

The Three Ghosts of Poverty*

Unlike the ghouls that make an appearance only on October 31, there are three ghosts that haunt millions of Canadians every day. These ghosts of poverty stalk far too many households involved in providing personal care and support to relatives with severe disabilities, or sick and aging parents.

The caregiving role can create serious financial strains. First, many seniors and persons with disabilities live on low incomes, and caregivers often must spend much of their own money for basic food, heat and shelter required by those receiving care. Second, caregivers' employment status and income can be jeopardized by the pressures of their caregiving responsibilities. Third, caregivers often have to pay the additional cost of disability-related goods and services not covered by medicare or private insurance.

These three ghosts of poverty, which hover continually, threaten to destabilize the

lives of the many caregivers trying merely to provide a decent quality of life for those they love.

The first problem is that persons with disabilities, regardless of condition, have on average significantly lower and more sporadic participation in the labour force. They often have no choice but to rely on income security programs, which virtually guarantee a life of poverty for many. An estimated half million Canadians with disabilities depend on provincial welfare for their income.

The solutions lie in shoring up and reforming the disability income system. If nothing else, welfare benefits for persons with severe disabilities should be bolstered and indexed to ensure that welfare does not equal poverty. Better still, persons with disabilities should not have to rely on welfare at all but instead should have available a new income program, ideally run by the federal government. The sizeable provincial savings

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that would result from shifting welfare recipients with disabilities onto a new federal program would be invested in disability supports to enable independent living.

There are some persons with severe disabilities who actually are employed – but they need to leave work occasionally because of episodic conditions, such as multiple sclerosis, AIDS or cancer. These conditions involve both remission, during which individuals function well, and recurrence which can be debilitating. Current income programs make no provision for these up’s and down’s – or in’s and out’s as the case may be. Possible reforms include changes to the Employment Insurance sickness benefit or to the Canada Pension Plan disability benefit to allow more flexible workforce participation.

The second financial pressure arises from employment-related insecurities for the caregivers. Many Canadians must reduce their hours or leave jobs altogether in order to carry out their caregiving responsibilities. They jeopardize their current income and future pension.

Reform options include expanding the Compassionate Care Leave provisions under Employment Insurance that allow up to six weeks’ paid leave to care for a gravely ill relative at risk of dying within 26 weeks. This measure could be expanded to permit leave for other caregiving circumstances, not just terminal illness.

Another possibility is a modest caregiver allowance. The UK and Australia, for example, pay a cash benefit to the family caregiver of persons requiring chronic at-home care. Ottawa currently provides a Child Disability Benefit, which delivers an

annual maximum \$2,455 per child to low-income parents with children with severe disabilities. This amount could be raised in recognition of the typically high cost of care. This type of benefit could also be extended to low-income households caring for adults over age 18 with severe disabilities.

The third economic strain derives from additional expenses linked directly to age or disability. These costs include charges for home care services, transportation for medical appointments, drug dispensing fees, technical aids and equipment, and structural modifications to a vehicle or residence.

There are both direct costs and hidden costs. Direct costs are readily itemizable. In some cases, they are offset by provinces or may be partially claimed under the federal medical expense tax credit.

Hidden costs, by contrast, cannot be easily measured even though they are still very real – the out-of-the-way trip to the accessible store or the wear-and-tear on clothing. In recognition of the additional hidden costs of caregiving and other financial pressures, Ottawa provides some relief through two income tax measures – the caregiver credit and the infirm dependent credit. These measures are intended to help caregivers by reducing their federal income tax.

The problem is that these provisions afford no assistance to Canadians too poor to pay income tax. Turning these measures into refundable tax credits would ensure that all households – including the very poor – receive some money in respect of their caregiving costs. The federal and provincial governments could also invest in the supply of disability supports and thereby reduce the expense incurred by individual households.

All caregivers struggle with these three ghosts of poverty that shadow them constantly. While it may be no mean trick to provide additional aid to these households – particularly to low-income caregivers – extra assistance to help offset the financial burden of caregiving would be a welcome treat.

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