

**CARE IN THE HOME:  
PUBLIC RESPONSIBILITY - PRIVATE ROLES?**

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### **Introduction**

This is a story about Emma Dunmore over the past two years. Emma is a fictional character who will illustrate some of the many issues surrounding home care in Canada. The issues are complex and interrelated, and prevalent throughout the country. Emma's story, however, is based in Ontario, where home care is coordinated by 43 Community Care Access Centres. These CCACs contract out to private agencies (for-profit and not-for-profit) which provide the care to clients.

The current state of home care in Canada is characterized by both promise and tension. There is enormous potential for home care to be a very significant component of Medicare. Meanwhile, the population is aging, new technologies enable care to be provided in the home on an unprecedented scale, and increasingly hospitals and long term care facilities are becoming less attractive as sites of care. In many ways, it seems, all roads lead home.

### **Emma's story begins...**

Emma Dunmore is a 73 year-old who lives alone. She has arthritis and is very frail. Her husband died twenty years ago from heart problems, problems which today can be easily addressed through surgery and drug medication. Her daughter, Marie, lives in another community 30 minutes drive away. One day Emma broke her hip while trying to do some gardening in her backyard. A neighbour called for an ambulance and she was rushed to hospital where eventually they decided to put a pin in her hip. Emma and her daughter thought that this would mean she would be placed in a nursing home.

A case manager came to see Emma, however, and advised that she would be out of hospital as soon as possible, and placed in the local home care program. Neither Emma or her daughter knew what that meant...

## What is home care?

Home care is “an array of services which enables clients incapacitated in whole or in part to live at home, often with the effect of preventing, delaying or substituting from long-term care or acute care alternatives.” (Health and Welfare Canada, 1990). Emma is one of about a million people who now receive home care each year in Canada.<sup>1</sup> As the case worker explained to Emma, home care is different from long term care. Home care can refer to services *based* in the community but coordinated through home care programs. Home care can be for a long term, but it can also be short period of time as people require post-acute care services in the home after having received medical treatment in a hospital (e.g., for changing bandages, assistance with medications and so on). “Long term care” typically refers to care that is based in residential long term care *facilities and* longer term *home care* programs. Long term care is the phrase used in Ontario. It has a similar meaning to the more commonly used phrase ‘continuing care’, which is used in most other parts of the country.

One of the major transformations in home care these days is that more and more individuals are receiving various types of ‘acute care substitution’ - services that used to be associated with the acute care setting. Home care programs are treating more clients with significantly higher levels of acuity than in the past. People are being discharged sicker and quicker from hospitals.

Home care is not simply care for the elderly, although this group receives a large proportion of home care services compared to the rest of the population. With increased levels of post-acute care more and more of the adult population is, and can expect to be, receiving home care. Many children with a wide range of illnesses and diseases also receive services through home care programs. Home care is generally available to everyone although the process of referrals for services varies across the country, as do eligibility criteria. In many provinces user fees are required for home support services and other programs (e.g., use of equipment).

## Why all the interest in home care?

One of the important questions regarding home care is whether it is cost effective. Although Emma had always been cautious with her money, she had never paid much attention to the issue in health care and just assumed the government knew what it was doing. Intuitively most people believe that care in the home is more cost effective than in the hospital. This belief has been one of the prime motivators in the shift of care from hospitals into the community. Although there appears to be some evidence of cost-effectiveness when compared to the acute and long term care settings for certain types of patients, there is much more research required to confirm whether *all* substitution functions are cost-effective in the home setting.<sup>2</sup>

The other attraction of shifting care is that people would prefer to be in their own home instead of a hospital. This was certainly the case for Emma. She was delighted to be able to go home. Her daughter, meanwhile, thought going home was a sign her mother was getting better. She also hadn't realised that increasingly, it would prove to be a strain on her own life.

## Functions of home care

The home care program was going to be able to serve its three recognised functions for Emma:

- **substitution:** services that are also provided in hospitals and long term care facilities;
- **prevention:** services and monitoring which, over time, lead to overall lower costs of care and an improved quality of life for clients; and,
- **maintenance:** allowing clients to stay independent in their current living environment instead of having to move to a more expensive situation.

There is a wide range of services that are provided in the home, some of which Emma would be assessed as requiring. These services include many that once would have been provided in hospital, nursing services for medical diagnoses, other professional services such as speech therapy, occupational therapy and physiotherapy, and services to assist the functional needs of individuals (e.g., personal care, bathing, cleaning, laundry, meal preparation). A number of other programs or services can also be offered, such as adult day programs, meal

programs, home maintenance, respite, counseling, medical supplies and equipment programs, self-managed care, and palliative care.<sup>3</sup>

Emma was discharged from hospital and within a day had been visited and assessed by a home care case manager. She discussed the options with Emma, and tried to determine how much care Emma's daughter would be able to provide. Within a few days Emma was receiving physiotherapy, some assistance with bathing, meal preparation, laundry services and housekeeping from two 'new' people in addition to the case manager - a physiotherapist and a home support worker. This was a bit confusing for Emma, especially as they didn't seem to work for the same organization as the case manager.

### **Who provides home care?**

There are actually thousands of professional and para-professional staff providing home care services across the country. There is a mix of casual and full-time workers, union and non-union workers, professionals and non-professionals. Physicians and other health professionals may play a greater role in the provision of home care services in some provinces compared to others.

Equally important, however, and some people would say increasingly so, are the substantial number of 'informal' caregivers across Canada, who are largely silent in the formal home care systems. It has been recognized that these caregivers are the backbone of care in the home.<sup>4</sup> These informal caregivers provide unpaid care to family and friends, without which, the publicly funded system could not function effectively. There are growing pressures being placed upon the informal caregivers as a result of changes taking place in the publicly funded home care programs.

"Informal" caregiving, as Emma's daughter soon discovered, is becoming more and more an issue in health care as the population ages.<sup>5</sup> If the current changes to publicly funded home care continue then much more will be expected of informal caregivers. The prevalence of Alzheimers disease, for example, is likely to become a major area of focus for home care programs. There is projected to be 314,000 cases by 2011, up from 161,000 in 1991 (i.e., 5.1% of the population 65 and over). In 1991, 34.5% of those aged 85 and over suffered from dementia (National Advisory Council on Aging, 1996). Additional cases will require additional supports, and education and training in the community for both the clients, and the formal and informal caregivers.

## Models of home care

There are four basic models of *publicly-funded home care* in Canada. These reflect varying degrees of public and private sector involvement with the *delivery* of professional and home support services in the provinces and territories. There has been a significant increase in the level of financing to publicly funded home care over the past few years. Indeed, home care expenditures for Canada have increased to almost \$2.1 billion in 1997-98, up from just over \$1 billion in 1990-91.<sup>6</sup>

All the models provide *some form* of streamlining function (e.g., intake, assessment, referral, case management); differences exist with the extent to which services are contracted to private organizations (both for-profit and not-for-profit agencies) that then deliver the care. Although most programs are integrated with other health care sectors (e.g., through Regional Health Authorities), some are still relatively separate (e.g., in Ontario and Nova Scotia). The four models are as follows:

**Public-provider model:** professional and home support services are delivered mainly by publicly-funded employees. Examples include Saskatchewan, Quebec, Prince Edward Island, Yukon, Northwest Territories and Nunavut.

**Public-professional and private home support model:** All professional services are delivered by public employees. Home support services are contracted out (for-profit and not-for-profit agencies). Examples include New Brunswick, Newfoundland, British Columbia and Alberta.

**Mixed public-private model:** Streamlining functions are provided by public employees. Professional services are provided by a mix of public employees or through contracting out to private agencies. Home support services are contracted out (for-profit and not-for-profit agencies). Examples include Nova Scotia and Manitoba.

**Contractual model:** Streamlining functions are provided by publicly-funded employees. Professional services and home support services are

contracted out by a public authority to private agencies (for-profit and not-for-profit agencies) which provide the care to clients. This model reflects the Ontario model of home care as organized through its 43 Community Care Access Centres (CCACs).

Public funding for home care is *allocated* to the various types of ‘home care organizations’ that then coordinate and/or deliver home care services in each of the jurisdictions across Canada. Veteran’s Affairs Canada also provides a range of services for Veteran’s across the country through their Veteran’s Independence Program.

### **Financing and delivery**

There are important distinctions to be made regarding the nature of public and private involvement in home care. The models above are all *financed* by the provincial governments. However, some services require co-payments or user fees. The federal government provides funding for the territorial programs and Veteran’s Affairs. The *delivery* of services through the publicly funded system, however, is made by the public *and* private sector. In turn, some private agencies are *not-for-profit* (e.g., Victorian Order of Nurses, St. Elizabeth Health Care), while some are *for-profit* agencies (e.g., ComCare, Gentiva, All Care). There has been a mix of not-for-profit and for-profit agencies providing home care services for many years. There are also *self-managed care* models within provincial programs and Veterans Affairs across the country, whereby clients may hire and direct their own workers to do the tasks deemed necessary. Self-managed care is of particular importance to individuals who have very specialized needs. Finally, there are home care services provided *outside* the publicly-funded system, where individuals pay directly to private agencies without any government involvement.<sup>7</sup>

Although we have information on the use of the publicly funded system, there are very little data on the nature and extent of individuals paying privately for home care services. Anecdotally it appears there have been substantial increases over the past few years. These services may be delivered by regulated and unregulated agencies. To many observers this reflects a growing need for home care (including the response by individuals to the perceived lack of services in

the publicly funded home care programs), and the increased market opportunities for small and large scale businesses to emerge.

If agencies are unregulated, or not sufficiently regulated (e.g., not enough regulators, infrequent reviews, etc) then *safety* concerns become, and indeed are, an issue. At present there are no national standards for home care. Many believe this is an essential first step in the development of a national home care program. Although different provinces and agencies have developed standards, there are inconsistencies in the standards and often no linkages to the quality of the care being provided. At the national conference on home care in 1998, delegates felt there should be a phased-in approach to developing national standards, which eventually would lead to standards formalised in federal legislation (Health Canada, 1998).

Similarly, there is relatively very little information on the exact numbers and roles, characteristics of informal caregivers.

For Emma and her daughter who delivers care - public or private, or type of provider - was irrelevant. What was far more important was that something would be provided to Emma that would maintain her in her home independently to the greatest extent possible. Ultimately it is the effect of care on individuals which makes the difference between an effective program or policy, and one that is not. Given all the commitment and national fervour about Medicare, Emma and her daughter saw home care as an entitlement.

Similarly, 'big picture issues', such as national standards, were very distant from the realities of Emma's situation. The need for standards, or the need or desire to contract privately for home care services, was not something that Emma had ever had to think about. Neither was the Canada Health Act. But they soon became much more important.

### **Human resources**

At first Emma didn't like the intrusiveness of the 'strangers' coming into her home and providing her with home care, but nevertheless she would tidy the house up before they came, the best she could. It would tire her out. After a few weeks, however, her mobility was improving, and soon the physiotherapist stopped coming. She encouraged Emma to do regular exercises and plenty of walking with her stick. Emma still had Helen, the support worker, who gave her



a regular bath, did the laundry and some housekeeping and helped prepare her meals. They become good friends and talked about all sorts of things. To Emma, the quality of care was excellent. Providing care in one's home requires a trusting relationship given the personal nature of it and the site in which it takes place. It can also be very intrusive.

The human resource dimension is the biggest issue in home care at present across the country (Anderson and Parent, 1999). From a policy perspective the concerns focus on the numbers of staff, inadequate wages, retention and recruitment difficulties, and conditions in the workplace. Unfortunately, for clients such as Emma, these issues translate into lost continuity of provider (which may affect the quality of care), uncertainty around actual care, lost friends, and in some cases, the reduction or loss of services. Helen was often the highlight of the day for Emma. Social isolation and loneliness can be a major issue for seniors living alone.

In many parts of Canada there is a high turnover of nurses, therapists, and home support workers. There are a number of reasons for this: the casual and part-time nature of the work (plus infrequency and uncertainty), the comparatively low pay compared to working in more stable environments such as an institutional setting or other sectors of health care, limited benefits, the uncertainty of each home environment (e.g., working alone, hazardous or unsanitary home environments, abusive behavior by clients or family), the costs of travel (in some cases not absorbed by the provider organization or the government), limited job security, long hours associated with transit connections if staff do not have their own vehicles, the need to provide care in hours outside the regular working week (e.g., evenings and during the weekend), limited incentives for home support workers to upgrade their skills. In small, rural communities and isolated communities it is often difficult to recruit and retain qualified staff. Recruitment and retention is also especially important to ensure specialist care can be provided to clients with special needs, such as palliative clients, those with HIV/AIDS, and clients with serious mental illness.

The shortages are especially compounded by the differential in wages between the institutions and the community. Given the working conditions in the community, there is considerable incentive to take higher paying jobs in more secure, stable and full-time positions in the institutions. What is more, the institutional sector in many jurisdictions is now hiring more staff, which makes

the predicament in home care of even more concern. In some parts of the country, it has been noted that nursing staff are older and many retirements can be anticipated in the next few years.

The differential is also a concern when considering the effects of non-union labor in home care (e.g., in some for-profit agencies). If nursing staff, for example, can be hired at a lower wage in the community then this may also reduce the incentive for new graduates to enter the home care work force. The competitive model whereby agencies compete with one another for home care contracts has also been cited as an incentive for home workers to pursue more stable employment in the institutional sector.

There is a well recognized need for more training for home support workers. This is particularly important when considering the unique needs of some clients (e.g., those requiring palliative care, those with progressive diseases such as Alzheimers, those with fluctuating needs, such as individuals with serious mental illness, and those with unique language requirements - especially in locations with large immigrant populations), clients discharged earlier from hospital (and hence with higher acuity than ever before), and in some places, with long term care facilities now only admitting higher levels of care clients, there are more debilitated seniors in the community than ever before. But who should pay for this training? How do you ensure workers receive the required training? Should the training be provided in-house, or through formal, standardized training programs in various community colleges? To many observers it seems ironic that the most fragile individuals in the community are being cared for by workers receiving almost minimum wage.

Low wages may drive the costs of care down and enable, or force, more to be done with less. But many stakeholders are concerned that this could compromise quality as well as reduce the incentive for working in the community setting. If wages are raised to the level of the institutions, the incentive to remain in the community would likely increase, but that will have the effect of raising the costs of care without necessarily increasing the numbers of those receiving care, or the amount of care to those individuals. Raising the levels of training required will also increase the costs of care.

## **The contractual model**

One day Emma was advised that Helen would no longer be coming in as a new agency had won the contract to provide services, and that would mean different home helpers. This was quite a shock for Emma and her family. It was a shock for Helen as well, who now had to look elsewhere for a job. As far as Emma could tell, you couldn't ask for better care than that provided by Helen, so it seemed odd that the new contract was 'won' by another agency. It all seemed quite confusing and unnecessary. Despite what she had read in the newspapers about for-profit agencies, all she was concerned about was continuity of care, and that the care was as good as it was with Helen.

Contractual arrangements in home care are becoming more common across the country. Ontario's home care program is now based on a competitive model in which not-for-profit and for-profit agencies compete for the delivery of services. The 43 Community Care Access Centres in Ontario each have their own request-for-proposal bidding process. There have been many concerns raised recently about more for-profit agencies being provided public funding to deliver services to individuals (profitization).

It can be expected that the debate will continue as to the mix of for-profit and not-for-profit delivery as there has yet to be discussions at a public level concerning whether 'profit' should be made from the delivery of home care services. As many areas of the country have traditionally had public or not-for-profit delivery, one challenge for governments will be to convince tax payers that they are getting value for money from for-profit agencies without compromising care or eroding the public home care system. Substantially greater levels of awareness of home care by the public, however, is required to make such discussions meaningful.

For Emma, she had to build a new trusting relationship with the new home support worker, or workers, coming in.

## **Fiscal pressures**

By this stage, the CCAC had begun a new wave of reassessment of clients. It had had trouble trying to do this in the past because the case managers had large case loads and clients now seemed to have higher needs. There were rumours, however, that the CCAC may be running at a deficit, and so reassessment seemed a logical thing to do in the hope of reducing the hours of care clients received. And as it turned out, the CCAC case manager assessed Emma as having improved from her initial assessment, and so reduced the level of housekeeping she received. Emma felt a bit guilty for having received the housekeeping over the past few months.

A few months later, she was advised that budget constraints had meant that she would be getting fewer baths and that she could no longer get laundry services or as much housekeeping or meal preparation as in the past. Emma wasn't sure what to do. She had got quite used to the home supports she had been provided. In fact, she couldn't imagine what it would be like without the services.

## **Loss of home supports**

Home care programs across Canada are providing services to clients with a higher level of acuity than ever before, which costs the system more money, and requires staff with new skills and training. With the growing numbers of clients requiring acute medical care in the community, concerns have been raised that home care is moving towards a medical model at the expense of other valuable components of the program such as the supportive services. Thus in many places, budgets have had to be reviewed and cuts to services made. Cuts to line items in budgets translate to very different living situations for clients, and there has yet to be research that has fully uncovered the effects of such changes (Parent et al, 2000a).

Although it is well recognized that providing acute care in the community is both appropriate and feasible, many claim it should not be at the peril of home support services. Most people believe that supportive services maintain people longer in their homes, while over the long term reducing costs to the health care system. Home supports also provide ongoing surveillance of clients, social interaction, and increased quality of life. Equally important to many, home supports provide valuable respite for informal caregivers. For policy-makers, effectively balancing the competing needs of post-acute care and chronic care

clients, both from a fiscal and health outcomes perspective, is essential to the development of home care in Canada.

The case manager explained that although she recognised Emma's situation and felt extremely frustrated that the fiscal realities had forced her to make cuts to Emma's services, there was little she could do, and that it was the governments fault for placing Emma in this situation.

Many CCACs have had to decrease their level of funding for home supports in the wake of substantial increases in post-acute care, rising numbers of clients and capped budgets. Case managers must allocate and reallocate services based, in theory, on client need, but in practice they must incorporate the fiscal realities of the CCAC, which may be different to that of an adjacent CCAC. Thus the effect of insufficient funding at the global level is ultimately translated into extremely challenging and difficult decisions for case managers, variations within and across jurisdictions in access to services, and ultimately affects the health and well-being of clients and their caregivers.

### **Shifting responsibility**

With fiscal pressures has come changes to the nature and extent of service provision, and cost shifting. Private home care services are looked at by clients and their families, clients may use other parts of the health care system more (e.g., family physicians, emergency), more clients may move into nursing or retirement homes, and informal caregivers may take on greater levels of care for their family member.

This is evident with the changes occurring with home supports. By default more than by design, the nation is allowing the emergence of a two-tiered structure for the delivery of home supports. While those who can afford it receive services through the private/ for-profit agencies, those who cannot afford it will, in many cases, go without if they are no longer eligible through the publicly-funded system. Emerging then is a growing 'home care divide' whereby some people will be in the position to receive private services while others will have to rely on the publicly-funded system, informal caregivers, or go without. There are many groups that are more susceptible to the lack of availability and access to home supports than others, such as people with serious and persistent mental illness, for example.

Is there enough funding in home care, or is it a question of appropriate resource allocation? The federal government insists that it will give the provinces more funding for health care, but not until some coherent strategy is in place based on the collective input of both the provinces and the federal government; funding based on strategy.<sup>8</sup> The provinces on the other hand, insist that what is needed is the funding first, and then *they* will decide how best to allocate *their* resources amongst their competing sectors of the health system.<sup>9</sup> Home care development is up against some stiff opposition. Most people would agree there needs to be more money put into home care; even though provinces are investing more, it is not sufficient to meet the growing demand.<sup>10</sup>

With cuts to her services there was little option but for Emma's daughter to take on more of the supports that Emma, and Marie and her family, thought were necessary. Marie took on the responsibility of doing the things home care had once done, even though she lived in another community and had a family of her own to look after.

### **Coping with coping**

Without virtually any warning, Emma's services had been almost eliminated. The ripple effect of cuts to services is significant, but no more significant than the effect it has on family caregivers. Tremendous stress was placed on Emma's daughter, Marie, although it didn't seem so initially. Marie took over all the functions that the home care program once provided, even though she had a full-time clerical job and three children of her own. With a growing family Marie had very little time to call her own, and even less now with the additional support she was giving her mother. She didn't mind at all and felt a deep sense of obligation and commitment, even though she was upset with the government for having made these changes to *her* life.

But Marie found she was taking more and more days off work, was coming in to work late and leaving early, losing sleep and was not able to do the things for her family she once did. It did not help matters that her mother lived 30 minutes away by car. Although her husband was very supportive it was clear that this unexpected commitment was changing the family dynamics. Marie's workplace meanwhile, was generally unsupportive of Marie's predicament, had no policies in place for addressing eldercare issues, and could not see the merits of any supportive eldercare policy, even though research has shown that elder care commitments affect the bottom-line in business. This, over and above any

corporate responsibility to its employees and the community in which they operate. To Marie, and more and more of her work friends, it was becoming clear that their company had to be made much more aware of the effects of changes in the publicly-funded health care system if it expected to retain its valued employees. The issues, they felt, was that anyone could become an informal caregiver at any time. The effects on family life and work life can be far reaching.

With a steady increase in the number of women in the workforce, caregiver burnout is quickly becoming a major issue in the workplace as families increasingly juggle work and home responsibilities. Elder care is likely to become a major issue over the next decade as the public system of care reduces its level of responsibility for clients and more emphasis is placed on individuals to assume more of their own care. The pressures facing individuals have already been shown to affect the workplace in terms of productivity, absenteeism, early retirement and so on (e.g., CARNET, 1993; Hoskins, 1996).<sup>11</sup>

The changing nature of the family is continuing, and will continue, to have an impact on home care.<sup>12</sup> If governments continue to expect families to play a key role in the provision of care and support, then consideration must be given to the amount of stress the provision of care will have on the informal caregivers physically, mentally, and financially. When discussions take place on where to allocate dollars for home care, it would be expected that informal caregivers would be part of that discussion.

Marie weighed up the options; continue working full-time, knowing that her work was suffering, reduce to part-time status, resign and potentially lose any career path she had and also lose the company benefits, ask her mother to move in with her, or talk to her mother about a nursing home. It seemed to be a hopeless position for Marie.

Emma didn't want, or ever expect, to be such an imposition on her daughter, and recognizing the growing anxiety and strain on Marie's life, hired a private agency to provide the services she once had received through the home care program. She couldn't pay for much but really felt the additional services were essential for keeping her safely at home and as independent as possible. And of course it would help her daughter.

Private agencies do provide an element of choice for individuals that would not be possible within the public system, although only for those who can afford it. In some cases people prefer to hire privately rather than risk having to share their financial information to determine their eligibility for publicly funded home care services. Not only may this lead some people to live ‘at risk’, it may also contribute to the ‘burnout’ of informal caregivers. To some people there is a belief that an aging parent has worked hard in their life and should be *entitled* to ‘free’ home care; that is the least the government can do. The reality, however, is that entitlement programs are increasingly rare and have been replaced by programs which focus on *eligibility* criteria, some of which may now have long waiting lists. The exact contours of the eligibility criteria vary from province to province and, in many instances are being tightened, forcing individuals in many cases to look at other options.

### **Canada Health Act**

The five principles of the CHA, as they were originally drafted, outline the conditions under which the federal government will fund health care.<sup>13</sup> It is important to understand the scope and limitations of the CHA in relation to home care.

The first principle of **universality** means that provincial health plans must insure all residents for medically necessary hospital and physician care, regardless of the individuals income status. What remains a concern, however, is that ‘medically necessary’ and , ‘health’ have never been clearly defined, leaving the interpretation up to each jurisdiction. The second principle, **public administration** requires that provincial insurance plans are accountable for the money they spend on the programs by a public authority. It also ensures that a private, for-profit insurance company can only administer insurance plans on behalf of the province. **Comprehensiveness** criteria states that all medically necessary services for the purpose of maintaining health, preventing disease or diagnosing or treating disease, illness or disability should be covered. The provinces do, however, have the discretion to determine what is medically necessary and therefore determine what will be covered. Home care remains an uninsured program under the CHA, listed only as an extended service of which the five principles do not apply. Once again, it is at the discretion of the provinces how far they expand the scope of services they will cover in the community. Herein lies the rub. The result is that provinces can allocate



resources to expand or contract the scope of the insured services. Presently, all provinces have expanded their insured services to cover professional services, such as nursing in the community setting. Home support services such as meal preparation, laundry, and housekeeping, in general, are not considered medically necessary and therefore are not an insured service, and subject to a user fee in some provinces.

The principle of **portability** means that Canadians can move from province to province and maintain their insurance coverage for medically necessary services. Home care, as previously discussed, is an extended service and therefore non-urgent home care services are not portable between provinces and generally require a period of waiting. The last of the five principles, **accessibility**, means that every insured person must have reasonable access to insured services without paying a fee. This criteria *entitles* Canadians to medically necessary services without cost. This sense of entitlement has created concern and consternation for the general public who find it difficult to understand why health care delivered in the community, at times, comes at a cost. What ever happened to universal health care?

Although Emma was not required to pay a user fee in Ontario for her home support services, the amount and duration of the publicly-funded services were extremely limited. With the reduction in services, she was now only eligible for one sponge bath a week and meal preparation once daily, and two hours of housekeeping a month. Emma certainly didn't expect, nor did she want, more help than she needed, but her arthritis prevented her from carrying out normal activities during the day and it was discouraging to feel that she wasn't able to cope. Emma had only three choices; either pay for additional services privately, hope that her daughter could help out, or do without services. At one point Emma considered staying with her sister in Manitoba, but she found that she would likely have to wait for home care services because she was considered "non-urgent"- Emma soon realized that her options were narrowing.

While she was in hospital all her medications were covered under the provincial health insurance plan. Once home, as a senior, Emma was fortunate enough to be eligible for the Ontario Drug Benefit plan where she paid a yearly deductible and a dispensing fee. It all adds up when you are trying to survive on a limited income.

The growing public concern and dissatisfaction with the direction of the health care system in Canada has once again elevated the debate around revising the CHA to more clearly reflect the context of a growing home care sector. Changes could be anticipated with a consensus on a national home care program and its components—a consensus to be reached between the provinces and the federal governments.<sup>14</sup> Changes will also require a principled debate engaging the general public. It will take political will and tenacity from all parties when trying to determine the appropriate scope and balance of medical and social services.

### **Private roles**

In some provinces that fund only not-for-profit agencies, for-profit agencies do provide an overflow function for publicly funded programs. These are typically in the urban areas, as rural areas, with sparse populations and long distances for travel, are for the most part uneconomical for the for-profit agencies; there is not the volume of work to make the development of for-profit care in rural areas feasible. Meanwhile, if clients do not ‘qualify’ for publicly funded services because they are over a minimum financial threshold, they may be encouraged by home care case managers to purchase services privately. Although some third party insurance may provide for this option, it may create hardship for many individuals, and may also result in many people going without home care. If unmet needs exist, then these could lead to further and perhaps more expensive use of the health care system.

It seems obvious that if someone elects to have home care provided privately that they would have the financial resources to do so. This may not always be the case. Moreover, many people may not even have the ability to pay the ‘user fees’ for home support services that are required in some provinces, and the numbers of these individuals may increase as the provincial governments, in the wake of fiscal pressures, increase the user fees (fortunately for Emma, there are no user fees in Ontario for home supports if she is deemed eligible for these services). Individuals or their families may then either choose to pay the user fees, go privately for services, or go without. It can be anticipated that insurance companies will play an increasingly significant role in the nature of home care delivery in the country.<sup>15</sup>

The use of a private agency did relieve the stress on Emma's daughter but it did not relieve her daughter's growing anxiety regarding her mother's future. What were the regulations governing private agencies? Were there any? Again, should she get her mother to move in with her? In any case, once her mother had made her mind up there would be no discussion. The last thing Emma wanted to do was disrupt her daughter's life.

### **After home care?**

Over time Marie began to look at the range of alternative options for her mother. These included supportive housing and nursing home options. As time went on, Emma's health deteriorated, she became less mobile and the arthritis worsened. Eventually her daughter called the home care program and asked if her mother could be placed in a nursing home. The home care program determined Emma was eligible.

In many parts of the country, home care is the single entry point for accessing nursing homes. But the very abrupt, distinct difference between living in your own home versus an institution - is receiving increasing attention. Many feel there needs to be more supportive housing - living arrangements which, although not an individual's home, are non-institutional, and provide various supportive services to enable an individual to function independently to the best of their ability, and remain out of a nursing home. Indeed, there is a strong interest for such housing and adequate home-based services.

But in Emma's case, she was put on the CCACs waiting list for a nursing home and after a few weeks offered a placement. Although not Emma's first choice, she decided to move in. This brought on considerable relief, guilt, and anxiety for her daughter.

Emma's story is only one of many, but it encapsulates a number of critical issues in home care. In terms of difficult issues that may arise, Emma's story is about average. There are some that are less difficult and there are some that are worse. Home care to many people is more than a medical intervention; it makes a huge difference to their quality of life.

## **National issues, individual realities**

The main point of Emma's story is that larger federal and provincial policy issues have very real consequences for individuals across the country. Funding for home care is allocated within health care budgets, and therefore competes with other important health issues such as cancer treatment, waiting lists for medical care, drug costs and so on. In terms of priorities, home care often lacks the immediacy or urgency that characterize many other health care issues. Within the home care budget, home supports are competing with, and losing out to, post-acute care services, which are taking increasing amounts of the budget allocations. Although home care budgets have been increased, in many cases this has not been enough to respond to the growing needs and numbers of clients. This has placed considerable pressures on government policy-makers and management, who have turned to different options such as increasing user fees for home support services or changing eligibility criteria to the extent that some individuals may no longer be eligible for care that would have been provided even just 2-3 years ago. Case managers, meanwhile, must balance the fiscal realities of limited budgets with the needs of their clients as they assess clients for the service mix available. Moreover, in many instances, case managers are taking on increasing numbers of clients and have difficulty finding the time to reassess client needs on a regular basis.

All this in a period in which there are growing shortages of people working in home care. Professional and paraprofessional staff are feeling the pressure of working in a system with comparably poor wages, and stressful working conditions. There is growing use of for-profit agencies providing care within and outside the publicly funded system, and with many of these being non-unionized, there is the potential for a downward spiral of wage levels, which further reduces the incentives to work in the home care sector.

The pressures lead to cost shifting; more individuals seeking care outside the publicly funded system, more expectations being placed on informal caregivers, and there is growing pressure on volunteer agencies and their volunteers, who are finding it stressful to help individuals with higher levels of care. In some cases, individuals are simply going without needed services. All this in a sector with great potential and enormous expectations placed on it, but relatively limited information capacity and little research.

Despite these issues, it is important not to lose sight of the positive aspects of home care in Canada. There are several elements consistently referred to as ‘strengths’ of home care. These included the quality, dedication and commitment of those working in home care, particularly the front line staff providing the care and assessment functions, the vast range of programs and services offered and effectively coordinated in the community to enable individuals to remain in their home and to function to the greatest extent possible given their health status, the increasing levels of integration with other parts of the health care system, and the benefits of a single point of entry to community-based care.

### **What’s next?**

The federal government has acknowledged the need for itself and the provinces to coordinate their efforts in some way to combine additional funding for health care with some form of coherent strategy for how the dollars will be spent. Home care appears integral to those discussions. In the meantime, the provinces continue with their own approaches to home care, taking into account their own other political, fiscal realities, and the competing concerns of other parts of the health care system. Many decisions require supportive evidence, and it is here where the research community can play a greater role.<sup>16</sup>

Assuming there is agreement amongst the federal and provincial politicians, what could a national home care program look like? One scenario is that funding be provided by the federal government in exchange for the provinces committing to using the funding to provide a range of specified services, possibly under the umbrella of an expanded Canada Health Act.

The establishment of a set of guiding principles may lay the basis for further development of a national home care program. The challenge will then be to determine the services that would be in that federally funded ‘*basket of goods*’, and what services the provinces themselves would continue to fund. For example, would all nursing and/or therapies be funded? Would home support services be funded, and if so, which ones and upon what evidence? The role of user fees will likely be discussed, and in particular, for what services and at what charge? Given the variation in the current delivery of services across the country,

it may well be expedient to leave how home care is to be *delivered* to the provinces themselves.

In any case, such developments will not happen overnight and it would be irresponsible to rush into a program without clearly articulating a vision, and the goals and objectives for the implementation of a detailed strategy, one which would engage the federal government, the provinces and other key stakeholders.

Another possible scenario is for the federal government to directly fund programs or initiatives that complement the provincial programs. Current initiatives, for example, include the funding of the national evaluation of the cost-effectiveness in home care research project. Others might include national training programs for home support workers, funding support for volunteer organizations, financial and other supports for informal caregivers and so on. Indeed, there is a distinct lack of information on family caregivers, and yet they are the largest group of caregivers. And although relatively unknown, silent, and unpaid, they must bear the consequences of the current cost-shifting in the publicly-funded system.

### **Care in the Home: Public Responsibility - Private Roles?**

The policy changes that are used to realign fiscal pressures should be congruent with the values, beliefs, and attitudes of Canadians. Although short-term monetary gains may be achieved by limiting the dollars available to home care, the long-term consequences may be more costly. The three functions of home care: substitution, prevention, and maintenance will certainly come under scrutiny if we continue to inadequately resource the program. The adequate provision of home care services cannot be left to the ebb and flow of fiscal pressures.

The challenge for governments will be to maintain fiscal prudence in the face of demographic changes, advances in medicine, and the often total reliance of the disabled elderly on the state and the family. Can the governments meet this challenge without further shifting the responsibility of care to families, volunteer organizations and the for-profit sector? The current trend with publicly funded home supports, for example, has seen a shift in care and responsibility to unpaid family members, a policy alternative that may not be sustainable given the changing nature of the family.

There are a number of compelling points that make the development of home care a logical next step in Canada's evolving health care system. The technology is available to provide services in the home more than ever before. There is a commitment by the federal government to have a national home care program, and the provincial governments insist on further, and much needed health care dollars. Informal caregivers meanwhile, are having to take on more and more care of their family members, and it can be expected that growing pressure will mount from grass-roots and national organizations to actively lobby on behalf of caregivers.

The governments are accountable to the Canadian public for the continuation of Medicare and the principles upon which it is based. If a national home care program is to be built upon those principles then there will be a necessity to delineate the contours of the program such that it reflects the public expectations of what should, and should not, be publicly funded in home care. If we assume that the definition of health encompasses both medical and social elements, then the scope of insured home care services under Medicare should be expanded to incorporate a broader array of services. There is a lack of awareness, however, of what home care is and can be, which makes a public debate about its future challenging.

What is perhaps easier to contextualize for many people is the way in which home care will be provided, and paid for privately. Although more and more home care is shifting to private funding and private delivery, with more expectations being placed on informal caregivers, there has yet to be any public confirmation that the increased private role in the provision of home care is what the Canadian public want. It may be time for that public debate; to determine just who should, and who will, pay for home care in Canada.

In the meantime, the Emma Dunmores of Canada and their families must face the consequences of cost shifting and policy changes occurring beyond their daily life spheres. They have had to react to change rather than participating in effecting the changes that reflect what Canadians truly want for their system of home care.

## ENDNOTES

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<sup>1</sup> The utilization of publicly funded home care services in a single year for Canada as a whole is likely to be close to one million clients. As can be expected given the population across the country, Ontario and Quebec have the highest number of users followed then by British Columbia and Alberta. The precise figures, however, vary according to the data source being used. Estimates for Ontario over a one-year period from provincial sources, the Canadian Home Care Association, Health Canada and Statistics Canada for 1996/97/98, for example, range from 224,787 to 361,918 (Health Canada, 1999). The estimates reflect the variation in definitions of home care programs and different reporting requirements within the provinces and territories. Indeed, such variation makes it difficult to compare provinces with one another and is one of the challenges to address when considering the potential development of a national home care program.

<sup>2</sup> There is a growing body of research that has examined this cost effectiveness issue (e.g., Coast et al, 1998; Hendrik and Inui, 1986; Hollander, 1999; HSURC, 1998; Hughes et al, 1997; Jones et al, 1999; Shepperd et al, 1998; Sodestrom et al, 1999; Weissert, 1985; 1991). More research is currently underway in Canada on this issue (see, for example, the 15 inter-related projects sub-projects of the National Evaluation of the Cost Effectiveness of Home Care, funded by the federal government).

<sup>3</sup> Improved technologies are changing the scope and delivery of home care in Canada. More costly technologies are being used in the home, especially with more and higher acuity, acute care clients. It is not unusual for clients to receive intravenous therapy, nutrition therapy, hydration, antibiotics, chemotherapy, or pain control in their homes. Other technology-intensive therapies include renal and peritoneal dialysis. There is more complex ventilator care, especially for children, more central line infusion treatment, more patient controlled analgesia pumps, different types of post surgical care (especially with more same day surgery in hospitals on backs, joints, mastectomies, and so on). Other advances have been made with drug therapy over the last five years, and advances also with thrombolytic treatment, etc. The changing technology is requiring home care personnel and caregivers to adapt to a growing number of clients with complex and expensive care needs.

The actual amount and nature of the services available varies amongst the provinces and even within the provinces. Health Canada reports that of those clients served in Canada, 38.8% received professional nursing services, 27.4% home support services, and 26.5% therapy services. In Ontario, of those receiving services, 37.8 % received professional nursing services, 26.8% home support services, and 34% for therapies (Health Canada, 1999).

<sup>4</sup> They are also referred to as family caregivers, primarily caregivers, and natural caregivers and carers.



<sup>5</sup> Using what is considered a realistic estimate, a medium growth projection by Statistics Canada estimates that by the year 2016 the Canadian population will reach just over 37 million. The percentage of those aged 65 and over will increase to almost 16% (5.9 million seniors), which is up from just over 12% in 1996. Those aged 80 and over will comprise just over 4% of the total population (1.5 million), up from 2.8% in 1996. The senior population is expected to grow even more rapidly once those born in the baby boom years (1946 to 1965) begin turning 65. Seniors 85 and over report the most serious health problems associated with age. They are also the fastest growing segment of the overall senior population. And not only will there be more seniors, they will also be living longer than in the past thanks to improved medical technologies and changing lifestyles.

<sup>6</sup> Based on a number of sources Health Canada (1999) reports that as of 1997-98, 4% of all publicly funded health expenditures were directed to home care, which is up from 2.25% as reported by Health Canada and the Canadian Institute for Health Information (CIHI) in 1990-91. Veteran Affairs Canada also spent an estimated \$161 million providing its Veterans Independence Program (VIP) in 1996-97.

Using the figures from Health Canada and CIHI, public health care expenditures by province per capita has increased from \$37 per individual in 1990/91 to \$69.20 per individual in 1997/98. Data from Health Canada (1999) indicate that there is considerable variation in per capita spending for 1997-98 across jurisdictions (e.g., depending on the data source, from \$55.90 to \$71.80).

There is also variation among the provinces and territories in the proportion of public funding allocated to home care (ranging from 1.7% in the Yukon to 5.8% in New Brunswick in 1997-98). Several provinces have substantially increased the proportion of funding directed to home care. Newfoundland, for example, has increased its proportion from 2.18% in 1990-91 to 5.15% in 1997-98, while New Brunswick has increased its levels over the same period from 3.13% to 5.8%.

<sup>7</sup> The public-private mix is shown below.

FUNDING	DELIVERY OF SERVICES
Public (using tax dollars allocated to health and social service budgets)	public employees
	private - not-for-profit agencies
	private - for-profit agencies
	private - self-managed care
Private (individuals paying directly for services - out-of-pocket or through third-party insurance)	private - not-for-profit agencies
	private - for-profit agencies
	private - individuals

Note: this table refers only to the formal system of home care.

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<sup>8</sup> A recent interim report from the provinces “*Understanding Canada’s Health Care Costs*” states that \$4.2 billion dollars in new money is required for the health care system to effectively respond to the growing and aging population. The final report is scheduled for release later in the year.

<sup>9</sup> Once funding has been earmarked for home care, it is typically allocated across a province as part of a regional funding envelope based on an age/sex formula. Within a home care budget, decisions must be made as to how the funding should be spent (e.g., on acute care substitution, home supports, specific programs at the expense of others and so on). From there, case managers assess clients to determine their need for services. This is a critical juncture in today’s current environment as there can be a classic confrontation between client need and fiscal reality.

<sup>10</sup> More significantly perhaps, there needs to be more research to determine when specific services do make a difference for the various client groups. For example, with the wide range of home supports, which ones are of the greatest benefit to which client groups? When are they essential? If it is firmly believed that home care can be pivotal in a new health system, substantially more funding will be required for this to occur.

<sup>11</sup> Increased responsibility could be expected of the corporate world to provide supports for their employees that face, or are about to face, elder care obligations. In a recent survey conducted by Aon Consulting exclusively for MacLean’s Magazine, for example, employees were asked what they wanted most from their workplace benefit programs; 34% stated they wanted it to be flexible-particularly as it relates to elder care (MacLeans, May 2000).

<sup>12</sup> There is now an increased participation in the labour force by women, and the majority of women are combining care responsibilities and full-time paid employment. The formations, or definition, of what comprises a family unit is also changing. The proportion of Canadians living in families has dropped from 87.1% to 80.8% between 1971 and 1994. The number of people living alone has increased due to declining marriage rates, increased rates of divorce and separation, and larger number of seniors who live on their own. (Vanier Institute of the Family, 1997).

<sup>13</sup> The Canada Health Act (1984) was passed at a time when there were major concerns about preserving Medicare. Policy makers needed to make the system work, balance the allocation of resources to both acute and chronic care hospitals, nursing homes, and home care programs, manage physician fees, and expand prevention and promotion programs. It was felt that Medicare could not be preserved by charging the sick or by determining who was poor—it had to be preserved on five principles: universality, public administration, comprehensiveness, portability, and accessibility (Taylor, 1987). With that vision and mission in sight the Canada Health Act was drafted and subsequently passed.

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<sup>14</sup> One step in the process came about in February 1999, when the Social Union was signed by all First Ministers, with the exception of Quebec. The agreement provides a collaborative framework for social policy in Canada. Governments reaffirmed their commitment to “respect the principles of Medicare, and recognized the importance of being accountable to Canadians for the health system, including measuring progress on both the performance of the system and the health of Canadians.”

<sup>15</sup> Overall, private health spending per person on health care has been steadily increasing since the early 1990s resulting in Canada ranking second behind the United States among G-7 countries (CIHI, 2000). Indeed almost 30% of total health costs in 1999 were paid privately through out-of-pocket spending or private insurance. While the percentage of the total health care costs paid out privately for home care is not known, the increase in the number of for-profit agencies providing services may well be an indication of increasing numbers of people purchasing their services.

<sup>16</sup> Research can play a major role. There is a growing body of literature, for example, that has discussed the funding of home care funding of home care (e.g., Coyte and Young, 1999), human resource issues (e.g., Anderson and Parent, 1999; Keefe and Fancey, 1998), home care case management (e.g., Alcock et al 1998), home supports (e.g., HSURC, 2000; Parent et al, 2000a) and privatization (e.g., Shapiro, 1997). A number of studies have also examined related areas such as informal/family caregiving (e.g., Chappell, 1993; Guberman, 1999; Hirdes, 1999; Joseph and Hallman, 1998; Keating et al, 1999), the voluntary sector role (e.g., Theriault and Salhani, 2000) and home care within the context of continuing care (e.g., Anderson et al 2000; Hollander and Walker, 1998; Parent et al, 2000b).

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