

**RESPECTING FAMILY CAREGIVERS:
WHAT'S BEEN HAPPENING RECENTLY?**

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Thank you for the opportunity to address members of the Family Caregiver Network Society (FCNS) at your annual general meeting.

In my remarks, I want to do four things: First, talk about the current state of home care in Canada, the causes for this state of affairs, and some of the consequences. Second, review proposals for a Canada-wide home care program, as suggested by the National Think tank on Gender and Unpaid Care, and by Romanow and Kirby. Third, discuss the Accord on Health Care Renewal and federal budget of last February. Fourth, end with some observations, including what we might expect from Paul Martin as the next Prime Minister.

THE CURRENT PATCHWORK OF HOME CARE IN CANADA

What is the current situation with respect to home care services generally across the country? These very questions have been the subject of examination by the Kirby and Romanow reports, among others, in recent years.

Home care may be said to include a number of services: post-acute care, that is, services for short periods of time falling hospitalization; long-term or continuing care, addressing for instance chronic illnesses and mental health issues; home support care dealing with daily living activities such as meal preparation and house cleaning; preventive care which involves providing advice, education and perhaps advocacy; and end of life or palliative care for terminally ill and care for people with life threatening diseases. Also included is the focus of your Society's work – the provision of care and support for adult family members or friends at home (or in a care facility) who may be frail, elderly, chronically/terminally ill, or have a disability causing dependency.¹ Thus, informal care is a crucial element of home care that, in turn, is part of the larger health care and social services systems.

Overall, home care in Canada presently has the following features:

- Some form of home care programming is offered by each province and territory although not as a medically necessary service as defined, governed and financed under the *Canada Health Act*;
- Great variations exist across jurisdictions in eligibility, scope of services covered, whether user charges apply and how much for what services;
- In the 2000-01 budget year, 76 per cent of funding for home care in Canada came from provincial and territorial governments, 23 per cent from private sources, and just 1 per cent from the federal government directly;
- Provincial expenditures on home and community care have grown significantly over the last 25 years relative to other aspects of publicly financed health care;

¹ For more information, see the Family Caregivers Network Society website at www.fcns-caregiving.org.

- Nonetheless, while the biggest spenders on home care by far, provinces and territories spend on average less than 5 per cent of their health care budgets on home care services, and most of this is concentrated on “support for people with chronic health problems or physical disabilities;”²
- Informal caregivers, that is, family members and friends, are estimated to provide between 75 to 90 per cent of all home care in Canada;
- An estimated three million Canadians - mostly women [an estimated 80 per cent of care givers are women] - provide unpaid care to ill family members in the home;³ and,
- Formal volunteers provide an important supplementary role in providing care and support in homes to the services given by family and by professionals.

Home care in Canada is, at best, a “patchwork quilt,” not a beautifully finished tapestry but instead a rather rough one. As a field, home care has variable access, fragmented services, inadequate funding and the unavailability of services.

Why Such a Frayed Patchwork?

Why do we have this state of affairs with home care? What are the causes or contributing factors? Let me suggest several factors.

1. Home care provided outside of hospital settings is not covered under the *Canada Health Act*. Therefore, until now, these areas have not been an explicit part of the federal transfers payments to the provinces and territories for health care. This lack of financial and policy leadership from the federal government was made worse by funding cutbacks by Ottawa and by most provinces in the 1990s in health care more generally. Greater pressure and demands on families to provide home care has come about from “hospital transformations through closures, mergers, reductions in lengths of stay, and changes to the sizes and functions of hospitals.”⁴
2. Home care, until recently, was tangential to larger federal-provincial issues and disputes. The focus of health care reform has been dominated by the sharp dispute between the federal and provincial and territorial governments mainly over federal transfer payments to the other governments for financing the so-called core services of the health care system. In the context of federal cutbacks to

² Roy J. Romanow, Commissioner, *Building on Values: The Future of Health Care in Canada*, Final Report, November 2002, pp. 174 and 187.

³ Senator Michael J. Kirby, Chair, Report, *The Health of Canadians – The Federal Role*, Final Report, October 2002, Volume Six: Recommendations for Reform, Part 3, chapter 8.

⁴ *The Health of Canadians*, chapter 8.

health transfers, alongside deficits and rising health care costs, provinces' priorities have been to get Ottawa to restore its level of contribution to health care, especially in the areas of acute care, diagnostic equipment and to ease waiting lists. Thus, federal proposals for greater funding of home care has been viewed by provinces as a secondary priority, one that should only be addressed after federal funds for acute care and other core services are fully restored. Otherwise, provincial health ministers and premiers have regarded palliative care and other home care proposals as "boutique" programming, that is, nice but not core to meeting the immediate needs and challenges facing the sustainability of the health care system. Provincial reluctance is fueled also by memories of unilateral federal cuts to previous shared-cost initiatives emanating from Ottawa, which colours their reluctance to embrace yet another reform from Ottawa.

3. Gender politics is another contributing factor. Home care and family care giving are very much a women's issue in at least three ways. Women are far more likely to rely on home care services, especially among the elderly; women make up the vast majority of home care workers; and women also provide 80 per cent (or more) of unpaid care to relatives.⁵ Would there be more recognition, respect and resources for family care giving in Canada if the bulk of the burden rested with men rather than women? As Pat Armstrong observes: "Although women make many of the daily decisions related to health care, they are only a minority of the policy and management decision makers."⁶
4. Still a further factor is the way the health system is structured with an uneven distribution of authority and responsibility. Control over and responsibility for hospital care and home care are not consolidated in our health care system but rather dispersed. This division is underscored by differences in payment methods between most physicians (fee-for-service) and most nurses and social workers (salary). In the words of the Kirby report, "This has created parallel sets of entrenched interests, pitting organizations responsible for hospital care against those responsible for home care, and creating conflict that has foreclosed on or restricted opportunities for service integration, stifled innovation and put unnecessary limits on cost-effectiveness."⁷

⁵ Jean Ann Lowry, "Why Having a National Home Care Program is a Women's Issue," *The Canadian Women's Health Network Magazine*, Spring/Summer 2002, Vol. 5, Number 2/3., p. 3. Available at website <http://www.cwhn>

⁶ Pat Armstrong, "The Evidence Is In... It's Time to Act on Homecare," *The Canadian Women's Health Network Magazine*, Spring/Summer 2002, Volume 5, Number 2/3, p. 1. Available at website <http://www.cwhn>

⁷ *The Health of Canadians*, chapter 8. For a further examination of expertise turf wars, see Patricia O'Reilly, *Health Care Practitioners: An Ontario Case Study in Policy Making*, Toronto: University of Toronto Press, 2000, chapter 6.

Consequences of the patchwork

This fragmented and underdeveloped system of home care has consequences for individuals who are frail or ill, as well as consequences for their families as caregivers and for the health care system:

- Unnecessary hospitalization or institutionalization occurs of people who could be cared for at home if appropriate services were available, thus placing additional costs on an already stressed acute health care system.
- The widely varied access, benefits and practices of care create serious inequities and inefficiencies in the distribution and utilization of resources in society.
- The lack of various community-based services places considerable burdens on family members and other informal caregivers that can result in lost wages, possibly lost jobs, a decline in the health of the caregivers and “burnout.” It also can silence or muffle the voice of the terminally ill, their caregivers and the bereaved to speak out for decent and humane services.
- “Women receiving or giving care are subject to violence and other physical risks” with little if any training and support.⁸
- With significant needs going unmet, there is a widespread loss of choice and personal autonomy among Canadians, a fundamental ethical concern. As the Kirby report points out, “while over 80 per cent of Canadians die in hospitals, fully 80 to 90 per cent would prefer to die at home, close to their families, living as normally as possible.”⁹
- Legal as well as ethical concerns arise in that the lack of quality services results in a loss of the right to die with dignity and in relative comfort, and the right to spend one’s dying days in a setting of one’s choosing, including culturally appropriate or respectful care.¹⁰
- With these gaps and limitations in existing provision of end of life care, there might be a political risk that people will conclude that the health care system is uncaring, and thus reduce their support for Canada’s largely public system of health care.

⁸ Armstrong, “The Evidence Is In,” p. 1.

⁹ *The Health of Canadians*, 2002, Vol. 6, chapter 8.

¹⁰ On the patients’ right movement and related legal developments more generally in Canada, see Maureen A. McTeer, *Tough Choices: Living and Dying in the 21 st Century*, Toronto: Irwin Law, 1999.

Documented in countless research studies and government reports nationally and internationally, these consequences indicate a number of priority issues for action by governments and other organizations in Canada.

PROPOSALS FOR A CANADA-WIDE HOME CARE PROGRAM

In recent years a number of federal, provincial and non-governmental reports have studied the issue of home care and put forward recommendations on moving forward to a national policy.¹¹

I will briefly discuss three reports: the Charlottetown Declaration on the Right to Care; the Kirby Senate report on the federal role in health care; and Roy Romanow's report to the federal government on the future of health care in Canada. Across these reports an emerging consensus is apparent on making home care an essential service in the health care system.

The Charlottetown Declaration on the Right to Care

In November 2001, 55 leading Canadian experts on home care met in Charlottetown, at a National Think Tank on Gender and Unpaid Care, organized by the National Coordinating Group on Health care Reform and Women.¹² The initial purpose was to review the research and evidence on home care, and consider how it might be translated into policy. A related purpose, therefore, was to strategize on how to move home care up the health policy agenda of governments across Canada.

The participants at the Charlottetown conference concluded that enough evidence existed to design and implement a home care system that would work equitably for all women and men in Canada. From the meeting, came a Declaration on the Right to Care, endorsed by the vast majority of the participants.¹³ In part, the Declaration stated:

Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life without discrimination as to gender, ability, age,

¹¹ While there have been several recent provincial government reviews of the health care system, most have given relatively little attention to home care issues. See Cathy Fooks and Steven Lewis, *Romanow and Beyond: A Primer on Health Reform Issues in Canada*, Discussion Paper No. H/05, Ottawa: Canadian Policy Research Networks, November 2002. An important exception is *Strengthening home and community care across Canada: A collaborative strategy*, Report to the Annual Premiers' Conference, August 2002.

¹² The National Coordinating Group was formed in 1998 by the Centres of Excellence for Women's Health across the country along with the Canadian Women's Health Network and Health Canada's Women's Bureau.

¹³ Of the 55 participants, 46 signed the Declaration. Some participants were not in a position to commit their organization or government organization.

physical location, sexual orientation, socioeconomic and family status or ethno-cultural origin. The right to care is a fundamental human right.¹⁴

The vision, then, was that home care be an integral part of a publicly administered health care system in Canada, a vision that would be echoed a year later in Roy Romanow's report. The Declaration went on to identify several principles and requirements for the right to care. These were:

- Access to a continuum of public services and supports;
- Appropriate conditions, including culturally sensitive care;
- The choice to receive or not to receive, or to provide or not to provide unpaid care;
- That there is no assumption of unpaid care; and,
- Access to reasonable alternatives and sufficient information.

“The Declaration,” in the words of Pat Armstrong, “represents a fresh vision for Canada’s health care system that recognizes the role played by unpaid caregivers, and the interests of patients.”¹⁵

The Declaration noted frankly that, “Homes are not necessarily havens and hospitals can be dangerous to the health of patients and providers if conditions do not meet their particular needs or ignore the determinants of health.” Supports are as important as services in care giving: “care givers and those receiving care need supports such a training, paid leave to provide care, job security and income programs.”¹⁶

The Declaration, as a high-level vision statement, understandably did not recommend any budget estimates or administrative arrangements for implementing this right to care. Rather, it was an assertion that we know enough of this field to move forward, and not wait for yet another study to be done. It was a strong statement of the needs and experiences of women in care giving. And, it was a concerted call to action more than a detailed blueprint for organization.

The Declaration did offer that the system of home care be based on evidence about the effectiveness and the appropriateness of care, and that this evidence would provide “guidelines for providers and standards against which care can be compared.” Such guidelines and standards could then be used in some enforcement capacity to ensure the actual provision of services and supports to realize the right to care.

¹⁴ Quoted in Armstrong, “The Evidence Is In,” pp. 2-3. Further information on the Charlottetown Declaration is available from the Canadian Women’s Health Network website, <http://www.cewh-cesf.ca>.

¹⁵ Armstrong, “The Evidence Is In,” p. 2.

¹⁶ On the Charlottetown Declaration on the Right to Care, see the website <http://www.cewh-cesf.ca>.

The Kirby Senate Report

The final volume of the Kirby Report on health care, issued in October 2002, proposed a new national home care program as one way of “closing the gaps in the safety net.” Kirby’s vision is of a national publicly funded program of three months’ insurance coverage under the *Canada Health Act* for post-acute home care for people requiring treatment at home following hospitalization.” The full cost, that is, “first-dollar coverage,” should be borne by governments with the federal and provincial/territorial governments sharing the costs on a 50-50 basis. The Kirby Report estimated such a program would cost \$1.1 billion a year, with the federal government therefore contributing \$550 million annually. Such a comprehensive program, Kirby recommended, needed to be phased in over time with a “fiscally feasible expansion.”

Kirby also proposed the introduction of a national palliative home care program, to be designed cooperatively by the federal, provincial and territorial governments, and funded by them on a 50-50 basis. The estimated annual costs Kirby put at \$500 million of which the federal government would contribute \$250 million a year.

To complement the national home care program, Kirby endorsed other measures aimed at family caregivers of family members who are ill or have disabilities. These measures would include changes to the Employment Insurance program “to assist those who leave the workforce temporarily to provide informal care.” As part of a package of measures to improve the end-of-life care for Canadians, Kirby also suggested that the federal government study the feasibility of expanding the Caregiver Tax Credit and amend the Canada Labour Code to allow employee leave for family responsibilities.

The Romanow Commission Report

In his final report released in November 2002, *Building on Values*, Roy Romanow devoted considerable attention to the issue of home care, a field that he defined fairly broadly. He argued for making home care “the next essential service” in health care policy by designating certain aspects of home care medically necessary and thus funded under the *Canada Health Act*. The aspects of home care addressed by Romanow are post-acute care, mental health support, and palliative care.

To embed these into the Medicare system as core services, Romanow called for a specific investment by the federal government for these activities, by means of a Home Care Transfer in the amount of \$1 billion a year for two years, with the funds then to be rolled into a more general Canada Health Transfer. Of that amount, Romanow estimated that \$90 million a year would be for palliative care. Like Kirby, Romanow saw the need to implement a home care strategy in stages. Romanow saw these additional federal dollars as freeing up “a substantial amount of funds in current home care budgets” of provincial and territorial governments.¹⁷ He also envisaged that the provinces and territories would

¹⁷ *Building on Values*, pp. 176-78 and 187.

match or exceed the federal dollars for priority home care services, thus moving toward an eventual national home care strategy.

In his examination of home care, Romanow devoted some attention to the role of informal caregivers. “Quite simply,” Romanow reported, “home care could not exist in Canada without the support of social networks and informal caregivers.”¹⁸ He observed that,

Informal caregivers play an essential role in the delivery of home care services and in the health and care of their families and friends. Many informal caregivers are more than happy to provide care and support to their loved ones, but the reality is that caregiving is becoming an increasing burden on many in our society, especially women.¹⁹

“With more and more Canadians being treated at home rather than in other care centers,” Romanow noted that “the burden on informal caregivers has grown significantly. ... Thousands of parents, loved ones, family and friends ... provide direct support in the home. That support should be recognized by allowing informal caregivers to take time off work to qualify for special benefits under Canada’s Employment Insurance program.”²⁰

Romanow abstained from making specific recommendations on eligibility criteria or costs of this measure, although he believed it could be funded with resources currently available in the Employment Insurance program.

THE 2003 ACCORD ON HEALTH CARE: IS HOME CARE THE CINDERELLA OF REFORM?

This past February, the prime minister and 10 provincial premiers (though not the three territorial leaders) reached agreement on a five year, \$27 billion expenditure of new federal funds for various health care initiatives.²¹ The accord is described as an action plan for reform with the ultimate purpose of ensuring that Canadians have, among other things, “access to quality home and community care services... no matter where they live.”

The heart of this accord is a Health Reform Fund of \$16 billion over the period 2003-04 to 2007-08. The Fund is directed at supporting program expansion in areas recommended by the Romanow and Kirby reports plus other recent studies on health care. The Health

¹⁸ *Building on Values*, p. 183.

¹⁹ *Building on Values*, p. 184.

²⁰ *Building on Values*, pp. xxxi-xxxii.

²¹ Two weeks later, on February 20, 2003, the three Territorial Leaders reached an agreement with the Prime Minister over an additional \$60 million for health care, in a new territorial health fund, to be shared among the three territories in recognition of the extraordinary costs of delivering health care in the North.

Reform Fund is for provincial and territorial activities in three areas, namely, catastrophic drug coverage, 24-hour primary health care clinics, and home care.

Directing substantial funds to reform the health care system was clearly a high priority of the Prime Minister going into the meeting with the other first ministers. An important trade-off to this federal initiative was the concession to provinces for flexibility in determining how much funds will be devoted to each of these areas, including relative amounts for palliative care, post-acute home support, and community mental health services. These are, after all, areas of primarily provincial jurisdiction and responsibility under Canada's constitution. In the words of the Health Accord:

Recognizing that provinces and territories are at differing stages of reforms in these areas [primary health care, home care and catastrophic drug coverage], the Fund will provide the provinces and territories the necessary flexibility to achieve the objectives set out below. Premiers and Territorial Leaders agree to use the Health Reform Fund to achieve these objectives. Therefore, these funds to be transferred to the provinces and territories will be available for any of the programs described within the Health Reform Fund, at their discretion. Achievement of the objectives of the Health Reform Fund by a province or territory will allow use of any residual fiscal resources in the Fund for other priority areas of their own health system.²²

On home care for Canadians, the Health Accord states:

Improving access to a basket of services in the home and community will improve the quality of life of many Canadians by allowing them to stay in their home or recover at home. First Ministers direct Health Ministers to determine by September 30, 2003, the minimum services to be provided. Such services provided in the home can be more appropriate and less expensive than acute hospital care. To this end, First Ministers agree to provide first dollar coverage for this basket of services for short-term acute home care, including acute community mental health, and end-of-life care. First Ministers agree that access to these services will be based on assessed need and that, by 2006, available services could include nursing/professional services, pharmaceuticals and medical equipment/supplies, support for essential personal care needs, and assessment of client needs and case management.²³

Within its own jurisdiction, the federal government will complement these home care efforts by introducing a "compassionate care benefit" to be delivered through the Employment Insurance program and for job protection through the Canada Labour Code,

²² 2003 First Ministers' Accord on Health Care Renewal, February 5, 2003, p. 2

²³ Ibid. pp. 3-4.

“for those who need to temporarily leave their job to care for a gravely ill or dying child, parent or spouse.”²⁴

Beginning in 2004, First Ministers agrees to prepare an annual public report to their citizens on these three areas, including information “on current programs and expenditures ... as well as on service levels and outcomes.”

The First Ministers’ Accord, both symbolically and substantively, demonstrates a level of shared leadership to restore Canadians’ confidence in the health care system. It does this, by government leaders publicly reaffirming the values of Medicare; by taking steps to improve the transparency and accountability to the public; by further restoring federal funding to core services; and by investing further funds to modernize and enhance health services.

On home care, Romanow had recommended a targeted fund specifically for this area over the next two budget years along with similar funds for primary health care and for catastrophic drug coverage. Romanow intended these three transfer funds to serve as a platform to generate the transformation of our health system. The 2003 Health Accord, by comparison, lumps the three transfers into the one Health Reform Fund, and providing provinces and territories with less money, but with more flexibility in allocating the funds, than either Romanow or Kirby had recommended.

Home care, then will have to compete with primary care and drug coverage for the resources allocated to the Health Reform Fund. There is no specific portion devoted to home and end-of-life care under the Fund.

A reasonable concern, I believe, is that home care will be the Cinderella to the favoured sisters of primary care and catastrophic drug insurance. So, at present, it is not known how much or how little of this \$16 billion investment is for home and palliative care. We will get an idea beginning in 2004 when provinces start producing public reports on their expenditure choices under the Fund.

Romanow also recommended that the *Canada Health Act* be amended to include priority home care services so as to ensure ongoing federal funding to this area and to have health care develop beyond hospitals and medical services. The Health Accord is silent on this, although the First Ministers’ did promise, “to set certain national objectives in regard to homecare.”

²⁴ In fact, the federal department of Human Resources Development Canada had been working on a national care leave benefit since 2001. Initially the focus was on a benefit for working parents who need to leave work to care for severely ill and dying children. This focus was expanded to include caring for terminally ill and dying family members of any age, a focus reflected in the September 30, 2002 Throne Speech. See Norma Greenaway, “Ottawa eyes compassionate leave benefits,” *Times Colonist*, December 9, 2002, p. A3, and “Ottawa readies compassionate leave scheme,” *Times Colonist*, January 7, 2003, pp. A1-A2.

The February 2003 Federal Budget

The general policy outline and some details of the Health Accord were confirmed in the federal budget delivered by Finance Minister John Manley in mid February. With respect to home care, the budget established the following elements:

- The long term funding framework for the Health Accord, including the \$16 billion for the Health Reform Fund;
- Replacing the Canada Health and Social Transfer with two new transfers, a Canada Health Transfer and a Canada Social Transfer effective April 2004; and,
- A six-week compassionate family care leave benefit, delivered and financed through the Employment Insurance program, to enable working Canadians to care for gravely ill or dying family members. To take effect January 2004, the benefit can be shared among family members who are eligible for the benefit under Employment Insurance. The estimated cost of this new benefit will be \$221 million a year starting in 2004-05.

Most of the \$16 billion for the Health Reform Fund - \$10 billion or 63 per cent – is not allocated until the final two years of this five-year commitment. Financial support under the Fund for primary care, drug coverage and home care grows from \$1 billion in 2003-04, to \$1.5 billion the next year, then \$3.5 billion, and then \$4.5 billion and finally \$5.5 billion on 2007-08. This staged-approach reflects what both Kirby and Romanow suggested as a funding approach. It also fits with the schedule of the Health Ministers to determine by October, 2003 the minimum services in home care and community care to be provided; and fits with the plan that governments will prepare annual public reports on these expenditures commencing in 2004. The federal budget also confirms that starting in 2008-09, the funding through the Health Reform Fund will be integrated into the new Canada Health Transfer.

On announcing the new compassionate family care leave benefit, Finance Minister Manley said:

Our renewed commitment to health care recognizes the individual contribution of Canadians in building a healthy and compassionate society. Those who are gravely ill and dying often want to be cared for in the place they know best, and by those they love best: in their own homes and by their own family. Too often family members must make difficult choices between work and being able to provide compassionate care. This budget expands the employment insurance

program to allow compassionate care leave from work for those who must look after a gravely ill child, parent or spouse.²⁵

This innovative federal program comes from recommendations advanced in recent years by federal reports and by other groups who have been promoting better support for family caregivers. In media reports about this initiative, the response has been positive, noting the leadership that the federal government is taking on end-of-life care and for the financial assistance this will offer.²⁶

A social policy think tank, the Caledon Institute offers, in my view, a balanced assessment of the new compassionate family leave benefit.

Because the compassionate leave provision will be embedded within an amended Employment Insurance Act, the measure not only will sanction a period of leave. It also will allow for *paid* leave so that caregivers will have some relief from the heavy costs of care giving.

Clearly, this important first step is just that – a first step. It will not include the many thousands of caregivers who either had to quit their job in order to provide care at home or who themselves are elderly spouses caring for their ailing partners. The needs of these caregivers are just as important and should be met in other ways. Nor will the new Employment Insurance benefit help the many thousands of caregivers who may need some paid leave for care giving responsibilities – but whose relatives are not gravely ill or dying.²⁷

The Caledon Institute optimistically views this new provision for compassionate leave as one of many in a growing package of supports for respite for caregivers. They also sense the politics of legitimate claims by other caregivers, not covered by this new benefit, for similar recognition of their work.

It is far too early to adequately characterize what these announcements will actually mean for the provision of home care. Many details remain to be resolved concerning policy, funding and delivery practices. Will home care, for example, be added under the *Canada Health Act*? Not in the foreseeable future. Have it's own federal legislation? There has been no mention of this option in Ottawa. Or, through regulations, perhaps home care will be added to a new Canada Health Transfer in a few years? This might be what occurs.

The First Ministers' Health Accord does promise a significant expansion of home care funding and thus coverage for Canadians, making home care an integral part of the public

²⁵ The Hon. John Manley, Minister of Finance, *The Budget Speech*, Ottawa: February 18, 2003, p. 4. Available at: www.fin.gc.ca/budget03/speech/speeche.html.

²⁶ See, Rod Mickelburgh, "Budget gives a hand to caregivers for terminally ill," *The Globe and Mail*, February 19, 2003, p. A12.

²⁷ Ken Battle, Sherri Torjman and Michael Mendelson, "The 2003 Budget: Political Legacy Needs Policy Architecture," Ottawa: Caledon Institute of Social Policy, February 18, 2003, p. 12.

health care system. This is an important first step in implementing a national strategy on community and home care. Despite the intergovernmental acrimony that surrounds this latest health care agreement, the Health Reform Fund has the potential to make our health care system not only more workable, but also more accessible, equitable and cost-effective.

STAY INFORMED AND INVOLVED

Provincial premiers together have identified several objectives in reforming home care. A possible risk, I think, is not that the premiers take no action in this area, but that they concentrate limited time and funds on politically easier or more attractive reforms at the expense of changes that are more fundamentally needed. My concern is that provincial ministries will focus on introducing health technologies; developing common data elements for classifying clients, services and outcomes; and changing organizational structures in the name of improving the co-ordination of system-level case management.

All of these initiatives are no doubt valuable and promise efficiencies, yet they do not directly attend to the pressing need for compassionate and active support to individuals, families and caregivers. One of the gaps in the Health Accord, in my view, was the lack of a specific reference to the respite, to the supports and services that offer relief to caregivers, ideally in a form that is appropriate to their needs.

Far more seriously, some provinces, including our own, are cutting ministry budgets for home support for the frail, the elderly and persons with disabilities. As a result, ever more responsibility for care giving is off-loaded onto already stretched and stressed family members and friends.²⁸ With diminishing public support, who benefits? Whose needs are being met? And who pays? Not just financially but also emotionally, physically and spiritually. Caregiver support groups will only become more critically needed in our community and others throughout British Columbia.

Enter Paul Martin

What might we expect from Paul Martin as our next Prime Minister in this area of home care and caregiving?

There are some encouraging signs. One is that when Finance Minister, Martin introduced numerous tax assistance measures for persons with disabilities and for family members caring for relatives. In 1997, for example, Martin introduced a new refundable tax credit for low-income working Canadians with high medical expenses. In 1998 he made tax changes to allow homeowners to use the Home Buyers' Plan, under Registered Retirement Savings Plans, to purchase a more accessible home or a home for a dependent

²⁸ See, for example, Friends of Women and Children in BC, "BC Health Care Cuts and Caregivers: Diminishing Support, Shifting Responsibility," *Report Card*, January 15, 2003, Vol. 2, No. 1. Available at website www.wmst.ubc.ca.

relative with a disability. In 1999, he introduced a new tax credit for caregivers for persons residing with and providing home care for elderly relatives or for an infirmed dependent relative.²⁹

A second promising sign is that during the Liberal leadership campaign, earlier this year, Martin pledged to develop a national home care program. At a leadership debate in Charlottetown, Martin stated, that a national home care program is “important because families want the flexibility to be able to take care of their loved ones at home. It’s important because we have an increasingly aging population. It must be an integral part of any health care system.” Martin is also quoted from that debate as saying, “the caregiver is essential if the home care system is going to work.” Reduced stays in hospitals can only be achieved, if there are home care services available. Martin’s program for a national home care strategy is admittedly sketchy, but, in language reminiscent of Romanow, includes providing access to a core set of insured services [likely under the *Canada Health Act*]; establishing acute and palliative care services as priorities; and providing tax relief and respite services to caregivers. Such steps would provide a platform for building a national approach to home care over the next several years.³⁰

Enter the Community

What to do at the community level? We can get involved at the local, regional, provincial or national levels. The FCNS can continue the important work of informing policy and program discussions with your experiences, your ideas, your information and knowledge. You can document the work of family caregivers, record and share personal stories.

Groups such as this one must continue advocating for the availability of accessible and appropriate support services and for respecting family caregivers as genuine partners in care.

In addition to discussing home care in terms of rights - the approach taken in the Charlottetown Declaration, for instance - there are, of course, deeper moral aspects that touch on our sense of community, humanity, dignity and choice. The reason why a wide cross-section of the public needs to be involved in this policy issue is because home care raises large questions about the respect and support we provide the frail and ill, family caregivers, and the formal health system. In short, what kind of society do we truly wish to be?

²⁹ For more details, see Michael J. Prince, “Tax Policy as Social Policy: Canadian Tax Assistance for People with Disabilities,” *Canadian Public Policy*. Vol. 27, No. 4, 2001, pp. 487-501.

³⁰ “Martin promises a national home care program,” May 24, 2003, at website <http://www.paulmartintimes.ca>.