

CALEDON



INSTITUTE OF
SOCIAL POLICY

*Proposal for a National
Disability Supports Initiative*

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A Priority Issue

Health care comes up consistently as the priority issue on the minds of Canadians. It is also a front-and-centre item on the agenda of First Ministers. Stories appear daily about the ‘crisis’ in medicare and about the job actions of health care workers striking various parts of the country. Politicians, pundits and interest groups muse regularly about the benefits or evils – depending upon their perspective – of user fees and other forms of privatization of public health care. There is continuing talk (and endless reports) about the need for major structural reform of health care.

While there is no single cure for what ails our cherished and still very popular medicare system, one reform is essential: We must put in place the supports that would enable many Canadians to live independently in communities and stay out of expensive hospitals and institutions. In looking for ways to reform health care, governments need to develop more community services that prevent institutionalization and help people live at home. An adequate system of disability supports is just one in a series of measures that would fill a major gap – the lack of community options for independent living – which is creating heavy pressures for costly, hospital-based care.

The evidence is mixed as to how large the financial savings resulting from the introduction of these supports actually would be. But the impact of these arrangements upon the quality of life is not in dispute: Care at home is a far better option than institutional or group care.

Governments throughout the country already have committed themselves – on paper at least – to taking action in this vital area. On October 27, 1998, all governments except Quebec signed a national agreement on disability entitled *In Unison: A Canadian Approach to*

Disability Issues. *In Unison* is seen as a vision paper because it sets out a clear picture of the ideals that the nation should strive to achieve in creating opportunities and ensuring necessary supports for Canadians with disabilities and their families.

It is a vision in which persons with disabilities participate as full citizens in school, work, culture, recreation and community life. *In Unison* identified three building blocks – disability supports, employment and income – in which changes are required to promote inclusion. These building blocks are intrinsically linked. Access to disability supports helps ensure that persons with disabilities can go to school, partake in training or get and keep a job. The ability to work reduces the need for income assistance. An adequate income enables people to purchase required supports.

In Unison commits all governments to work toward ensuring access to disability supports, decent employment and adequate income. Equally important, it represents a commitment for all governments to work *together* to reach these objectives. The area of disability supports provides a perfect starting point for the disability agenda because it links so closely to the key issue – health care – at the heart of the broader social policy agenda in Canada.

Indeed, disability supports apply to far more than the 16 percent of Canadians – or 4.2 million people – identified as disabled by the Health and Activity Limitation Survey for 1991, the latest available national data. The demand for care at home will rise with an aging population that is living longer. Statistics Canada reports that nearly half of older Canadians experience some form of functional limitation. The disability rate for Canadians age 65 and older is 46 percent; it jumps to 70 percent for those age 85 or older.

But disability supports refer not only to health services delivered at home. They also include other important forms of assistance that enable individuals to live independently. These supports are described more fully below.

Disability Supports

Disability supports are the goods and services that assist people with disabilities overcome barriers to participating fully in daily living, including economic and social activities. These goods and services can be classified into three main streams: technical aids and equipment, personal services and modification.

Technical aids and equipment include such items as wheelchairs, visual aids, volume control devices and prosthetic appliances, and work-related equipment such as scanners, TTYs (teletypewriter devices) and large computer screens.

Personal services include several major components. *Attendant services* provide assistance with personal needs such as feeding, bathing and dressing. *Homemaker services* help with household tasks, such as meal preparation and home maintenance. *Respite* refers to assistance primarily for families caring at home for children with severe disabilities – and aging parents. *Interpreters, readers and intervenors* assist with communication needs. *Brokerage* includes the information and counselling services required to identify, organize and manage disability supports.

Modification refers to alterations or additions to a primary residence, workplace or vehicle for accessibility purposes. These changes include, for example, wider entrances, ramps,

special doorknobs or handle bars, lower counters, visual fire alarms, emergency call systems or steering wheel hand controls.

Delivery of Disability Supports

Disability supports are delivered primarily by provinces and territories. The federal government shares in these costs through the Canada Health and Social Transfer and delivers supports directly to Aboriginal Canadians on reserve. The current system of delivery (if ‘system’ is not too ambitious a term) is plagued by myriad problems. These include access and availability, affordability, responsiveness and portability.

i. Access and Availability

The availability of disability supports varies widely throughout the country. The supports provided in one jurisdiction may not exist elsewhere. The services to which individuals have access are a function of where they live; problems of availability are particularly acute in rural and northern regions.

Disability supports are provided through various programs – whether they are institutional or residential settings, educational or training programs, or income – benefits, such as social assistance (welfare). Individuals who are not affiliated with a particular residence or program or who derive little or no benefit from current income tax provisions must purchase these goods and services on their own. Those who cannot afford to make the up-front payments or pay the required user fees often must rely on provincial/territorial welfare programs to help with these costs.

ii. Affordability

Affordability also restricts access. The cost of disability supports can be prohibitive and only limited assistance is available to help offset this cost. The Health and Activity Limitation Survey reports that 36 percent of adults face costs related to their disability that are not reimbursed by any public or private plan.

Goods and services that are more health-related in nature usually are provided in various health settings and are delivered without additional user fees because these supports are considered to be ‘insured services’ under the Canada Health Act. Similarly, goods and services deemed essential for basic education generally are subsumed within provincial education budgets (although there have been serious restrictions on these funds in recent years).

But user fees may be charged if the services are delivered outside a hospital, clinic or physician’s office. Charges may apply, for example, to some services delivered at home. These charges often are determined on a sliding scale that takes into account the user’s ability to pay the fee.

iii. Responsiveness

Even when disability supports are available or affordable, problems can arise around responsiveness. Supports for persons with disabilities need to be highly individualized. Each individual requires a different configuration of disability supports – a unique package to meet his or her needs.

But disability supports often are not available at the place they are required. While some

services may be provided to people in their own homes, these may not be delivered in settings such as public schools, workplaces or recreation centres.

Certain services operate as though they are needed only between 9:00 am and 5:00 pm on weekdays. Individuals typically have little say in how services are delivered or managed. Consumers often are afraid to voice their concerns for fear of reprisal or losing the service altogether.

iv. Portability

The provision of disability supports should not be tied to a designated location or income program, as is currently the case. Disability supports should be ‘portable.’ They effectively should ‘follow’ the person – into the classroom, training program, workplace, home or recreation facility – wherever these are required.

As noted, individuals with disabilities often receive the supports they need through provincial or territorial welfare programs. While this special assistance is helpful, it can create problems. The provision of this income-in-kind makes it difficult for many recipients to move off welfare for fear of losing special supports. An improvement in financial circumstances resulting from employment, inheritance or other source of income means that persons with disabilities risk their security, and possibly their lives, if they cannot gain access to these supports. One-quarter of Canadians with disabilities on income support programs cite the potential loss of supports as a reason for not looking for work.

Policy Options

There are several approaches to improving the availability, affordability, responsiveness and portability of disability supports. One route involves incremental improvements to the existing system: enhancing the quality of current services, ensuring that persons with disabilities have more income to purchase these supports and providing more assistance for offsetting costs through the medical expense tax credit and the disability tax credit.

But none of these options would do anything to expand the *supply* of available supports. There still would be fundamental problems of access because the supply of supports cannot meet the demand for them.

A more far-reaching proposal for reform focusses upon building the supply of disability supports. We propose the introduction of a National Disability Supports Initiative that would invest in the network of provincial and territorial disability supports. This proposal is consistent with the spirit of the Social Union Framework Agreement, which speaks to the need for joint federal-provincial/territorial investment around key areas of social policy.

There is precedent for this kind of collaborative effort. In September 2000, all governments (except Quebec) signed a federal-provincial/territorial Agreement on Early Childhood Development Initiatives. Provinces and territories agreed to make investments in four streams of early childhood development programs, levered by a federal contribution of \$2.2 billion over five years. The four major categories of early childhood development services investment are: promoting healthy pregnancy, birth and infancy; improving parenting and family supports; strengthening early childhood development, learning and care; and strengthen-

ing community supports for families with children.

National Disability Supports Initiative

i. Purpose

The purpose of a National Disability Supports Initiative is to promote the development of a comprehensive network of goods and services for persons with disabilities and their supporting families throughout the country. The Initiative would achieve this objective by expanding the quantity of existing supports, reducing their cost, improving their quality and ensuring their portability across sectors and regions.

The proposal recognizes that the federal, provincial and territorial governments already invest in a wide range of disability supports. The proposed Initiative would help generate new and continued investment in this crucial area over a sustained period of time. The federal portion allocated to provinces and territories would be directed toward the three streams of disability supports – technical aids and equipment, personal services and modification – and not solely to one area.

ii. Financing

In order to make a significant dent in the availability problem, the federal government would invest a substantial sum of money in respect of disability supports – in the order of at least \$.5 billion a year over a five-year period for a cumulative total of a minimum \$2.5 billion. Federal funds would be allocated among the provinces and territories according to a for-

mula based on projected population growth and economic need.

The federal investment is intended to lever associated provincial and territorial contributions derived from a combination of sources: provincial and territorial revenues, municipalities, community funds and geared-to-income fees. Subsidized goods and services would be available to low-income individuals and households.

In order to ensure adequate investment as well as stability in the financing arrangement, the National Disability Supports Initiative would set out a five-year schedule of financing. Adequate and stable funding is an essential prerequisite to a successful initiative. The arrangement would be monitored and assessed on an ongoing basis and modified accordingly. It would be evaluated and renegotiated at the five-year point.

While provinces and territories would be the primary beneficiaries of federal funds, the disability community in all jurisdictions ideally would be involved actively in decisions regarding the design, delivery and governance of disability supports in all jurisdictions.

The proposed financing would take the form of a block fund that would allow flexibility in design and delivery and would enable the integration of disparate supports. Integration would help eliminate the barriers created by current funding arrangements that effectively require artificial distinctions among health, social and educational services.

Another major strength of this proposal is that a National Disability Supports Initiative would establish a mechanism separate from income programs to provide for disability supports. It no longer would be necessary for persons with disabilities to turn to welfare or other

income programs in order to obtain essential supports – a ‘Catch-22’ that often creates barriers to employment and independence.

Despite the flexibility that the proposed National Disability Supports Initiative would allow with respect to program design and delivery, it nonetheless would operate according to clear guiding principles to which provinces and territories would adhere in order to receive federal funds.

This practice is consistent with the current funding arrangement for medicare. The Canada Health Act sets out the key principles which provinces and territories must respect in order to maintain federal transfers. Moreover, all jurisdictions would be required to provide financial and program information on their use of dollars allocated under the proposed initiative.

iii. Guiding Principles

The following guiding principles have been identified in numerous reports over the years, including federal Parliamentary Committees and Task Forces as well as federal-provincial/territorial reviews.

Self-determination means all services, ideally, would be self-directed and self-managed in order to meet individual requirements. Consumers would play an active role in the design and planning of disability supports at both the policy and delivery levels.

Comprehensiveness: Disability supports should be provided through a coherent system, assuring a wide range of goods and services. The system would be ‘seamless’ – i.e., disability supports would be available wherever required rather than in disaggregated pieces that fall under the separate auspices of education, health care,

social services, employment or recreation.

Accessibility means that disability supports would be available to all Canadians who need them. Functional ability would be the primary eligibility criterion. Access would not be based on such factors as age, employability or cause of disability.

The principle of *portability* seeks to ensure that persons with disabilities have access to the forms and levels of support they require in any part of the country without having to establish residency, undergo a waiting period or 'present with' a certain medical condition. The provision of disability supports would not be tied to a designated location or income program.

To honour the principle of *accountability*, governments would agree to organize in their respective jurisdictions an advisory group consisting primarily of the consumers of disability supports. The group would include representatives from the community, and the research and policy sectors. Governments would be expected to monitor the provision of disability supports and report publicly on their progress on an annual basis.

Why Do This?

Success in this area is important not just for persons with disabilities. A National Dis-

ability Supports Initiative embodies more than an appropriate policy for an aging society. There is an important political imperative that should be noted as well.

The Social Union Framework Agreement (SUFA) sets out three substantive areas in which the federal and provincial/territorial governments agreed to make progress: the children's agenda, disability and labour market programs. While various measures have been effected with respect to the children's agenda (including the National Child Benefit and the Agreement on Early Childhood Development Initiatives) and labour market issues, there has been only minor progress on the disability agenda. The primary changes have taken the form of improvements to existing income tax measures and the introduction of the federal Opportunities Fund. While these developments are important, the joint investment potential inherent in SUFA has not yet been tapped in this area.

Because the Social Union Framework Agreement is up for assessment, there are good political reasons to have a 'success' in this policy area. They would demonstrate through their actions that they have been able to work together to improve the standard and quality of life for families with children, for persons with disabilities and for all Canadians.