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Desperate for Respite

by

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Desperate for Respite

Diane cares at home for her ailing mother, who is dying of cancer and needs around-the-clock care. She can't walk and is unable to feed or bathe herself. Diane has thought about having her mother admitted to a palliative care unit in a hospital. But she knows that her mother would prefer to live the last few weeks of her life at home. So Diane works around the clock, keeping her mother comfortable and tending to her needs. Diane feels guilty about neglecting her young children but she has no choice under the circumstances. She'll make it up to them later. In the meantime, she is suffering from exhaustion. It would be nice to have occasional relief for a night shift so she can catch a few hours of uninterrupted sleep. Even once a week. But that is impossible; hiring someone to take the night shift is simply too expensive.

Helen spends the better part of her days - and nights - caring for John, her severely disabled son. Her days are long and exhausting. Because of the severity of her son's disability, she could have placed him in an institution. But she refused, knowing that she would be confining him to an empty life. Helen often thinks about how nice it would be to have a few hours for herself - to walk, to go for groceries, to have coffee with a friend. But she can't. There is no one to take care of John and she can't afford to pay anyone else to do it. His care is costly because of his special needs. She can't simply leave him with a regular babysitter.

Ray cares at home for his wife who has Alzheimer's. Despite urging from his children, there is no way that he will place Joan in a nursing home or psychiatric hospital. But he knows that he is risking his own health through the continual strain and fatigue of caring for her and worrying about her safety. He is afraid to leave her alone and lies in bed awake at night in case Joan starts wandering through the house - and out the door as she once did. He knows he needs help - but asking the children only increases their pressure to 'have her sent somewhere.' So he soldiers on, unsure of how long he can continue but knowing that he just can't stop.

Diane, Helen and Ray share something in common. They desperately need respite.

what is respite?

Respite (or 'respite care' as it is sometimes called) is a service for caregivers. It provides relief for the individuals - usually women - who care at home for a severely disabled or ill child, an ailing spouse or a frail or sick parent. The primary purpose of respite care is to provide occasional relief to caregivers to give them a temporary, but badly-needed, break from their caregiving duties. In addition to the needs of caregivers, the Canadian Association for Community Care has pointed out that more attention is now being paid to the needs of the person being cared for as well as the other family members.¹

Respite care is usually required for people living under exceptionally stressful circumstances. Not only do these caregivers work for no pay (because they are typically family members) but they often give up paid work and future pensions in order to care for the ill or severely disabled individual.

Respite care, like all social services, is generally considered to be the responsibility of provincial governments. However, it is delivered in a variety of ways - by provinces or municipalities, nonprofit agencies or private businesses. Respite services may be provided at home or outside the home; in the

latter case, the individual being cared for is moved temporarily to a different setting.

Payment for respite care varies by the type of delivery. Sometimes the cost is covered fully by the province or municipality; in other cases, families must pay on their own; in still other cases, a modest government subsidy must be supplemented by a private family contribution.

the need will grow

Respite care is in short supply - relative to both the current and anticipated demand for this service. The problem will get worse in future as a result of two key factors: the aging of the population and the deinstitutionalization of persons with disabilities.

Canada's population is aging rapidly. In 1951, the one million women and men 65 and older constituted just 7.8 percent of the population; by 1991, their numbers had grown to 3.2 million or 11.6 percent of the population. Seniors are projected to reach 8.3 million or 22.7 percent of the population by 2031. One in five Canadians will be age 65 early in the next century.

Moreover, the risk of disability rises with age. In 1991, 46 percent of all persons aged 65 and over had severe disabilities compared with 27 percent of people aged 55 to 64, 14 percent of those aged 35 to 54, eight percent of those aged 15 to 34 and seven percent of children under age 15 [Statistics Canada 1995: 5].

The aging of the population represents a serious pressure on pensions, health care and a wide range of social services. It has been described as "the economic problem that dwarfs all other national issues" [Petersen 1996].

Some would argue that this concern is unfounded. The seniors of tomorrow are expected to be healthier than those of today due to improvements in diet and lifestyle as well as advances in medical care and public health. But this good news is offset by the fact that these healthy seniors will live longer and there will be far more of them in future.

Many seniors will want to live at home for as long as they can. This quality-of-life issue often creates pressures on the children to ensure the well-being of their parents.

Yet many of the primary caregivers of the live-at-home elderly are themselves employed in the paid labour market. These caregivers are struggling to balance the demands of work along with the demands of raising children - hence the proverbial characterization as the 'sandwich generation.' This balancing act has become all the more difficult for working parents because high-quality, affordable child care is becoming increasingly scarce.

There will also be a greater demand for a wide range of personal supports - especially in the form of homemaker services, attendant care and meals-on-wheels. Homemaker services allow the elderly to live at home by providing assistance with shopping, cooking, cleaning and other household tasks. Attendant care helps seniors and persons with disabilities live in the community by assisting them with the activities of daily living - eating, bathing, dressing and grooming. 'Meals-on-wheels' is a service which delivers nutritious hot meals directly to the homes of seniors - usually for those who are frail or housebound.

Another factor that has created a demand for respite care is the trend towards closure of institutions for persons with disabilities. This move has been advocated widely by organizations representing persons

with disabilities who correctly have called for these closures on human rights grounds. Some provinces have been only too happy to oblige. They have shut down institutional facilities as a means of cutting costs - without putting in place alternative community-based resources. Parents and siblings are often left to care for a severely disabled family member who may require extensive care.

A factor that is generally overlooked in public policy discussions is the role that respite services can play in providing relief to parents who suddenly face extraordinarily stressful circumstances - e.g., mother and children fleeing a violent household; a parent has just been diagnosed with a terminal illness; a sole earner in the family has just lost a job. In all these circumstances, there may be a need for temporary relief from caregiving to allow the family to regain its equilibrium. Sometimes all that is required to help a family get back on its feet is a limited period of respite for a few hours a day over several weeks.

Despite the current and expected growth in demand for respite care, government support for this vital service is sparse. Voluntary agencies are increasingly hard-pressed to fill the gaps left by the shrinking public sector.

Recent changes to the financing of social services at the federal level will only make matters worse. On Budget night 1995, Ottawa announced its intention to withdraw the Canada Assistance Plan (CAP) under which the federal government shared half the cost of provincial welfare and social services, as well as the Established Programs Financing (EPF) arrangement under which Ottawa contributed to provincial health care and postsecondary education. These acts were replaced in 1996-97 by the Canada Health and Social Transfer (CHST) which combines the two previous financing arrangements into a single block fund for human services.

The CHST arrived with a big cut in federal cash payments. On a year-over-year basis, the cumulative reduction in cash transfer payments over the life of the CHST until 2002-03 will amount to an estimated \$8 billion [Battle 1996].

Equally important as the loss of federal funds was the loss of the national legislative base for the support of social services. The various forms of assistance and services financed under CAP provided essential supports to help seniors and persons with disabilities live independently in communities. Under CAP, Ottawa shared with the provinces the cost of respite services. It also shared the cost of homemaker services, attendant care and meals-on-wheels. CAP helped support medically-prescribed diets and medical supplies for certain households unable to afford these health-related costs. It paid for wheelchairs, special eyeglasses and prosthetic appliances for people unable to purchase such disability-related equipment on their own [Torjman 1995b].

It is likely that many social services will be substantially cut back or withdrawn entirely because CAP will no longer be in place to share the costs. Respite care and other social services will now have to compete for scarce funds with the far more popular - and better understood - health care and postsecondary education. The CHST likely will hasten the growth of private social services. And it is primarily lower-income Canadians who will bear the brunt of the proposed changes in federal social transfers. CAP essentially helped offset the cost of services for low- and modest-income Canadians. The well-off don't need help paying for the many social services supported under the Act - especially with respect to respite. Well-off Canadians have long purchased respite care on their own - such as private nurse or companion, housekeeper, nanny, private day care or summer camp for children. The need for respite is particularly acute for those who can't afford the costs [Torjman 1995b].

The great irony is that there always seem to be enough public funds for more costly institutional care if a family decides that it can no longer cope with caregiving pressures. If Diane had decided to place her

mother in a palliative care unit of a hospital, that care would have been fully paid through the provincial health budget. If Helen had decided to put John in an institution, the bulk (if not all) of the costs would be covered by the province. Ray would have paid nothing had Joan been admitted to a psychiatric hospital.

But there are rarely sufficient funds for less formal types of support which help sustain families in their natural roles. Both the health and social service systems are skewed towards crisis and costly forms of institutional care.

Moreover, there are always funds available when children have to be removed from their homes because of neglect or abuse. They become part of the child welfare system in which they are sent for foster care or adoption. Yet neglect or even abuse is often the result of exceptionally stressful circumstances in which a parent desperately needed some temporary relief.

While there are scarce funds to help support parents in their natural roles, millions of dollars are forthcoming for systems which remove children from their parents to place them with other-than-their-own families. This is not to say that the availability of respite care would eliminate the problem of child neglect or abuse. But opportunities for respite certainly would relieve the stress on many parents and likely would reduce the high incidence of child abuse for which we pay dearly - not only in terms of remedial services, but more important, in the legacy of physically and emotionally bruised children.

conclusion

There is a great need for respite care to help families in their caregiving roles. While the need for this service is growing, the financing to support it is far from adequate and is actually declining.

Perhaps the only fair conclusion is that 'respite care' is a misnomer. This service is more appropriately called 'despite care.' Despite its importance, the service rarely gets mentioned in public debate. Despite its invisible profile, it provides a crucial support to an increasing number of families; in fact, every Canadian family experiences a need for respite at some point. Despite the fact that respite services could help save money in the long term by bolstering natural forms of care, most health and social service dollars go towards costly treatment, institutional care and remedial forms of support.

In the face of an aging population and spiralling health costs, we ignore this crucial area of public policy at our peril.

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Endnote

1. In the case of children, in particular, respite care can offer opportunities to develop social skills, reduce family stress and enhance the quality of life for families with children with disabilities or chronic illnesses [Canadian Association 1996: 5].

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