story's heroine as she begins to negotiate the coordination and planning of her mother's care, demands of other family members and friends, and decisions about her future.

With a touching blend of music, comedy and drama, *Balancing Act* thoughtfully captures the essence of caregiving.

For a complete copy of the script, please contact:

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What's Next?



he forum represented a successful start to the dissemination of Healthy Balance research findings.

Interest from television, radio and print media 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. For details on the discussion, visit http://www.gov.ns.ca/legislature/hansard/han59-2/house_06may05.htm.

Over the coming months the Healthy Balance Research Program will be engaged in a number of projects.

Policy recommendations based on the research findings are being developed for presentation to policy and community

groups in the fall of 2006. 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 activities are underway to disseminate the research findings and improve the lives of caregivers in Nova Scotia. To stay informed on the latest activities of the HBRP, visit our website at www.healthyb.dal.ca.



How can you help?



You can 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: http://www.canada.gc.ca/directories/direct_e.html

Visit our website at www.healthyb.dal.ca, where you will find information on the latest activities of the HBRP, including reports, presentations and contact information.

HBRP Publications

Amaratunga, C., Neumann, B., & Clow, B. (2006). **Moving population and public health knowledge into action: Women's health.** Ottawa, ON: Canadian Institutes of Health Research.

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Brannen, C. (2006). **Women's unpaid caregiving and stress.** *Centres of Excellence for Women's Health Research Bulletin*, 5(1), 12-13.

Brannen, C., & Petite, K. (2005). **Caregiving, health and work of Canadian Forces members: Literature and policy review.** Halifax, NS: Healthy Balance Research Program.

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MacDonald, M., & Phipps, S. (2004). **Total packages of work: Why do women in Atlantic Canada report more hours?** *Atlantis*, 30(1).

Neumann, B. (2006). **A Healthy Balance: Applied research on women's paid work and unpaid caregiving in Nova Scotia, Canada.** In V. Lasch, W. Freitag, & U. Sonntag (Eds.), *Gender, Health, and Cultures* (pp. 97-118). Kassel, Germany: Kassel University Press.

Rajnovich, B., Keefe, J., & Fast, J. (2005). **Supporting caregivers of dependent adults in the 21st century.** Halifax, NS: Healthy Balance Research Program.

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Varga-Toth, J. (2005). **A Healthy Balance: A summary report on a national roundtable on caregiving policy in Canada.** Canadian Policy Research Networks Research Report.



Thank-you!

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 shown 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.

Sincerely,

Barbara Clow

Brigitte Neumann

Carol Amaratunga

Co-directors, Healthy Balance Research Program

Thank you to our forum sponsors:

Nova Scotia Health Research Foundation
Seniors' Secretariat
Nova Scotia Federation of Labour
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Nova Scotia Teachers' Union
Canadian Labour Congress
Canada's Association for the Fifty-Plus (CARP)
Office of African Nova Scotian Affairs

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