Promoting social change through policy-based research in women's health

### **Unpacking the Shift to Home Care**

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May 1999





### **A**CKNOWLEDGEMENTS

This research was funded by the Maritime Centre for Excellence in Women's Health. I would like to thank Fran Gregor, Kathy MacPherson, Fiona Bergin and Hope Beanlands for getting this project off the ground and for the all the insight and information I gained from the sessions we had discussing home care issues. I would also like to thank Martina Munden for her invaluable research assistance. All errors and omissions remain my sole responsibility.

This project was funded by Maritime Centre of Excellence for Women's Health (MCEWH). MCEWH is financially supported by the Centres of Excellence for Women's Health Program, Women's Health Bureau, Health Canada. The views expressed herein do not necessarily represent the views of MCEWH or the official policy of Health Canada.

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### 1.0 Introduction

Home care has recently become a significant policy issue in Canada and in many other developed countries. This paper focuses on the factors that have fuelled and are fuelling the recent and rapid shift from the provision of care in hospitals and institutions to home care. The goal is to analyze which members of society will bear the costs of this shift and to explain why the distribution of these costs has largely been ignored. Unpacking the larger forces causing the shift to home care will help Canadian citizens, particularly Canadian women, better understand why this shift is occurring and its likely impact on their lives. Having this information should also help women to critically analyze arguments for and against different home care policies and identify and to advocate against those policies that will have a detrimental effect on vulnerable women.

There are six sections to this paper. The first section provides a description of the deinstitutionalization process both in Nova Scotia and in Canada. The second section describes the growth in publicly-funded home care. The third section tackles the issue of what is encompassed by the phrase "home care." The fourth section outlines the forces contributing to the process of deinstitutionalization and the shift to home care. In particular, this section focuses on how an economic analysis of health care markets and a "determinants of health" approach has fuelled the shift from caring in institutions to caring in the home. The fifth section of this paper discusses the distributional implications of the shift to home care, which members of society will bear increased costs as a result, and why the distribution of these costs has been largely ignored. Finally this paper concludes with some thoughts on advocacy for a home care program that is both equitable and efficient and pitfalls to avoid.

## 2.0 DESCRIPTION OF DEINSTITUTIONALIZATION

### 2.1 Nova Scotia

In recent years, health care reform in Nova Scotia has primarily focused on reducing the numbers of hospitals and hospital beds and on reducing hospital budgets.

With regard to the number of hospitals, two rural hospitals were closed, two facilities were converted into community health centres, and one facility was converted into a veterans' hospital. The Department of Health initiated two major hospital mergers, one involving the merger of four hospitals into the Queen Elizabeth II Health care service Centre and the other involving the merger of two women's hospitals. With regard to the number of hospital beds, by 1994/5, the number of short-term hospital beds had been reduced by almost 35% from the 1986 levels from 5.9 beds per 1000 to 3.5 beds per 1000.1

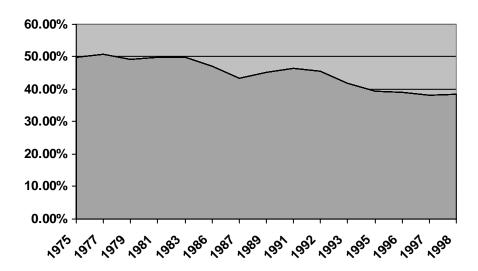
With regard to hospital budgets, between 1992 and 1996, hospital budgets were reduced 12.24%.<sup>2</sup> In addition, as Diagram 1 demonstrates, the proportion of total expenditures devoted to hospitals has fallen significantly. For example in 1986, 47.12% of total health care spending in Nova Scotia was devoted to hospitals compared to 39.1% in 1996.<sup>3</sup>

As one would expect, these reductions in hospitals, hospital beds and hospital budgets have impacted on the supply of hospital services. Between 1991/92 and 1993/94 there was a 17% drop in hospital admissions. The average length of stay in a short-term hospital unit declined by 2.87% between 1991-2 and 1993-4, from 9.05 bed days to 8.79 bed days.

### 2.2 CANADA

Deinstitutionalization is not a phenomenon peculiar to Nova Scotia. The shift from caring

Diagram 1: Hospital Expenditures as a Percentage of Total Health Expenditures in Nova Scotia



Source: Graph constructed from data obtained from the Canadian Institute for Health Information. Online. <a href="http://www.cihi.ca/facts/novahe.htm">http://www.cihi.ca/facts/novahe.htm</a> (Accessed 1 March 1999)

in institutions to caring in the home is occurring throughout Canada and, indeed, in most other developed countries.

At a national level, between 1986/87 and 1994/95 the number of public hospitals declined by 14% and the number of hospital beds declined by 11%.6 The number of staffed beds per 1000 population, both short and long-term, fell from 6.6 to 4.1.7

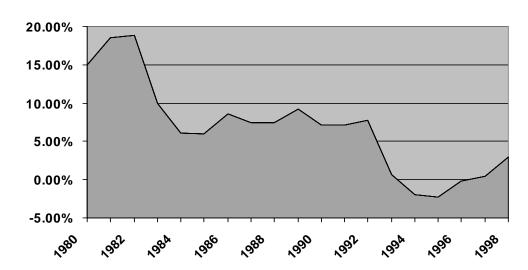
As Diagram 2 demonstrates the proportion by which actual expenditures on hospital care (in current dollars) has

increased each year has steadily declined and through 1994-1996 there were unprecedented reductions in the actual number of dollars spent on hospital care.

Statistics Canada reports that the rate at which Canadians were hospitalized reached an all-time low in 1995/96 with the discharge rate (the number of hospital discharges or deaths) being 11,165 per 100,000 popula-

tion, well below the peak of 16,802 in 1973.8 It also reported that the average patient spent 10.7 days in hospital, about a day less than a decade earlier.

Diagram 2: Annual Percentage Change in Hospital Expenditures (Canada)



Source: Graph constructed from data obtained from the Canadian Institute for Health Information. Online. <a href="http://www.cihi.ca/medrls/10nov.htm">http://www.cihi.ca/medrls/10nov.htm</a> (Accessed 14 May 1999.)

The process of deinstitutionalization is still on going in some provinces. The Health Care Services Restructuring Commission's Metropolitan Toronto Health Care Services Restructuring Report (March 1997) recommended the outright closure of nine hospital sites in Metropolitan Toronto, which will result in a reduction of acute care beds from 6,173 (as at 31 March 1996) to 4,414 (almost a 29% reduction).

There has been some resistance mounted on the part of hospitals forced to close or merge with others. In a series of cases in Ontario, hospitals such as Women's College Hospital, challenged the Health Care Services Restructuring Commission's orders. To date, all these actions have been without success. In one case<sup>9</sup> the court noted:

[t]he court's role is very limited in these cases. The court has no power to inquire in the rights and wrongs of hospital restructuring laws or policies, the wisdom or folly of decisions to close particular hospitals, or decisions to direct particular hospital governance structures...The only role of the court is to decide whether the Commission acted according to law in arriving at its decision.

While litigation has not been successful, political lobbying did force the Commission rethink its decision to close the francophone Montfort hospital. <sup>10</sup> In general, however, there has been disproportionately little resistance to the deinstitutionalziation juggernaut and this lack of real resistance is itself an interesting phenomenon. Given widespread public concern and media coverage of hospital closures and growing waiting lists, this lack of resistance speaks to the strength of the forces that have converged to cause the shift from hospital to home care.

### 3.0 Public Spending on Home Care

In conjunction with the deinstitutionalization process has been an increasing emphasis on home care. In Nova Scotia, the percentage of government health expenditures devoted to home care increased from 0.49% in 1980-1 to 1.63% in 1990-91 to an estimated 5.1% in 1997/98. Across Canada, on average, the percentage of public expenditures devoted to home care increased from 2.3% in 1990/91 to 4.0% in 1997/98.

Although government spending on home care has, on average, nearly doubled in recent years as a percentage of total spending, the investments made in home care still pale in comparison to spending on hospitals. In 1996, 34.4% of total health care spending was on hospital care although this was predicted to fall to 33.7% in 1997 and to 33.4% in 1998.13 More importantly, increased government spending on home care does not reflect the magnitude of the cuts made to hospital spending. Between 1993 and 1996, total spending on hospital care fell \$1,205 million.<sup>14</sup> (I use the figures for total spending as there is very little private spending on hospitals in Canada because of prohibitions contained in the Canada Health Act.) By comparison between 1992/93 and 1995/96, public spending on home care only increased \$452.8 million.15

Every province now has put in place a home care program. However, there are significant differences across the provinces in terms of the percentage of total public health expenditures devoted to home care. In 1997/98, spending on home care as a percentage of total public health spending ranged from lows of 1.75% (Yukon), 2.29% (PEI), 2.39% (Quebec), and 2.77% (Alberta) to highs of 5.3% (Ontario) and 5.8% (New Brunswick). <sup>16</sup> Similarly, the range and volume of services that are publicly-funded varies from province to province as does eligibility, for example on the basis of

means testing, and the extent to which user charges are imposed. As discussed further below, variability in home care programs across the country may in part be explained by the absence of a national home care program. Recognizing this, in 1997 the National Forum on Health recommended a national home care program.<sup>17</sup> Subsequently, the federal government promised in its Red Book to put in place a national home care program and a Pharmacare program. Towards this end in 1998, the federal government hosted a national conference in Halifax with a view to formulating a national home care policy. Progress towards a national home care program has stalled, however, as the provinces been very resistant to another cost-sharing national program. This is understandable given that their experience with Medicare is that the federal government has continually reduced its financial contributions, whilst still expecting the provinces to maintain national standards.

### 4.0 DESCRIPTION OF HOME CARE

Despite the rising importance of home care as a public policy issue there are remarkably few instances where "home care" is defined. For example, the National Forum did not define home care despite calling for a national home care program. A 1990 Health Canada publication, *Report on Home Care* defines home care as:

an array of services enabling Canadians, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives.<sup>18</sup>

What is lacking in this definition are details of the "array of services" to be provided.

The Report on Home Care suggests that home care can be defined narrowly as a post-hospital care service aimed at people with specific

health problems or broadly as a province wide program making no conceptual or administrative distinction among needs for medications, homemaking, or income support. 19 "Home care" narrowly defined, includes services that have historically been provided in hospitals. For a number of reasons these same medical needs are now being serviced outside of a hospital and in the home. Hospital services are protected by the Canada Health Act<sup>20</sup> and are allocated free at the point of delivery to the poor and to millionaires alike. In other words, allocation occurs on the basis of medical need as opposed to ability to pay. The concern is that many services that, pursuant to the Canada Health Act, must be fully paid for by provincial governments if delivered in a hospital setting do have to be fully funded if provided in a home. Thus, with the shift from caring in hospitals to caring in homes, there is the prospect of services being allocated on the basis of ability to pay rather than need. There is also the risk that as provincial governments do not have to bear the full cost of the shift from hospital care to home care there will be a disproportionate emphasis on such a shift as a cost-saving device.

The problem of private financing of home care services stems from the fact that pursuant to the constitutional division of powers it has been interpreted that the provinces have the sole power to directly regulate health insurance and medical services.<sup>21</sup> As a consequence, the federal government is limited to using its spending power to encourage provinces to meet minimum standards in their provincial health care plans.<sup>22</sup> Thus the Canada Health Act is a mechanism by which the federal government attempts to achieve national standards by offering cash payments to those provinces that comply with the criteria set. It is important to realize that the Canada Health Act's five criteria of universality, portability, accessibility, non-profit administration and

comprehensiveness and the specific prohibition against user charges and extra billing only apply to hospital and physician services as defined in the *Act*. Thus there is nothing in the *Canada Health Act* discouraging provinces from allowing means testing or user charges to patients for drugs, medical equipment, nursing services, home-making services, food services, etc. that are needed in the home. This is so even if these services are needed for the treatment of needs that would otherwise have to be treated in a hospital.

"Home care", broadly defined, includes services that substitute for services provided by longterm care institutions for the elderly, disabled or chronically ill. Also included in a broader definition of home care would be preventative services that would forestall or delay admission into either a hospital or a long-term care institution. Services that fall within this broader definition of home care have not traditionally been fully publicly-funded. For example, long-term care services have not been treated as a core component of Medicare and have not been fully publicly-funded. In Nova Scotia, an applicant for admission to a nursing home is means tested (considering income from all sources except his/her principal residence) to assess how much they can contribute to the costs of care.<sup>23</sup> Different provinces have different assessment criteria with some provinces, like Nova Scotia, setting fees according to income whereas in other provinces everyone pays a standard rate.<sup>24</sup>

The key difference between the narrow and broad definitions of home care is the time frame over which the services are required. In the narrow definition, home care services are generally required for a limited period as an individual is restored to full capacity. In the broader definition, services are generally required over a much longer period as a person moves along a continuum from functional independence to total dependence. The array

of services included in both the narrow and broad definition of home care are broad. The services needed may include physician, registered nursing, nurse-aid, physiotherapy, occupational therapy, social work, food preparation, general housekeeping, and transportation services. Goods needed may include drugs, medical equipment such as wheelchairs, lifts, etc., and medical supplies such as bandages, drips, etc. Complementary services required are assessment and case management services.

The broad array of services that may be included in home care results in home care overlapping the traditional Medicare system and social service systems. Home care is unique in the health care system as the services required may include not only traditional medical services but also what may be thought of as community or social services such as social work and home making. However, the principles underlying Medicare are that services are allocated on the basis of medical need as opposed to ability to pay. Thus a millionaire and a homeless person are equally entitled to hospital and physician services without payment. By contrast, Canada's social support system generally only provides assistance on a means tested basis to those on low incomes. Thus, there is no universal entitlement to housing or to nutrition as there is to Medicare.

The fact that home care occurs at the intersection of the Medicare and social service systems, which are premised on different principles of access and entitlement, makes the question of how to design a home care system very complex. The integrity of Medicare is sought to be achieved by essentially prohibiting private financing of hospital and physician services. The theory runs that by forcing nearly every Canadian into the publicly-funded system the quality of Medicare will be assured for rich and poor alike. As Weale notes "[t]he principle that services for poor people are poor services is about as well attested an observation as we are

likely to find in social affairs."<sup>25</sup> However, with home care services, are we similarly persuaded that citizens should be prohibited from privately buying or have private insurance covering additional housekeeping, homemaking, and nursing service beyond that which is publiclyfunded? Should there be prohibitions on user charges and extra-billing for home care services as there are for hospital and physician services? We may have different answers to these questions depending on whether home care services are needed in response to acute care needs as opposed to long-term care needs.

In order to preserve the integrity of Medicare it seems at a minimum that there should be publicly-funded home care covering services, which, if they were not provided in the home, would otherwise require the patient to be admitted into hospital. This is necessary so that there is no resistance to the most cost-effective good or service being supplied in response to a particular health need. In other words, it is a misconceived system that forces or encourages patients to stay in hospital because they cannot afford the drugs or care they need at home. If it is expected or assumed that family or community members will supply services, that are substitutes for hospital services, then this raises questions of the quality of care delivered. Above and beyond safety and quality concerns, there must also be a public debate about the fairness of expecting family and community members to provide this kind of care. It is one thing to facilitate and encourage those family members who want to provide home care services. It is another thing again to demand and expect a patient's family or community to provide care and only to supply publicly-funded care when the family or community are incapable of so doing or are stretched to breaking point. With regard to home care services that are not substitutes for hospital services we must, as a community, determine whether these services are of such significance and

importance that justice demands that they too be publicly-funded for everyone. In other words, should long-term care services be allocated on the basis of need as opposed to ability to pay? Or should responsibility for long-term care be something that is largely left to personal responsibility with government assistance for the poor? Given that, barring premature death, old age and a decline in functional independence is predictable, it does not seem unjust to require individuals to take some degree of personal responsibility and save for the possibility of needing long-term care associated with aging. However, as long-term care can be very expensive there is a need for a safety net for those on low incomes.

In every province, home care is unique and distinct from other health care services as publicly-funded home care services are viewed as a top-up to whatever can be provided in the community or by family members. For example, the mission of Home Care Nova Scotia is to "deliver an array of services to assist Nova Scotians of all ages, who have assessed unmet needs, in order that they can achieve and maintain their maximum independence while living in the their own homes and communities." Unmet needs are defined as "needs which are not being met by existing formal services, or informal family or community supports."26 Similarly, one of the objectives of the Saskatchewan home care program is to provide "supportive, palliative, and acute care that family, friends and neighbors cannot provide."27 Thus, provincial home care programs are generally premised on the assumption that publiclyfunded services will only be provided when family and community are unable to provide the necessary care "for free".

In contrast to the Medicare system where entitlement depends solely upon an assessment of medical need, provincial home care programs like Home Care Nova Scotia takes into consideration a person's entire circumstances by exploring physical, psychological, functional, and social support needs. Thus the assessment process for home care services is presently much more complicated than for Medicare services and has three components:

- 1. determination of the nature and degree of disability or medical need;
- 2. determination of the kinds of services needed to meet these needs; and
- 3. determination of whether family members or others in the community are willing and able to provide the services needed.

The last element of the assessment process, determination of whether family members or others in the community are willing and able to provide the services needed, is fraught with the potential for stereotyping and bias. Stereotypical assumptions may be made about the ability of elderly men and elderly women to respectively care for themselves, about the ability of working daughters as opposed to working sons to care for elderly relatives, about the capacity of mothers to care for physically and/or mentally disabled children, and of the capacity and obligations of women with existing caring responsibilities, e.g., for children, to take on additional caring responsibilities, e.g., for elderly family members.

# 5.0 THE FACTORS FUELLING DEINSTITUTIONALIZATION

There are at least five identifiable factors that underlie the deinstitutionalization process and the shift to home care. These factors, discussed further below, are developments in technology, changing demographics, an economic analysis of health insurance and health care service markets, governments' desire to reduce public spending and concomitantly deficits, and a shift to what is known as the "determinants of health" approach. In temporal terms, it is not

apparent which if any factor arose first nor is it possible to say that each factor is wholly independent of the other four factors. What is clear, however, is that these factors have converged to create a very strong force to shift care away from hospitals and other institutions and into the home.

### 5.1 TECHNOLOGY

Technology has played an important role in the deinstitutionalization process. Advances in surgical techniques combined with new and improved drugs has enabled patients to recover faster than ever from surgical procedures and be in less need of intensive medical care in the recovery process. Examples include the use of computers to aid in surgery, 28 laparoscopy, 29 endoscopic surgery,<sup>30</sup> and the use of new drugs and devices. Advances in technology has enabled patients to receive treatments in the home that previously required hospitalization, for example, insulin pens, portable infusion pumps,<sup>31</sup> portable and stationary oxygen systems, and mechanical ventilators.<sup>32</sup> Advances in telecommunications technology have enabled the supply of various medical services at a distance 33 thus, indirectly, enabling further centralization of service providers into large hospitals in urban centres.

Advances in technology, however, also contribute to increased pressure on hospital budgets as new interventions, sometimes of questionable marginal benefit, are developed and introduced into the system. Often it seems that technology results in cost-increases rather than decreases. This is because technology is developed with a view to improving quality of care or meeting new or previously unsatisfied health needs and not with a view to achieving the same outcome more cost-effectively.

### 5.2 CHANGING DEMOGRAPHICS

The aging of the population is a factor bringing pressure to bear upon the health care system and the shift to home care. This pressure is likely to continue for the next 40 years at least as the baby-boomers age. In 1996, 12.1% of the population was aged over 65 whereas it is estimated by 2016 that 15.9% of the population will be over 65.34 By 2041, 22.6% of the population will be over 65.35 Within the over 65 age group, the sharpest increase will be seen in the over 85 age group with an increase from 1.0% in 1995 to a projected 4.0% of the population in 2041.36

As the population greys, there will be an increasing proportion of people in transition from functional independence to functional dependence and in need of both medical services and social services. This demographic trend will result in increasing pressure for more home care. However, it is very important to acknowledge that the magnitude of this pressure does not necessarily reflect a demand for home care instead of care in hospitals or other institutions. The received wisdom is that the elderly and others prefer to receive medical services and care in the home rather than in institutions.<sup>37</sup> Prima facie this seems a reasonable assumption but closer examination reveals its limitations. A preference for care in the home as opposed to in a hospital or other institution itself rests on the assumption that the quality of care will not be unacceptably diminished. Clearly the substitution of trained skilled health care professionals by untrained home care workers or family members must at least raise the question of the quality of resultant care. The prospects and costs of monitoring the quality of care delivered is diminished where care is shifted from a large institution into patients' homes. Home care patients may feel unable to voice complaints over the quality of care delivered by family members. Issues also arise as to liability for injury as a result of a

family caregiver's negligence. Moreover, for some Canadians, the reality is that home may not be a warm, inviting, peaceful haven. Home may in fact be characterized by stress, overcrowding, a lack of proper heating, lack of adequate food, poverty,<sup>38</sup> loneliness,<sup>39</sup> or even abuse.<sup>40</sup>

Presently there is very little evidence with regard to the quality of care received in institutions as opposed to the quality of care received in a home whether formal services or supplied by family members. What work has been done has focused on recovery times and the need for readmission as key outcome measures.<sup>41</sup> However, it is notoriously difficult to measure the effectiveness of health care. Simply focusing on outcome measurements such as readmission rates, mortality, morbidity, etc. misses significant aspects of quality that most people would consider important, e.g., minimization of pain and discomfort, caring kinds of health care services, respect for ones wishes, and personal dignity.

#### 5.3 HEALTH ECONOMICS

A critically important factor that has fuelled the deinstitutionalization process and the shift to home care has been the impact of health economics. An economic analysis has a vital role to play in designing a health care system. A society needs to allocate resources to all its different health care needs commensurate with the value its members place on satisfying those various needs. A society also need to ensure that each health need is satisfied with the least expenditure of resources possible to allow resources for the satisfaction of other health needs or other general needs/wants. However, there are problems with relying too heavily upon an economic analysis for, as I discuss below, it is often insensitive to the distribution of costs and benefits. Moreover, an economic analysis has little to contribute in terms of the value a society places on satisfying various

health care needs and, indirectly, various health care services.

An economic analysis reveals two major problems with health insurance and health care service systems: moral hazard and information asymmetry.

There are two forms of moral hazard. First, a person with full insurance may take fewer preventative steps than they otherwise would take to lessen her own risk of requiring healthcare services in the future, e.g., engaging in known high-risk activities like smoking, eating fatty foods, mountain climbing or driving without a seat-belt (ex ante moral hazard). Secondly, moral hazard is said to arise when a patient demands more (or more expensive) health care services (ex post moral hazard). In Canada, as the government pays for hospital and physician services, patients do not pay directly for services at the point of consumption and thus are insensitive to the cost of care services demanded. This leads to a climate of rising expectations with people believing that all their health care needs should be met with the highest quality services available, regardless of cost. Thus, a patient may have no compunction in demanding a drug that is ten times the cost of an alternative yet which only results in small health gains. What is often not recognized is that moral hazard is more or less of a problem depending on the type of health care service in question. For example, I am very unlikely to demand more hip operations than I really need (although I may be insensitive to the fact that one surgeon has much lower costs than another) but may demand more massage therapy or, more relevantly in the context of home care, more housekeeping services.

The second problem economists recognize is that physicians and other health care professionals have significantly more knowledge than patients do. This is sometimes referred to as the "information asymmetry problem." Patients rely on physicians not only to identify their health needs but also to advise them what services and goods they need to respond to those needs. In other words, physicians not only tell patients what is wrong with them but also what they need to fix the problem. Canadian health economists, whilst acknowledging the existence of moral hazard, also recognize that patients will not be able to demand health care services in the absence of physicians, who are the gatekeepers to the system. Economists generally view the fact that physicians are insensitive to the cost of the varying services and treatments they supply or recommend as the key cause of cost escalation in health care systems.<sup>42</sup> Economists make the point that physicians have no incentive to be sensitive to the costs of the various services and treatments they recommend. In fact, they contend, many ineffective treatments are prescribed.

Economists' estimates of the cost of physiciangenerated inappropriate use of health care services vary but are sometimes as large as 30-40% of all health care services. Alan Maynard, a well-known British health economist, who often is invited to speak at Canadian health economics and policy conferences states:

It seems that as faith in religion has declined in some countries, faith in medicine has increased. Pharmacological innovation and improved diagnostic capacity has augmented the mystique of the medical profession. Due to third party payers, moral hazard and the reluctance of policy makers to design appropriate incentive structures to manipulate the behaviour of practitioners in efficiency and cost containing ways, physicians have been able to enhance demand for their services...Government and insurers have been uncritical of the basis of this increased demand for health care. The rhetoric of "everything must be done for

all patients" and "if it 'works', the intervention must be used" has been accepted uncritically in part because of the brilliant advocacy of provider agents and in part because of the ignorance of policy makers and society.<sup>44</sup>

In essence, economists assume that there is a significant amount of waste within the system as physicians do not choose treatments that are most cost-effective. They also emphasize that the increased expenditures in the health care system has done little in the way of producing additional "health." Moreover, they argue, physicians resist having resources diverted away from the health care system to other areas, such as education, income support, tax reduction, etc., as all money spent on the health care system, in one way or another becomes incomes for physicians and other healthcare providers. Two well-known Canadian health-economists, Robert Evans and Greg Stoddart note:

... the growing field of health care services research has accumulated extensive evidence inconsistent with the assumption that the provision of health care is connected in any systematic or scientifically grounded way with patient "needs" or demonstrable outcomes ... Accordingly, the greatly increased flow of resources into health care is perceived as not having a commensurate, or in some cases any, impact on health status. Nor is there any demonstrable connection between international variations in health status and variations in health spending.<sup>45</sup>

Economists have documented physicians' ability to influence demand for their own health care services both in Canada and in other countries. A striking example from the U.S. is a 1990 study of six imaging procedures. This study found that physicians who self-

referred (i.e., performed the procedure in their own offices) not only charged more per procedure but ordered more than four times as many as physicians who referred patients to an independent radiologist.<sup>47</sup> Adding cost and extra utilization, total expenditures on imaging ranged from 4.4 to 7.5 times higher for physicians that had a proprietary interest in the imaging services. Within Canada, variations between and within provinces with respect to the utilization of health care services that do not appear justified on the basis of differing health needs provide evidence for economists' arguments.<sup>48</sup> So, for example, there are significant variations in the number of hysterectomies performed with no underlying objective clinical reason why there should be such wide variations.49

Thus health economists conclude the more doctors and health care professionals in a system than the greater the total cost irrespective of real health needs. Similarly, the more hospital beds, nursing staff, and technology, the greater total costs will be irrespective of real need as beds, staff and technology are simply resources used by physicians to supply more profitable services. Economists advocate reductions in health expenditures by cutting the number of hospital beds and cutting patients' length of stay in hospital, claiming that such reductions will not adversely impact on Canadians' "health." <sup>50</sup>

I have three criticisms to make of the assumption that cuts can be made to the health care budgets without adversely affecting Canadians' health. First, focusing on health outcomes alone misses many aspects of the quality of care that people are concerned about. The difficulty is that health outcomes are presently only able to be measured by very crude indicators of life expectancy, infant mortality. But the maxim "all that can be measured does not necessarily matter and all that matters cannot necessarily be measured" applies here. Relying on these

outcome measures alone fails to address what many consider important aspects of quality of care, e.g., how long a patient is left in distress or in pain without assistance, how quickly a diagnosis and treatment is given so as to relieve anxiety etc., and whether a patient is treated with dignity and respect and her/his wishes respected. Reliance on outcome measures means that the provision of "caring" services such as nursing, for which the quality and impact thereof are often difficult to measure, are seriously discounted by economists.<sup>51</sup> As a striking example of the economic perspective in this regard, Evans and Stoddart note:

Providers of care, particularly nurses, often emphasize their caring functions. The point here is not at all that caring is without importance or value, but rather that it is by no means the exclusive preserve of providers of health care. Furthermore, the "social contract" by which members of a particular community undertake collective (financial) responsibility for each other's health narrowly defined does not necessarily extend to responsibility for their happiness. "Caring" independently of any contemplated "curing" or at least prevention of deterioration, represents an extension of the "product line" - and sale revenue – of the health care system. If collective buyers of these services, public or private, have never in fact agreed to this extension, its ethical basis is rather shaky.52

The second critique of the argument that health care resources can be cut without adversely affecting health is that this argument assumes that physicians, when faced with limited resources, will allocate resources optimally. However, physicians often lack good information about the cost-effective-

ness and even effectiveness of many interventions. The Canadian system also does not provide them with a framework for decision-making to choose between and prioritize different health care needs as there is a reluctance to publicly acknowledge that rationing occurs. Physicians may find it easier, rather than changing the way they practice medicine, to simply transfer costs to others through longer waiting times and lists.

The third and final critique I have of the argument that health care resources can be cut without adversely affecting health is the assumption that the system must be oriented towards maximization of "health" as a measurable outcome. This perspective betrays the utilitarian philosophy that underlies economics. Although the total health of the population is undoubtedly important, the primary reason justifying government intervention in health care markets is an egalitarian one, e.g., that everyone, as a matter of justice, is entitled to fair share of health.<sup>53</sup> There is a sharp distinction between a system that is designed to maximize total health in the aggregate (which is insensitive to the distribution of health benefits) and a system that aspires to ensure a fair share of health for each individual. Equity in the context of health is, however, generally characterized as achieving a fair distribution of health care services rather than achieving a fair distribution of health, as the latter goal is viewed as too problematic.<sup>54</sup> One can see the limitations of a focus solely upon aggregate health when considering the position of the dying, the disabled, and the chronically ill. For these vulnerable populations, the provision of additional health care services may do little if anything to add to the population's "health."

### 5.4 THE DETERMINANTS OF HEALTH

The focus on "health" outcomes rather than health care services supplied by physicians and the shift from institutional care to home and community care, has also been supported by groups keen to see a shift away from the purely "medical model" to a more integrated, holistic, approach. It has also converged with the rise in what is known as the "determinants of health literature". <sup>55</sup> Essentially, this literature argues that there are many other factors that contribute to health beside the consumption of medical services, for example, nutrition, employment, socio-economic status, marital status, position at hierarchy in job, etc. Arguably, then we may be better to transfer some of the resources from expenditures on expensive hospital services to these other areas if our goal is the maximization of health.

The difficulty with the determinants of health approach is that just as there is a paucity of evidence demonstrating the ultimate impact on health of curative health care services so too is there a paucity of evidence about the impact of preventative measures. If the standard for public funding is conclusive evidence of an impact on health outcomes, then this justifies both significant cuts to spending on the health care system without savings being transferred to other areas of social spending. Yet the difficulties inherent in measuring the quality of health care are well documented.<sup>56</sup> The lack of evidence does not mean that health care services do not have an impact on health but that it is difficult to establish the magnitude of this effect conclusively. This suggests the need for further investment in monitoring and measuring the impact on health of various health care services rather than retrenchment of health care spending in general.

### 5.5 Public Spending Retrenchment

The thinking on the part of health economists and on the part of advocates of the determinants of health approach has dovetailed with the desire of governments in many countries on fiscal and sometimes ideological grounds to constrain the level of increases in government

expenditures on health care services. In Canada, the key health reform initiative has been to reduce the flow of resources into the system on the assumption that faced with limited resources physicians and other health care providers will direct resources to the greatest need and eliminate inefficiency and waste. Provincial governments have focused their cost-cutting efforts upon hospitals for two reasons. First, hospitals comprise the largest components of health care spending. Second, provincial government have significant control over hospital budgets compared to, for example, budgets for physicians (who are paid on a fee-for-service basis and to some extent can simply provide more services in response to fee reductions) and for drugs (where is there is a significant amount of private expenditure).

Over the last four years, Canada has been successful in pursuit of its general policy of expenditure reduction and has reigned in the total amount spent on health in terms of real total health expenditures (\$1,819.19 per capita in 1992 to \$1,765.74 per capita in 1996).<sup>57</sup> The total spent on health care services as a percentage of GDP has fallen from 10.0% in 1992 to 9.2% in 1996.<sup>58</sup> However, having been given a rationale that allows health care budgets to be cut, governments in Canada have not transferred resources to other areas of social spending such as education, public health programs, and social welfare, that may impact on health.

Cost-cutting and improving efficiency are often assumed to be one and the same thing. It is very important to make the simple but often overlooked point that cutting government expenditures is not the same as improving efficiency. Efficiency, from an economic perspective, takes into account all costs, wherever incurred in the public and private sector. Thus cutting government expenditure will not be efficient if the result is that costs are simply shifted to others in the private sector. Despite the strong push towards deinstitutionalization

and care in the home, there has been little evaluation of the cost-effectiveness of the delivery of different health care services in the home whether provided by unpaid family members or by paid professionals. It is simply assumed to be cost-effective often on the basis that care by family-members is "free". However, a true economic analysis would consider all the costs associated with shifting care away from institutions and into homes.

Some of these costs of the shift to home care were identified (although not quantified) in a study released in March 1997 by researchers in Alberta. They created a taxonomy of the hidden costs of informal elder care in the home which included emotional costs, physical and social well-being costs, labor costs, loss of employment opportunities, and out-of-pocket costs for the caregiver and costs for the caregiver's employer arising from employees "accommodating their paid employment to their caregiving demands" (absenteeism, lower productivity, etc.) and costs associated with the "development and administration of family-friendly employee benefits." <sup>59</sup>

A report released in March 1998 by Saskatchewan's Health Care Services Utilization and Review Commission found that providing patients with home care where appropriate instead of keeping them in the hospital would save between \$150 and \$230 per day.60 Although this research attempted to identify broader economic costs such as unpaid caregiver time it still did not quantify employment costs of caregivers reducing their hours of work or giving up employment, foregone employment opportunities, foregone tax revenues, costs to employers or accommodating employees who need to engage in informal caregiving and costs associated with absenteeism, missed overtime, re-hiring and re-training.

# 6.0 THE DISTRIBUTIONAL IMPLICATIONS OF DEINSTITUTIONALIZATION AND THE SHIFT TO HOME CARE

In terms of distributional implications, I want to discuss the impact on people in rural areas, impact on people on low incomes, and the impact on family members.

With regard to people in rural areas, the deinstitutionalization process has particularly focused on closing small rural hospitals and consolidating hospitals in urban areas. It is true that there is evidence that some surgical procedures are more effectively and safely done in institutions that perform large volumes of procedures. 61 However, these better outcome rates have to be balanced against the longer traveling times for rural people to hospitals, distance to emergency services, and the costs to patients, their families, and their employers of having to take time off work to travel to urban centres. The burden on family caregivers in rural areas is higher than in urban areas because of both the distance from, and the uneven distribution of, publicly-funded supports.62

The shift from caring in institutions to caring in homes places additional burdens for those on lower incomes. Because of the fact that the *Canada Health Act* only protects hospital and physician services, the shifting of care outside of hospital walls and into homes and communities has resulted in increased private costs for patients and their families in terms of drugs, medical equipment, and the direct and indirect costs of informal or formal care-giving services. Private sector expenditure on health care has steadily increased over the last decade (\$560.31 per capita in 1990 to \$746.98 per capita in 1996).

When considering the distributional implications of shifting costs away from the public sector and into the private sector one has to be aware of the well-documented correlation between medical need and low socio-economic status.<sup>64</sup> To put it simply, the poorer a person is the more likely it is they will need medical services. Thus, privatizing care and shifting the cost of caring on to patients and family members necessarily involves a net loss for the poor in society if the resources saved are not transferred back to them through other social spending.

Poor women are particularly affected by the transition from institutional care to home care. First, they are affected as representing the majority of the elderly in need of care and assistance. Not only are there are a greater proportion of women that are elderly (as women live longer than men), but research indicates that a greater percentage of elderly women are in need of more assistance than their male peers for example, with housework, meal preparation, shopping, and moving around the house.<sup>65</sup>

Elderly women are also more likely to live alone than any other group in the population. Statistics Canada reported that in 1996, 24% of the population were in one-person households, 66 and of these individuals, more than one-third (36%) were aged 65 and over. 67 29% of people over the age of 65 lived alone, 68 and 58% of women aged 85 and over live alone. 69 Of all seniors, 58% are women, with the percentage increasing to 70% in the over 85 age group. 70 Thus, women as the receivers of care are disadvantaged by a move to home care as they may not have family members living with them to provide care or to provide supplemental care to whatever is publicly-funded.

Women also bear a disproportionate share of the costs as caregivers. Although the figures vary from study to study the general consensus is that women are not only significantly more likely to be caregivers but also supply significantly more hours of care. According to Statistics Canada, 66% of informal caregivers

are women and that this amounts to approximately 14% of all Canadian women over 15.<sup>72</sup> Female caregivers are also more likely to be called upon to provide the most stressful and intensely personal kinds of care. For example, of those who are caring for dementia sufferers, 72% of informal caregivers are women.<sup>73</sup> Thus women, as caregivers, are more likely than men to incur the wider costs of home care such out-of-pocket costs for drugs and medical equipment and lost employment opportunities.

### 7.0 Conclusion

I would like to conclude with thoughts on advocacy for establishing a home care policy that is both efficient and equitable and pitfalls to avoid.

1. First, one should be careful when banding around the popular rhetoric that the system should focus more on health and less on the medical model. Economics is grounded in a utilitarian philosophy and emphasizes the aggregate production of health regardless of distributional considerations. Similarly, the "determinants of health" perspective is grounded in looking at health from a population or public health perspective. The rhetoric of "health" may in fact mask discrimination or discounting of services for vulnerable population such as the terminally ill and the disabled, as devoting extra resources to their health needs will contribute little to the overall healthiness of the population. What is clear is that we need better and more sophisticated measures of health than life expectancy and infant mortality, more research on the values Canadians place upon satisfying various health needs, and more research on the value of caring services like nursing, the quality and impact of which are intrinsically difficult to measure.

- 2. My second point is that any future home care program will not be able to be all things to all people, and that choices are going to have to be made between competing needs as a dwindling tax base supports a rapidly aging population. When considering the future development of home care policy, the needs of the poor and particularly poor women must be addressed first as they are burdened with a disproportionate share of the costs in the shift from institutional care to care in the home. A key measure of any society's health care system is the degree to which it serves its most vulnerable members.
- 3. My third point is that advocates of a national home care program must realize that to truly serve the poor and those on lower incomes, any home care program must include coverage for drugs and medical equipment. The Liberal government did promise in its Red Book to develop both national Home Care and Pharmacare programs. The political momentum for a Pharmacare program has fallen away, partly because of opposition by drug companies but also because many Canadians do not view it as a key issue as they have drug coverage through their employer and the very poor and elderly are generally covered by a provincial plan. Middle class Canadians, particularly women do, however, consider home care a very big issue as they try to juggle work, family, and caregiving commitments. Nonetheless, a full 14% of Canadians have no drug coverage and for these individuals, the financial burden of shifting from care in the hospital to care in the home can be very heavy. Also serious consideration should be given to compensating individuals on low incomes for the time they spend in caregiving.
- 4. It is often difficult to measure the quality of health care and to draw linkages between the consumption of health care and health care outcomes. The costs of monitoring quality will increase with the shift to home care as there are numerous sites of delivery (i.e., homes) rather than one central hospital or institution. Home care patients may be reluctant to complain or question the quality of care delivered by loved ones. We must begin to research how to ensure the quality of care and the safety of home care patients. Quality control should focus on the most vulnerable individuals. Assessors need to assess not only the willingness and capacity of family members to provide care but whether the home itself is suitable for the delivery of care.
- 5. Finally, the assessment process (an assessor, generally either a nurse or social worker, is sent to the home to assess the ability of family members to provide needed care) will be key to ensuring women are not discriminated against. This assessment process is ripe with the possibilities for stereotypical assumptions about the ability of men and women to care for themselves and for others and stereotypical assumptions about the importance and demands of other tasks men and women perform, either in the workplace or at home. It is important to ensure that assessors do not assume that women, particularly women who are already at home with other caregiving responsibilities or are looking or training for work, are a free pool of labour to care for the elderly. Clear central guidelines are required for the assessment process to make sure that the work women do. whether in the home or in the marketplace, is valued and considered when considering the capacity of women to provide home care to family members.

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