

Healthy Balance Research Program

Recommendations to Support Unpaid Caregivers in Nova Scotia

July 27, 2006

1 Offer a Bundle of Services to Caregivers

Terminology	Defined
Replacement Care/ Respite Care	Appropriate care provider assisting and/or replacing care provided by caregiver as need arises.
Client Centred	Appropriate service responding to diversity and complexity of needs of caregiver client population.

- Flexible options, a list of available choices to suit needs of specific caregiver / care recipient situations and relationships
- The rural/urban divide in NS landscape necessitates service and support options which are tailored to meet the needs of caregivers living and/or caring in one or both of these geographic zones.
- Redesign home care and provide increased funding to a Replacement Care /Respite Care Service, responsive to the needs of clients, a client centred service approach in which each client is provided the option to choose the right services for them at the right time.
- Replacement care or respite care would be structured so that an entitlement is provided for home care worker family member/friend/neighbour/professional of choice.

- Provide caregivers with a list of possible services and supports which are standardized in terms of quality and flexible to support caregivers of diverse circumstances, communities and localities.

*See appendix A for Replacement Care Items

HBRP Research Findings:

- Research supports moving beyond a one-size-fits all service model and suggests that we design programs and changes to policy in consideration of diverse identities, situations and needs of caregivers, responsive to ethnic identity, sexual orientation, place of residence and legal status (Beagan et al, 2005)
- The needs of caregivers with disabilities, for example are not going to be the same as the needs of able-bodied caregivers. (Gahagan et al, 2004)
- The gendered characteristics of unpaid care reveal that flexible policy is needed to address different roles and tasks taken on by women and men in the provision of care (Keefe et al, 2006).
- Women in Atlantic Canada for example perform 11.7 more hours of unpaid care work, are predominantly responsible for caring for children as well as elderly persons (MacDonald & Phipps, 2004)
- Women perform activities which require frequency, intensity and emotional and physical strength on a more regular basis than do male caregivers as 78% of women and 60% of men provide assistance with activities of daily living including household cleaning, laundry, meal preparation/clean up, personal care and nighttime checks (Keefe, Hawkins & Fancey, 2006)

- HBRRP research findings suggest enabling processes by which caregivers can make the best possible choices for care recipients (Beagan et al, 2005) as opposed to being limited by a one-size fits all model of care.

Benefit to Nova Scotia:

- Avoids duplication of services, meets need to fill service gaps and fulfills efficiency standards by providing the services most needed without overlapping programs
- Provides the Province of Nova Scotia an opportunity to address fiscal imbalance concerns by streamlining and efficiently delivering only necessary services and programs.
- Provides the opportunity to address the age demographic crisis of NS population in a preventative and fiscally responsible manner.
- Opportunity to adopt a preferred model of client centred service delivery

2 Facilitate Culture of Community Care

- Provide entitlements to caregivers enabling seniors and persons with limitations or disabilities requiring assistance to remain in their homes.
- Such entitlements may include travel and mileage vouchers for caregivers or long distance telephone claim options to support long-distance care.
- Extend accessibility entitlements for housing maintenance and or remodeling to better enable caregivers to support care recipients from a distance.
- Provide transportation support resources and services to caregivers in rural areas, including accessible transportation for both caregivers and care recipients.

HBRP Research Findings:

- The majority, or over 60% of caregivers provide care to someone who does not reside with them (Keefe, Hawkins & Fancey, 2006)
- Findings illustrating who receives care requires a community response to care:
 - Approximately half of caregivers provide care for an elderly parent, however approximately ¼ of caregivers provide unpaid care for a friend, neighbour or co-worker (Keefe, Hawkins & Fancey, 2006) whom is unlikely to reside with the caregiver.
- The rural geography of Nova Scotia demands additional transportation support for caregivers in rural areas. Data from participants living in rural areas, specifically ethnic minority and marginalized socioeconomic communities suggests a service gap for transportation from rural community to urban hospital appointments (Beagan et al, 2005).

Benefit to Nova Scotia:

- Saves money and resources by reducing amount of institutional care:
- Each day person requiring care is able to receive care in their home as opposed to hospital saves the Province of Nova Scotia \$____.00
- Each day a care recipient is able to receive adequate care in their home instead of an institutional care facility saves the Province of Nova Scotia \$ ____ .00
- Allows specifically those most in need of institutional care, such as those requiring significant palliative care and support to access these services and professionals
- Addresses the looming institutional care facility bed shortage crisis as the NS population is changing to reflect a significantly more senior and elderly demographic.

3 Employer Incentives to Support Unpaid Care

Terminology	Defined
Employer/Workplace	

work

- Provide employers with a choice of incentives from tax deductions to tax credits for creating leave days for employees in respect of unpaid caring

- Ensure all part-time and full-time workers are paid a living wage
- Encourage employers to include unpaid caregiving as a legitimate work-life balance responsibility in employee handbooks/guidelines
- Provide similar incentives to self-employed and part-time workers through the tax/transfer system as a tax deduction to enable unpaid caregiving and reducing likelihood of opt-out of formal employment for employees with caring responsibilities; establish incentives to have greatest benefit to those at the lowest income levels
- A Compassionate Care leave with a time standard equal to Parental leave

HBRP Research Findings:

- Prevalence of employees who are caregivers; issues for women/men employed ie. self employed, non-unionized, part-time requires flexible employment-related policy
- The HBRP survey team has found the following employment data:
 - 47% of unpaid caregivers in NS simultaneously work full-time in paid employment (Keefe, Hawkins & Fancey, 2006)
 - 12% of unpaid caregivers simultaneously work in part-time formal employment (Keefe, Hawkins & Fancey, 2006)
- Health Canada data from 2002 reveals that nationally 1 in 5 women has left paid employment or retired early as a result of unpaid caregiving which is needed for a family member. Women are far more likely than men to leave paid employment for this reason: 22% of women compared with 11% of men (Shillington, 2004).

Benefit to Nova Scotia:

- Reflects an effort to meet demands for workers in Nova Scotia, by enabling employees to enter or sustain formal employment while having caregiving responsibilities.
- Creates a tax base that will help NS to sustain itself by ensuring women are participating in formal employment and contributing to the tax system

- Provides a reasonable solution to the workforce needs and skills shortage crisis for employers in Nova Scotia.
- Employers are currently providing a patchwork of supports to caregivers. A system of tax credits or deductions makes providing this support more financially viable and improves working conditions across sectors in Nova Scotia.
- Reduction of health risks of time stress and employment related negative health outcomes of persons participating in caregiving and the formal labour market simultaneously
- Contributing to the chronic disease prevention strategy
- Preventing poverty-related illness of future elderly CPP recipients as women are able to choose to remain in employment and generate stringer CPP contributions
- Economic growth over the past year has been in sectors in which the labour force is predominantly women- supporting unpaid caregiving increases the likelihood of continued economic growth (Evidence: *Canadian Economic Observer*, June 2006, Labour force participation among women of the baby boom generation has accounted for 80% of growth between 1999-2005, half being 55 years old and over (p.3.7) This demographic of women are or will be faced with the responsibility of elder care, having implications for employment participation and chronic health status related to work-life balance.

Roy, Francis. (2006). From she to she: changing patterns of women in the Canadian labour force. *Canadian Economic Observer*. Ottawa, Canada: Statistics Canada.

4 Compassionate Care Program Re-Structuring

- Compassionate Care Benefit Program must be removed from the EI system and redesigned to better reflect the proportion of and financial situation of unpaid caregivers in need of benefit support.
- Patterns of women's employment, including earnings disparity, greater time spent in part-time work, parental leave time and self-employment necessitate a readjustment of eligibility criteria and support provisions.
- Bring wage replacement rates above Low Income Cut-Off for all claimants
- A compassionate care benefit program outside of the EI system will enable caregivers to access benefits at various points including onset or continued caregiving commencing from hospital discharge, change of residence, increase in intensity of care required, diagnosis and so forth as verified by a family physician and/or residence claim.
- Transition funding for caregivers post-care and/or in work/caregiving transition situations should be made available as part of the Compassionate Care Benefit Entitlement.

HBRP Research Findings:

- Women are less likely than men to benefit from programs like the Caregiver Tax Credit and Compassionate Care Benefit because women are more likely to have lower average incomes, more likely to work part-time and more likely to have left paid employment because of their caregiving responsibilities (Shillington, 2004)

Benefit to Nova Scotia:

- A responsive and supportive compassionate care benefit connected with a transition fund as described will reduce poverty in Nova Scotia and decrease the poverty-related use of the health care system.
- Transition funding for caregivers as part of this program will enable caregivers to avoid unnecessary use of the Welfare System if they choose to intermediately opt-out or transition in the formal employment sector.
- A Compassionate Care Benefit and Transition fund will also enable caregivers to maintain attachment to the labour force which boosts participation rates and quells workforce decline addressing labour force shortage issues in NS.

5 CPP Entitlement Adjustment to Reflect Value of Unpaid Care to Economy

- A credit must be made available in the CPP to allow a reasonable period of time for exacting contributions to reflect women's hours and years of participation in unpaid caregiving.
- Longer-term caregiving, such as that provided to a child with a disability, who then is potentially a dependent adult with a disability, must be granted consideration under CPP guidelines to ensure a reasonable time credit for years of caregiving.
- CPP opt-out and contributions must be matched to a reasonable salary paid to that of a formal home care worker, enabling women to retire from caregiving rather than retiring into poverty. Recognition of the social contribution of caregiving, the tangible expenses incurred by caregivers as well as expense of choosing to remain in the informal economy can be returned by this means.
- Remove disincentives that encourage women of the baby boom generation to opt out of the workforce ie. enable work-life balance and caregiving support while employed
- Remove GIS clawback for seniors still earning low employment income
- Assign market value to unpaid work

HBRP Research Findings:

- Women and men are equal in terms of workforce participation rates and contribution to the CPP yet the value or amount of CPP return is far less for women due to women's inconsistent labour force attachment as a result of parenting, other family obligations and caregiving (Shillington, 2004).
- The average amount of years spent caregiving according to an HBRP report is 10 years (Gahagan et al, 2004)

Benefit to Nova Scotia:

Women maintain workforce attachment longer, contributing to tax base and receiving higher CPP benefits when retiring

- Poverty reduction among elderly, specifically among elderly women population resulting in less use of (decreasing wait times) and cost to the health care system due to poverty-related illness and disease.
Average amount of CPP disbursement received per month: Men – Women-
- CPP disbursement is structured to replace 25% of lifetime earnings (adjusted to reflect inflation) Women's earnings disparity equals a low CPP income as women tend to be paid lower wages and this on average receive ½ of the maximum CPP disbursement.(Barnwell, 2006)
- Barnwell, Georgia. (2006). Women and Public Pensions: Working Toward Equitable Policy Change. Ottawa, Canada: Status of Women Canada.

6 Bridge Service and Information Gaps with Online/Tele Informal Carer Support Access Program linking with 211

- Establish funding and bureaucracy to support a central coordinating body to provide all information about the bundle of services/ supports available to individual caregivers for specific situations based on type of care provided (ie. long-distance care, palliative care etc.)
- Provide funding and political support for 211 service to include caregiver specific information as proposed by the United Way
- Ensure these initiatives are responsive to a diverse community of caregivers, providing information relevant to caregivers of Aboriginal communities (on and off- reserve), Immigrant and Newcomer caregivers (in addition to care-specific information such as in-hospital/clinic translation services, support such as: MISA, English-language training, Newcomer services, culturally-specific community links) Acadian caregivers (French language accessible information and services), African Canadian community (faith-affiliated support groups, transportation support and community networks) and supports and services specific to the needs of Disabled Caregivers (contact with DAWN, employment opportunities for caregivers with a disability etc/ entitlements through tax/transfer system and transportation).
- This resource must be both immediately updateable encompassing both government and non-profit agency data and responsive to community changes and needs as they evolve, ie. emergence of a specific caregiving community in need of response such as an Arabic community.
- Online component of this resource will be searchable mimicking a *Google* engine.

HBRP Research Findings:

- Forum participants reveal that post-traumatic stress resultant of loss of care recipient, and a lack of resources to address this mental health issue as well as the lack of coordination among programs and services for unpaid caregivers results in negative stress and health impacts (*Finding a Healthy Balance: Research, policy and practice on women's unpaid caregiving in Nova Scotia*, May 2-3, 2006, Halifax, N.S.).
- Many Focus Group participants discussed neither they, nor most members of their support networks were aware of formal supports available to unpaid caregivers. Participants blame the absence of central coordination and inadequate dissemination methods for this gap in support (Gahagan et al, 2004).

Benefit to Nova Scotia:

- Increased level of satisfaction with services as the appropriate services are recommended /accessed for each client.

- Efficient use of resources and improved efficiency in service delivery.
- Responsive to and respectful of community diversity.
- Improved uptake of existing services encourages positive health and well-being outcomes for caregivers resulting in fewer long-term costs to the health care system/ social assistance etc.

7 Training and Credentialing Program for Unpaid Caregivers

- Provide a choice of adult learning models/modules for those who want to seek skills upgrading, prior learning assessment and/or credentialing.
- Adult learning models/modules will be responsive to needs of caregivers and care recipients with an interactive web-based component and discussion forum including access to appropriate supports and financing for materials.
- This model is to be options-based, culturally inclusive and appropriate, diversity-focused, accessible to diverse communities and persons with disabilities, language sensitive and empowering.
- Credits from Skill Development Program to count toward Home Care Support Worker Training and/ or related programs to be incorporated into a Community College/ Adult Education curriculum as a distance learning option.
- A policy approach which includes skills upgrading must acknowledge the right to education for unpaid caregivers, financial support for upgrading program development and sustainability, employer incentives to hire individuals with the completion certificate and/or credential. CPRN recommendations to improve adult access to upgrading programs, from their recent research study Too Many Left Behind: Canada's Adult Education and Training System would be particularly useful in this context, including a coordinated approach encompassing accessible points of entry to the program, information about the program and curriculum data, guides to learning opportunities, information on costs and benefits as well as interpersonal counseling (CPRN e-network, June 9, 2006).

HBRP Research Findings:

- Findings from analyzing the current tax/transfer system in relation to unpaid caregiving results in a recommendation for the creation of a Disability Income System incorporating training, rehabilitation and employment to redress access and inequity issues with CPP and income system experienced by caregivers and/or care recipients with a disability (Shillington, 2004).

Benefit to Nova Scotia:

- A recent CPRN study, Too Many Left Behind: Canada's Adult Education and Training System, reveals the enormous benefit of facing the challenge posed by under-skilled adults and entrance to the labour market. One finding of CPRN is that "Recent research shows that the returns on investment in skills upgrading of less educated workers are three times as great as for investment in physical capital." (CPRN, e-network, June 9, 2006, *A High Return on Investment: Adult Education in Canada*).

8 Accept Unpaid Caregiving as an Indicator of Health and Wellbeing in Province-wide Programs and Strategies

- Include unpaid caregiving in Provincial health and well-being programs as a determinant of health status.
- Provincial areas where inclusion of unpaid caregiving as a determinant of health is needed include the Voluntary Planning vision for Nova Scotia; the Community Counts initiative (still in development) Workplace Wellness initiatives, Education programs as well as Prevention Programs where health, well-being and work-life balance are relevant.
- Specifically, the Nova Scotia Community Development Policy, which has been approved by the Nova Scotia Cabinet and is in the process of developing an implementation plan through a Voluntary Planning Board which took the opportunity to engage in discussion in the province-wide consultations.
- The Nova Scotia Community Development Policy has identified specific priorities and includes specific “goals” which relate directly to the experiences of unpaid caregivers including Social Inclusion, Aboriginal Issues, Infrastructure and Education and Skills Development.
- Content related specifically to unpaid caregiving must be included as an indicative measure of achieving positive outcomes from these set priorities.
- Unpaid Caregiving is subsumed in many areas included in the Genuine Progress Index Report, The Socioeconomic Gradient in Health in Atlantic Canada: Evidence from Newfoundland and Nova Scotia 1985-2001. ; consulted community members have instructed the Voluntary Planning Board to engage with this as a determinant for community health and benefit.
- The specifics of unpaid caregiving within the Genuine Progress Index can be evidenced in measures of Social Support, Stress, and Income as a determinant of health and well-being. As the GPI Report suggests “Social networks and social supports have been shown to strengthen immunity, increase compliance with behaviours that promote health, and enhance adaptation and recovery from disease” whereas impediments to social support , “may be as great a risk to health as poor diet, lack of physical activity, or smoking” (Rogers et al, 2005).

HBRP Research Findings:

- Prevalence of care being that 36% of Nova Scotians provide care to someone experiencing an illness or health related limitation, which is greater than national averages and greater than previous findings for the Nova Scotia population (Keefe, Hawkins & Fancey, 2006).
- HBRP Research Findings can inform the priorities of the Nova Scotia Community Development Policy in respect of unpaid caregiving and community-identified areas of concern, specifically, Social Inclusion, Aboriginal Issues, Infrastructure, Education and Skills Development.

Social Inclusion: Diversity of the caregiver population and marginalization of those performing invisible work outside of the formal economy as an informal health service necessitates social policy.

Aboriginal Issues: Policies affecting Aboriginal and First Nations persons and communities include those related to caregiving. Particular concerns arising from focus group consultations with Aboriginal caregivers include:

- The disjuncture between on and off reserve services and the lack of services for individuals under the age of 19.
- Existing programs are non-Native institutions or services which do not reflect the cultural values of the Aboriginal community (Beagan et al, 2005)
- There is a distinct lack of access to funded services on the First Nations reserve that are available in the city due to jurisdictional divides, and a social history of government exclusion and moratoriums on services (Beagan et al, 2005)

Education and Skills Development: Training and credentialing needs of unpaid caregivers need to be addressed to provide caregivers with skills needed to care as well as skills to transition to formal employment post-caregiving.

Infrastructure: Affirming the Community Consultation results of the Community Development Policy Initiative, transportation has been found to be a significant challenge for caregivers in rural communities (Beagan et al, 2005; Gahagan et al, 2004).

HBRP finding of prevalence of long-distance care and examples of weekend traveling to provide care (80% of caregivers not residing with caregiver, Keefe, Hawkins & Fancey) is reflected in the Community Consultation Report, finding “The lack of public transportation in many areas outside Metro Halifax limits the ability of people to live in rural areas while working in urban areas, and to take part in community development initiatives and activities.”

The Community Consultation Report includes community resident recommendations for changes which would positively impact caregivers, including “The infrastructure necessary for Government to deliver its programs and services equitably across the Province; Subsidized transportation for greater mobility of rural populations; Accelerated expansion of broadband technology to provide more opportunity for those in outlying areas to use digital communications in their work (*this is particularly relevant for online/tele care information service recommendation*).

Benefit to Nova Scotia:

- Given the higher prevalence of unpaid caregiving in Nova Scotia, the health and well-being implications of this work will have a significant impact on the health and well-being of the provincial population overall.
- Assurance that social inclusion and inter-sectoral collaboration are government priorities
- Including unpaid care as an indicator of health and well-being will therefore provide a more accurate measure of population health.
- This improvement of accuracy in health indicator measurement will allow for better modeling and development of health promotion/risk prevention models.

Appendix A: List of Replacement Care Items

Choice of Five Items (An allotment of funds/subsidy or credit to be spent on necessary items and exchanged as needs change)- a cap on each

- Replacement Care Services of RN
- Replacement Care Services of Personal Care Worker
- Replacement Entitlement for alternate family* member
- Discharge Planning Assistance
- Care Coordinator Assistance
- Transportation Support/ Entitlement
- Long-Distance Care Entitlement
- Caregiver Support Group Transportation/ Replacement Care
- Skills Recognition and Development Support Program
- Childcare Entitlement
- Family Mediation/ Counsellor
- Financial Planning Counselling
- Entitlement for Home Maintenance
- Technical/ Medical Aids Benefit
- Pharmacare Benefit
- Long Term / Institutional Care Coordinator
- Grief/ Post-Traumatic Stress/ Mental Health Support
- Other (caregiver situation specific need)

*Family: In this context family is broadly defined as:

*Demographic Time Bomb: In this context the demographic time bomb is a descriptor for the looming crisis resultant of the age profile transition occurring in Nova Scotia as the baby boom generation become pensioners, drawing CPP, requiring significant health care and informal care while a smaller population of younger workers contributes to the shrinking CPP fund and struggles to support the health care system through the tax base while also ensuring the elderly have adequate informal care and support.