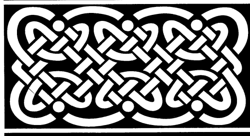

Proposal for a National Personal Supports Fund

by

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National Priorities

Health care emerged as the number one issue on the agenda at the recent meeting of First Ministers in Winnipeg. The provinces and territories want Ottawa to restore the funds it had withdrawn over the years as part of major federal cutbacks.

An issue apparently not high on – and not even on – the First Ministers' list was supports for persons with disabilities. These supports ensure that people are able to live independently in communities and stay out of hospitals, group homes and institutions.

Ironically, these are the very supports that would help respond to rising demands on the health care system. In looking for ways to reform costly health care, governments need to develop more community services that prevent institutionalization and enable people to live at home.

An adequate system of personal supports would fill a major gap – lack of community options for independent living – that is creating huge pressures for costly, hospital-based care. This concern applies to more than the 16 percent of Canadians – or 4.2 million people – identified as disabled by the 1991 Health and Activity Limitation Survey (latest national data).

The costs will only increase with an aging population. The incidence of disability rises with age. 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 more [Alcock 2000: 3].

If governments took action to ensure the availability of personal supports, they would be making great strides on both the disability and health care fronts. Yet while they are pressing for restored health care dollars – almost at the expense of everything else – the disability agenda moves nowhere. This lack of action is distressing, especially in light of a written commitment governments already have made.

A Commitment to Act

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 a nation should strive to achieve.

It is a vision in which persons with disabilities participate as full citizens in school, work, culture, recreation and community life. It is a vision in which they have access to required supports and in which barriers that prevent participation in the mainstream are removed. It is a vision in which persons with disabilities have control over their lives, the policies and programs set up to meet their needs and the decisions that affect them.

In Unison identifies three 'building blocks' – personal supports, employment and income – in which changes are required to promote full participation. These building blocks are intrinsically linked. Access to personal supports helps ensure that persons with disabilities can go to school, partake in training or get a job. The ability to work reduces the need for

income assistance. An adequate income enables the purchase of required supports.

In Unison commits all governments to work toward ensuring access to personal supports, decent employment and adequate income. Equally important, it represents a commitment for all governments to work *together* to reach these objectives.

There is no question that *In Unison* embodies a bold agenda, made more complex by the fact that its essential parts are closely intertwined. But while the agenda is big, it is not impossible. The best way to tackle the broad agenda set out in this vision document is to carve out small steps along the right path. One way to start is for governments to ensure that personal supports are more widely available.

Personal supports

'Personal supports' refer to a range of goods and services that help offset the effects of a disabling condition. These can be classified into three streams: technical aids and equipment, personal services and brokerage.

Technical aids and equipment include such items as wheelchairs, visual aids, volume control devices and prosthetic appliances, and work-related equipment such as scanners, TTDs (teletypewriter devices) and large computer screens. This category also incorporates health-related goods such as special dressings, oxygen equipment, dialysis equipment and surgical dressings.

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. Home health care provides health care services, such as dialysis, at home. Respite refers to assistance primarily for families caring at home for children with severe disabilities – and even aging parents. Interpreter, reading and other communication services are another important component of personal services.

Brokerage includes the information and counselling services required to identify, organize and manage disability supports. Brokerage services ideally are delivered independently from the provision of aids and personal services. Brokerage helps ensure that personal supports can be chosen and supervised in ways that respect the preferences, choices and dignity of the individual.

Access to Personal Supports

i. Technical aids and equipment

The provision of technical aids and equipment defies simple description. Patients in hospitals or special residences generally receive the aids and equipment they need as part of their treatment.

Access is far more complex for those 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 have access through different routes, depending on the jurisdiction and types of programs in which they are involved.

Some provinces operate programs designed solely for the provision of technical aids and equipment. In some cases, these programs include a range of assistive devices. Alberta Aids to Daily Living, for example, helps individuals who have a chronic disability or illness gain access to medical supplies and equipment required for independent living at home. The Saskatchewan Aids for Independent Living Program and the Assistive Devices Program in Ontario also make available a range of technical aids for those who qualify on the basis of the program criteria. In other jurisdictions, only certain types of equipment (e.g., hearing aids, respiratory equipment or wheelchairs) are provided or only persons with designated conditions (e.g., paralysis, cancer or cystic fibrosis) can qualify for assistance under the program.

ii. Personal services

It is difficult to generalize as to how these services are provided. Ministries of health and/or social services throughout the country control the financing and delivery of personal services. Some provinces, such as Newfoundland and New Brunswick, have combined these two domains within a single department responsible for health and community services.

Services that are primarily health-related tend to be furnished through various health settings. Certified professionals or paraprofessionals may deliver home health care in the person's own residence. User fees may be charged if the services are delivered outside a hospital, clinic or physician's office.

Supports that are clearly social in nature, such as homemaker services and respite, generally are provided – or at least paid for – by ministries of social services. These supports often are delivered by nongovernmental organizations (e.g., visiting homemakers' associations) in local communities. User fees may be charged to help offset costs.

It is not easy, however, to distinguish between 'pure' health and social services. Attendant services are an example of a support that may combine elements of both health and social services. These supports may fall under the responsibility of provincial ministries of health or social services. Services may be provided directly by governments and through voluntary organizations. Often both are involved – governments pay for the services which are delivered by voluntary organizations.

Finally, ministries of education are involved in most jurisdictions in the provision of supports required for educational purposes. But these same supports may not be available once the child has left the school. An attendant who assists in the classroom may not be provided to enable the child to attend a recreational program in the community. Parents may have to pay privately for this service or approach a local organization, such as a service club, to sponsor this support.

iii. Brokerage

There are only a few nonprofit organizations throughout the country that offer independent brokerage services. The earliest model of community-based brokerage was developed in British Columbia in 1976 by the Woodland Parents Group to ensure appropriate community options for the deinstitutionalization of their

children. Brokerage services – where they exist – typically are funded by provincial departments of social services. Some provinces, such as Alberta, include an additional amount within a person's package of services in respect of the assistance and management required to coordinate a diverse range of personal supports.

iv. Welfare 'special needs' provisions

Persons with disabilities who have no access to supports through an existing program must purchase these goods and services on their own. They may claim certain costs under the medical expense tax credit. Those who cannot afford to make the up-front payments generally must rely on provincial/territorial welfare programs to help pay for personal supports.

The primary role of welfare is to provide financial assistance for basic needs such as food, clothing, shelter and utilities. But welfare also plays the important role of making provision for special needs arising from health-related or disabling conditions – e.g., wheelchairs, hearing aids, prosthetic equipment, medications or medically prescribed diets, special eyeglasses or other assistive devices for independent living or work. There are serious limits, however, in that certain items may not qualify or the special needs budget may be exhausted.

Some provinces, such as Alberta and Ontario, have set up a designated income program intended only for persons with disabilities. The Ontario Disability Support Program, for example, provides income benefits to persons over age 18 who meet the definition of disability and are in financial need. Recipients also may be eligible to receive prescription drugs, dental services, eyeglasses, hearing aids, benefits for special diets and special necessities, such as surgical dressings and wheelchair batteries. But problems in access arising from tight eligibility criteria have been reported, including a high incidence of legal appeals [Torjman 2000].

v. Tax credits

In addition to various programs supported by provincial and territorial ministries of health and/or social services and/or education, there are several relevant federal income tax measures: the medical expense tax credit, disability tax credit, infirm dependant tax credit and caregiver tax credit. These measures do not provide any supports directly but rather help offset their cost once purchased by a household.

a. Medical expense tax credit

The medical expense tax credit reduces the cost of a designated list of disability supports. Because the credit may be claimed in respect of the health-related expenses of an individual, spouse or dependents, it is available to all Canadians and not just persons with disabilities.

Total medical expenses must be more than $1,614 or three percent of net income, whichever is less. The expenses deemed eligible for the credit include:

- payments to medical practitioners, nurses and hospital services
- attendant care

- registered nursing services, including home care
- care at a school or institution where special care and training are provided
- ambulance services
- personal transportation for medical care (trips over 40 km.)
- travel costs of an attendant
- medical devices (e.g., artificial limbs, wheelchairs, braces, eyeglasses and a list of prescribed devices)
- expenses for guide and hearing-ear dogs
- expenses related to bone marrow and organ transplants
- home modifications for accessibility
- rehabilitation therapy
- prescribed drugs
- diagnostic services
- dental services
- contributions to private health services plans.

Taxfilers also may claim an amount for attendant care (up to $5,000) if the individual is entitled to claim the disability tax credit. The expenses must have been paid to a person who is not a spouse and who is 18 years or older. The expenses were paid for care in Canada that enabled the individual to earn income from employment or self-employment, take a designated training course, or conduct research or similar work for which a grant was received. These costs cannot be claimed as medical expenses.

b. Disability tax credit

The disability tax credit provides modest tax relief for the additional – but often hidden and indirect – costs of disability. In contrast to the medical expense tax credit, there is no designated list of allowable expenses. The hidden costs of disability include, for example, higher utility costs for heat or air conditioning, additional transportation costs, higher prices for goods because of fewer shopping choices and reduced capacity to earn income.

There are also hidden costs related to the care of children. A child with a disability may require, for example, a trained caregiver rather than a babysitter. The child with a disability may need a caregiver or babysitter even at an age when a child typically would not require such supervision. Other hidden costs include dietary supplements, special toys, adapted equipment, tailor-made clothing or other goods, such as diapers.

In order to qualify for the disability tax credit, claimants must have a physical or mental disability that is severe and prolonged, which markedly restricts their ability to perform one or more activities of daily living all or almost all of the time. 'Prolonged' means that the impairment has lasted or may be expected to last for a continuous period of at least 12 months. 'Severe' and 'markedly restricted' mean that all or almost all of the time the person is unable, or requires an inordinate amount of time, to perform a basic activity of daily living, even with therapy and the use of appropriate devices and medication.

The specific diagnosis or condition is irrelevant. What is important is the impact of that condition upon the person's ability to carry out one or more basic activities. These include feeding and dressing oneself; eliminating (bladder or bowel functions); walking; perceiving, thinking and remembering; and speaking so as

to be understood in a quiet setting, by another person familiar with the individual.

The 2000 federal Budget introduced several changes to the disability tax credit. It brought in a supplement of up to $500 to provide more assistance for the caregivers of children with severe disabilities. Eligibility for the disability tax credit was broadened to include individuals with severe and prolonged disabilities who require extensive therapy on an ongoing basis. The unused portion of the disability credit may be transferred to a wider group of supporting relatives, such as siblings or aunts and uncles.

c. Infirm dependant tax credit

The infirm dependant credit is available to the caregiver of an infirm dependant who must be age 18 or older and must have a net income of less than $13,853. While the income tax provisions provide no clear guidance as to the meaning of 'infirm,' the credit may be claimed in respect of dependants with physical or mental disabilities. The lack of standard eligibility criteria and information about the credit means that there is no consistency in who claims the credit and in the determination of eligibility.

d. Caregiver tax credit

As of the 1998 taxation year, a caregiver tax credit may be claimed by taxpayers who maintain a dwelling, either alone or with another person, in which an adult dependant lives. The credit is intended to provide some support for family caregivers.

The dependant must have been born in 1980 or earlier. The dependant must be reliant upon the taxpayer by reason of mental or physical infirmity, except for taxpayers' parents and grandparents over 65 for whom evidence of infirmity is not required. The dependant must have a net income of less than $13,853.

Problems with Personal Supports

While there appear to be many avenues for obtaining personal supports or offsetting their costs, the current 'system' is plagued by myriad problems. Many Canadians who require assistance to live independently or who want to participate in education, training or the labour market are unable to do so because they have limited access to these supports [Crawford 1997].

Forty-four percent of persons with disabilities are not in the paid labour force; they cite barriers and other disincentives, such as lack of supports, as the reason. One-quarter of Canadians with disabilities on income support programs cite loss of supports as a reason for not looking for work. Problems have been identified with respect to availability, cost and responsiveness.

i. Availability

The availability of personal supports 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. In many cases, nonprofit organizations actually deliver the services – when these happen to be available.

The supports that may be 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 of the country.

The provision of technical aids and equipment illustrates the complexities of the system. As noted, patients in hospitals or special residences generally receive the aids and equipment they need as part of their treatment. 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 an employment or 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.

Goods and services that are more health-related in nature usually are provided through various health settings and are delivered without charging additional user fees because these supports are considered 'insured services' under medicare. But user fees may be charged if the services are delivered outside a hospital, clinic or physician's office or at home.

Persons with disabilities also may be denied access to supports because of age; level of income; the nature, cause and severity of their condition; or participation in training or the labour market. In some cases, for example, medical diagnosis rather than functional ability is the primary eligibility criterion for certain equipment, such as wheelchairs. Persons with disabilities may be denied access to a given support because they do no have the 'correct' diagnosis even though their functional capacity may be almost identical to those with the designated condition.

Traditional service providers who carry out needs assessments often define consumer requirements within the parameters of their own services. If an agency delivers homemaker assistance, for example, a person's needs typically are translated into a given number of hours of that service. Similarly, when a health care worker determines needs, these take the form of hours of nursing or therapy.

Aboriginal Canadians with disabilities face even more barriers. (The percentage of aboriginal Canadians with disabilities is more than double the 16 percent national average.) They too experience a lack of personal supports and serious problems related to availability and access. But their problems are compounded by jurisdictional complexities. Their eligibility for personal supports is determined not only by the factors earlier identified but also by their status – whether they are Inuit or have been deemed by government to be Status Indians, non-Status Indians or Métis.

ii. Cost

Affordability creates problems of access. The cost of personal supports can be prohibitive and only limited assistance is available to help offset these costs. The national 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].

The cost of certain supports can be reduced by various income tax measures. As noted, the medical expense tax credit helps offset the cost of a designated list of personal supports. The disability tax credit also provides some tax relief for the additional expenses associated with disability.

But these tax credits are not without their problems. While the medical expense tax credit, for example, currently comprises a long list of allowable claims, many areas are not covered. Nutritional supplements are excluded, for instance, even though these are essential for persons with certain conditions, such as AIDS.

The credit also gives scant recognition to the care provided by families. The current tax credit helps offset the medical expenses incurred for care delivered by professionals primarily outside the home. Yet many families with a child who is disabled provide hours of care – often around-the-clock – to their child at home. Ironically, the cost of this child's care would be paid for fully or at least partially by governments if the parents were to place the child in a home or institution – an unacceptable and inappropriate solution [Torjman 1999].

There have been some minor enhancements to the medical expense tax credit in the past few years. The 1998 federal Budget announced that a medical expense claim may be made for the amount paid for a taxfiler, or the relative of the taxfiler, to learn to care for an individual who is mentally or physically infirm. The infirm individual must live in the taxpayer's household or depend on the taxpayer for support.

The 1999 Budget allows a medical claim for the amounts paid to individuals providing care and supervision in a group home for persons with severe physical and mental disabilities who are eligible for the disability tax credit. This is an admittedly small but welcome measure. The change does nothing, however, to afford additional assistance to families looking after their members at home, again reinforcing the institutional bias of the credit.

Perhaps the most serious problem with the medical expense tax credit is that many persons with disabilities could not benefit from its provisions. Prior to 1997, the medical expense tax credit was nonrefundable. This means that the credit reduced income taxes owing but did not benefit Canadians with incomes below the taxpaying threshold. The medical expense credit was therefore of little or no assistance to very poor households.

The 1997 Budget rectified this problem somewhat by making the credit partially refundable. It announced that the existing medical expense tax credit would be supplemented by a refundable tax credit for low-income working Canadians with high medical expenses. The maximum credit is the lesser of $500 and 25 percent of eligible medical expenses. Taxfilers must earn at least $2,000 to qualify for this refundable portion.

While this change is an important step in the right direction, the fundamental problem remains. Low-income earners typically cannot pay up front for medical expenses, even if they will be reimbursed later.

Households that have no access to technical aids and equipment through an existing program or that derive no benefit from current tax provisions must purchase these goods and services on their own. Those who cannot afford to make the up-front payments generally must rely on provincial and territorial welfare programs to help offset these costs.

While welfare may provide last-resort assistance, it 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.

Moreover, there is no guarantee that welfare actually will pay for all – or even some – disability supports. If a province or territory has exceeded its special needs budget prior to the end of the fiscal year, it may decide to stop paying for special assistance until the next fiscal year. The required item may not be included in the list of permissible costs altogether – e.g., a wheelchair designed for sports or recreation may not be covered.

iii. Responsiveness

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

Supports often are not available at the place they are required. While some services may be provided to individuals 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 a.m. and 5:00 p.m., Monday to Friday. Individuals typically have little say in how services are delivered or managed. Consumers often are afraid to voice their concerns for fear of personal reprisal or losing the service altogether.

Approaches to Reform

There are several approaches to improving the availability, affordability and responsiveness of personal supports. One route involves incremental improvements to the existing system: enhancing the quality of existing services, ensuring that persons with disabilities have more income to purchase supports and providing more avenues for offsetting costs.

The quality of existing services could be improved in several ways. An important start would be to ensure that consumers have more say in the governance of these services to ensure their appropriateness and responsiveness.

There are also many possible options for bolstering the income of persons with disabili-

ties [Torjman 1996b; Beatty 1992; Muszynski 1992]. Increased income would enable persons with disabilities to purchase the supports they require.

Another possibility is to improve various tax-related measures [Torjman 1999; Beatty and Baker 1996]. As noted, specific reforms include enhancing the value of the medical expense tax credit, increasing its refundable portion and expanding the list of items that may be claimed.

The disability tax credit also can be made refundable to provide some assistance to persons too poor to pay income tax. Its eligibility criteria can be relaxed somewhat to ensure that persons who could qualify are not left out. The rules now require that the impairment be continuous for at least 12 months, effectively eliminating many individuals with severe and prolonged disabilities that happen to manifest themselves episodically or intermittently rather than chronically. The infirm dependant tax credit can be enhanced and gradually extended downward in terms of ages covered.

But none of these options – improving the quality and responsiveness of existing services, bolstering basic income or offsetting costs through tax breaks – does anything to expand the supply of available supports. There still would be fundamental problems of access.

A more far-reaching proposal for reform focusses upon building the supply of personal supports. The existing network of personal supports not only must be *improved*. The network also must be *expanded* because it is inadequate to meet the range of needs of persons with disabilities. Nor will it be sufficient in future to respond to the increased demands of an aging population.

One way to augment the network of services is through a Personal Supports Fund that invests in the network of provincial and territorial services. The Fund also would allow for the payment of supports through individualized funding, described below.

This proposal is consistent with the spirit of the Social Union Framework Agreement. In February 1999, the federal and provincial/territorial governments except Quebec signed a Social Union Framework Agreement that sets out the general rules for how governments should work together in future. It is intended to promote a respectful and collaborative approach to resolving social issues that are not clearly defined as exclusively federal or provincial. The Agreement speaks to the need to protect the mobility rights of Canadians and the importance of accountability – both priority issues for persons with disabilities.

Personal Supports Fund

i. Purpose

The purpose of a Personal Supports Fund is to consolidate existing programs and promote the development of a comprehensive network of goods and services throughout the country. The Fund 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 personal supports. The proposed Fund would help generate new and continued investment over a sustained period

of time in the provision of personal supports. The federal portion allocated to provinces and territories would be directed toward all three streams of personal supports – technical aids and equipment, personal services and brokerage – and not solely to one area.

ii. Financing

To make a real dent in the availability problem, Ottawa would invest a substantial sum of money in respect of personal supports – in the order of $1 billion a year over a five-year period. Federal funds would be divided among the provinces and territories according to a formula based on projected population growth and economic need.

The federal investment is intended to lever similar 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 Personal Supports Fund would set out a five-year schedule of funding. Adequate and stable funding is an essential prerequisite to a successful initiative. The arrangement would be evaluated after three years and modified accordingly. It would be assessed again and renegotiated at the five-year point.

While provinces and territories would be the primary beneficiaries of federal funds, the disability community would be actively involved in decisions regarding the design, delivery and governance of personal 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. The integration of these services would help eliminate the barriers created by current funding arrangements which effectively require artificial distinctions among health, social and educational services.

Another major strength of this proposal is that a Personal Supports Fund would establish a national mechanism separate from income programs to provide for personal supports. It no longer would be necessary for persons with disabilities to apply through welfare systems or to rely on a given income program in order to obtain essential supports.

Despite the flexibility that the proposed Personal Supports Fund 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. All jurisdictions would be required to provide financial and program information on their use of dollars allocated under the Personal Supports Fund.

iii. Guiding Principles

The system of personal supports would operate according to a clear set of guiding principles identified as essential in reports over the years, including *A Consensus for Action*: *The Economic Integration of Disabled Persons* [Canada 1990]; the *Mainstream Review* [Federal/Provincial/Territorial Ministers 1992]; *The Grand Design*: *Achieving the Open House Vision* [Canada 1995]; *Equal Citizenship for Canadians with Disabilities*: *The Will to Act* [Federal Task Force 1996]; and *In Unison*: *A Canadian Approach to Disability Issues* [Federal-Provincial-Territorial Ministers 1998]. The principles identified in these reports include self-determination, comprehensiveness, accessibility, portability and accountability.

Self-determination is a central guiding principle. Ideally, all services 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 personal supports at the policy level as well as in their local governance to ensure responsiveness. Direct cash payments in the form of individualized funding (described below) could be made to allow greater choice and flexibility.

Comprehensiveness: Personal supports should be available within a coherent system, assuring a wide range of goods and services. The system would be 'seamless' in that these goods and services would be available wherever required rather than in disaggregated pieces that fall under the auspices of education, health care, social services, employment or recreation.

Accessibility means that personal 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 Quebec method of determining eligibility by functional ability is an exemplary model.

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. Personal supports would follow the person – into the classroom, training program, workplace, home or recreation facility. The provision of personal 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 personal supports. These groups also would include representatives from the service-providing community, and the research and policy sectors. Governments would be expected to monitor the provision of personal supports and report publicly on their progress on an annual basis.

A Note on Individualized Funding

The purpose of the proposed Fund is to bolster the *supply* of personal supports throughout the country. In some cases, however, provinces and territories may wish to ensure the availability of certain supports by means of individualized funding.

Individualized funding refers to the transfer of dollars directly to individuals to enable them to purchase personal supports

[Torjman 1996a]. Individualized funding allows services to be tailored to individual needs. By definition, it requires differential treatment. In fact, this is precisely what individualized funding seeks to achieve: a unique response to each person's unique circumstances. The amount of payment is different for every person and is determined on an individualized basis depending on specific needs.

In order to arrive at an appropriate amount of individualized payment, an assessment is carried out – with the involvement of the person with a disability – which identifies the required supports and, in the case of a service, how much time is needed. An amount is allocated for each component of need and a total is determined. The individual then purchases the required supports according to his or her preference.

The dollars enable consumers to create the most appropriate set of arrangements. For example, they may need a certain service early in the morning, in the evenings or on weekends – requirements that are often difficult to meet through traditional provision. Moreover, needs are not necessarily met only through formal services. Often there are other solutions that do not involve traditional service providers.

Individualized funding also has the potential to respond to the lack of disability supports. It is not simply a transfer of dollars to allow consumers greater choice among existing options. It represents, in effect, a form of purchasing power that can play an important role in generating a greater supply of supports. If consumers require various forms of assistance that are not available – and this is particularly relevant to rural and northern regions of the country – then the money to purchase these supports may help create the supply.

Despite the many advantages of individualized funding, there are several potential problems in this arrangement. There are limits to what it can achieve – especially in the short term. It may not produce new services right away or even in great numbers.

Certain services do not appear simply because they are required in a given community. It may take months or even years to develop something like specialized apprenticeship or job coaching arrangements. Appropriate housing will not spring up just because individuals happen to have the money. Many persons with disabilities decide to 'buy a bed' in a group home even though they have individualized dollars because it is the only realistic option; the group home may be physically accessible, may provide interpreter services, may be well located or may be less expensive than other arrangements.

These limitations mean that funds must continue to be directed toward the supply of personal supports – *to ensure the presence of a basic core of goods and services*. There must be something to purchase.

A major concern with respect to individualized funding is the issue of accountability – i.e., how to monitor the use of funds paid directly to individuals. But this concern should not prevent progress in this area; safeguards can be built into any program to ensure accountability. Claimants would enter into agreements with the providers most appropriate to their requirements. Individuals would agree in writing that funds would be spent only for disability-related purposes and that all expenditures would be documented and receipted.

In fact, there is precedent in the country for a widespread system of individualized funding. It is called the income tax system.

Next Steps

The next step is the first step. The Federal/Provincial/Territorial Working Group on Disability Supports and Services must begin to put in place a concrete plan for how to improve the availability, affordability and responsiveness of personal supports. Whether it is through this proposal or some other means, there is a pressing need to make real the *In Unison* commitment to action.

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