

6. CONCLUSION AND RECOMMENDATIONS

Through our research and analysis, we have demonstrated that *current home care policies and practices contribute to the vulnerability of women to poverty* in the following ways.

By taking advantage of gender stereotypes and expectations that women will do the “women’s work” of caregiving for low or no wages.

- Women are under institutional, social and often familial pressure to provide unpaid home care for family members, in spite of the effect this has on an individual’s earning ability, career plans or ability to assume the unsupported costs which may be incurred during home care work. Women who leave or reduce their paid employment to manage their families’ care as unpaid caregivers face diminished financial resources not only during the provision of care, but for the rest of their lives, due to missed promotions and opportunities, reduced pension contributions and decreased ability to save for retirement. Men are usually not expected to quit their jobs or relocate to provide full-time care to family members.
- As with most female-dominated occupations arising from what is viewed as “women’s work,” home care workers are underpaid and undervalued. We found that a nurse or LPN is sometimes paid less than half for the very same services when performed in the home rather than in a medical facility.
- Home support workers, in particular, are viewed as “cleaning ladies.” They are expected to perform duties for free outside their job descriptions as if they were indentured servants, are assigned casual and irregular hours throughout the week and on weekends at short notice as if they had no other life but to serve others, and are paid such low, usually part-time, wages that those we interviewed were living at the poverty level or had to maintain themselves with several different jobs. Even so, they are expected to subsidize their own jobs by paying transportation costs and even buying meals and equipment for poor clients.
- There is a stigma associated with home care work, and it is viewed as the bottom rung of the health care hierarchy—possibly because it is seen as the caring work that women have performed with no pay in the home for thousands of years. Home care work has been deprofessionalized, to the point that many clients have told us that their workers lack the necessary training to perform the tasks required of them. Due to the low wages, low prestige, lack of career advancement, high stress, insecurity and often irregular hours of these occupations, there is a high turnover and constant shortage of staff.

By not taking into account the realities of women's socio-economic status and lives.

- Means testing for seniors in Newfoundland and Labrador excludes all but the very poorest from free-of-charge care, leaving many low-income elderly women living at a social assistance standard and without money for food after they pay for their portion of care.
- Female home care workers are assigned to dangerous situations with violent clients, convicted sex offenders or work all hours in unsafe neighbourhoods.
- Home care workers and unpaid caregivers are exposed to significant health and safety risks. Not all of the former, and none of the latter, are covered by workers' compensation for injuries sustained in the home.
- Casual hours and split shifts interfere with home care workers' own responsibilities as unpaid caregivers for their own families.
- Some women with disabilities and older women requiring care are also the primary unpaid caregivers of their own families.
- In the case of self-managed care, sick, elderly or disabled women, or their daughters, daughters-in-law, sisters or mothers, must also be business managers (e.g., completing tax forms, employment records, insurance forms, hiring workers). Most are untrained in this area and are unaware of employer and employee rights and responsibilities.

By underfunding the system, viewing it as a cost-saving measure and taking advantage of the fact that home care operates outside the *Canada Health Act*.

- Home care recipients and their families pick up many of the costs associated with home care, which would be provided free of charge in a hospital. This varies greatly by jurisdiction and can include drugs, equipment, renovations to homes to accommodate illness and disability, repairs and maintenance of the care environment, additional medical and cleaning support when circumstances make this necessary.
- The number of hours of care women are assessed often do not meet their care needs.
- Home care is not portable across provinces and territories, so an elderly woman who needs to move in, for care, with a daughter in another province, may not be eligible for home care services in that province due to residency requirements. The alternative would be for the daughter to quit her job, leave her family and move to her mother's province.
- Waiting lists of up to eight months in rural Newfoundland and Labrador are leaving people without care or having to hire their own care at their own expense during the waiting period.

- Training, standards and quality control are often not implemented or enforced even where they do exist; there is no monitoring or consequences for private agencies hiring workers with inadequate or inappropriate training.
- Cutbacks to medical facilities and prohibitive fees for chronic care homes (varies by jurisdiction)—even though the population is growing and ageing, so demand is greater—mean that home care is sometimes the *only* viable choice, the “lesser of evils.”

By not providing women with enough support.

- Respite care is not readily available, women are not always aware of existing services, and fees are required for certain types of respite care.
- Inadequacy of income support programs for seniors and people with disabilities are leaving unattached women over 65 and women with disabilities in poverty.
- Addressing the issue of the impoverishment of caregivers with a program such as the federal Caregiver Tax Credit, for which most caregivers do not qualify, is shameful.
- A complaint process or ombudsperson for harassment on the basis of gender, race, ethnicity, language, religion, sexual orientation, ability, size, socio-economic status or any other characteristic, or simply about inappropriate or poor quality care is lacking completely.
- No human rights and conflict management training exist for workers.
- Lack of information and choices about care, and poor communication among agencies, workers and clients continue to occur.
- Most home support workers are isolated, casual women labourers without direct representation by a professional association or union to advocate on their behalf.
- Agencies are allowed to pay workers lower wages for services performed at a higher level, for example, hiring an LPN who performs LPN duties at home support worker wages.
- There are few culturally sensitive services or outreach to First Nations, Inuit and Métis peoples and those for whom English or French is not a first language—women family members in these communities *are* the home care system.
- Remote communities have poor or no service.

Recommendations

Goals

- Develop a holistic approach to health care, of which home care is a part, to take into account women's needs, realities and human rights.
- Implement commitments to gender equality by reducing women's vulnerability to poverty.

Practical Steps

We suggest nine practical steps toward these goals.

1. Develop a Canada Home and Community Care Act

The federal government should work with the provinces, territories and stakeholders, including women with disabilities, seniors and low-income women, ensuring minority groups are represented, to develop Canadian home and community care legislation and related policy agreements and declarations that would incorporate the following features.

Based on the principles of the *Canada Health Act*: The principles of the *Canada Health Act* (accessibility, portability, universality, comprehensiveness and public administration) should be explicitly included in home care legislation. This would mean that home care would be publicly funded and based on need, rather than ability to pay; there would be no residency requirement in any province; and home care would be administered and provided on a not-for-profit basis. This may take the form of one public provider or one, or several, private not-for-profit providers.

Co-ordinated with a streamlined assessment process: The co-ordination of services should be a public, single window (single point of entry) system, with offices and information in hospitals, community agencies and government offices.

Publicly accountable: Home care standards, practices and financing should be accountable and transparent to the public. An independent appeal process or an ombudsperson should be in place in each province and territory for persons not receiving adequate hours or quality of care and to handle complaints about, or from, home care workers.

Offering good wages and working conditions: Home care should not be an excuse or an opportunity to deprofessionalize services, contract out or lower wages, benefits and working conditions. Professional bodies of home care workers should be established in every province for the purposes of accreditation, training and ongoing skills and career development, and for negotiation of wages, benefits and working conditions.

Offering choice and appropriate care: Home care should be a choice for both recipients and their families. No one should be forced or bullied into home care, or have to resort to home care because of hospital or institutional cutbacks requiring an earlier discharge than appropriate. The nature of care needs varies from intimate care to care requiring medical

skill. Family members may be uncomfortable with certain aspects of care and should never be made to provide care they are unable or unwilling to perform. In a country with a universal health care system, home care is a right and not a privilege.

Women should never be expected to sacrifice their own financial and social security, mental and physical health, to provide unpaid care for family members. The principle of choice and respect for the choices of family members should be a guiding principle in every home care program.

Hospitals should be legally liable for the consequences of early discharge and inadequate provisions made for home care.

Respecting human rights: Home care services should respect the provisions of the *Canadian Charter of Rights and Freedoms* for all recipients, workers and family members.

- No recipient, worker or unpaid caregiver should be subject to harassment, offensive comments or discrimination on any grounds prohibited by the Charter, or on the basis of size, appearance, income, social class, occupation or any other characteristic.
- The definition of “family members” should always include same-sex partners, who should have the same access to respite care and all services, as well as being specifically included in research on the impact of home care on unpaid care providers, paid workers and recipients.
- Children under the age of 18 should never be left to provide medical and homemaking care for an incapacitated parent.
- Home care services should be offered in the recipient’s first language where possible.
- Specific measures must be taken to improve access to home care for rural, immigrant, linguistic minority, First Nations, Métis and Inuit persons, by working with these communities on solutions.

2. Act Now

Provinces, territories and regional authorities do not have to wait for federal provisions to be in place before acting on the principles outlined in the above recommendation. In particular, they can begin by implementing these measures.

- Eliminate any and all *fees for service*.
- Issue directives to employees performing home care *assessments* that medical need alone should determine the number of hours of care a person is eligible to receive and not assume that family members (women) will perform any part of the care for no pay.

- Establish or support the establishment of *professional bodies for home support workers* or expand any existing body—also for any other home care workers who are not currently represented by an association—to develop training standards, provide training, licensing, advocacy, negotiation of wages and working conditions for non-unionized workers, and establish complaints procedures. All public and private home care agencies should have to hire workers licensed by the professional body.
- Require any public or private agency receiving public funds for home care to be *transparent and accountable to the public*, to provide an annual audit, collect and disclose data about wages, hours of work, staff training and qualifications disaggregated by gender, disclose the salary and benefits of top executives, and disclose the percentage of their budgets spent directly on service delivery, administration and profits (the latter where applicable).
- Create an environment to help agencies implement the recommendations directed at them in item 9 (under Role of Home Care Agencies) below.

3. Respite Care

Provincial and territorial governments should invest in respite care for unpaid care providers that would be provided at no cost to the user. Health Canada should fund innovative projects in respite care.

It should be mandatory for home care case co-ordinators and agencies to provide information about respite care, and where it is available, to the family members and other unpaid caregivers of home care recipients. The information should list the benefits of respite care to the health and well-being of unpaid caregivers and therefore, ultimately, to the home care recipient.

All home care recipients, particularly longer term recipients who are able to leave their homes, should have access to publicly funded adult day centres. These day centres would provide relief to family members and the opportunity for stimulation and socialization for seniors and people with disabilities.

4. A Holistic View of Health Care

Health funding: As a priority, all health care funds cut from the system over the last decade should be restored, and hospital and institutional care be made available where appropriate.

Psychological support: Psychological and emotional support for home care recipients, unpaid caregivers and paid workers should be an essential part of any home care program.

Pharmacare*: Drug costs, including prescription and over-the-counter medications and nutraceuticals, should be covered by public insurance for all home care recipients.

Dentist care: Dental work and home dental check-ups where necessary should be covered by public insurance for all home care recipients.

Child care: Home care should include child-care assistance for people with disabilities or post-acute care where necessary.

Health promotion, nutrition and lifestyle counselling*: The services of dietitians, health promotion personnel, and persons who can help home care recipients with budgeting and other specific tasks should be available to all home care recipients.

Medical expenses*: All medical expenses and equipment, including renovations to homes to facilitate wheelchairs and other equipment, should be covered by public insurance for all home care recipients.

Community supports: The federal government should support national organizations, and provincial and territorial governments should support provincial/territorial and local organizations involved in advocacy and support for seniors, people with disabilities and other home care recipients. Specifically, governments should support the development of workshops for unpaid caregivers and recipients on topics such as payroll and taxes (where there is self-managed care), and other skills and topics designed to help unpaid caregivers and recipients cope as well as maintain and enhance their health and well-being.

Transportation: People discharged from hospital or other institutions may not have transportation home, especially those who live in rural areas or otherwise at some distance from the institution. As well, seniors, people with disabilities and post-acute home care recipients may not be able to afford or arrange transportation to appointments. Transportation assistance should be part of any home care program.

Additional services: Delivery of meals, foot care and other services may be necessary to keep seniors, people with disabilities and persons discharged from hospital in the community.

Cultural sensitivity: All personnel involved in home care, including government and agency officials and workers, should be required to take anti-racism, anti-homophobia, and cultural sensitivity training, as well as general training on human rights and the respect that should be accorded to recipients and unpaid caregivers.

Home care programs should be involved in outreach to ethnocultural communities to inform them of the existence of the program. Home care workers, unpaid caregivers and recipients belonging to ethnoracial and linguistic minority groups should be part of any advisory board or design team of home care programs.

Adequate income: Income is a major determinant of health. The provincial and federal governments should ensure that home care recipients have an adequate income. This may range from increasing social assistance rates or relaxing entry requirements for people who are ill and not covered by Employment Insurance sickness benefits, to increasing the Guaranteed Income Supplement for seniors.

Social housing: The provincial and federal governments should renew their commitment to safe and accessible housing for seniors, people with disabilities and low-income people by reinvesting in affordable housing.

* This currently varies by jurisdiction. Some already provide partial or complete public funding in these areas. An asterisk is not placed beside adequate income or social housing, as these are deemed wholly inadequate across Canada by the United Nations Committee on Economic, Social and Cultural Rights (1998).

5. Home Care for Aboriginal Peoples

First Nations, Inuit and Métis peoples should have access to culturally sensitive, good quality home care services. This would require a complete overhaul of existing services and the identification of Aboriginal peoples who by reason of their geography, treaty status or other barriers are not receiving services from either federal or provincial governments. It would require an investigation and audit of the home care services currently provided by Indian and Northern Affairs Canada, as well as adding a home care transfer agreement for bands whose health care transfer agreements do not cover funds for professional home care services.

Aboriginal elders, Aboriginal people with disabilities, Aboriginal people who have received home care after being discharged from hospital and Aboriginal unpaid family caregivers should be part of the design team for home care services for Aboriginal peoples.

6. Women with Disabilities

The federal and provincial/territorial governments should provide funding to disability organizations to assist people with disabilities in dealing with the government, and to play a strong advocacy role in policy development in all matters affecting people with disabilities, including the design of home care services.

We endorse the recommendations outlined by Shirley Masuda (1998) in her cross-Canada research and interviews with women with disabilities.

That eligibility criteria for disability benefits be clearly and fairly defined and that this be done in consultation with members of the disability community in each province to ensure the weight of hidden disabling factors of disabilities are recognized. These criteria should take into account the needs of women with disabilities, and not be based solely on a medical diagnosis.

That each province clarify in simple and plain language what persons on welfare and disability benefits are entitled to receive, and that this information be made available to every person who is applying for, or is already receiving, disability benefits.

That the right to appeal decisions regarding financial assistance be reinstated in every province and territory, and that every person applying for benefits be given information about their right to appeal with clear instructions on how to proceed with an appeal; and that every person already receiving social benefits receive this same information.

That every person whose application for financial assistance is rejected or disqualified be given written, clear, plain-language reasons so decisions can be appealed with clarity and objectivity.

That every person, when applying for disability benefits, or who has been refused disability benefits, be advised of organizations that can assist with the appeal process.

That if benefits are terminated for any reason, they be reinstated during the time of the appeal process, and if the appeal is rejected that the individual not be required to repay benefits received during the period of the appeal.

That all disability-related costs be handled separately from everyday costs.

That women who share safe and accessible living accommodation not be threatened with loss of benefits.

That the federal government, in consideration of the extraordinary cost of living with a disability, not limit refundable tax credits for disability-related expenses to persons who are employed; and that refundable tax credits be given to all people with disabilities for expenses related to their disabilities that are not covered under welfare disability benefits or other disability benefit plans or health insurance plans.

7. Self-Managed Care

In order to give home care recipients more control over the services provided to them, self-managed care should be an option, but not the only option. This would mean that vouchers could be provided directly to home care recipients to purchase their own services if they so choose. The vouchers should reflect the wages of public, unionized workers so recipients are not limited to hiring untrained or low-wage staff from private agencies.

If self-managed care is an option, recipients and their unpaid caregivers should have access to workshops and advice about payroll, taxes, employment laws and their rights and responsibilities as employers, with the option of having an accountant perform these tasks at no charge.

People who choose self-managed care should not forfeit their right to home care co-ordinated by government or agencies if they should change their minds. As the capacities of home care recipients may change, a switch away from self-managed care may become necessary.

Recipients of self-managed care should be allowed to hire family members as their caregivers, and have training available for these family members.

All home care workers should be represented by a professional organization that can advocate on their behalf regarding issues of wages, working conditions and workplace safety, and provide them with resources and information concerning their rights and career development.

8. Research

All research in any jurisdiction into the costs and benefits of home care should always include a component measuring the financial, social, health and emotional impact on women. *A gender analysis should be an integral part of all research on home care.* Research should also pay attention to human rights issues in home care. In particular, we recommend these areas for further research.

A national inquiry into the wages and working conditions of paid and unpaid home care workers should be established with a view to recommending improvements. The inquiry members should include groups that represent home care workers, home care workers themselves, unpaid caregivers and recipients, including women with disabilities, seniors and low-income women. In addition to examining and suggesting changes directed at all levels of government and agencies in terms of improving the status of paid home care workers, remuneration for family caregivers should also be investigated. One explicit principle of this study should be that paid and unpaid caregivers ought not to be expected to shoulder any financial or other burden in relation to their caregiving role.

Existing home care programs should be audited and evaluated, with a view to improving the conditions of home care workers, streamlining and co-ordinating the process, and reducing the burden on recipients and unpaid caregivers. *This would include a gender audit.* Home care is a vibrant and changing field that has seen a dramatic increase in demand and caseload, against a context of health and social cutbacks. What worked even a few years ago may no longer meet the need. Ongoing evaluation and comparison to best practices in other provinces and territories are essential.

In addition, where public funds have paid for home care studies, the public should be made aware of them and have access to them. These studies could be listed on the Health Canada Web site.

9. Other

Role of Employers

Employers should offer paid family responsibility leave, and health plans which include home care benefits for employees and their families.

Role of Home Care Agencies

Agencies ideally should undertake the following actions.

- Develop policies on harassment focussing on prohibited grounds of discrimination as identified in the *Canadian Charter of Rights and Freedoms*.
- Establish policies to ensure safe work and home places for home care delivery.
- Establish ways of dealing rapidly and effectively with complaints made by workers and recipients.
- Create a co-operative relationship with employees, and realize that a good work environment will attract better-trained and qualified staff and reduce staff turnover, which can confer a competitive advantage. In particular to:
 - avoid the tendency toward an assembly-line fragmentation of tasks model of health care;
 - offer or expand a paid training programs for workers;
 - incorporate social time for workers to reduce their isolation from each other; and
 - review pay scales and hours of work to ensure quality and continuity of care, development of career patterns for workers, ensure pay equity between male and female workers.
- Encourage the formation of extra-agency worker or management organizations to deal with and develop strategies on:
 - government underfunding of home care;
 - ensuring quality standards;
 - issues of concern to employees;
 - issues of concern to management; and
 - community relations
 in a way that would improve the quality of care and the image of the home care field across the board for all agencies, without fear of losing any competitive advantage.
- Establish a co-operative intra-agency management or worker committee to focus on:
 - improved working conditions;
 - health and safety concerns of workers and recipients; and
 - quality control.
- To re-examine, with a view to improving, the assessment processes used for recipients, or where assessment is centralized outside the agency, to report client complaints about the assessment process.
- To lobby governments and regional authorities for aid in making these recommendations a reality where budgetary restraints or other obstacles exist.

Private Insurance Companies

In the current absence of government relief for costs associated with home care, private insurance companies should offer home support services for the insured person and family

members, including the parents of the insured person, as part of their health plans and benefit packages. This package should include coverage for transportation and child care costs.

Unions

If there is no movement toward establishing professional associations for home care workers, trade unions should make organizing non-unionized home support workers a priority, and proceed then to organize other non-unionized home care professionals, as our study shows that unionization has a direct impact on wages. Because many workers are living in poverty, are isolated from each other and have no recourse, unions may have to develop innovative measures to reach them. Funds should be set aside for campaigns that seek to organize employees of all agencies operating in a local area at once, and to raise public awareness in each area of the wages and working conditions of home care workers.

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APPENDIX A: INTERVIEWEES FOR THE POLICY PORTION OF THIS RESEARCH

Pat Armstrong, PhD
Director, School of Canadian Studies, Carleton University
Author of numerous books and articles on health care and women's work

Sharon Baxter
Manager of National Programs
Canadian AIDS Society

June Callwood
Author, journalist, broadcaster, involved in home and palliative care

Kathleen Connors
National Federation of Nurses Unions
Canadian Health Coalition

Denyse Côté
Professeure, Université du Québec à Hull

Carol Donovan
Senior Policy Advisor
Home Care Development Branch
Health Canada

James Dunn, RN
Aboriginal Nurses Association
Board member for Quebec

Sheila D. Genaille
President, Métis National Council of Women

Amy Go
National Action Committee on the Status of Women
Manager of a Toronto home care program

Kapil Khatter, MD
Acting Assistant Director
National Anti-Poverty Organization

Lesley Larsen
Executive Director, Canadian Home Care Association

Linda Lysne
Executive Director, Canadian Palliative Care Association

Janice Miller
Canadian Institute for Health Information

Maria Elisa Montejo, PhD
Coordonnatrice de recherche
CLSC René-Cassin/Institut universitaire de gérontologie sociale du Québec

Louise Plouffe
Manager of Knowledge and Development Section
Division of Aging and Seniors
Health Canada

Carole Pressault
Senior Advisor, Government Relations
Canadian Nurses Association

Donna Roe
Executive Director, Victorian Order of Nurses (retired)

Traci Walters
Executive Director
Canadian Association of Independent Living Centres

And one other Health Canada official who declined to be named.

APPENDIX B: GENDER ANALYSIS QUESTIONS

A gender analysis of home care starts with questions: Who are the recipients of home care? Who are the providers? Who are the informal family caregivers in terms of gender?

Step 1: Identifying the Issue

Gender-analysis questions include the following.

- In what ways are both women's and men's experiences considered in identifying the issues?
- How is diversity being considered?
- How does the definition of the issue take into account government's objectives regarding equality?

Step 2: Defining Desired/Anticipated Outcomes

Gender-analysis questions include the following.

- What does the government want to achieve with this policy, and how does it fit into its stated commitments to social and economic equality between women and men? How can this be measured in practical and statistical terms?
- How will you determine if diversity, in addition to gender, will be a factor in the outcomes? What information have you sought (statistics, studies, consultations) to determine this?
- Who will be affected? How will the outcomes of this policy be different for women and men? What other policy outcomes may be indicated by looking at gender and diversity?

Step 3: Information Gathering

Gender-analysis questions here include the following.

- Are available data disaggregated by gender at all levels of analysis? Is information regarding equity groups, including Aboriginal peoples, people with disabilities and visible minority groups disaggregated by gender? If not, where can this information be obtained?
- In collecting basic information in your subject area, have you ensured that the resulting data will support gender-based analysis, if necessary?
- How will both qualitative and quantitative data be collected?

- Will you consult with women's organizations and key women in the area about available resources and about women's experiences with this issue?
- Have you consulted documents about the gender implications of the issue, including pamphlets, parliamentary briefs and statements by women's organizations?
- If you are conducting primary research, are data collection questions appropriate and respectful of the dignity of the research participants? Have affected groups participated in developing the research design?
- In what ways does the research you consult or conduct address the differential experiences of gender and diversity? Are the documents you are using, or the researchers to whom you are assigning tasks, aware of gender issues?
- If you are using a computerized simulation model, are you using gender as a factor? Do you have access to the expertise of someone knowledgeable about gender issues to help interpret the results?

Step 4: Development and Analysis of Options

Gender-analysis questions include the following.

- In what ways will the option disadvantage some groups or provide an advantage for others?
- Will further consultation take place with women's organizations and key women in the area about the impact of each policy option on women?
- Will the analysis of each option outline how it supports equity and point out where equity may be compromised?
- Have you attempted to develop innovative solutions to gender and diversity issues you have identified? What solutions have the affected groups identified?

Step 5: Communication

- How will any differential consequences based on gender and diversity, and their social and economic costs, be communicated to decision makers?
- In what ways will gender equity be a significant element in weighting and recommending options?
- Will the recommendation suggest how to implement the policy in a gender-sensitive and equitable manner?

- Have communication strategies been designed to ensure information is accessible to both men and women, and fair to diverse communities?
- How will the information be communicated to women who are members of other equity groups (Aboriginal women, women with disabilities, visible minority women)?
- How will the participation and contributions of both women and men in the policy development process be acknowledged and communicated in an appropriate and respectful way?
- How will the aspects of the policy supportive of gender equality be highlighted and communicated?

Step 6: Evaluation

Gender-analysis questions include the following.

- Are gender-equality concerns incorporated into the evaluation criteria?
- What indicators will you use to measure the effects of the policy on women and men?
- Who will review or analyze the quality of the analysis? To whom will the assessment be reported? Will this include consultation with women's organizations or key women in the area?

APPENDIX C: INTERVIEW QUESTIONS FOR POLICY PORTION OF THIS STUDY

Information Sheet

Project Title: The Changing Nature of Home Care and Its Impact on Women's Vulnerability to Poverty

You are invited to take part in a study on home care in Canada currently being conducted by the Canadian Research Institute for the Advancement of Women (CRIAOW). The study, which is investigating the extent to which home care policies contribute to women's vulnerability to poverty, will result in recommendations for policies that redress the economic and other costs currently borne by women.

CRIAOW is a national research organization, founded in 1976, which is dedicated to advancing the position of women in society, promoting research about women's lives and affirming the diversity of women's experience.

As part of this study, we are conducting a survey on the views of organizations concerned with home care policies and programs. The interview will take about a half hour of your time, and be done at your convenience, either in person or over the telephone. It will be carried out by Sherry Galey, M.S.W., or Marika Morris, M.A. Sherry can be reached at (613) 233-2105 (telephone), (613) 233-4425 (fax) or sgaley@cyberus.ca (e-mail). Marika can be reached at (613) 234-5927 (telephone), (613) 237-1105 (fax) or at mmorris@magi.com (e-mail).

Here is the definition of home care we have adopted for our study.

Home care enables individuals with major or minor limitations to live at home or in supportive housing. Home care services can assist in preventing, delaying or replacing long-term care or acute care alternatives. Such services include professional services, medical supplies, homemaking and attendant care, as well as maintenance and preventive care. These are currently provided through formal subsidized, insured or private arrangements as well as by informal caregivers for families, community networks and volunteer agencies.

If you agree to participate in our survey (and you may withdraw at any time), you will find the questions that we would like to explore with you on the next page.

We are very grateful for your assistance. If you have any questions or concerns related to the study, feel free to contact Lise Martin, executive director of the Canadian Research Institute for the Advancement of Women at (613) 563-0681. We would be happy to provide you with a copy of the full report when it is completed.

The Changing Nature of Home Care and Its Impact on Women's Vulnerability to Poverty

Interview questions for policy analysis component.

Introduction

How is your organization involved in the home care issue today? Where does home care rank in the organization's list of priorities?

State of Home Care in Canada

What is your assessment of the current home care situation in Canada, in general?

What are the strengths and weaknesses in the way home care is being provided across Canada? What are the main problems or gaps? What, if any, groups are being poorly served or disadvantaged? Are professional support services adequate and accessible?

What do you see as the key social, political, economic or technological changes creating the shift to home care? Is there any one main factor driving the shift?

Policy Issues - General

What do you think of the way home care policies are being implemented in the provinces? Is there a gap between policy and practice? Between policy and need? What is working? What needs to change?

How has the federal government been involved in home care policy so far? What should be the elements of a national home care policy or program? What are the impediments to establishing such a policy?

Are the current financial resources for home care adequate? What services do you think should be covered by publicly funded home care?

[Specific questions to probe for, if appropriate: Should there be some co-payment or deductible? Is there any role for private insurance? Is there a role for not-for-profit or commercial providers?]

Impact on Women

Are women or men differentially affected by home care and home care policies, as users, paid providers and informal caregivers? In what ways?

Do you know of studies on the gender breakdown of home care providers and individuals receiving home care? Do you know of any studies of unionization among home care workers with a breakdown by gender?

Are there other factors which have an effect on women as home care users, paid providers and informal caregivers, such as location (rural/urban, region), identity (ability/disability,

age, ethnicity, immigration status, sexual orientation, etc.) or status (employed, unemployed, family status)? How?

What do you see as the economic costs to women of providing informal home care (in their role as employees, caregivers, etc.)?

What are the costs to society of women providing informal care (lost wages, taxes, pension accumulation)?

What do you see as the health costs to women of providing paid or unpaid home care?

Are current policies increasing women's vulnerability to poverty?

- By moving paid home care work into the voluntary or semi-voluntary sector?
- By deprofessionalizing occupations which have traditionally been occupied by women?
- By affecting the work/home balance and pensions?
- In other ways?

What policy options would reduce the costs faced by women? Should informal caregivers be remunerated? Should publicly funded services be expanded? What should be the role of employers and unions? What should be the role of the tax system? Do you think the tax credit for caregivers will be of significant benefit?

Are there gender differences in insurance coverage for home care services? What kind of regulations exist for private plans?

Do you know if a gender analysis is being used to develop home care policies? How should a gender analysis be better integrated into the development of home care policy?

What links need to be made between home care policy and pension, employment, housing and family policies in the interests of women? What other related policies need to be put in place to support home care (such as pharmacare)?

Conclusion

Can you recommend resources, studies, ongoing research or people to talk to about home care issues?

Is there anything you expected me to ask that I didn't, or are there any other issues you would like to raise?

APPENDIX D: AGENCY QUESTIONNAIRE

**Home Care Study
Agency Information Sheet**

This form requests some basic information about your agency. To save time during the interview, we are asking you to complete it and return it to _____ at the time of the interview.

1. What is the mandate of your agency? (Please provide us with a copy of your brochures and a recent annual report if available.)

2. When did your organization begin operating?

3. Please outline the management and administrative structures of your agency. (An organizational chart would be helpful.)

4. Is your organization affiliated with other national or international home care agencies/organizations? Yes No

What is the name and mandate of the organization(s)?

5. Please provide a profile of the employees of your agency by completing the following table.

Employee	No. Full-Time Employees		No. Part-Time Employees		No. Casual Employees		Total		Salary Range	Benefits* Yes/No
	F	M	F	M	F	M	F	M		
Registered Nurse										
Licensed Practical Nurse										
Occupational Therapist										
Physical Therapist										
Respiratory Therapist										
Other Rehab (please specify)										
Home Support Worker										
Personal Care/Attendant										
Other (please specify)										

Notes:

* Y/N indicates benefits are provided to full-time staff.

Full-time employee (over 30 hours per week).

Part-time employee (under 30 hours per week).

Casual employee (2 -20 hours per week).

- Please provide a profile of the individuals who receive home care services from your organization by completing the following table. (If you do not collect information in this manner, please supply any client information you have available. Thank you.)

Client Classification	No. Male	No. Female	Total Hours of Service per Month
Elderly (with chronic disease and or functional ability conditions, possible cognitive impairment)			
Younger disabled			
Palliative terminal care			
Short-term acute (e.g., post-surgical, wound management)			
Medically complex technology dependent children			
Other			
Total			

7. Are there any agencies / organizations which are your partners in offering home-care services to clients? Yes No
If yes, please name the organizations.

8. What do you see as your organization's areas of specialization in the home care market?

9. Has there been an increase in the last year, in the number of organizations with whom you compete for the delivery of home care services to clients? Yes No

How has this affected your organization?

APPENDIX E: INTERVIEW SCHEDULE FOR HOME CARE AGENCIES

Employees

1. Has the number of your home care employees changed in the past year? Yes No
If yes, by how many females_____? How many males___? (note increase/decrease)

2. Does your agency have a policy for recruiting home care employees? Yes No
If yes, please describe:

3. What kind of orientation does your organization provide for new employees?

4. Are in-service training and skills upgrading available for home care staff?
 Yes No If yes, please describe (probe for what constitutes “in-service”):

5. Do care providers pay a portion of the cost of these in services?

6. Are there opportunities for home care workers to develop specializations and advance in the field?

7. What is the procedure to handle concerns of home care employees (i.e., re: clients, organization procedures, harassment, etc.)?

Services to Clients

8. What are the rates charged to clients for the various home care services your agency provides? (Probe: What are the rates paid to you by government for these services?)

Service	Rates Charged to Client	Rates Paid to Agency
RN/BN		
LPN		
OT		
PT		
Personal Care/Attendant		
Home Support		
Other		
Other		
Other		

9. How does your organization monitor the quality of services it provides to clients? (Probe for feedback procedures and mechanisms.)

10. Do your clients have difficulty paying for the care they need? Does it vary with gender? Can you give an example?

11. Given that your organization provides quality care to all clients, are you aware of inequities in care that clients are able to organize for themselves? Yes No
Please describe. (Probe for gender, economic status, race, Aboriginal.)

12. Do you have some ideas about how these inequities can be addressed?

13. How long does it take, on average, to get services in place for a new client? Are there waiting lists for any services?

14. Can you describe your organization's involvement in the assessment process for a potential client? (Probes: Is the process client centred? Who are the other partners? How do you take into account client characteristics/ wishes?)

15. Can you tell us what proportion of your clients care, by gender, is:

- a) 100% subsidized by gov't _____ Female ____ Male
- b) 85%+ subsidized by gov't _____ Female ____ Male
- c) 50% subsidized by gov't _____ Female ____ Male
- d) 15% or less subsidized by gov't _____ Female ____ Male
- e) covered by insurance _____ Female ____ Male
- f) covered by family _____ Female ____ Male
- g) wholly paid by client _____ Female ____ Male

16. Approximately, what proportion of your agency's work load is subcontracted?
_____ %

Can you provide some examples of the kind of work contracted out on a regular basis?

17. Can you give us an idea of what proportion of your organization's budget is used for direct care of clients?

Administration and Policy

18. What does your organization consider to be gaps in service delivery in the home care system?

19. What attempts have been made in your province to standardize the care provided by home care agencies?

20. How has your agency participated in these efforts?

21. How could provincial home care policy be improved to facilitate your work?

22. Are there any specific changes in home care regulations, procedures and practices that your organization would like to see?

23. Do you have any other comments about gender issues related to home care delivery?

Thank you very much for your time. We would like to send your organization a copy of CRIAW Home Care Study report and if you agree, we will send it directly to you.

APPENDIX F: INTERVIEW SCHEDULE FOR HOME CARE PROVIDERS

Personal Information

The following information is being collected so we have some background information on the people who answered the survey.

1. Age: _____

2. Gender:
 Female
 Male

3. Do you live...? (please check all that apply):
 alone
 with partner (e.g., married, common law)
 with children
 with friend(s)
 other (specify) _____

4. What is your ethnic or cultural background?
 French Ukrainian Aboriginal/Native
 English Chinese Métis
 German Dutch (Netherlands) Inuit
 Scottish Jewish Italian
 Irish Polish African-Canadian
Other: (please specify) _____

5. Number of Children: _____
Age Range: _____

6. What is the highest level of education you received?
 no formal education
 grades 1 - 8
 some secondary/high school
 high school graduation
 some post-secondary
 post-secondary certificate or diploma
 some university
 university degree(s)

7. Income range (probe your own/your household)
- | | |
|--|--|
| <input type="checkbox"/> \$0-\$4,999 | <input type="checkbox"/> \$25,000-\$29,999 |
| <input type="checkbox"/> \$5,000-\$9,999 | <input type="checkbox"/> \$30,000-\$39,999 |
| <input type="checkbox"/> \$10,000-\$14,999 | <input type="checkbox"/> \$40,000-\$49,999 |
| <input type="checkbox"/> \$15,000-\$19,999 | <input type="checkbox"/> \$50,000-\$59,999 |
| <input type="checkbox"/> \$20,000-\$24,999 | <input type="checkbox"/> \$60,000+ |

Initial Involvement with Home Care

8. How and when did you first get involved in home care work?

9. Have you lost income or missed other employment opportunities since you began home care work?

10. How do you balance the work you do with home care with your other responsibilities (e.g., work paid and unpaid, family, time for yourself, etc.)?

11. What kinds of work have you done in the past (career path, health care work, etc.)?

12. What training have you received in the field of home care? Experience?

13. What particular experience, skills, knowledge or attributes do you bring to your home care work (e.g., links with AIDS community, experience with Alzheimer, cancer)?

14. Do you see home care work as a potential long-term career?

Yes No Please explain:

Work and Working Conditions

15. Which of the following are part of your home care work responsibilities (please check all that apply)?

- Family Caregiver
 Volunteer Caregiver
 Home Support Worker
 Personal Care Worker/Attendant
 Licensed Practical Nurse
 Registered Nurse
 Occupational Therapist
 Physical Therapist
 Rehabilitation Worker
 Respite Worker with children with adults
 Other (please specify)

16. What kind of specific home care services do you provide?

17. Are all of these duties included in your job description? Yes No
Please comment.

18. In your home care work, are you:
 Self-employed With a contract
 Employed by non-profit agency
 Employed by for-profit agency
 Employed by government
 Volunteer
 Other (please specify)
-
19. On average, how much do you work per week?
 Casual (2-20 hours/week)
 Part time (under 30 hours/week)
 Full time (over 30 hours/week)
20. What are your hours of work?
 Shift pattern – no. hours/shift _____
 Split shifts – no. shifts/day _____
 Other (please specify)
-
21. How many clients do you work with during a typical week?

During a typical month? _____
22. Do you receive a different wage for different work you perform?
 Yes No Please explain:

23. What is your wage/salary per hour?

24. On a scale of 1 to 5, with one being strongly agree, and 5 being strongly disagree, how would you rate the following statement:
I am fairly paid for the work I do.
1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree
25. Do you work unpaid overtime? Yes No
If yes, how many hours per month?

26. Do you ever get paid "cash" for any work you do? Yes No
27. Do you combine home care work with other paid work? Yes No
Please comment (pros/cons):

28. Do you know of any cases where women and men have been paid differently for the same work in your field? Yes No Please explain:

29. What kind of coverage or benefits do you receive/subscribe to?
 Holiday Pay
 Sick Pay
 Medical
 Extended Medical
 Dental
 Liability Insurance
 Disability Insurance
 Life Insurance
 Other (please specify)

30. Do you belong to a union or professional association which works to improve working conditions in home care? Yes No

Name of organization:

Please comment:

31. Does home care work provide you with opportunities to train or improve your skills or branch into new career directions? Yes No

Please comment:

Description of Work

32. What would a typical work day look like for you? (Include paid and unpaid work, transportation, contact with agency, schedule, breaks, child care, errands, sharing information, etc.) For example, describe your last working day:

33. Are you aware of particular expectations of you because you are a female or male caregiver?

34. Do you perform work outside your job description? Yes No
If yes, how do you account for this to your employer?

35. If you have suggestions and recommendations, in general, how does:
- a) the client respond _____
 - b) the family respond _____
 - c) the agency(ies) respond _____
 - d) government respond _____

36. (For family caregivers only) How has the provision of home care within the family affected your life?

37. Is responsibility for caregiving shared equally among family members?
(Probe gender.) Yes No
Please comment:

38. What are some examples of difficulties which arise in your home care work?

39. How do you deal with these (e.g., family meetings, right to refuse unsafe work, etc.)?

40. What health and safety issues are you concerned about in your work?

41. What forms of support or consultation for yourself can you draw on (emotional, backup, respite)?

Assessment

42. What has been your involvement in the assessment process of clients/family members?

43. Please comment on the assessment process.

a) What are some of the pros and cons of the assessment process as you see it (e.g., input of family members, expectations placed on families, gender issues, etc.)?

b) Do you think family income should be considered in the process? Yes No
If yes, how should it be considered?

General Questions

44. How do you feel about the way home care is administered in the province?

45. What would you like to see changed in the home care system in the province?

46. This study is looking at the issue of women and poverty as it relates to home care. Do you feel that you are economically poorer because you are doing home care work and not other paid work?

Thank you for your assistance with this project.

APPENDIX G: INTERVIEW SCHEDULE FOR HOME CARE RECIPIENTS

Personal Information

The following information is being collected so we have some background information on the people who answered the survey. Please fill in, or check (✓) the appropriate answer for each question.

1. Age: _____
2. Gender:
 Female
 Male
3. Do you live... (Check all that apply.)
 alone
 with partner (e.g. married, common law) How old is your partner? _____
 with children
 with friend(s)
 other (specify) _____
4. What is your ethnic or cultural background?
 French Ukrainian Aboriginal/Native
 English Chinese Métis
 German Dutch (Netherlands) Inuit
 Scottish Jewish Italian
 Irish Polish African-Canadian
Other: (Please specify.) _____
5. Income range (Probe your own/your household.)
 \$0-\$4,999 \$25,000-\$29,999 \$50,000-\$54,999
 \$5,000-\$9,999 \$30,000-\$34,999 \$55,000-\$59,999
 \$10,000-\$14,999 \$35,000-\$39,999 \$60,000+
 \$15,000-\$19,999 \$40,000-\$44,999
 \$20,000-\$24,999 \$45,000-\$49,999

Initial Involvements in Home Care

6. What health or disability problem required you to seek out home care services? (Check all that apply.)
 heart HIV/AIDS
 respiratory (breathing) disability/mobility problem
 bowel/bladder post-surgery (e.g., hip/knee replacement)
 diabetes mental health
 arthritis cancer

- stroke
- IV Therapy
- Other (please specify) _____

7. How long have you been receiving service?

8. At the beginning, was your need for home care services:

- extremely urgent
- very urgent
- urgent
- somewhat urgent
- not very urgent

9. The time I waited for the first visit was:

- a few hours
- a day
- two to seven days
- more than one week
- more than two weeks

10. Who determined that you needed care? (Check all that apply)

- Hospital
- Doctor while I was living at home
- Self
- Family member
- Friend
- Other (Please specify e.g., community agency, church.) _____

11. How did you manage while waiting for service to start?

12. How has your home care changed over time? (Probe needs, services provided, costs.)

The following are services you may be using. Some are fully or partially covered by the government home care program. Some are covered by other programs (e.g., Blue Cross, church, family, friends). Please tell us what services you receive, how often you receive them, and indicate how they are paid for.

Service	Use	How often? (daily, weekly,etc.)	How are they paid for?	How should they be paid for?
Personal Care (assistance with dressing, bathing, transferring)				
Home Support (assistance with housecleaning, shopping, household management)				
Family Care/Pet Care				
Yardwork (e.g., grass cutting, snow shovelling)				
Nursing				
Physical Therapy				
Occupational Therapy				
Respiratory Therapy (e.g., home oxygen)				
Speech Therapy				
Other Rehab (please specify)				
Medical Re-assessments (e.g., doctor visits)				
Transportation (e.g., seniors or wheelchair transportation service)				
House Renovations				
Home Delivered Meals (e.g., Meals on Wheels)				
Emergency Response Service (e.g., Lifeline, 911)				
Adult Day Care/Day Programs/Support for Visiting or Outings				
Respite Care				
Mental Health/Social Work/Psychologist/Psychiatrist				
Equipment (e.g., walker, bath seat)				
Prescription Drugs				
Delivery of Medications, Equipment, Supplies				
Other (please specify)				

13. Who co-ordinates the home care services you receive?
- self
 - family member
 - volunteer
 - home care employee (please specify) _____
 - other (please specify) _____
14. When I have a question, concern or complaint about my care, I know who to contact get results. (Probe: If you had a problem with a caregiver, what would you do?)
- strongly agree
 - agree
 - neutral
 - disagree
 - strongly disagree
- Comments:
- _____
- _____
15. I feel that all my needs are being met.
- strongly agree
 - agree
 - neutral
 - disagree
 - strongly disagree
- Comments:
- _____
- _____
16. Do you generally have the same home care providers on a regular basis? (Probe for continuity – same workers, same organizations, turnover rates, sudden changes to the care you are eligible for.)
- Yes
 - No
- If you answered no, please explain why. _____
- _____
17. Do you and your family have a say in who is paid to provide home care for you?
- Yes
 - No
- Comments:
- _____
- _____

Financial Issues

18. Are there extra financial burdens placed on you and your family because you need home-care?
 Yes No

If you answered yes, what kind of concerns do you have?

Safety and Security

19. How safe do you feel when receiving home care services?
 very unsafe
 somewhat unsafe
 neutral
 somewhat safe
 very safe

Can you explain? (Probe physical abuse, fatigue, living alone, protection from abuses by family members or caregivers.)

20. What would make you feel safer?

21. Besides home care, what other supports or people assist you on a regular basis?
(Please check all that apply.)

- family members (specify relationship: e.g., mom) _____
 friends: female male
 volunteer: female male
 church
 other (please specify)

22. What kind of activities do they help you with?

23. What other things (e.g., resources, hobbies) have helped you to cope with your situation?

24. Are you worried about changes to home care that you are hearing or reading about?

25. What would you like to see changed in the home care or family caregiving that you receive?

26. Do you have any other questions or comments?

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