

# **National Reference Group**

March 13 and 14, 2003

Halifax, Nova Scotia

Report

## TABLE OF CONTENTS

<b>Healthy Balance Research Program</b>	3
<b>National Reference Group</b>	4
<b>Welcome and introductory remarks</b>	4
<b>Report from the Equity Reference Groups</b>	4
<b>Research updates</b>	
* Secondary Analysis - Dr. Shelley Phipps	6
* Team Q - Focus Groups - Dr. Jacqueline Gahagan	7
* Survey Team - Carla Johnson	7
* Caregiving Portraits - Dr. Brenda Beagan	7
<b>The architecture of policy - how can Healthy Balance have an impact?</b>	8
<b>Knowledge Translation</b>	12
<b>Thoughts on the role of the National Reference Group</b>	13
<b>Evaluation</b>	14
<b>Appendices</b>	
Appendix A	17
Appendix B	19
Appendix C	21
Appendix D	25
Appendix E	29
Appendix F	31
Appendix G	35
Appendix H	37

## Healthy Balance Research Program

The Atlantic Centre of Excellence for Women's Health (ACEWH), Dalhousie University and the Nova Scotia Advisory Council on the Status of Women (NSACSW) are providing leadership in the form of an innovative and collaborative program of research to better understand the connections between women's health and well-being, family life and earning a livelihood. The **Healthy Balance Research Program** is funded by the Canadian Institutes of Health Research (CIHR); other principal partners include the Nova Scotia Family Caregivers Association; the IWK Health Centre for Children, Women and Families; Mount Saint Vincent University; and the National Centres of Excellence for Women's Health Program.

It is well known that throughout their adult lives, women are more likely than men to experience stress and overwork as a result of their multiple care and work responsibilities. There is uncertainty, however, about possible health benefits to women in the paid workforce. We are only beginning to understand the extent and nature of women's unpaid caregiving work and its stress and health impacts -- whether this caregiving work is done on its own or combined with paid work.

This innovative partnership program will improve our understanding of the ways in which caregiving is now organized (e.g., unpaid caregiving shared between women and men), how caregiving affects people's sense of empowerment in their lives, and, in turn how that affects their health and well-being. Researchers will study different kinds of unpaid caregiving in Nova Scotia and will determine which unpaid caregiving situations -- on their own or combined with paid work, are associated with positive or negative health. The program will also examine how social and economic factors interact with paid work, caregiving, empowerment and health status -- for example how ethnicity, race and culture, as well as rural and urban location, income, age of the caregiver and other factors affect the health and well-being of care providers in Nova Scotia. On a practical level, the program will consider current policies and programs that address paid work and family life and how these can be improved.

The ultimate goal of this program is to foster a "healthy balance" between Women's health and well-being, family life and earning a livelihood. The interrelated and dynamic program objectives include knowledge generation, knowledge transfer and transformation, uptake of new ideas and practices, and strengthening research capacity. Specifically, we intend to: examine the relationship among unpaid caregiving work (performed on its own or in combination with paid work), empowerment and health status; foster "uptake" of new ideas and practices in policies; promote innovation in programs and health-service delivery that reflects new insights into the values and expectations we bring to caregiving and paid work; strengthen research capacity in Atlantic Canada by recruiting and retaining health researchers.

### **National Reference Group**

The National Reference Group (NRG) is composed of senior researchers, doctoral students, policy makers and community group members. Its responsibilities are threefold:

- to propose mechanisms and venues for disseminating HBRP findings to appropriate and applicable audiences
- to recommend policy makers, institutions, agencies, groups and individuals for whom HBRP findings are relevant
- to identify and propose research opportunities to build national and international linkages with HBRP

The NRG plays a key role in developing a policy framework for HBRP and in shaping the knowledge translation component of the program.

### **Welcome and introductory remarks - “... a real development moment”**

Greetings were extended from Carol Amaratunga, Atlantic Centre of Excellence for Women’s Health, and Brigitte Neumann, Nova Scotia Advisory Council on the Status of Women, co-directors of the Healthy Balance Research Program (HBRP), and also from Susan Nasser, HBRP Coordinator.

Opening comments focused on the following:

- Healthy Balance is approaching the midway point of its 5-year timeframe
- There are both operational and developmental aspects to consider
- Spreading the word, partnerships and linkages are vital to the program
- The wage gap persists in Canada
- Caregiving is a gendered issue
- These realities reinforce the importance of the Healthy Balance research

The purpose of the meeting was reviewed - to conceptualize the policy and knowledge translation components of the Healthy Balance program, with a focus on building frameworks and making links between research and policy.

### **Report from the Equity Reference Groups**

The deliberations of the Equity Reference Groups (ERGs) provide an important perspective for the National Reference Group (NRG) to take into consideration in its own thinking about HBRP.

There are four ERGs: Aboriginal women. African Canadian women, immigrant women and women with disabilities. Their mandate is to inform the Healthy Balance research about the particular contingencies faced by women traditionally under-represented in research and to invite and facilitate their active engagement in the research process.



*Participants in the February 2003 ERG Meeting*

There are important messages from the ERGs, who met recently in Halifax.

❑ ***There are differences between the groups and within the groups***

While all of the Equity Reference Groups share some common experiences, recognition of the particular circumstances of each group is key to valuing their unique potential to contribute to the Healthy Balance research.

None of the groups is homogeneous. All experience rural/urban differences and other differences particular to their group. For instance, in the immigrant women group, new arrivals in Canada have a different set of concerns and issues than those who have been here for a number of years. In the group of women with disabilities, the concerns and issues of women with mobility disabilities differ from those of women with sensory disabilities, and mental health consumers are faced with another set of challenges.

❑ ***Representation is an issue***

Members of the ERGs want to see the experience of their group reflected in the data that is collected, the analysis which is undertaken and the findings that emerge. This presents a challenge if the research is meant to provide an aggregate

view that captures the common experience of caregiving. The issue is complex. For example, in response to feedback from the ERGs, the number of focus groups specific to each ERG was increased from one to two. Even so, two groups of African Nova Scotian women, for instance, cannot be said to be representative of the entire community of African Nova Scotian women.

One important aspect of this issue is the dissemination of findings. The ERGs are aware of the most effective way to share findings with members of their communities.

❑ ***Different methods might work better but present methodological challenges***

A good example of this is the dilemma of the survey. A population-based telephone survey will only yield small numbers of respondents from the ERG communities. However, over-sampling in these communities or using different methods identified by community members as being more appropriate compromises the rigour of a population-based survey. A telephone survey in itself is limiting in that it misses those who do not have a phone. A possible solution to this dilemma is to seek funding for targeted studies that will capture the issues and concerns of the ERGs.

❑ ***Sharing the findings will be labour intensive***

It is clear from feedback from ERG members that the most effective way to share information with their communities is to identify key informants, groups and communication vehicles in each community and to provide them with material relevant and useful to them. Speakers Kits were identified as a good tool.

## **Research Updates**

Research Team Leaders presented updates on the work of their teams.

### ***Secondary Analysis - Dr. Shelley Phipps*** (see appendix C)

*Taking its Toll* has been written based on the GSS Cycle 12 census data from 1998. The paper has been submitted to *Feminist Economics*. The main themes are:

- ❑ Time stress is a serious problem for ‘prime-aged’ Canadian men and women
- ❑ Women do the lion’s share of child care, housework and eldercare, whether or not they also work for pay.
- ❑ More paid work is associated with more reported stress for both men and women.
- ❑ Women in the ‘sandwich generation’ are particularly likely to experience stress.

A dissemination luncheon is planned for April 15, 2003. for a combined audience of academics and policy makers.

***Team Q - Focus Groups - Dr. Jacqueline Gahagan*** (see appendix D)

The focus groups took place in the spring and summer of 2002. There were a total of eighteen: five based on providing care for a particular group of care receivers and thirteen based on characteristics of the care receiver. The data was transcribed and is now being coded. Preliminary themes have been identified and further analysis is taking place.

***Survey Team - Carla Johnson (Dr. Janice Keefe, Team Leader, was unable to participate)*** (see appendix E)

A draft survey instrument has been developed and is being pre-tested with volunteers. Feedback was also received from members of the ERGs. Modifications will be made based on these review mechanisms. Once the survey instrument has been finalized, the telephone data collection will be contracted out. The survey should be in the field in the fall of 2003.

***Caregiving Portraits - Dr. Brenda Beagan***

This team is still being assembled and plans will gel once team members are in place. The intent is to carry out micro-ethnographies in twelve caregiving households structured to include ERG communities and other special situations. Photo-documentation is another method that will be used. The research questions are:

- What is the experience of caregiving in the home or within families like? What do caregivers actually *do* to make the giving of care happen?
- How is the doing of caregiving affected by differences among caregivers: culture, age, abilities, class background, geographic location, relationship to care recipient?
- Where do caregivers experience ethical tensions or moral distress? How do they attempt to resolve these tensions?
- How are the experience of caregiving, and the tensions that may arise, shaped by social institutions, organizations, systems, and policies? What shapes the caregiving experience to be the way it is?

Research assistants (RAs) will spend time in the selected households observing, interacting with the caregiver, the care receiver and others, and carrying out interviews. Because of HBRP 's commitment to building research capacity, RAs will as much as

possible be recruited from the communities in which households are selected. Data collection is targeted for early 2004.

### **The architecture of policy - how can Healthy Balance have an impact?**

Policy discussions began with a review of analysis tools available for use, including:

- gender-based analysis; gender lens
- inclusion lens
- family lens

These were reviewed in terms of their values and guiding principles and the questions which they posed when conducting an analysis. These can be seen in Appendix F.

Discussion focused on the utility of such tools. It was agreed that they are most useful when applied in a particular context. Troubling questions were raised about whether women were actually excluded from the inclusion lens since, in some analyses, women are no longer considered to be disadvantaged.

Small groups then considered a series of questions related to developing a policy framework for Healthy Balance and reported back in a plenary session. The material from the small group sessions was summarized by the facilitator and used to generate further discussion. These notes are organized by question; following each question is the facilitator's summary and the ensuing discussion.

#### ***What is policy anyway?***

*Facilitator's summary: a means to be proactive in framing our values so that resulting programs and services minimize gaps and inequities in application*

Discussion:

- this summary would answer the question "What is good policy?" ; it addresses what policy should be, not necessarily what it is
- we should look at other definitions of policy, of which there are several
- the definition should provide a framework for a Healthy Balance working group on policy which addresses policy concerns of particular relevance to the research findings
- it is important to keep in mind the different levels of policy when figuring the best way for Healthy Balance to insert itself into the process



### ***What are some key policy areas?***

*Facilitator's summary: there are a vast array of policy areas; the vastness contributes to the gaps and inequities that burden caregivers and care receivers*

Discussion:

Key policy areas include:

- rights; social justice; discrimination
- workforce
  - employment
    - how people stay in the labour force
    - forecasting
  - labour standards
- health and social services
- finance
  - sustainability, costs, price tag, savings, cost/benefit analysis
  - financial support for caregivers and care receivers
- transportation

Of these, rights/social justice/discrimination is a cross-cutting issue. Other cross-cutting issues are demographics and costs/savings.

It is important to keep levels of policy in mind. For instance, the five key areas just mentioned represent the perspective of researchers and policy makers. From the perspective of caregivers, the key policy areas include:

- respite support
- financial resources, in particular out-of-pocket expenses

While not strictly policy areas, other elements should be kept in mind

- the need for evidence to assist in evidence-based decision making
- ways of influencing public opinion
- the process of changing agendas
- outreach

### ***What policy tools do we have available?***

*Facilitator's summary: already existing programs and policies that are meant to address work/life balance (CPP, EI, tax system); various frameworks already developed; new lenses and frameworks that could be developed (e.g caregiver lens)*

Discussion:

- Charlottetown Declaration of the Right to Care
- United Nations declarations
- legislation in other countries
- take a look at provincial and federal legislation, services and program; make sure we know what we have available
- look beyond government - e.g. Canadian Union of Postal Workers (CUPW) family support program
- collective agreements; take a look at the factors that put an issue on the bargaining table

### ***Who are the key decision makers?***

*Facilitator's summary: decision makers vary depending on the policy under consideration and whether it is a broad directive or a rule as and regulations approach; includes*

- government departments - federal, provincial*
- elected officials - federal, provincial*
- Senate*
- think tanks*
- research funders*
- advocacy groups*
- lobbyists*
- business, small business*

Discussion:

This list should be clarified/expanded in the following ways:

- within government departments, target deputy ministers, policy analysts, other bureaucrats
- add service agencies - they cannot call themselves advocacy groups because of tax regulations governing not-for-profits
- add unions
- add media in their role as influence peddlers



## ***How should we link research findings to the shaping of policy?***

*Facilitator's comments: There were some clear directives*

- articulate clear policy recommendations from HBRP findings*
- identify “hot ticket” items (home care, privatization) and take the initiative in demonstrating HBRP links to them*
- engage with other groups who have identified similar issues but have a recognized power base - e.g. family physicians*
- learn from the experience of other shifts in thinking, such as smoking/second-hand smoke; drinking and driving. The point is that these issues affect everyone (you don't have to be a smoker to be affected by second-hand smoke). For caregiving, the message is that one day we will all be caregivers (the question is not if you will be a caregiver, but when you will be a caregiver*
- learn from international experience*

### Discussion:

The reference to “hot ticket” items should be expanded to encompass making sure that Healthy Balance work and messages are relevant to current discourse on work/life balance issues.

We should focus on fact sheets, media lines, sound bytes, questions and answers and other concrete dissemination tools.



## ***Should Healthy Balance form a Policy Working Group?***

- yes - it is time to get this task onto the critical path for the work of Healthy Balance*
- a working group is somewhere between a research group and a reference group in terms of function*
- How do academics fit in? Are academic papers possible?*
- possible models - all directed towards formulating a sustained policy critique*
  - examine the process used by the Canadian Policy Research Institute (CPRN) - they commission work, then organize and facilitate round table discussions about it*
  - think tank model - e.g. Canadian Centre for Policy Alternatives (CCPA), Canadian Council on Social Development (CCSD) - they can frame their work in terms of media uptake*
- consider the connection with programs - programs generally follow policy, but not always. Policy implies program.*

### ***Who should be part of this group?***

- policy practitioners
- program and service delivery practitioners
- academics and researchers as appropriate
- one suggestion was for the policy working group to mirror the identified decision makers. It was agreed that the policy working group should be broader in its composition, including members who were not decision makers

\*\*\*\* Go back to the original proposal for the Healthy Balance Research Program for potential members; many were identified in that document

### ***Next steps***

Create terms of reference for a policy working group and circulate the document to the National Reference Group, the Equity Reference Groups, research team leaders and research team members for comment.

Susan will facilitate the creation of terms of reference, assisted by Carol Amaratunga, Brigitte Neumann, Stella Lord, Gail Bruhm and Brian Taylor.

### **Knowledge Translation**

To set the scene for the knowledge translation exercise, participants reviewed the CIHR definition:

*... the exchange, synthesis and ethically sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system*

Discussion in small groups then centred on ways in which *Taking its Toll*, the paper written by the Secondary Analysis Team, could be presented to the public in general and to policy audiences in particular. Questions which guided the discussion can be found in appendix G.

### **Key points**

- An important audience for the paper is mainstream economists - the goal is to see unpaid work included in mainstream economics; the paper makes unpaid work visible.
- Taking its Toll* will be better understood by the public and by policy audiences if it is broken down into smaller pieces; it is too much to absorb in its entirety.
- The information must be understandable and meaningful for those we hope to influence.

- ❑ Research subjects - those from whom data was gathered - are another audience to take into consideration.
- ❑ Decision-makers who have personal experience with an issue (for example, both Alan Rock and Michael Kirby had experience with providing care to an aging parent) can be useful allies.
- ❑ Creative ways of connecting the various HBRP components might increase the impact on policy-makers. For instance, collaborative papers could combine the quantitative data of the secondary analysis with the qualitative data from the focus groups. Community partners could also contribute because of their relationships with caregivers willing to share their stories
- ❑ Local data is more meaningful to both local policy audiences and local media.

### **Thoughts on the role of the National Reference Group**

It was agreed that it was important to clarify the role of the NRG in particular in relation to the policy working group discussed previously in the meeting. There is also the possibility of a knowledge translation working group.

There was general consensus that a group with members from across the country is not generally conducive to the demands of a working group; this reality reinforces the importance of clarifying the role of a national group that meets once per year.

The NRG was initially structured as a way of linking the Centres of Excellence for Women's Health across the country, and the involvement of other centres is key. Other members from outside Nova Scotia were added in order to create pool of expertise from which HBRP could draw when mapping out its critical paths. There seem to be three disparate ways of approaching the challenge of increasing participation in NRG meetings.

- ❑ Refresh the membership by recruiting new members to replace those who have resigned; community partners could bring a different perspective and their participation should be encouraged
- ❑ Continue to clarify the role of the NRG in order to reinforce a sense of commitment to the work.
- ❑ Plan the annual meeting at a time that allows the greatest number of members to participate; consider a retreat at a location that would be appealing to members and allow for quality working time without distraction

It was agreed that the next NRG meeting be planned for late October - early November 2003 in the format of a retreat.

## Evaluation

Participants felt positive and enthusiastic about the meeting and about the Healthy Balance program. They found the meeting focused and task oriented and several commented on the synergy which emerged. The deliberations on policy were highlighted as a particular accomplishment. The feedback forms can be found in appendix H.



**Back row standing:** (left to right)

Kristy Evans, Susan Roche, Nadine Chaulk, Heather Chandler, Crissy Swallows, Gail Bruhm, Brian Taylor, Valerie White, Marlie Manning

**Front row sitting:** (left to right)

Carol Amaratunga, Brenda Beagan, Susan Nasser, Brigitte Neumann, Stella Lord

**Appendices**  
**A - H**

## **Appendix A**

### **National Reference Group participants**

**March 13 &14, 2003**

Healthy Balance Research Program

**Carol Amaratunga**, Co-Director

**Brigitte Neumann**, Co-Director

**Susan Nasser**, Coordinator

**Nadine Chaulk**, Admin. Assistant

**Crissy Swallows**, Student, Mount Saint Vincent University

**Kristy Evans**, Student, Dalhousie University, Note-taker

National Reference Group Members

**Gail Bruhm**

**Heather Chandler**

**Stella Lord**

**Susan Roche**

**Brian Taylor**

**Valerie White**

Healthy Balance Research Program Scholarship Award Winners

**Marlie Manning**

**Kate Hemeon**

Healthy Balance Research Teams

**Brenda Beagan**, Team Leader, Team P; Caregiving Portraits

**Jacqueline Gahagan**, Team Leader, Team Q; Focus Groups

**Carla Johnson**, Graduate Student, MSVU presenting for Dr. Janice Keefe, Team Leader, Survey Team

**Shelley Phipps**, Team Leader, Secondary Analysis



**Appendix B**

**NRG Meeting Agenda**

**Please note: The session on *Reading Romanow* was cancelled.**

**Appendix C**  
**Secondary Analysis PowerPoint Presentation**

## **Appendix D**

### **Team Q Presentation**

***Please note:*** This presentation at the NRG meeting was originally presented at the ERG meeting in February 2003.

**Appendix E**  
**Survey Team PowerPoint Presentation**

## **Appendix F**

### **Policy Analysis Tools**

#### **Gender-Based Analysis**

Reference: *What is GBA? In An Integrated Approach to Gender-Based Analysis, Information Kit*, Status of Women Canada, 2003

#### Values and Assumptions

- constructive partnerships are needed between women and men
- every action, policy, program, project and socio-economic trend affects men and women differently
- gender equality does not mean that women become the same as men
- women must participate equally as agents of change in economic, social and political processes
- specific measure must be designed to eliminate gender inequalities
- women's empowerment is a key to success in this process
- men and boys can also be negatively affected by actions, policies, programs, projects and socio-economic trends

#### Key Questions

\*\*\*\*\* Collect information that is sex-disaggregated

- Does this policy/program/trend improve the well-being of women/men?
- What resources does a person need to benefit from thei policy/program/trend? Do women and men have equal access to the resources needed to benefit?
- What is the level and type/quality of women's and men's participation in the policy/program/trend? Has this changed over time?
- Who controls the decision-making processes related to this policy/program/trend?
- Who controls/owns the resources related to this policy/program/trend?

- Does this policy/program/trend have any unexpected negative impacts on women and/or men?
- Does this policy/program/trend benefit men more than women (or vice-versa)? If so, why?

## **Family Lens**

Reference: *A Family Lens: A tool for Family Advocacy*, Canadian Association for Community Living, 2003

### Guiding Principles

- Families are the cornerstone to inclusive community life and inclusive communities
- Children should grow up in families and all families are entitled to the necessary supports to raise their children at home
- It is normal for families to need different forms of support at different times
- Supporting/strengthening families contributes to community well-being
- Families provide the greatest degree of continuity in the lives of their sons and daughters with intellectual disabilities and that connection should be honoured and supported
- For families, inclusion is naturally rooted in their love for their sons and daughters
- Policies should be designed to strengthen all families, respect and honour all families and facilitate inclusion in all aspects of family and community life

### Categories of Questions

- Context: The bigger picture
- Family Relationships: What does this mean for families?
- Costs: Who pays?
- Quality and Safety
- Perception: How do things look?
- Inclusion: Belonging and being valued
- Administration: How much administrivia?
- Appeals: When they say no!
- Overall view: What does your gut tell you?

## **Inclusion Lens**

Reference: *An Inclusion Lens: Workbook for Looking at Social and Economic Exclusion and Inclusion*, Health Canada, Population and Public Health Branch, Atlantic Region, 2002

### Values

- social justice
- valuing diversity
- opportunities for choice
- entitlement to rights and services
- working together

### Questions

#### Questions about exclusion

- Who is being excluded? From what?
- How do you see exclusion working?
- Who benefits from exclusion?

#### Questions about inclusion

- Who are the people to be included
- How do you see inclusion working?
- Who benefits from inclusion?



## **Appendix G**

### **Knowledge Translation Questions**

- \* Why translate? What is our objective?
  
- \* Who are our audiences?
  
- \* What strategies will reach each audience?
  
- \* What communications products and approaches will we need?

**Appendix H**  
**Feedback form**

**Healthy Balance Research Program**  
**National Reference Group Meeting**  
**March 13 & 14, 2003**

*Feedback Form*

- \* **What did you like *most* about the meeting?**
  
- \* **What could have been improved?**
  
- \* **What are some of the things you learned?**
  
- \* **What are some questions you still have?**
  
- \* **Do you have suggestions for the next meeting?**
  
- \* **Should we use the two-day format again?**
  
- \* **What do you think of the facility? (If you have a suggestion for a better facility, please let us know - we will be happy to check it out!)**
  
- \* **Final thoughts?**