MARITIME CENTRE of EXCELLENCE for WOMEN'S HEALTH

Equity and Diversity Approaches for Women Care Caregivers: The Impact of Health Reform

Centre of Excellence for Women's Health - Consortium Université de Montréal

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EXECUTIVE SUMMARY

The health and social services system reform in Quebec, as in several Canadian provinces, is focussing on the development of continuous care in people's living environment. A number of services are affected, including in relation to the *trend toward more ambulatory care*, which makes it possible to avoid or shorten hospitalizations and which is in addition to the deinstitutionalization of persons suffering from mental health problems or from physical or intellectual impairments and to home care for the frail elderly, including end-of-life home care. The rate at which the changes are occurring has increased very quickly and under pressure from such large reductions in public health spending that the measures which should have been developed first were neglected - that is, reinvesting sufficiently in CLSC[1] home care, in order that persons released early from hospital might receive in their home the care they need.

This reform is aimed at promoting integration and complementarity of services, as well as co-operation among the various health institutions, against the background objective of improving the efficiency of the overall system. It calls for a new division of responsibilities between families and the State. However, analysis of the policies of the Quebec department of health and social services, the regional boards and the CLSCs reveals that the public system is tending to redefine its role as one of support or back-up for family and community resources, and that it generally considers caregivers necessary resources in connection with its objective of keeping dependent persons in the community. The services provided to caregivers essentially serve to keep them from suffering burnout, in order that they may continue to fulfil their commitment. Thus, the availability of assistance from the family is becoming a routinely used criterion in assessment of needs and allocation of home care services.

Over-representation of women among caregivers has been found in most of the research on informal care for family members who are sick or frail, regardless of the community. Various studies also confirm that, if the caregiver is a man, use of formal and informal support is different. This points to the pressure exerted by the social roles women are expected to play.

In the context of the trend toward more ambulatory care, the home is becoming a formally recognized location for provision of care and family members are increasingly being considered caregivers. The complexity of care is increasing, without sufficient preparation of the caregivers, whose responsibilities are growing. The role of caregivers is no longer limited to providing psychological support or assistance with the tasks of daily living; rather, it involves increasingly difficult and complex care. The caregiver is often obliged to provide co-ordination of fragmented services and to learn to provide care with little preparation, and this is a source of anxiety and raises ethical and legal issues with respect to responsibility when errors are made in treatment. In addition, the transfer of costs that used to be covered in the institutions, with these costs becoming private expenditures by households, is increasing, such that some organizations are talking about the "soft privatization" of health services.

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[1] In Quebec, the mission of a local community service centre (CLSC) is to "offer, at the primary level of care, basic health and social services of a preventive or curative nature, and rehabilitation or reintegration services to the population of the territory served by it. (R.S.Q., Chapter S-4.2, section 80).

Some writers speak of the impact of this role on the living conditions and quality of life of women, as well as on their health (stress, anxiety, physical and psychological burnout), and on their personal and family life and life as part of a couple (role conflicts being a sources of tension on many levels), and in terms of obstacles to participation in other social activities in their jobs, recreation or volunteer work. Considering the increased presence of women in the labour force, the demands connected with the role of caregiver are therefore exacerbating the problems connected with reconciling family responsibilities and responsibilities as a paid employee.

The consequences of care responsibilities for someone who is sick are different in some respects in the ethnocultural communities. Women who have recently arrived in Canada and find themselves caregivers, in accordance with Quebec's health and social services system standards, are finding themselves torn between their childcare responsibilities and their responsibilities with regard to support for sick parents, in a context of often unstable working conditions. In addition, the excess workload and the isolation that flow from these many responsibilities are contributing to slower adjustment to the host society and are increasing these women's vulnerability. Certain specific aspects of family dynamics, cultural norms, social relationships between men and women, and the meaning assigned to assistance must also be considered in the orientation and implementation of more culturally suitable home care.

In Aboriginal communities, studies on intergenerational co-residence show that this situation is nearly twice as frequent among Aboriginals than in the rest of the population, owing to factors related to the persons' socio-economic situation and to family and cultural values. Elders are considered active members and play an important role in family life, providing support to younger generations both on a spiritual level and with regard to protecting cultural heritage. In addition, jurisdictional issues complicate delivery of continuous care in the living environment for the First Nations and Inuit communities. Consequently, there is a need to study the situation of female caregivers in Aboriginal communities more systematically, in order to understand the dynamics of care, the burden created by and the specific characteristics of the caregivers' responsibilities, the impact on their health, and the socio-community support available in the community.

Increasing efforts are being made in Quebec to correct the negative impact of the health system reform on female caregivers and to develop support in the population, in order that these women's needs may be recognized and in order that appropriate support measures may be put in place. To feel comfortable in their role as caregivers, these women must have the choice of helping of their own free will, without pressure from public services. They must also have available to them real alternatives to family care. With the action of caregiver support groups, women's networks and community and union organizations, more and more attention is being paid to the issues of respect for personal choices, effective support and empowerment of female caregivers in discussions concerning the impact of health system reform in Quebec.

INTRODUCTION

The purpose of this document is to analyse health care reform in Quebec and its impact on women caregivers.[1] The gender equity perspective which informs this analysis provides a means of highlighting a number of unexpected consequences of health and social service policies that were developed without due consideration for their specific impact on women, particularly women caring for sick or dependent family members. This analysis also considers the diverse experiences of women caregivers with respect to such factors as family relationships, living conditions, place of residence, and ethnocultural background, in order to shed light on the role of diversity in a multiethnic and multicultural society. A review of research findings on women's experience as caregivers will provide guidance in formulating recommendations which address the difficulties of caregiving.

The issues which are shaping the environment of health care "reform" in Quebec, as well as decision-making processes in such areas as policy, planning and service organization, must also be considered, since the goal of influencing policy will not be achieved merely by presenting convincing data. In Quebec, the actions of caregiver groups, feminist, community and union networks, health care professionals, researchers and allies within government are converging, in an effort to ensure that the situation of women caregivers is placed at the forefront of social concerns. Recognition for the contribution and the needs of all women who provide care, as well promoting the health and well-being of women, and eliminating gender bias in health and social service policies and programs, are emerging as important goals.

A brief overview of the health care system in Quebec and the constraints under which it must operate will serve to contextualize the changes which the health care network and service delivery are undergoing, particularly in the area of home support. This overview is followed by a summary of the effects of health care reform on families and on women in particular, based on a review of recent research on this subject. Against this backdrop, the Quebec situation can be examined with its challenges, strengths and potential for action.

AN OVERVIEW OF HEALTH CARE SYSTEM REFORM IN QUEBEC

Reform of the health and social services system in Quebec was undertaken in order to respond to the evolving health needs of a changing population, the emergence of new knowledge, and a range of internal and external constraints which have become more acute throughout the system during the past decade.

INHERENT CONSTRAINTS OF THE HEALTH CARE SYSTEM

Public health insurance, which, since the late 1960s, has ensured the achievement of the important principles of universality and of equal access to services enshrined in the Canada Health Act, enjoys widespread popularity among Canadians. It also confers legitimacy on government intervention and the significant public funds which are dedicated to health services. Since the late 1980s however, economic globalization has led governments to exercise greater control over public spending in order to maintain their competitiveness, as well as their autonomy in the face of the pressures exerted by the financial markets. The health care system, which consumes a large portion of government expenditures, has been targeted, not least because the rising cost of maintaining the system appears to have had little effect in terms of improving population health (Conseil des affaires sociales 1990; Ferland and Paquet 1994; Contandriopoulos 1994).[2]

A variety of constraints have increased financial pressures, as well as the need for change in the area of health care delivery. They include: demographic changes, (increased life expectancy and decreasing fertility rates, leading to population aging and increased life expectancy for people living with impairments); the greater diversity of cultural norms and values within the population associated with the influx of new immigrants from a variety of backgrounds; the development of new biomedical technology, (which offers the possibility of providing more complex levels of care in outpatient clinics and in the living environment, as well as in-home care for people with increasingly severe degrees of impairment); the emergence of new diseases that require a significant investment in research and expensive treatments (AIDS, Alzheimer's disease, antibiotic-resistant infections, etc.); new knowledge about the determinants of health, (a factor which places the contribution of the health care system to population health in a new perspective); centralized regulation and institutional rigidity, which leads to the fragmentation of services (Angus et al. 1995; Armstrong and Armstrong 1996; Contandriopoulos 1997).

Improved access to health information has also brought about a change in service utilization patterns within the population. Increasingly, those who seek medical services are refusing to be treated simply as "patients" and are taking on the role of informed consumers who wish to participate in the decisions concerning their health; this is particularly evident among the more affluent and educated members of the population. These kinds of attitudinal changes signal a shift in values toward greater individual autonomy, the social integration of people living with impairments, and a greater involvement of patients in treatment choices, including the choice to die at home. Feminist discourse on women's autonomy and control over their own bodies has also contributed to

this shift in values toward a greater involvement on the part of health care consumers; in turn, these changes require health care professionals to modify their approaches.

These changes call for complex choices. A variety of models have been proposed to review regulatory frameworks, health system functioning, as well as service delivery mechanisms, while striking an appropriate balance between efficiency, equal access to services and users' freedom of choice.

CHANGES IN THE ORGANIZATION OF THE HEALTH AND SOCIAL SERVICES SYSTEM IN QUEBEC

In 1985, the Quebec government directed the Commission d'enquête sur les services de santé et les services sociaux (the Rochon Commission) to conduct an in-depth review of the orientations and organization of the health and social services network established in the 1970s. The work of the Commission, which tabled its report in 1988, led to the health and social service reforms of the 1990s.

The purpose of these reforms is to promote greater service integration and complementarity, to encourage joint action by health institutions and, ultimately, to improve overall efficiency within the system. The goal of equal access to services is no longer predicated on the quantity of services which are offered to the population; rather, it refers to efficiency in the area of treatment choice, as well as access to the services which can contribute most effectively to improving the health of individuals. Since the 1980s, these changes have taken place in the context of health care funding cuts, regardless of which political party has been in power in Quebec City or Ottawa. The situation has been much the same in most developed countries[3] (Contandriopoulos 1991; National Forum on Health 1997).

In the 1990s, the restructuring of Quebec's health and social services system has been

effected through the service organization plans developed by the Régies régionales de la santé et des services sociaux (Regional Health and Social Services Boards).[4] This has involved transferring a portion of health and social services to families and friends (most often women), as well as to the community sector, which is increasingly feeling an obligation to meet the needs which the public system is no longer capable of addressing[5] (Regroupement des organismes communautaires de la région 03, 1997; Regroupement intersectoriel des organismes communautaires de Montréal 1998). These "reforms" are an extension of the deinstitutionalization of the mentally ill and the elderly which began in the 1970s and comprise a complex range of political, legislative, financial and regulatory interventions.[6]

A highly diversified range of services are affected by this sweeping reorganization. The *shift to ambulatory care* has led to an increase in day surgery and a reduction in the length of hospital stays, not only for medical or surgical treatments, but also for childbirth; there is also greater emphasis on deinstitutionalization and maintenance in the community of individuals of all ages who suffer from mental illness or physical or intellectual disabilities, as well as on home support for frail seniors, up to and including end-of-life home care.

The *shift to ambulatory care* was implemented precipitously, in order to meet the *zero deficit* objective set at the socio-economic summit of March 1996, an event which involved stakeholders from a variety of sectors.[7] As the average length of hospital stays went from 8 days in 1993-1994 to 4 days in 1997-1998 and the rate of day surgery increased by 20%, more than 5,000 hospital beds were being closed in Quebec and nine Montreal hospitals were either closed or converted into other types of facilities.[8] This *shift* was accompanied by a significant reallocation of financial resources in order to effect the substitution of more costly

institutional services with less expensive services in the living environments of individuals.

Clearly, the success of this reorganization is directly dependent on the availability of resources which provide alternatives to hospitals, namely services provided in the home or in the living environments of individuals. However, as events quickly unfolded under the pressure of significant funding cuts in health spending, the services that needed to be in place were in fact neglected. Sufficient funds should have been reinvested in CLSC home care to ensure that patients discharged early by hospitals could obtain the care they needed at home. Although total budget of the CLSCs[9] grew considerably, increasing from $686 million in 1993-1994 to $870 million in 1997-1998, it should be kept in mind that CLSC funding accounts for only 8% of the total budget of the publicly-funded health and social services network and that most of the new funding was not made available until the final year of the three-year plan developed by the regional boards for 1995-1996 to 1997-1998. Efforts were made to improve access to services, an example being the implementation of Info-Santé CLSC, a telephone information service in which nurses provide front-line health information. This service, which is available 24 hours a day, seven days a week, was being offered by all CLSCs by 1994-1995.[10] It is primarily intended for those who are sick or incapacitated and living at home, as well as their families, and may be viewed as an integral part of the home care continuum. Moreover, the overflow caused by the sudden increase in demand for post-hospitalization home care and a lack of adequate resources to respond to this demand, has meant that CLSCs have had to neglect the prevention work which is central to their mandate.[11]

Although the portion of health spending dedicated to home care rose in Quebec from 1.7% in 1990-1991 to 2.4% in 1997-1998, the

province has lagged behind the Canadian average, which increased from 3.3% to 4% during the same period.[12] The rapid development of home care occurred during a period in which the health and social services system was experiencing significant budgetary constraints. This paved the way for private providers in the home care and home services sector (nursing care, diagnostic and remote monitoring equipment, technical aids) to fill the gaps in the public system.

QUEBEC HOME CARE POLICY

The Quebec home care program has three aims: social integration of disabled individuals and the prevention of institutionalization; substitution of home care for accommodation and hospitalization services; and the participation of individuals and the community (MSSS 1994). In addition, the Quebec government's health and welfare policy recognizes the important role played by care givers and acknowledges that "[translation] the continued social integration of individuals involves the development of various types of support in the community, in particular a definite increase in support to informal caregivers, increased amounts of home care and the availability of light respite and relief care resources" (MSSS 1992: 126).

Still, a far different reality emerges from a recent study which analyses the policies of the ministry of health and social services (MSSS), as well orientation documents produced by the regional boards and the Fédération des CLSC du Québec (now known as the Association des CLSC et CHSLD du Québec), and internal CLSC policies:

> [translation] At the same time, the network and, therefore, the government of Quebec, have shown a tendency to redefine their role as that of performing a supportive or adjunctive function in relation to family and community re-

sources. The state sees women caregivers as an important resource, although largely because they are an essential part of achieving the goal of maintaining dependent persons in the community. It is in this capacity only that women caregivers are provided support by the state: services are only offered to the women who are most heavily involved in providing support to dependents, and are essentially granted so that caregivers do not become burnt out and unable to maintain their level of involvement (Lavoie et al. 1998: 81).

Clearly, the availability of support from family has become a criterion which is regularly used in assessing need and allocating home care services.

This representation of women caregivers as a resource, and the essentially utilitarian approach that is taken to providing them with support, reflect a lack of consideration for their needs. This is at odds with the general portrayal of family and community resources as partners in achieving the goal of maintaining frail persons at home. In reality, there is little room for involvement of care recipients and caregivers in the negotiation of goals and strategies. A more useful approach would be to "[translation] offer a range of solutions to care recipients and care providers so that they may have a choice. Such a paradigm shift implies a recognition that caregivers who assume a predominant role in caregiving should be entitled to receive a high level of support from the state" (Lavoie et al. 1998: 81).

A few regional boards and CLSCs have attempted to avoid narrow or utilitarian attitudes towards the role of women caregivers, although they admit that the limited resources at their disposal seldom permit them to implement their more generous philosophies.

THE IMPACT OF HEALTH CARE REFORM ON FAMILIES AND WOMEN

Health and social services reform raises a number of key issues for society in general and for women in particular. Moreover, the transfer of services under restructuring is not yet over: "[translation] three quarters of all care given to seniors is given in facilities, and only one quarter is given in the home. Ultimately, within the next few years, Minister Rochon would like to see this ratio brought to 50-50, which would be in line with current trends in many industrialized countries" (Gagnon 1998: A-21). This represents a substantial transfer of services, responsibilities and costs to families and friends, and the trend will accelerate in the future.

THE TRANSFER OF SERVICES, RESPONSIBILITIES AND COSTS TO FAMILIES

The restructuring which is underway calls for new ways of sharing responsibilities between families and the state. In the case of home care for the elderly, which was developed before the current restructuring, families have been the primary, if not the only, source of support. A survey of Canadian, Quebec and American research on the care of the elderly, conducted in the early 1990s, revealed that 70 to 80 percent of personal care services were provided by family, whereas community groups and the state contributed only 10 percent (Garant and Bolduc, 1990). More recent research has confirmed that families still provide 70 percent of the nursing care and assistance required by the frail elderly who live at home and receive services through the health and social service network (Hébert et al. 1997).

The transfer of services will increase the role of caregivers, which will no longer be limited to providing psychological support or assistance in the activities of daily living, but will involve the provision of increasingly complex levels of care.[13] Both the time needed to dispense services and the level of concern about the changes which are taking place have increased considerably. The transfer of care and services to the home is accompanied by a transfer of responsibilities: caregivers are often obliged to coordinate fragmented services and must learn to provide care with little preparation; this leads to anxiety and raises the question of liability in the event of errors in the delivery of treatment, as well as a number of ethical issues.

These responsibilities, which are largely assumed by women, entail significant human, social and economic costs. A study published by the ministry of health and social services (MSSS) "[translation] confirms the value of support provided to the frail elderly living in the home by friends and family. This contribution accounts for more than half of all costs and generally represents between $37 and $60 per day, depending on the value ascribed to it (private or public sector costs). Many studies have demonstrated that natural caregivers, most of whom are women, take on a considerable physical, psychological, social and economic burden (Garant et Bolduc 1990). Such stress is harmful to women's health and can interfere with their ability to function, thereby generating significant indirect social costs" (Hébert et al., 1997: 260). The same study proceeds to demonstrate that "with costs assumed by the public sector, there is a clear demarcation between home support, light residential care, and chronic care" (Hébert et al. 1997; viii).

In addition, the cost of services which were formerly covered by the state when provided in institutions is increasingly being transferred to families. Notable examples include the cost of drugs and equipment formerly provided free-of-charge in hospitals, increased transportation costs for medical appointments, and private insurance costs to add liability coverage for in-home post-hospital care. This trend is being

referred to by some as the "privatization by stealth" of health services.[14]

Economic analyses of the reorganization of health and social services must take into account not only the improved efficiency of the public network in the short term, but also cost-effectiveness prospects regarding the longer-term health of care recipients and caregivers (MSSS 1991, 1994, 1996; Angus et al. 1995). Unexpected consequences of the reorganization of services could generate further long-term costs in order to provide care to the caregivers themselves, as well as to the sick or disabled individuals receiving home care whose reinstitutionalization could be made necessary by the exhaustion of their support network. We should also add that efficiency analyses in terms of public health spending must be contrasted with overall costs, including private expenditures for families as a result of the reorganization of services. Such considerations cast doubt on a narrow vision of the efficiency of the health and social services system which focuses exclusively on reducing public spending and the budgets of institutions and under-estimates the economic impact of health system restructuring on families and on caregivers in particular.

THE GENDER EQUITY PERSPECTIVE

Restructuring is taking place without due consideration for gender relations within the family sphere. During the past thirty years, family life in Western countries has undergone significant changes, including declining fertility rates, a greater diversity of family models (single parent families, step-parent families, immigrant families with different cultural norms, homosexual couples), increased life expectancy, as well as changes in intergenerational relationships. Emotional connections between family members continue to play an important role in the development of personal equilibrium, and mutual support among family members remains an important social norm. Today, however, intergenerational relationships are increasingly being negotiated and they no longer have the same meaning as they did for earlier generations. The family network has become smaller and women – increasing numbers of whom now work outside the home – are faced with heavier responsibilities, including, in some cases, the provision of care for both their children and their aging parents. Such changes are having an impact on the ability and willingness of families to assume responsibility for sick or dependent relatives.

The policies which are guiding the restructuring of the health care system are affecting men and women quite differently, given the expectation that women have the primary responsibility of care for family members. A brief overview of recent research into women's experience of providing care illustrates how this reality plays itself out. "[translation] In general, a single family member assumes the primary support role towards frail seniors, and this individual is a woman in 70 to 80 percent of cases. One out of every two women in Quebec between the ages of 35 and 64 can expect to take care of an elderly parent (Garant and Bolduc 1990: 33). North American studies are all in agreement on this point: natural or family caregiving are euphemisms for care given by women" (Brody 1981, 1987, 1990; Horowitz and Dobroff 1982; Stone et al. 1987). (AFÉAS et al. 1998:7). In addition, with life expectancy increasing, both the persons receiving care and their caregivers are living longer (Victorian Order of Nurses 1997; Canadian Study on Health and Aging 1994).

Clearly, the experience of caregivers varies according to gender. A number of studies confirm that when the caregiver is a man, a different balance is struck between formal and informal care, whereas women must face the pressure of societal expectations: [translation] Male principal caregivers receive more assist-

ance from other family members than do female principal caregivers (Walker, 1991). Men who assume the responsibility of caring for a dependent spouse receive the assistance of their daughters; this is less often the case for women who are caring for their husbands (Roy et al. 1992). In less common instances where sons assume responsibility for the care of elderly parents, wives, (in other words daughters-in-law), must often take on significant caregiving responsibilities. According to Mathews and Rosner (1998), daughters who find themselves unable or unwilling to provide assistance to an elderly parent experience feelings of guilt and are expected to justify their choice. With sons, non-involvement in parental care is seen as more acceptable (Vézina and Pelletier 1998: 8). These dynamics often cause women caregivers, including those who provide shelter to dependent parents, to experience feelings of guilt. This plays a role in the reticence of families, and of women in particular, to secure support from formal services: "[translation] It appears that men are less reticent about seeking assistance ... Men are generally more vulnerable in situations where they must assume responsibility for care because they feel unprepared to handle tasks that have not traditionally been entrusted to them" (Paquet 1997: 117).

Despite the fact that women have entered the work force in large numbers in recent decades, the division of domestic labour within the family remains largely unchanged, although a slow evolution is discernible.

> [translation] Women who are in the labour force are no less involved in caregiving; they simply balance their jobs, family obligations and caregiving tasks, while foregoing time for themselves. Some choose to work part-time, others stop working. These findings do not diminish the contribution of other family members, but simply highlight the predominant role played by women when care is provided within the family sphere. They also tell us that the role of "natural" caregiver is still a highly gendered one, and that little has changed in the division of household tasks between men and women (Guberman and Maheu 1997: 19).

Although it may be difficult to quantify, the contribution of women who provide care to family members dealing with acute or chronic health problems is clearly significant.

With women present in the work force in ever-increasing numbers, the requirements of caregiving add to the difficulty of balancing career and family obligations:

> It is estimated that one third of women providing care to a dependent elderly relative are employed (Lesemann and Chaume 1989; Stone et al. 1987). This number rises to 50 percent for women caring for a parent, thus excluding spouses (Stone et al. 1987) ... [translation] According to the Conference Board (cited by Armstrong 1996), women are twice as likely to report that their opportunities for career advancement have been affected by their responsibilities as caregivers. It is estimated that 9 percent of women caregivers who work outside the home ultimately stop working as a result of their caregiving obligations (Canadian Study of Health and Aging, 1994) (AFÉAS 1998: 7-8).

Over a third of women caregivers in Canada work outside the home and a third of these report that their responsibilities as caregivers have interfered with their professional obligations (Canadian Study on Health and Aging 1994; Gottlieb et al. 1994; Guberman and Maheu 1993).

The caregiver role affects numerous aspects of women's lives, causing many to experience

difficulty in balancing home care tasks and family responsibilities:

> [translation] Most caregivers to elderly dependents find it difficult to take a vacation or to work on a regular basis; as well, their physical and mental health can be affected. Daily routines are disrupted, planning social activities and hobbies outside the home becomes more difficult, and issues of intimacy become problematic. In some cases, providing care for a close relative can pose a financial burden and render the caregiver less available to other family members (Paquet 1990: 107).

A number of studies have examined the impact of the role of caregiver on the living conditions, quality of life and health (stress, anxiety, physical and mental exhaustion)[15] of women; on their personal, family and conjugal lives (role conflicts being a source of many tensions); and on obstacles to the performance of other social activities in their jobs, recreation or volunteer activities. When the care required is long-term, the impact on living conditions and health can be significant:

> [translation] Many individual and situational factors must be taken into account in determining the nature and scope of negative effects experienced by natural caregivers. However, there is no doubt that, over time, caregiving can exhaust the physical and psychological resources of caregivers and lead to physical and mental health problems. For example, a large number of gerontology studies ... have shown a higher incidence of psychiatric and somatic symptoms among those caring for dementia sufferers than among control group members and members of the population of the same age and gender (Schultz et al. 1990; 1995). It would seem that the work of providing care has a

negative impact on the immune system (Gottlieb, 1998: 462).

The constraints which women caregivers encounter must also be taken into account. Such constraints include those related to: the degree of impairment of care recipients and the duration of the care that is required; family resources, both financial and in terms of its ability to seek assistance; family structure and climate, which are more or less conducive to support for women, particularly those in more vulnerable situations, (e.g., single parents, victims of spousal abuse and family violence); ethnocultural background, which influences social roles and family dynamics; the personal situations of women caregivers, including their family responsibilities, jobs and place of residence, (since living conditions are very different in rural and urban environments (Lauzon et al. 1998).

Assessments of the various caregiver support programs, in order to determine their impact and their most worthwhile components, do not always produce conclusive results[16] (Gottlieb 1998). Therefore, a variety of support strategies stemming from the community sector (self-help groups, support and respite services for caregivers), government (tax deductions for home care of a frail person) and the private sector (flexible working hours, family leave) should be tested in combined fashion (Guberman 1999).

THE ROLE OF WOMEN CAREGIVERS IN THE CONTEXT OF THE SHIFT TO AMBULATORY CARE

The shift to ambulatory care also signals a paradigm shift. Home care is now required by persons of all ages, including large numbers of seniors, who are given early discharges after surgery or in-hospital treatment. While long-term care is not required in all cases, relatives must nonetheless be available, often on very short notice. The home has become a formally

recognized place of care and, increasingly, women are expected to play a caregiver role. These changes have placed increased pressure on families and on women in particular.

> [translation] A survey conducted by the Régie régionale de Québec reveals that eight out of ten discharged patients had received assistance from relatives. In order to provide this assistance, 19% of caregivers to persons having undergone day surgery or surgery requiring a more extended hospital stay, and 2% of caregivers to persons hospitalized for non-surgical medical problems, were forced to miss work. The assistance of friends and family is appreciated by discharged patients: only one respondent in ten would have preferred to receive the assistance from the public network. However, 16% of surgical patients and 17% of medical patients indicated that their friends and relatives had found it difficult to provide the necessary care (Conseil du statut de la femme 1999: 59).

The care required in these situations is becoming increasingly complex; however, the caregivers who are faced with more demanding responsibilities are not being adequately prepared. This is an added source of stress, particularly for older women:

> [translation] In "simple" situations, where home care consisted of administering medications, providing limited assistance in daily activities, or occasionally monitoring an operation site, women generally took a more positive view of the shift to ambulatory care ... In more complex situations, in which women were required to provide care on the order of nursing care (dressings, wound irrigation, administering and monitoring medications, hygiene, diet, etc.), 75% were receiving the services of health professionals [for them-

selves] ... The main difficulties encountered by these women included: lack of choice with respect to their situation; personal health problems linked to the burden of fulfilling the caregiver role; the complex nature of the care required, leading to feelings of insecurity; lack of planning in the discharge of patients and the provision of home care services after discharge; the transfer of costs from the health care system to service users (Ducharme et al. 1998).

In the context of the shift to ambulatory care, the relationship between caregiver and care recipient unfolds within a very different framework than does a formal intervention which is supported by professional expertise and standards. Within the family sphere, the relationship includes an emotional component which can make it difficult to set limits with respect to caregiving activities.

Studies have shown that women seldom refuse to help close relatives and that some find the experience to be a positive one, particularly in less complex situations (Ducharme et al. 1998; Brault 1998). In order to feel comfortable in the role of caregiver, women must freely choose this responsibility, without pressure from social agencies, and with real alternatives from which to choose. It is important to ensure that the consent of women caregivers is based on an understanding of both the relationship between caregiver and care recipient, and the expected outcome of the care recipient's problems. The heavy physical and emotional load which caregivers must assume can be difficult to assess at the outset.

While caregivers are identified as partners in some home care policies, they are not routinely consulted with regard to the organization of home care services. Public agencies often view families, and women in particular, as having the primary responsibility to provide care, and

view their own role as secondary. Women caregivers are still not recognized as potential users of health and social services, the latter being geared essentially to those who are sick or frail. The need to promote the health and well-being of women caregivers, or the right of caregivers to obtain support from public services in order to meet their own needs, are seldom mentioned in the policies which have guided the restructuring of health and social services (Lavoie et al. 1998).

A variety of corrective measures are required in order to lighten the burden placed on caregivers, provide them with greater support, and avoid the deterioration of their physical and mental health. Problems associated with the liaison process between the public system and families include: the delays which caregivers encounter in accessing services when relatives are discharged from hospital; service allocation criteria which refer to family responsibility and the obligation to care for relations; and the difficulty in securing support and respite services which are adapted to the needs of caregivers. Increasingly, as the effects of health care restructuring are being documented, persuasive data is emerging which argues for changes in policy, even though a number of studies have shown that formal service and community service utilization rates are low among individuals who have the support of family networks (Renaud et al. 1987; Leseman and Chaume 1989; Roy, Vézina and Paradis, 1992; Paquet, 1994; Roy, Vézina and Cliche, 1998). A umber of possible solutions emerge from the research conducted thus far. In a context where the health care system is viewed as a determinant of population health, it is imperative that the effects of restructuring on the health of women caregivers be assessed and that significant measures be taken in order to provide the necessary support.

THE DIVERSE EXPERIENCES OF WOMEN CAREGIVERS

The overrepresentation of women among caregivers is a constant which is confirmed by most studies that examine informal care of the sick and elderly, irrespective of background (Therrien 1987; Mathews 1987; Garant and Bolduc 1990; Guberman and Maheu 1991, 1993; Saillant 1992; AFÉAS et al. 1998). Numerous factors influence women's experience of giving care:

> [translation] A systematic survey of the literature which deals with the experience of women caregivers from an emic perspective confirms that informal caregiving can take on a variety of connotations, depending on factors linked to the situation of the caregiver (gender, age, place of residence, personal and family history), the motives and meanings associated with caregiving (awareness of the developing relationship with the care recipient, ethical dilemmas), relationships with family and health professionals, as well as the strategies which caregivers develop to deal with their situation and feelings (strategies for organizing and negotiating services, reconciling divergent expectations, and respecting individual limits) (Lauzon et al. 1998: 10).

Studies have also examined differences linked to living conditions. For example, there is greater reticence to request services among groups that tend to be apprehensive about the introduction of an unknown professional into personal family life, particularly among people from underprivileged socio-economic backgrounds (Paquet 1996). In rural communities, where young people are often few in number, older people tend to rely on informal support networks (friends, neighbours, relatives, volunteers), since the availability of formal services is often limited by distance or because services

are less developed than in urban areas (Roy and Vézina 1998). This situation produces two effects: older people turn for support to more distant relatives (such as cousins or nieces), and women caregivers find they must assume responsibility for more than one dependent, either concurrently or on an alternating basis.

THE EXPERIENCE OF WOMEN CAREGIVERS IN ETHNOCULTURAL COMMUNITIES

In ethnocultural communities, the experience of providing care in the home for sick or frail dependents is similar in some respects to that of families of Quebec origin. A qualitative study which examines the situation of women caregivers of Haitian and Italian origin in Montreal contains the following observation:

> [translation] our analysis of the situation of caregivers shows that the Italian and Haitian families in our study were very similar to families of North-American origin in matters relating to mutual support among family members and the distribution of care-related tasks. These tasks are, in most cases, the responsibility of one person, sometimes two, and there is every likelihood that the person in question is a woman (Guberman and Maheu 1997: 103).

The consequences of assuming a supportive role toward a sick or disabled person are different for women who have recently arrived in Canada and who find that they have become "caregivers" as defined by the standards of the Quebec health and social services system.[17] Such women must balance child-rearing responsibilities, as well the care of frail parents, and must often contend with precarious working conditions. The difficulty of reconciling work and family obligations, as well as the work overload and isolation which can result from these accumulated responsibilities, can impede the caregiver's own process of adapting to the

host society, thereby adding to their feelings of vulnerability. An American study which examines the experience of women caregivers of Asian origin underscores the complex factors which are at play:

> The stereotypes of extended family support, reverence for the elderly, and reluctance to institutionalize offer a superficial picture of self-efficiency. A more complete view involves an individualized understanding of language issues, acculturation levels, immigration pattern and family resources and how these impact on caregiving roles (Chase Goodman, 1990: 110).

Specific aspects of family dynamics, as well as cultural norms, social arrangements between men and women, and the meaning given to care, must all be considered in developing and implementing more culturally sensitive home care services. "[translation] Immigration and the stress of living in a new place, surrounded by new cultural models, as well as isolation from one's support networks and, in many cases, from family, add a new dimension to family life" (Status of Women Canada 1998: 75). In immigrant communities, the norms which govern intergenerational relationships differ from those that prevail in the host society. In some communities, support for the elderly is viewed as a mark of respect to which all elderly people are entitled, regardless of their level of physical or mental fitness. In a number of ethnic communities, seniors play an active role in family life, by caring for young children when both parents work outside the home and by participating in family decisions.

Dealings between families and formal services in the provision of home care are often influenced by specific factors which can hinder the adaptation of services to the needs of families. These factors include the cultural sensitivity of professionals, linguistic and cultural barriers, as

well as problems which can result from a lack of understanding of the needs of ethnic communities (Vissandjée et al. 1998). A study examining community intervention models which are adapted to the needs of multiethnic families providing care to persons with physical or sensory impairments attests to "[translation] social isolation due to the inability to communicate in their own language, difficulty understanding the workings of the health care system, differences in cultural behaviour, beliefs, and religious practices. (...) They are doubly marginalised. On the one hand, linguistic and socio-cultural barriers prevent them from using services and, on the other, service providers lack sufficient understanding of their needs and expectations to be able to assist them in accessing services" (Talbot et al. 1998).

Difficulties encountered in dealing with public service agencies vary depending on the cultural gap which exists between the community and the broader Quebecois society. "[translation] Faced with a variety of stressors, clients adapt to the extent that: internal and external stimuli are structured and predictable; resources are available to deal with the challenges at hand; and the challenges themselves represent a worthwhile motive for investing energy" (Vissandjée et al. 1998: 38). The communication problems which arise as a result of cultural gaps can limit the effectiveness, as well as the use of services, particularly in the unpredictable home care climate created by the shift to ambulatory care: "[translation] When the caregiver is an immigrant woman with a poor knowledge of French, how will she react to the shift to ambulatory care? How does one ensure that instructions have been properly understood? How can immigrant women gain access to the Info-Santé telephone information service?" (Conseil du statut de la femme 1996: 23).

However, in the conclusion to their study of Italian and Haitian families caring for elderly

relations at home, Guberman and Maheu stress the following point:

> [translation] our results confirm that we must avoid overestimating the importance of the cultural variable to the exclusion of structural variables, namely those linked to the socio-economic environment, and conditions determined by the resources available. These variables cannot be isolated and must be examined in combination if we wish to understand the reality of caregiving in ethnocultural communities and, in particular, the problem of health and social service underutilization among ethnocultural families (Guberman and Maheu 1997: 256).

Linguistic barriers and the pressures of adapting to Quebec society can significantly increase the resource needs of families. In many cases, however, families are more comfortable dealing with a person from their own ethnic group when seeking home care services or the services of an intercultural interpreter to facilitate their dealings with public network institutions. At the same time, the public health and social services network is frequently turning to various self-help and community support networks as it attempts to reconcile standardized institutional services with the specific needs of families from diverse ethnic backgrounds. This suggests that the informal support provided within ethnic communities extends beyond family relationships and is based in shared cultural references that includes a sense of moral obligation to provide assistance; this manifests itself most strongly in communities that feel marginalised.

Therefore, community organizations that work with the various ethnocultural communities are summoned to play a role which falls into the category of informal support; indeed, their contribution is often essential in reducing the isolation of families, disseminating information

on available services, developing support mechanisms which are sensitive to the values and culture of communities, and facilitating the adaptation of services. In this context, organizations within the various ethnic communities are called on to provide both supportive care and practical assistance, along with the other tasks which are increasingly being transferred to them as a result of the shift to ambulatory care. In this light, the contribution of ethnic community groups to the formulation and implementation of home care policies acquires considerable significance (ACCÉSS, 1998).

THE SITUATION IN ABORIGINAL COMMUNITIES

An analysis which seeks to address the diverse experiences of women as caregivers must also pay close attention to the reality of women in the various Aboriginal communities of Quebec and Canada as a whole; their reality is different from that of women from ethnocultural communities:

> [translation] Beyond the fact that Aboriginals are the first inhabitants of this country, the political autonomy which they are claiming prevents us from speaking of their integration into the majority Quebec culture, whereas the issue of integration is central to the debate on cultural diversity as it pertains to immigration (Conseil du statut de la femme 1997: 9).

The socio-economic conditions and health status of Aboriginal communities have markedly deteriorated compared to that of the Canadian population as a whole (Guyon 1996; First Nations and Inuit Regional Health Survey National Steering Committee 1999). A survey on the health status of Aboriginal communities conducted in 1991 estimated that close to one third of all Aboriginals over the age of 15 (31 percent) suffered from some form of impairment, which is double the national rate for the

same period (First Nations and Inuit Regional Health Survey National Steering Committee 1999: 151). Assistance in performing everyday tasks is generally provided informally, within the family sphere. According to this study, dealing with the impairments associated with chronic illness will emerge as a major issue as life expectancy in Aboriginal communities increases:[18] "Although the family is the first line of support in a continuing care system, the living arrangements of First Nations and Labrador Inuit people suggest that people, regardless of age, may not have the necessary support in the household. For instance, single women who have no children living at home reported the most activity limitations" (First Nations and Inuit Regional Health Survey 1999: 172).

Studies examining intergenerational cohabitation reveal that such living arrangements are twice as common among Aboriginals as in the general population, as a result of socio-economic factors, as well as familial and cultural values (Guyon 1996; First Nations and Inuit Regional Health Survey 1999: 37). Elders are viewed as active members of Aboriginal communities and play an important role in family life, providing support to younger generations, both spiritually and in the preservation of cultural heritage (Gagnon 1999).

Various studies published by the *First Nations and Inuit Regional Health Survey National Steering Committee* also raise a number of issues linked to the concept of continuing care services provided in the living environment of individuals:

> These findings have important implications for the development of a continuing care system for First Nations people on-reserve and the Inuit. Barriers to continuing care services are due to jurisdictional problems between federal departments, between provincial governments and the federal government, and between provin-

cial governments and First Nation and Inuit governments. Isolation and non-isolation from health services will complicate the development of this system. People with activity limitations living in isolated regions may have to travel great distances to access continuing care services. The demand for home care and other continuing care services will increase due to the reduction in the number of hospital beds available, the shift to ambulatory care, and the early discharge of patients (First Nations and Inuit Regional Health Survey 1999: 173).

For First Nations and Inuit communities, these jurisdictional issues complicate the delivery of continuing care in the living environment of those who are sick or disabled.

In the absence of studies dealing specifically with the situation of primary care providers in Aboriginal and Inuit families, it is impossible to gain an accurate and well-documented picture of the situation; however, there is no reason to believe that the observations pertaining to North-American society, particularly with respect to the predominant role of women as principal caregivers, do not apply to Aboriginal communities. Still, the unique demographic makeup of Aboriginal families, the larger number of children per family, difficult socio-economic conditions, and the problems of domestic violence which have documented in some communities provide strong arguments for examining Aboriginal women's experience of giving care. This will enable us to gain a better understanding of the dynamics of caregiving, the scale and specific nature of the work performed by caregivers, the health effects experienced by them, as well as the social and community supports available.

Aboriginal women living in urban environments have been overlooked by all levels of government and many do not know where to obtain services. For these women, access to services is dependent on their status under the Indian Act, which confers the right to services funded by the Department of Indian Affairs and Northern Development to some, but not others. Since the Act is poorly understood in urban areas, simple things, such as obtaining prescription drugs, can turn into a complicated procedure, serving to heighten the feelings of marginalisation of women who are already lacking financial resources and information. Similarly, Aboriginal women from other provinces and those from communities within Quebec have different access to services. The information needs of Aboriginal women are not being met; at the same time, those who use health and social services must deal with the obstacles that result from a lack of cooperation among the various levels of government.

Services which are adapted to the needs of Aboriginal women residing in urban areas are also lacking: "[translation] The services offered in urban areas do not meet the needs of Aboriginal women. Difficulty communicating with service workers is a common problem. Services are highly structured and individualized and have rigid criteria. They are also poorly understood by Aboriginal women. For these reasons, Aboriginal women seldom use them" (Gill et al. 1995: 38). Many Aboriginal women have a concept of health which is based on a system of traditional values and practices which includes an emotional and spiritual component. These values are often at odds with North-American medicine, with its largely biomedical orientation. Addressing such cultural gaps is an important issue for women who are doubly marginalised as a result of their isolation from their communities of origin and their lack of integration into Quebec society, particularly in urban areas (Gill et al. 1995).

Community networks of urban Aboriginal women, those in Montreal in particular, are also called on to provide informal support for

people from their communities of origin who come to Montreal for treatment. In the absence of family-based support structures, health and social service professionals also turn to the services of community networks in an attempt to provide support for people who are dealing with serious mental health problems and addictions. However, these self-help groups are not provided with the training and resources required to assume such responsibilities.

In the current climate of fiscal restraint, the public system has increasingly come to rely on the informal support of families and the volunteer efforts of community groups in both ethnocultural and Aboriginal communities. Consequently, caregivers and volunteers often experience high levels of stress, which is increased as a result of belonging to a marginalised group.

INITIATIVES UNDERTAKEN BY WOMEN'S GROUPS IN RESPONSE TO HEALTH SYSTEM REFORM IN QUEBEC

The policies which guide the restructuring of health and social services in Quebec and a number of other Canadian provinces focus on the achievement of lower rates of institutionalization, as well as the development of a continuing care system within the living environment of sick or disabled persons. Studies have shown that the reorganization of services has transferred a large burden onto women caregivers and has had an impact on their lives and health. In Quebec, efforts are increasing to correct the unanticipated effects of health care restructuring on women caregivers, as well as to address the needs of women through appropriate mechanisms of support.

Health system reform poses many challenges, some of which have already been mentioned in these pages:

- the health system has been overwhelmed by change, cuts to funding, and loss of expertise as a result of early retirement programs;

- home care services are fragmented; the roles and responsibilities of the various service providers need to be clarified;

- home care policy views women caregivers as a resource, rather than as true partners, and is redefining health system intervention as an adjunct to family-based support;

- there is little understanding of the contribution which women caregivers make, either directly through the care they provide, or indirectly through the income they forgo; the direct costs which are transferred to families are also poorly understood;

- the increased presence of private services in the wake of health system reform (nursing care and home care agencies, private convalescent centres, social economy enterprises); as well, billing for support services is increasing;

- the lack of services which are adapted to the diverse needs and family dynamics of ethnocultural communities;

- the development of practical assistance and interpretation activities involving families and formal services in ethnocultural and Aboriginal communities;

- the problems of jurisdiction, availability and access to continuing care in Aboriginal communities;

- the difficulty of overcoming the reticence of some families about seeking formal services, and the scarcity of services which meet the specific needs of women caregivers.

In recent years, a number of efforts have been undertaken to improve services as part of health system reform. As well, such issues as personal choice, effective support and the empowerment of women caregivers are increasingly coming to the fore in discussions about the effects of health system reform in Quebec. Women caregiver groups and networks have spoken out, in particular at a retreat held in the fall of 1998, with the theme *Au coeur de l'aide, au coeur du changement*.[19] More than 250 people (the majority of whom were women caregivers) took part in this retreat, which was followed by a number of regional and interregional cooperative endeavours undertaken by caregiver groups.

Women's groups and networks, as well as community and labour groups have also examined the impact of health system reform on women and on caregivers in particular. Several women's groups participated in a study on the experience of women caregivers and later came together to share their findings and to develop recommendations for protecting the interests of women in the context of health system restructuring. These groups include the Réseau québécois d'action pour la santé des femmes, the Coalition féministe pour une transformation du système de santé, and the Association féminine d'éducation et d'action sociale (AFÉAS).

A number of university and health network researchers are currently studying the effects of health system restructuring on women caregivers and are contributing to the literature dealing with the experience of these women. Their work is producing convincing data that could serve as a basis for developing policy recommendations and innovative measures to recognize the important contribution of women caregivers and to respond to their specific needs.

In some government circles in Quebec there is also greater concern about the impact of health system reform on the health of women and caregivers, as demonstrated by the action plan on the status of women which was adopted by the ministry of health and social services (MSSS) in the fall of 1998 (MSSS, 1998), as well as by comments made by the Conseil du statut de la femme du Québec concerning the service improvement plan developed by the Régie régionale de la santé et des services sociaux de Montréal-Centre (Conseil du statut de la femme 1999).

The Centre of Excellence for Women's Health – Consortium Université de Montréal (CESAF) is involved in these initiatives, particularly those which focus on the diverse experiences of women caregivers and the need to develop culturally sensitive support measures which reflect the realities of Aboriginal and immigrant women.

The usefulness of gender-differentiated analysis in assessing the effects of health system reform and the need to adopt a global approach to women's health have been advocated by CESAF and other women's groups and are now gaining acceptance and credibility. However, it will be important to pursue efforts with decision makers and those who manage the health and social services network. A number of initiatives to develop services which are diversified and adapted to the needs of women caregivers are presently underway in the health network;[20] efforts to adapt existing services to an ethnoculturally diverse clientele have also been undertaken and will need to be developed further.[21]

Future measures must reflect a greater respect for the personal choices, contributions and autonomy of women caregivers and ensure that caregivers are represented within the organizations which are responsible for planning and programming home care services. However, a

number of strategic questions will need to be answered before concrete measures can be taken: How will the various levels of government assume responsibility for the impact of restructuring on women caregivers and to which level should policy and program recommendations be directed? How may we best respond to ethnocultural diversity within the framework of a universal health care system? How can we develop strategies to provide Aboriginal women with the support they need to deal with the profound social transformation which their families and communities are undergoing? How can social policies be modified in order to improve the situation of women caregivers, without reinforcing the traditional role of women within the family? Should specific legislation or policies be developed to ensure that the rights of women caregivers are protected?

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1. This term refers to women who provide care to family members who are sick or incapacitated in some way. The role of caregiver comprises many facets: emotional support, patient escorting and supervision, help with personal grooming, assistance in activities of daily living, housekeeping, monitoring of dysfunctional behaviours, etc. The differing social roles of men and women and the care which women have traditionally provided to family members have contributed to imposing this "natural caregiver" role on women.

2. Ferland and Paquet indicate the following: "[translation] It is now recognized that the health status and well-being of communities is linked to a range of factors that fall outside the curative system ... the argument in favour of the overwhelming influence of living conditions on the health and well-being of individuals gained international recognition in 1986 with the adoption of the Ottawa Charter for Health Promotion."

3. The federal government, which provided funding for a significant portion of health expenditures in the 1960s, began to unilaterally reduce its transfer payments between 1982 and 1994. In its 1995 budget speech, the Liberal government announced a series of measures to reduce public spending and the national deficit, including the replacement of existing programs (CAP, EPF) with the Canada Social Transfer, and a significant reduction in transfer payments to the provinces.

4. The Régies régionales were created in Quebec in the early 1990s to replace the Conseils régionaux de la santé et des services sociaux, which had a strictly consultative mandate. The regional boards held consultations on the plans to restructure health and social services which they had developed within the framework of directions and standards established by the ministry of health and social services (MSSS). CESAF participated in the recent consultations held by the Régie régionale de la santé et des services sociaux de Montréal-Centre concerning the organization of services in Montreal for 1998-2001. CESAF pointed out that the consultation paper, *Le défi de l'accès,* is not very explicit with regard to the recognition of women as the principal providers of care in both the formal and informal networks.

5. According to the *Étude sur les attentes et la satisfaction des usagers à l'égard des services de santé et des services sociaux*, a study of user expectations and satisfaction with respect to health and social services published by the Régie régionale de Montréal-Centre, the rates of hospital and CLSC use increased by 9% and 8.6% respectively between 1994 and 1997. The use of community agencies over the same period increased by 125%, with the average number of visits per year increasing from 10 to 22.5 per person.

6. According to a recent study by AFÉAS et al. (1998): "It entails a profound reorganization of the system not only from a management perspective, but also in terms of the delivery of services" p. 4.

7. The *Sommet* was attended by representatives from government, the business community, labour and community groups. The discussion centred around government priorities, particularly means of revitalizing the economy and employment and balancing public finances. Following on the *Sommet*, the Quebec government adopted budgetary policies designed to eliminate the deficit in four years, a move which has had an impact on all government expenditures and social policies, in particular the mission of MSSS, which accounts for close to a third of public expenditures. Measures undertaken as part of health and social services reform in Quebec interact with other measures implemented in areas not directly linked with this sector of activity; examples include social assistance (the reduction of drug benefits for recipients of social assistance as a result of the introduction of pharmacare), manpower policies (public sector negotiations), occupational codes (the definition of exclusive fields of practice),

employability policies (labour force reentry projects with social economy enterprises which offer home support services and are now part of the service plans developed by the regional boards), etc.

8. Source: Service d'analyse statistique (SAS) [statistical analysis department] of MSSS and Med-Echo.

9. The CLSC mission is to "[translation] provide the population of the territory [they serve] with front-line health and social services. They offer curative, preventive, rehabilitation and reintegration services" (LRQ., C. S-4.2, art. 80).

10. This service plays an evaluation-advice-guidance role and serves as a gateway to the health care network within the direct services framework. In 1994, the ministry of health and social services (MSSS) provided funding and directed the regional boards to implement a service that would ensure a timely response to general information needs concerning physical and mental health.

11. In order to absorb the impact of the shift to ambulatory care, a number of CLSCs eliminated the positions of nurses who were conducting preventive interventions in schools.

12. Source: Health System and Policy Division, Health Canada. To illustrate this discrepancy, Bégin points out that: "[translation] the Régie régionale de Montréal-Centre allocates $66 per person for these kinds of [home care] services. This is a decided improvement over the $47 allocated in 1995, but remains well below the $70 per person which Ontario was providing three years ago." Bégin, J.F. (1998), La Presse, p.A-6.

13. This change of role signals a shift in emphasis from "caring" to "curing".

14. In Quebec, the Coalition Solidarité Santé, which comprises 24 labour organizations (CSN, FTQ, CEQ, FIIQ, etc.) and community groups (Quebec coalition of Seniors, Fédération des femmes du Québec, consumer federations, groups of community agencies), has developed a common vision on this subject. This position is echoed by the Regroupement intersectoriel des organismes communautaires de Montréal (1998), pp. 138 et seq.

15. According to data from the most recent Santé Québec survey, 35% of women caregivers exhibited a high level of psychological distress.

16. According to Gottlieb (1998), p. 472: "[translation] it is still too soon to draw definitive conclusions about the intervention formulas which work best for caregivers, because research work and pilot programs have not been evaluated long enough to determine whether the results can be reproduced or given widespread application."

17. The cultural communities which were part of the first waves of immigrants in the early years of this century and after World War I now comprise increasing numbers of seniors. In addition, 9% of immigrants to Canada are seniors, many of whom are sponsored by children who have already settled here.

18. Life expectancy for male and female status Indians is 13 and 11 years shorter, respectively, than that of Canadian population as a whole.

19. This event was organized by the Regroupement des aidants et aidantes naturel(le)s de Montréal. The proceedings have been published under the title: *Au coeur de l'aide, au coeur du changement. Journée de réflexion des personnes aidantes* [Assistance and change: a day of reflection for caregivers], RAANM, 1999.

20. A number of CLSCs have developed support groups for women caregivers, including the Centre de soutien au aidants naturels du CLSC René-Cassin in Montreal; in addition, some regional boards have conducted research into the situation of women caregivers, while others have provided assistance to volunteer support and self-help groups for caregivers.

21. For example, the Régie régionale de la santé et des services sociaux de Montréal-Centre has developed a regional plan to improve access to services for ethnocultural communities (*Plan régional d'accessibilité aux communautés ethnoculturelles* 1997-1999).

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