caledon commentary

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Home Care: More Than Care at Home

the right thing to do

The importance of home care finally has hit home. The federal government has stated that it is time for action on this long-standing need. Ottawa has held preliminary discussions with the provinces about the possibility of a national home care program.

The Liberals lost their reputation as 'bleeding hearts' after bleeding billions from health care in recent years. They now recognize that the cuts may have gone too far, too fast, shaking Canadians' faith in the quality of health care.

This shattered faith is a problem not only from a health care perspective but also from a political point of view. Medicare is the darling of Canada's social programs. Governments threaten health care at their peril.

But politics aside, investing in home care is the right thing to do. The challenge is to do it right.

Home care is the right thing to do because the health care system has been skewed over the years towards costly medical and hospital-based treatment. Some blame governments for the imbalance – the federal-provincial funding arrangements that had been in place since the mid-1960s effectively favoured this form of care. There is now an attempt to introduce a better balance away from institutional treatment to forms of care that can be provided more effectively at home.

Home care is also the right thing to do because of the aging population. One in five Canadians will be over age 65 by the year 2021. A graying population means that home care no longer can remain a gray area of social policy: Demographics alone will move the policy train in this direction.

Finally, home care is the right thing to do because the institutions that once provided long-term care and assistance with daily living are being closed. But the problem lies not in the closure of institutions. The problem is that these

closures have not been matched by the provision of associated community supports. Residents of long-term care institutions have been sent back into communities with little support. There are now more homeless people on the streets – due largely to the closure of mental health facilities and cuts to social housing and welfare.

do it right

For all these reasons – politics being the least important – home care should be a priority for both the federal and provincial governments. However, the provinces have been decidedly negative about the new federal enthusiasm in this area. They argue that the existing health care system first should be restored before contemplating new initiatives.

The deep cuts in federal funding that accompanied the new Canada Health and Social Transfer (CHST) in 1996 have made provinces skeptical of federal cost-sharing for innovations in health. The First Ministers' meeting in December 1997 made clear the provincial position: Medicare should be restored and bolstered before Ottawa embarks upon so-called 'boutique' programs – i.e., fancy 'extras' such as pharmacare and home care.

It could be argued, however, that home care is far from a 'boutique' program. Rather, it is an essential component in the continuum of health care. Home care has emerged as a central part of the acute care system as hospitals discharge patients as early as possible and perform more and more procedures on an outpatient basis.

But the current debate is framing the issue far too narrowly. Home care is being seen as an alternative to costly hospital care. Yet it embodies far more than active medical or nursing treatment.

Public discussion of a national home care program should be conceptualized and designed right from square one as an undertaking to support independent living. Supports for independent living not only promote early release from hospital. They also provide assistance to individuals – the elderly, those with a chronic health condition and persons with disabilities – who are trying to live independently outside of an institutional setting. At some time in their lives, most Canadians will require supports to help with everyday living.

In short, home care is far more than the provision of care at home. And it is more than just a way of cutting hospital costs. Home care is a means of improving the quality of life for many Canadians and their families.

comprehensive home care

At the very least, a national home care initiative would have at its core the provision of certain forms of health care at home. It would deliver at home some of the acute care services available in a hospital or medical facility. Clearly, it would not be possible to provide all such services at home – especially those that involve sophisticated and expensive technology, such as magnetic resonance imaging or other diagnostic equipment. Certain services always will have to be delivered within a hospital or medical setting.

But a truly comprehensive home care program has several other components as well. These include technical aids and equipment, attendant services, homemaker services, respite, brokerage, and information and referral services.

Technical aids and equipment refer to items that help individuals perform the activities of daily living – e.g., moving, eating, hearing and speaking. Technical aids and equipment include, for example, wheelchairs, visual aids, hearing aids and prosthetic appliances.

Attendant services provide personal assistance with daily living activities such as eating, bathing, dressing and grooming. Attendant services differ from nursing care in that the former can be delivered by paraprofessionals. While attendant caregivers may require less formal training than nurses, they still must have some basic training in order to safely transfer and move individuals with mobility or neurological problems.

Homemaker services are another important dimension of home care. They refer to the provision of help with household tasks such as cooking, shopping, meal preparation, cleaning and home maintenance.

Other important components of a comprehensive home care program include *respite care* – i.e., temporary relief for families caring at home for a sick, elderly or severely disabled individual [Torjman 1997]. *Brokerage* and management supports recognize the need for coordinating a comprehensive package of care for persons with complex needs or for those who receive individualized dollars in respect of required services [Torjman 1996]. *Information and referral services* help identify, organize and manage home supports.

the current 'system'

The availability of disability supports and services varies widely throughout the country. The current 'system' – such as it is – defies simple description. It is a hodgepodge of public and private arrangements. Provinces and territories (municipalities in some jurisdictions) are responsible for the provision of these supports and services. In many cases, local nonprofit organizations actually deliver the services - when these happen to be available.

The supports that may be provided in one jurisdiction may not be available in another. The services to which individuals have access are very much a function of where they live. The problem is exacerbated by the fact that disability supports need to be highly individualized. Each person requires a set of supports unique to his or her needs.

The provision of technical aids and equipment illustrates the complexities of the current system. Patients in hospitals or special residences generally receive the aids and equipment they need as part of their treatment. Problems typically arise outside hospital walls. Access is far more complex for persons living independently in the community.

Ministries of education or health usually assume the cost of technical aids and equipment for children in public schools. Adults gain access to technical aids and equipment through different routes, depending on the jurisdiction and types of programs in which they are involved. Those participating in some form of rehabilitation or training funded under employment-related legislation or an income program, such as workers' compensation, may receive these supports as part of the program. Individuals not involved in rehabilitation or training – e.g., they may be at university, seeking work or at home – generally must make provision for special needs on their own.

Some provinces operate programs designed solely for the provision of technical aids and equipment. These programs differ through-

out the country. In some cases, they include a range of assistive devices. In other cases, only specified pieces of equipment, such as hearing aids, respiratory equipment or wheelchairs, are provided. Often only persons with designated conditions – e.g., paralysis, cancer, kidney ailments or cystic fibrosis – can qualify for assistance.

The cost of certain supports also can be reduced by various benefits delivered through the income tax system. The medical expense tax credit helps offset the cost of a designated list of disability supports such as attendant care; nursing home care; care at a school or institution; ambulance services; and medical devices such as artificial limbs, wheelchairs, braces and special eyeglasses.

The medical expense tax credit can be claimed by the person incurring the expenses or a spouse or relative paying such costs. To benefit from the medical expense credit, which is 'non-refundable' (i.e., it reduces income taxes owing), a claimant must owe income tax. Until recently, the nonrefundable nature of the medical expense tax credit meant that it provided no help to persons too poor to pay tax (unless a relative is paying medical expenses for them) - often the very people who most need assistance with their health-related expenses in the first place. However, a new refundable tax credit was made available in the 1997 tax year to working poor taxpayers with high medical expenses, though the maximum payment is a relatively modest $500.

The disability tax credit also provides some tax relief for the additional – but often hidden and indirect – costs of disability. These include, for example, higher utility costs for heat or air conditioning for persons with respiratory problems, special or additional transportation, and higher prices for consumer goods because of fewer shopping choices. In contrast to the medical expense tax credit, the disability tax credit has no fixed list of allowable expenses. The disability tax credit can be claimed either by persons with disabilities or a supporting relative.

Households with no access to technical aids and equipment through an existing program must purchase these goods and services on their own. Those who cannot afford to make the up-front payments generally must rely on provincial welfare programs to help offset these costs. The special needs provisions of welfare provide essential disability-related supports – a not-well-known but crucial function of the welfare system.

But there is no guarantee that welfare actually will pay for all – or even some – disability supports. If a province has exceeded its special needs budget before the end of the fiscal year, it may decide to stop paying for special assistance until the next fiscal year. Or the required item may not be included in the list of permissible costs – e.g., a wheelchair designed for sports or recreation may not be covered. Finally, special assistance is made available only when applicants have no other resources or there is no appropriate program in place to help offset these costs. Welfare is considered the social program of last resort.

The delivery of disability services can be equally problematic. These services may be provided to individuals in their own homes but not in schools, workplaces or recreation centres. Another difficulty arises from the fact that disability services often are attached to residential care, such as group homes, nursing homes or institutions. The individuals who require these supports become 'tied' to these residences. Because the funds go to the actual facilities, the

services are not portable - i.e., they are not 'attached' to the residents but remain with the institution, making it difficult for residents to seek independent living arrangements.

Affordability also creates problems of access. The cost of disability supports can be prohibitive and there is only limited assistance to help offset these costs. The Health and Activity Limitation Survey estimated that some 36 percent of adults face costs related to their disability that are not reimbursed by any public or private plan [Crawford 1997: 6].

Welfare may provide last-resort assistance, but is a classic case of 'Catch 22': The provision of this 'income-in-kind' makes it difficult to move off welfare for fear of losing special supports. An improvement in financial circumstances through employment, inheritance or other source means that persons with disabilities risk their security - and possibly their lives - if they cannot gain access to these supports.

Finally, even when disability supports are available or affordable, problems may arise around *responsiveness*. Individuals typically have little say in how services are delivered or managed. Some services operate as though they are needed only between 9:00 a.m. and 5:00 p.m., Monday to Friday.

Services may not available at the place they are required. Attendant services, for example, may be delivered at home but not at a workplace or school even though the same attendant would carry out precisely the same task. Consumers often are afraid to voice their concerns for fear of personal reprisal or losing the service altogether.

the road to comprehensive change

The many problems in the current patchwork 'system' make clear the fact that the road to comprehensive home care is long and complicated. It cannot be completed overnight. But it is essential that the framework which comprises the foundation of home care be conceptually broad enough to move in the direction of a comprehensive system.

Home care is far more than the provision of certain types of medical care at home. It is a way to encourage independent living and to prevent hospitalization and long-term institutionalization. It is a way to promote the quality of life not only for persons with disabilities and their families but for all Canadians - most of whom will require certain forms of supports and services at some point in their lives. The design of any home care system should take into account these equally important purposes.

The first step should be to resolve many of the long-standing problems with respect to the availability, affordability and responsiveness of disability-related supports and services. This goal would be entirely consistent with the new national agreement on disability, *In Unison*: *A Canadian Approach to Disability Issues*, adopted on October 27, 1998, by the federal and provincial ministers responsible for social services on behalf of their respective governments.

If the new home care design does anything, it should introduce an overarching framework within which a coherent system can develop over time. The framework should make provision for improving the component parts of a comprehensive system and developing the links among these dimensions. A new national home

care initiative should ensure a smooth transition along the continuum - from treatment to independent living.

Sherri Torjman

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