

**Labour Force Participation and Social Inclusion  
for People Living with HIV and  
Other Episodic Disabilities**

**A Policy Review and Analysis**



Canadian Working Group on HIV and Rehabilitation  
CWGHR



**Social Program Evaluation Group  
Queen's University  
September 2005**

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**Final Report for  
The Canadian Working Group on HIV and Rehabilitation**

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## **Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities**

### **EXECUTIVE SUMMARY**

The Social Program Evaluation Group (SPEG) at Queen's University was contracted by the Canadian Working Group on HIV and Rehabilitation (CWGHR) to conduct a literature-based review of key aspects and ingredients of effective labour policies and programs affecting people with Episodic Disability, and to make preliminary policy recommendations. This work was completed as part of CWGHR's more encompassing project titled, "Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities" for Social Development Canada, to be completed in 2007.

The review begins with the current state of general income and support programs in Canada. Next, we establish common concepts and definitions, as the terms 'disability' and 'social inclusion' and, in particular, 'episodic disability' which are subject to variation and confusion. Then, by examining specific Canadian policies and programs, along with recent structural changes, we identify key problems in the financial assistance and labour support areas. We highlight the essential principles on which revised disability policies should be based if they are to become genuinely effective for the financial assistance and employment needs of people with episodic disabilities.

In 'New Directions for Canadian Policy and Programs', we analyze the financial assistance and employment support literature to establish best practices internationally, and to pose preliminary recommendations for Canada. Since detailed program evaluations of initiatives have not been done in the field, by necessity the recommendations are general, rather than specific. This provides CWGHR with the opportunity to consult its stakeholders adequately before posing pilot projects and final policy recommendations to authorities.

The recommendations below are grouped according to multiple policy issues that need to be addressed, rather than by sectoral responsibility. At this stage in the project, and as repeatedly emphasized in the literature, a multi-stakeholder responsibility should be fostered in planning. The issues we address are:

**A. Definitional/Conceptual Changes**

- A broad and inclusive common definition of disability needs to be established in Canada across diverse government programs of assistance (financial, social, legal, etc.).
- Widespread restrictions based on the use of two key terms, 'severe' and 'prolonged', need to be revised, to permit increased access to financial assistance by people experiencing episodic disabilities.
- Eligibility criteria should be framed as continua, on a broad range of factors rather than as simple dichotomies in the permanence of medical conditions.

**B. Policy/Legal Changes**

- A policy goal of “employable, if and when able” should be explored.
- Available funds could be spent more efficiently if administrative complexity was reduced, integration across programs were increased and costs were shared more widely.
- Financial assistance that provides a reliable and adequate level of income security should be readily available throughout the entire disability experience.
- Legislation should oblige employers and other employees to be aware of their duty to accommodate, within reasonable limits, to the needs of employees with episodic disabilities.

**C. Administration**

- Financial assistance programs in Canada should be more proactive, providing for earlier and faster eligibility assessment (and appeals).
- A clearer order of jurisdiction in responsibility for the provision of benefits needs to be established across various government levels (and with private insurance plans)
- An array of local 'one-stop' sites to acquire user-friendly information should be made widely available
- Case management needs to be holistic, addressing physical and psychological qualities of clients and their social contexts and personal relationships, as well as relevant characteristics of the workplace and the people who work there.
- Faster and more efficient appeal procedures should be available to applicants who are denied or disqualified from benefits.
- Pilot projects need to be initiated, sufficiently funded and thoroughly evaluated, in order to investigate various models and methods of delivering financial assistance to people with disabilities.
- On the workplace level, disability policies should be monitored on an ongoing basis, assessed regularly and revised when necessary.

**D. Income Benefits**

- Canadian programs, especially on the federal level, need to be more supportive of the many people with episodic disabilities who want to do part-time or periodic work.
- Private insurance coverage should be accessible to a greater variety of workplaces –for-profit and not-for-profit, corporate and cooperative.

## **E. Employment**

- Workplace policies that address job retention and rehabilitation of workers with disabilities, should be implemented, reviewed and updated regularly.
- Federal, provincial and territorial governments need to provide an array of financial incentives as well as information and technical support to encourage employers to subscribe readily to the idea of a 'duty to accommodate'.
- To make the varied kinds of re-integration assistance viable, increased encouragement for multi-sectoral partnerships is essential at the community level.
- Income and other disability supports should be available without penalty to people with disabilities who decide to pursue self-directed employment and business development.

## **F. Integration Strategies**

- Support programs in Canada should provide financial security to people with disabilities who have recovered sufficiently to consider and attempt return-to-work.
- Reinstatement of benefits for people with episodic disability should be guaranteed and immediate.

The conclusion notes that there are key unresolved issues in planning policy initiatives for Episodic Disabilities. These are largely because of:

- a) The need to position episodic disabilities in the mainstream
- b) The need to build political and employer resource support
- c) The complications of serving specific needs in episodic disability within an inclusive approach, and
- d) The practical demands of benefit administration.

## INTRODUCTION

### A. Background

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is coordinating a project titled, “Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities”. A Project Advisory Committee representing expertise in particular disability areas, rehabilitation and health care, disability management, government policy planning and implementation, human resource management and labour union concerns supports CWGHR. The project is supported by a grant from Social Development Canada with the goal of examining the financial security and social inclusion needs of people with episodic disabilities.

The Social Program Evaluation Group (SPEG<sup>1</sup>) at Queen's University was contracted by CWGHR to conduct an analysis of key aspects and ingredients of effective policies and programs regarding this issue in Canada and elsewhere, and make policy recommendations.

Research questions were identified and agreed upon to focus and guide the report:

- What are the significant elements of policies and programs in Canada, as well as other countries in North America, Europe and including Australia, that facilitate or inhibit income support, and meaningful labour force participation of people living with HIV and other episodic disabilities?

What public and private (insurance companies, corporations) policies and programs facilitate or inhibit income support, and meaningful labour force participation of people living with HIV and other episodic disabilities?

What are some examples of the integration of income support programs and workplace policies that promote economic well-being as well as social inclusion benefits such as labour force participation?

How are these examples of income support programs and workplace policies financed, implemented and evaluated?

- What recommendations can be made regarding the implementation of policies that promote the equitable and meaningful labour force participation of people living with HIV and other episodic disabilities?

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<sup>1</sup> <http://educ.queensu.ca/~speg/>

These questions flow from interrelated challenges facing people with episodic disabilities who have the same goal: the need to achieve and sustain both social inclusion and financial security. (For the purposes of our work, employment was identified as the major aspect of social inclusion to be considered). These same challenges confront people with other kinds of impairments, as well. However, people with episodic disabilities experience the additional disadvantage that this particular kind of impairment has long been less adequately conceptualized, less clearly articulated, and less effectively addressed, by disability policies and programs on every level, in Canada and elsewhere.

## **B. Research Approach**

The broad scope of the subject quickly became apparent when the research commenced. Complex factors needed to be taken into account, as well as their interactions and the multiple social changes occurring simultaneously within each. These factors were most immediately apparent, including:

- Government policy orientations in various areas and on several levels
- Program formats and funding strategies
- Legal and administrative arrangements
- Political climates
- Economic conditions (local, regional, national)
- Population characteristics
- Social values and perceptions
- Labour market circumstances
- The nature of work
- Labour/management relationships
- Technologies and procedures in healthcare and rehabilitation, and
- Ingredients of community organization.

In addition, a wide array of stakeholders has significant roles to play, including:

- People with disabilities and disability organizations
- Government leaders and departments
- Employers and workplaces
- Employees and their unions
- Private insurance companies and their associations
- Healthcare providers, notably rehabilitation specialists
- Legal professionals
- Employment assistance agencies
- Education and training institutions, and
- Centres for research and policy analysis.

In addition, there are wide variations in characteristics and circumstances across disabilities and long-term medical conditions, and even within the concept of episodic disability, itself.

When all of these factors, stakeholders and variables, as well as the interactions between them, are also addressed internationally, the research context of episodic disability becomes formidable<sup>2</sup>. In our search for useful sources of information, we looked for consensus among disability experts about basic directions and essential ingredients of effective disability policies and programs in the specific areas of financial security and employment – especially those aspects that might have special relevance for people whose disabilities are episodic in nature, and which are applicable to the Canadian political and administrative context.

For this investigation, we envisaged 'episodic disability' as:

*a serious mental or physical condition characterized by fluctuating periods and degrees of wellness and impairment. These periods are often unpredictable in severity, duration and potential for resolution.*

People with episodic disabilities may need, or desire, to move in and out of the labour force in recurrent and unpredictable ways, while still needing to maintain for themselves and their dependents a satisfactory level of financial security.

To accomplish the research tasks, we needed to decide how to address episodic disability within the broader field of disability concerns. Should potentially effective policies and programs be identified for consideration here only when and if they specify episodic disability as a separate and distinct category? Or should potential solutions to problems and challenges facing people with episodic disabilities be viewed as part of a broader, more inclusive constellation of changes and improvements needed in disability policies and programs?

For several reasons, the second option was chosen. The challenges of financial security and employment, as well as the implications of their inter-connections, are already familiar to most people with disabilities. Their personal experiences and insights, as well as those of disability groups and experts who have done substantial investigations in Canada and elsewhere, can provide valuable information about the kinds of changes that can also benefit people with episodic disabilities. It did not make sense to seek solutions to current problems in the direction of establishing or reinforcing yet another bureaucratic category for program eligibility, assessment and operation – namely, a specific initiative for 'episodic disability'. Overwhelming and often discouraging bureaucratic

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<sup>2</sup> For further details of the research methodology, refer to Appendix B.

complexity is already part of the problem. Rather, a more helpful direction seemed to identify effective steps to reorient and restructure disability policies and programs in ways that would benefit people with episodic disabilities as well as others similarly disadvantaged by their current operation.

In the body of this document, therefore, episodic disability is included as one major kind of disability, different in relevant characteristics from other kinds of impairments and similar in many ways as well. Indeed, the major changes that will substantially improve disability policy and programming in Canada, especially for financial security and employability, will benefit all people with disabilities, including those with episodic disabilities.

This report is intended to assist the on-going efforts of CWGHR and its Project Advisory Committee to achieve several goals:

- Clarify important differences between episodic and other disabilities
- Identify directions for improved research, policy development and programming on behalf of people with episodic disabilities
- Identify best practices in the management of episodic and other disabilities which help to establish financial security and social inclusion
- Create alliances among disability groups and others, and
- Advocate for changes in appropriate directions, with government departments, employers and their associations, labour unions, private insurance providers, health and rehabilitation service-providers and other stakeholders in the area of disability assistance.

This document is intended to provide a framework for further analysis, planning and concrete action by CWGHR and its Project Advisory Committee. Its content is informed by attention to some of the best thinking currently being done by people with expertise about disability issues in Canada and around the world. A number of specific examples of policy directions and program ingredients are included, drawn from Canada and elsewhere. Because of the immensity of the scope of the investigation, as well as the limited time available to accomplish it, the content of the document is inevitably general in focus<sup>3</sup>. In its preparation, neither the timeliness nor significance of the work

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<sup>3</sup> There are 4 appendices that include:

- Appendix A. A list of Key Concepts generated during the process of collecting materials and refined during the move to description and analysis.
- Appendix B. Methodology used by SPEG to produce this report
- Appendix C. An annotated bibliography describing 99 entries, listed separately in alphabetical order (by author). Each annotation contains two parts: a brief 'Summary' and highlights of 'Relevant policy/program ideas'. Just over half of the entries are from Canadian sources, slightly less than half from elsewhere.
- Appendix D. The SPEG Project Team

being undertaken, nor the capacity of project participants to translate the insights and conclusions of this document into concrete actions, has been underestimated. The need to accomplish change is substantial, and the opportunity for this project to do so is at hand.

## INCOME AND JOBS IN CANADA

In labour and income policy, the emphasis is often on how a lack of certain social resources (income, food availability, housing, employment and working conditions, health and social services, etc.) negatively affects individuals' health and well-being.

This report, in contrast, starts with the observation that it is the condition and social circumstances of disability itself that negatively affects one's enjoyment or attainment of these social resources. In particular, it is the episodic nature of some disabling conditions that creates a specific risk for non-attainment of social security, particularly income, and also employment as a means of social inclusion.

It is important not to forget the fundamental effects of such social deprivation on individuals' health. In countries, such as Canada, that have a fair degree of inequality in social resources (especially income) between the rich and poor, there are three mechanisms for multiplying this negative effect on individuals more broadly across the entire population:

1. Income inequality can result in systematic under-investment and reduced support for social spending, for example on disability support programmes.
2. Income inequality can lead to frustration and stress in disadvantaged groups that is harmful to their health and impedes their own advocacy.
3. Income inequality can lead to diminished social cohesion and community solidarity that might alleviate these social gaps.

All of these mechanisms make it more difficult for social support programmes in Canada to be established, well nourished and maintained.

Few of the articles reviewed for this report embed the ideas of income and employment support for those with episodic disabilities into the broader national socio-economic environment. It is worth briefly reviewing some current trends that will have an impact on this policy goal.

## **The Changing Workplace**

In the context of the knowledge economy and global trade in products and services, the labour market has been transformed in Canada, in the name of ‘flexibility’ and increased competitiveness. Fragmentation of careers, diversity of work locations (including home, on the road), and business structures has become the norm for many Canadians. Short-term employment on ‘projects’ that require knowledge for a limited time period is increasing. Businesses are more valued for their available ‘skill network’ and its potential for adapting to the project demands than for their stable work force. New forms of work organization such as self-employment, team work (requiring coordinated inputs from all members) and virtual communities of practice are being developed.

At the same time, in some sectors, parenting and care-giving are increasingly recognized as legitimate activities, for example through maternity/paternity leave and care-giver leave, which emphasizes the distinctions accepted between work and non-work with life-balance issues increasingly being taken into consideration<sup>4</sup>.

For those interested in episodic disability support programmes, these changes in practice should be examined carefully as they may have both benefits, as well as threats, to people with disabilities. Planners must recognize that traditional notions of disability support, such as vocational training, on-the-job training, and long term employment support in stable business organizations, may not be appropriate in the future. An over-emphasis on copying older ‘implementation models’ for disability support may in fact disadvantage disabled persons in the long run as the economy and work place continue to evolve.

## **Job Security**

A second dynamic, related to the concept of ‘security’, is the degree of public support and employer interest that can be expected in this new work environment. Job security, as a concept, has changed in Canada. In 1999, only half of all ‘employed’ Canadians had a single, full-time job that had lasted 6 months or more. At that time, the labour force included the following<sup>5</sup>:

- 16% self-employed workers
- 10% temporary workers

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<sup>4</sup> Tremblay, Diane-Gabriel (2004). Unemployment and the Labour Market. In, D. Raphael (Ed.) *Social Determinants of Health: Canadian Perspectives*. P 53-66. Toronto, Canadian Scholars’ Press Inc.

<sup>5</sup> Lowe G, Schellenberg G, Davidman K. (1999). Re-thinking employment relationships. Canadian Policy Research Network Discussion Paper no. W-5. Ottawa: CPRN.

- 11% regular part-time workers
- 6% employed in their current job for less than six months, and
- 2% employed in more than one job.

Today only about one in two workers is eligible for employment insurance. As everyone's job security, work continuity and employment support is decreasing, is it reasonable to expect that there will be broad support for advantaged conditions for people with disabilities?

In many cases, the availability of general employment security measures in a country 'sets the standard' for less common situations such as episodic disability. For example, at one end of the spectrum, most countries in Scandinavia provide active financial support for everyone's entry into regular employment – this policy was facilitated by nearly full employment, that is, a high demand for workers in the region. Scandinavia also supports general integration into work through job training programs, work time adjustment measures, family-friendly policies, and longer family leaves. All these initiatives have improved the Scandinavian public's support for state-funded job programs.

In contrast, in Canada there has been more emphasis on palliative (that is, dire need) social security measures and workfare. There are fewer alternate work schedule arrangements and support. Family support policies are minimal in Anglophone Canada, except for parental leave. In Quebec, policies are slightly more developed with lower costs for state-provided childcare. Overall, Canadian public support for government-funded job programs is only marginal.

Interestingly, the concept of a basic income as the ultimate security measure has been posed in Canada, and many other countries, in the past<sup>6</sup>. In the 1970's, it almost became a reality – but the

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<sup>6</sup> A standard Basic Income scheme ([www.policylibrary.com/redistribution/basicincome.htm](http://www.policylibrary.com/redistribution/basicincome.htm)) has the following features:

- It is a regular cash payment. Services provided in kind may add up to a "social wage" but they are not a basic income.
- Neither is it a one-off lump sum such as a stakeholder grant. The arguments between advocates of a basic income and those who argue for a Stakeholder Grant are set out here.
- It is paid to everyone within a nation state or other political unit. If payment is restricted to those who are legal citizens then it is sometimes termed citizen's income. Some variants exclude children, pensioners and prisoners.
- It is paid to the individual rather than the household.
- It is paid at a flat rate to both rich and poor. There is no means test - Basic income is not withdrawn as other income rises. For more details of schemes which taper the payment as income rises please visit the Tax Credit and Negative Income Taxes section.
- It is paid regardless of employment of family status - to the unemployed, the employed, to the childless and those and bringing up children, to students, surfers and tramps. Proposals have also been put forward to restrict payment only to those engaged in "productive activities" - usually defined as childcare, eldercare, volunteering and studying - this is termed Participation Income.

Canadian economy was stronger at that time and the concept of national debt costs had not yet made an impact. In essence, the concept of a basic income acknowledges the state's responsibility for providing either employment or compensatory income for all. Such an approach would logically dilute the need for special support measures for those with disabilities. A problem with the notion is that it overlooks the non-financial advantages of work, which are well appreciated for those with disabilities who want to contribute to society and benefit from the work environment. As well, the cost of providing a universal citizen's income would be extremely high and unlikely to be supported by working people<sup>7</sup>. Even a restricted program, such as the minimum integration income introduced in France, is costly and could drift towards the punitive aspects of workfare if not done properly. In France, gains were made by those needing it least and the program was unable to help those with less formal education or lower skill levels escape their dependence<sup>8</sup>. This experience has lessons for those concerned with not marginalizing those with episodic disabilities in Canada even further.

### **Flexibility**

Thus, there are two principles, often conceptualized at their extremes that need to be managed in Canada's economy today: business 'flexibility', from a liberal market perspective, which might ignore worker well-being and working conditions; and worker 'security', from a social welfare perspective, which might ignore global economic competition with other countries that provide no security for workers. All-inclusive, integrated, completely secure programs for people with disabilities fall, at least conceptually, into the latter and may find it difficult to gain public support.

A third view falls in the middle. It suggests that there are potential benefits to be gained by all in the emerging flexibility of work. It also suggests that employee and citizen security is important for material comfort and social cohesion. Old notions of job security in the form of full-time, permanent employment are not retrievable in the new economy. However, economic insecurity is also not acceptable. Instead, this view aims to develop a new framework of 'flexicurity' (flexibility-security<sup>9</sup>), by accepting the reality of employment flexibility and short-term jobs, while providing

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<sup>7</sup> Ireland has estimated tax rates that are required to achieve a true Basic Income to be approximately 50%. A partial Basic Income has been implemented in Alaska (financed through oil revenues). A Canadian Guaranteed Income discussion paper is available at <http://www.canadiansocialresearch.net/gai.htm>

<sup>8</sup> Paugam S. (1998). Le revenu minimum d'insertion en France après six ans: un bilan contrasté Interventions Economiques, Montreal 28, 21-45. [www.teluq.quebec.ca/interventionseconomiques](http://www.teluq.quebec.ca/interventionseconomiques)

<sup>9</sup> European Foundation for the Improvement of Living and Working Conditions. (2002a) Quality of work and employment in Europe: Issues and challenges (Foundation paper). Dublin: EFILWC.

generous social welfare and unemployment benefits along with active training support for the unemployed (including those with episodic disabilities).

Among the key features of ‘flexicurity’, as demonstrated in Denmark in the past decade are:

- A ‘golden triangle’ employment system, wherein all workers are enabled to move between different positions within work, welfare and active labour market training programmes – without major loss of income, and
- A non-restrictive employment protection legislation, which allows employers to hire and fire workers with short notice.

Together, when well implemented, these features may lead to flexibility and competitiveness, as well as security and well-being.

This review of the Canadian and international income/employment context can help in thinking about possibilities for policy and program development regarding those with episodic disabilities. As mentioned in the Introduction, we suggest that establishing new programs for those with episodic disabilities, separate from other disability initiatives, is counter-productive. Similarly, we encourage thinking about all disability initiatives, including those regarding episodic problems, in the context of existing Canadian social programs that should be available to all. Doing so could automatically ensure public support for these particular needs for those with disabilities, as well as achieving social inclusion in very basic ways – through participation in normalization and citizen rights.

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## **ASSESSMENT OF POLICIES AND PROGRAMS FOR EPISODIC DISABILITY**

Analysis of policies and programs (in this case, for financial and social assistance) is usually based on the core definitions of terms and basic principles to be achieved. Often such definitions and principles are made manifest within policy statements and program descriptions; in others, they remain implicit. Whether or not they are expressed clearly, core definitions and principles establish the focus of the policy and indicate a vision for its directions and scope. These indicate who should be included in participation and coverage, who should be excluded, the kinds and levels of assistance that are deemed valuable, and the processes considered relevant for program delivery.

The definitions and principles of government policies and programs that address problems of people with disabilities in Canada routinely disadvantage people whose disabilities may be episodic in nature. The episodic nature of this context is not, conceptually, difficult for government to address. For example, Employment Insurance policy is well established as an approach that provides financial assistance for many people whose employment may be episodic or transient due to economic conditions. The same is true for substantial numbers of policies and programs established by employers and service-providing agencies. That disability conditions may similarly cause periodic employment lapses and financial needs should not be seen as an insurmountable policy obstacle. Revised definitions and basic principles for economic and work support need to be put in place on all levels, so that the initiatives they generate will be fair and effective for all Canadians with disabilities, including those with episodic disabilities.

### **A. Key Definitions**

- ***Disability***
- ***Social Inclusion***

#### ***Disability:***

In many Canadian social and health policies and programs, definitions of disability rely heavily on a medical model. The common presumption is that the problem exists within a physiological and/or psychological condition of an individual, and must be diagnosed according to medical criteria and expertise, and then resolved by interventions designed primarily to address the medical condition itself. Typically attached to this definition are two limiting qualities, also invariably defined in

medical terms, that must be satisfied in order for individuals to qualify for financial and/or social assistance: the condition must be *severe* and it must be *prolonged*. By relying heavily on a medical model to define disability, Canadian policies and programs focus major problem-solving attention on disabled individuals themselves, without equal attention being given to what must be done to remove barriers that exist within the various contexts (social, economic, administrative and physical) of people's everyday lives.

With reference to employment and employability, the medical model places greater emphasis on people with disabilities *inability to work* than on their *ability to work*. It also leads to an all-or-nothing approach (disabled or not disabled) to employability, along with fragmentation (rather than integration) of initiatives for financial assistance, employment, training, community involvement and disability supports. Such limitations of definition are especially problematic for people whose impairments are episodic in nature: present for some periods of time and relatively or completely absent at other times.

Increasing numbers of Canadians live with **episodic disabilities**. Examples include mental illness and mood disorders, various kinds of cancer, lupus, multiple sclerosis, diabetes, HIV/AIDS, long-term pain (including back pain), chronic fatigue syndrome and spinal cord injury (with episodic bouts of serious urinary infection, depression, etc.). An episodic disability can be permanent or temporary, life-threatening or chronic, progressive or stable. What makes disability 'episodic' is that it produces recurring, sometimes cyclical, usually unpredictable periods of good and poor health. An episode can force a person out of the workforce without warning and then resolve itself through treatment or rest, enabling return-to-work. This process can recur repeatedly over an extended period of time.

By requiring that disabilities be severe and prolonged, major Canadian policy emphasis in financial assistance has been directed toward people likely to be economically inactive for the long term and who are assumed to rely on employment for income. Substantial numbers of people whose disabilities in fact may be episodic are excluded from consideration and are assumed to rely on employment for income. Insufficient attention is given to effective steps that can be taken by a variety of actors (government departments and program staff, employers and workplace staff, helping professionals, community-based groups) to reduce employment-related and other handicaps

faced by people with episodic disabilities. For example, the potential value of partial disability benefits for episodic problems is excluded from consideration by these disability qualifiers.

Instead, Canadian policies and programs on income security and employment need to define disability by using a non-medical model, commonly known as a social model. 'Impairment' (some quality of a person's physiological or psychological condition) should be distinguished from 'disability' (a functional restriction on the person's performance of a normal or routine activity, which is caused by an impairment), and handicap (a disadvantage in participation produced by the relationship between an impairment and a particular social context<sup>10</sup>). As much policy and program emphasis should be given to the social nature of handicap as to the medical aspects of impairment<sup>11</sup>.

A number of non-medical models of disability have been articulated<sup>12</sup>. Broadly speaking, these social models conceive disability in broad terms, including both present and past conditions. These models acknowledge the significance of how people with disabilities see themselves, as well as the potentially debilitating effects of others' attitudes toward them. For example, even a minor impairment can cause a person to be treated unfairly at work. Social models emphasize human dignity, respect and the right to equal treatment. All social models accept that physical and mental limitations arise from impairments and need to be addressed in policies and programs. However, they also emphasize the need to remove the barriers in the environment that are generated by attitudes, economic forces, policy orientations, administrative arrangements and program procedures<sup>13</sup>.

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<sup>10</sup> International Classification of Impairments, Disabilities and Handicaps, World Health Organization, 1980, cited in Parliamentary Library, "Disability Support and Services in Australia", Parliament of Australia, October 2002; Neufeldt, Aldred, "Ways of Thinking about Disability", GLADNET website, Winnipeg, September 2002; Burt Perrin Associates, "Lessons Learned for Evaluations of Disability Policy and Programs", Evaluation Services, Human Resource Development Canada, Ottawa, 1999.

<sup>11</sup> By comparison, in areas of health and education policy, a social model of disability is increasingly being used, to encourage accessibility, civic participation and social inclusion.

<sup>12</sup> Penney, J. A Constitution for the Disabled or a Disabled Constitution? - Toward a New Approach to Disability for the Purposes of Section 15(1). *Journal of Law and Equity*, 1(1) 2002.

<sup>13</sup> Sources see Appendix C – B BCPWA; Berkowitz; Burt Perrin; CAS, Providing benefits counseling; CAS & CWGHR; Disability and Info Tech; Durand; Eur Foundation; Manitoba Human Rights; MS Society, Brief; MS Society, MS and CPP-D Issues; Neufeldt; OECD, Transforming; Office of the Commissioner; Ontario Human Rights Comm; Proctor; Return, Policy Guidelines; Roehner, Towards a common approach; Weir; Wellesley; Wittenburg.

***Social Inclusion:***

Social inclusion (or social integration) is a general idea that refers to the extent to which people are attached to, or involved in, relationships, activities and groups in society. It also refers to the qualities of those attachments, and to the meanings they provide for people's lives. It is a concept dependent on characteristics of both individuals and situations. Because we highly value social inclusion as a contributing factor to our quality of life, we share a concern for the conditions that foster it in Canada.

In our market-driven society, employment is a key component of social inclusion, as well as a major means to achieve it. Income from employment, or alternate financial assistance, is both a significant outcome of social inclusion and a basis for sustaining it in other aspects of a person's life. Income profoundly affects the standard of living and the style of life that a person can accomplish and maintain, affecting one's personal sense of financial security and comfort.

In simplest terms, *employment* is understood as productive activity for pay. It is a more limited concept than work, which can also include a variety of productive but unpaid activities on one's own behalf, in the home, with friends and family, or in volunteer positions of various sorts. People who are not currently working for pay are considered unemployed if they are available and looking for work, and out of the labour force if they are not.

As noted earlier, the contexts and conditions of work in Canada are currently undergoing rapid and substantial changes.

Canadians seek and find employment in a wide array of circumstances and social contexts:

- Alone or with others
- As an employee or an employer
- At home or outside the home
- In new or familiar fields
- In the local community or far away
- In the public or private sector
- At a unionized or non-union workplace, and
- In small or large enterprises.

Likewise, the terms and conditions of employment show considerable variation:

- Self-employment or hired by others
- Permanent or temporary, part-time or full-time
- Contracted or informally hired
- Associated with supplementary benefits or not
- Congenial or unpleasant
- Challenging or easy, or
- Respected and stigmatized.

For most adults, prior to the onset of retirement and old age, work is a key activity for social inclusion. Other important areas are family, neighbourhood and wider community contacts, voluntary memberships and recreational pastimes. Work is the only social activity that can generate a comprehensive and productive context for social involvement. It provides income to sustain a desired standard of living for people and their dependents, occupies a considerable amount of their time and personal energy, provides major focus for their lives, produces a basic sense of identity and self-satisfaction, and generates social respect<sup>14</sup>.

## **B. Overview of Financial Assistance and Employment Programs for Disability**

Employment is so significant an element of social inclusion that the right to work should be established as a major entitlement of every adult living in Canada, honoured and protected whether a person is able-bodied or disabled, and whether a disabled person's impairment is severe or moderate, stable or progressive or episodic.

People with disabilities face an array of special challenges that can make their lives dramatically different from the everyday experiences of most able-bodied Canadians. These include:

- Developing and maintaining effective treatment and rehabilitation strategies
- Establishing and protecting financial security
- Finding, retaining or returning to jobs within a rapidly changing labour market; constantly encountering physical and other barriers in regular activities
- Protecting the confidentiality of private information about their impairments
- Confronting the stigma associated with disabilities of various kinds
- Establishing contact with community-based agencies working in their behalf, and
- All the while sustaining enough personal energy and optimism to move forward in their lives successfully in spite of the challenges.

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<sup>14</sup> Sources see Appendix C – BCPWA; CAS & CWGHR; Disability and Info Technologies, Disability; Proctor; Roehrer, Policy Approaches; Weir.

For people whose disabilities are episodic in nature, the situation can be further complicated by the insensitivity of many existing assistance programs to the particular needs and requirements caused by the transitory, and unpredictable, nature of their impairments.

Financial assistance is one component of a national strategy to assist people with disabilities to lead the full and self-satisfying lives to which they, like all Canadians, are entitled. The other part is support for social inclusion, in which employment plays a central role along with other avenues for social integration. In order for people with disabilities, their families, their communities and the wider society to function effectively, these two components must be comprehensive and well-integrated, rather than be expected to function separately.

A range of programs currently exists in Canada to provide *financial assistance* to people with disabilities. These programs are of two kinds:

1. Income benefits and other financial supports provided by federal and provincial/territorial governments, and
2. Private insurance purchased by employers for their employees or by individuals.

Federal government financial assistance includes CPP-D benefits, EI payments and income tax disability credits. In some circumstances, special arrangements are available to people with disabilities under CPP-D, such as:

- Retroactive benefits
- 'Fast-track' reapplication after unsuccessful return-to-work
- Supported education and training
- 3-month allowable-earnings benefits, and
- Specialized job-search and vocational rehabilitation assistance.

Provincial/Territorial level assistance includes social welfare assistance and Workers' Compensation. For some people with disabilities, additional support is made available for participation in rehabilitation, employment, training and education programs, and through money for assistive devices, transportation and personal care-giving. Private LTD insurance provides earnings replacement and, in some cases, support for the rehabilitation process.

OECD<sup>15</sup> research has found that in countries like Canada, with both contributory (CPP-D) and means-tested (provincial welfare) benefit schemes, the proportion of people with disabilities on means-tested benefits is increasing, with a resultant decline in average per capita benefit income. Women are under-represented in private insurance schemes and over-represented on means-tested schemes.

Social Inclusion as the second component of a national strategy is also substantial. Canada, like the U.S., the U.K., Australia, the Netherlands, and most other nations around the world, uses two legislative formats to assist the *labour force participation* of people with disabilities, including people with episodic disabilities. One is anti-discrimination legislation; the other is labour market policy to encourage employment and employability. Both anti-discrimination and labour market policies have important roles to play for the social integration of people with disabilities.

Environmental and attitudinal barriers can pose greater impediments to employment than the functional limitations of individuals. Anti-discrimination legislation prohibits discrimination at work based on disability, and it establishes a 'duty to accommodate' the special needs of workers with disabilities on the part of employers. Canada's anti-discrimination strategy is based in the federal Charter of Rights and Freedoms, the Canadian Human Rights and Employment Equity Acts, and provincial/territorial human rights legislation. In all these places, disability is identified as a prohibited basis for discrimination. Criteria are established to determine whether discrimination has occurred, as well as standards for applying such criteria to particular situations and complaints, 'reasonable' exclusions, mechanisms for enforcement, penalties for non-compliance, and procedures to educate employers, workers and advocates about the implications of such laws. Anti-discrimination and duty-to-accommodate legislation function best when standards are clear, enforcement is proactive and supportive information and expertise are readily available.

Labour market policies can be designed to encourage an adequate level of labour force participation for those with disabilities. Quotas for the hiring of workers with disabilities (typically enforced by regulatory sanctions) are used in a few countries (not currently in Canada). A voluntary or 'redistributive' model is more widespread: identifying people with disabilities as a target group, establishing the goal of assisting them to find and maintain employment, and providing work-related

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<sup>15</sup> Organization for Economic Cooperation and Development (OECD), *Transforming Disability into Ability*, Paris, 2003, p. 98.

incentives to employers and supports to workers with disabilities – thus 'redistributing' resources from employers and workplaces which are unable or unwilling to encourage hiring and retaining disabled employees to ones which are able and willing to do so. Canada uses such a voluntary model.

Canadian governments on all levels, similar to most other nations around the world, fund three kinds of programs to assist the labour market participation of people with disabilities:

- Those directed specifically to the disabled
- Those with a significant disability component, and
- Programs aimed at the general population for which people with disabilities can also qualify<sup>16</sup>.

### **C. Recent Changes in Structure and Programs**

- *Financial Assistance Programs*
- *Employment Programs*

The decade of the 1990's in Canada brought substantial policy and program changes on federal and provincial/territorial levels that profoundly affected the provision of assistance to people with disabilities.

At this time, insight was growing about the delicate but crucial relationship between support for financial assistance and support for social inclusion, and especially about the importance of giving major attention to the employability of people with disabilities while at the same time protecting their financial security. After decades of lobbying by many disability groups, the special significance of episodic disability was starting to gain recognition, particularly in the matter of employment. In CPP-D, for example, a 3-month 'work-trial' was established; along with 'fast-track' pension reapplication when return-to-work was unsuccessful.

Other developments were occurring, however, which significantly limited the impact of these insights and reduced their potential for effective policy development and program implementation. Principal among these developments was a federal political context in which reducing public debt/deficit and increasing taxation levels were primary strategies. This not only reduced the

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<sup>16</sup> Sources see Appendix C – Anderson and Brown; Boyce; Prince; Improving; Torjman; Weir, CAS, Providing Benefits Counselling; Eur Indus Relats Obs; OECD, Transforming; Burt Perrin; Roher, Policy; Soc Dev Canada, Advancing

availability of money for social programs, but also decreased public willingness to pay for supports for others.

Entire federal departments and their jurisdictions were substantially rearranged, renamed and refocused. Major funding sources were restructured, and levels of program funding were reduced. Essential programs were consolidated, and cost-cutting measures became routine. Two major departments, Health and Welfare Canada and the Employment and Immigration Commission, were split, and their responsibilities were reconstituted under Human Resources Development Canada (HRDC), Health Canada and Immigration and Citizenship Canada.

### ***Financial Assistance Programs***

During this decade, Unemployment Insurance became Employment Insurance, with tightened eligibility requirements and reduced benefits for all. Between 1995 and 2000, total expenditures on adult disability benefits through CPP-D declined substantially, along with the number of adults receiving financial assistance.

The Social Union Framework Agreement established new relationships between federal and provincial/territorial governments, after extended negotiations that created significant bilateral tensions. The Canada Assistance Plan was replaced, first by the Canada Health and Social Transfer, later by the Canada Health Transfer and the Canada Social Transfer. The altered relationships between federal and provincial/territorial governments reconfigured financial transfer schemes at lower levels, giving provincial and territorial governments a more prominent role in administering social support and social services, with less funding to do so, and reducing federal leadership in these areas. Important provincial responsibilities were reallocated within larger bureaucratic structures. As program funding declined in all directions, worker caseloads grew and energy for inter-program coordination waned<sup>17</sup>. Simultaneously, some provinces (i.e. Ontario) downloaded the fiscal responsibility for social assistance to the municipalities.

Levels of financial assistance were either reduced outright or prevented from keeping up with the rising costs of living. A number of disability-specific programs were eliminated, with claimants

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<sup>17</sup> Boyce, Will, "Lean and Mean Times: Employment and Income Support Policies for Persons with Disabilities", in press; Canadian AIDS Society, Force for Change: Labour force participation for people living with HIV/AIDS, Ottawa, 1998; Burt Perrin Associates, "Lessons Learned from Evaluations of Disability Policy and Programs", Evaluation Services, Human Resources Development Canada, Ottawa, 1999; Roehrer Institute, "Improving the Odds: Employment, Disability and Public Programs in Canada", Toronto, 2004.

absorbed into more general categories. Ironically, it became disadvantageous for a disabled person to be classified 'employable', because levels of financial return were comparatively lower for the difficult, but personally and socially valuable, process of moving off benefits and returning to the world of work. In most programs of financial assistance when eligibility rules were made tighter and more restrictive, such restrictions were particularly disadvantageous to people with episodic disabilities.

In a nation known for voluntarism and community-based involvement, less money was made available for local and national disability organizations to participate in the delivery of various kinds of assistance and to advocate for the needs and interests of their members. Simultaneously, voluntarism by people with disabilities in their own organizations declined, in part because of their fear of losing federal and provincial benefits if, by being more socially and politically active, they were considered employable. Across a growing segment of society, a sense of intolerance and suspicion seemed to accompany the provision of social assistance to people in need. At the same time, nationwide changes in the nature of work meant that more people with disabilities held part-time and contract jobs, making them unable to qualify for workplace-based LTD coverage.

Thus, the turn of the century brought in a disability strategy that could best be called 'normalization to market models' – that is, a 'market model' of disability<sup>18</sup>.

### ***Employment Programs***

On the federal level, Employability Assistance for People with Disabilities (EAPD) was replaced in 2003 by the Multilateral Framework for Labour Market Agreements for People with Disabilities. On federal/provincial/territorial levels, an important policy statement is contained in 'In Unison: A Canadian Approach to Disability Issues (1998)'. General principles of both policy documents include participation, equality, inclusion and independence. Emphasis is given to labour market involvement. Mainstreaming is claimed to work effectively for the employment of many people with disabilities. Sheltered employment is increasingly seen as inappropriate in Canada and elsewhere.

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<sup>18</sup> Sources see Appendix C – Boyce; Burt Perrin; CAS, Force for Change; OECD, Transforming; Prince; Roehrer, Improving; Soc Dev Canada, Advancing; Torjman.

The Multilateral Framework proposes to enhance the employability of people with disabilities and to increase their access to jobs. Related goals include:

- Multi-lateral opportunity and flexibility in the area of social integration programming
- Provision of individualized, holistic and portable integration assistance
- Partnerships between government, community-based groups, business, labour and other stakeholders, and
- Increased accountability and reporting.

Although Quebec did not formally endorse the Multilateral Framework, it has supported its general principles. The Secretary of State, which had been responsible for the status of people with disabilities for a decade, was dismantled and replaced, in part, by HRDC. The Disabled Persons Participation Program, which had previously provided valuable financial support to community-based disability organizations to enable them to encourage the social integration of people with disabilities, was eliminated, along with the National Welfare Grants program, which had also assisted disability organizations in this role. Their replacement, the Social Development Partnerships Program, was funded at a much lower level. A new HRDC program, the Opportunities Fund, was established with the announced goal of assisting people with disabilities to find employment. It replaced initiatives previously available under the Canadian Jobs Strategy, however with a reduced budget for that responsibility, and with a more limited role for community-based disability organizations.

In administrative terms, the situation has become extremely complicated: a circumstance not only limited to Canada. In Australia, the U.S., the U.K. and Germany, responsibility for disability employment assistance is divided among federal, state and local levels, yielding a fragmented, confusing and sometimes contradictory array of program initiatives. In the Netherlands, five federal ministries are involved in the delivery of disability assistance. Functioning in inter-ministerial committees, these ministries administer more than fifty laws to implement labour market policy<sup>19</sup>.

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<sup>19</sup> Sources see Appendix C – Boyce; CAS, Force for Change; Rocher, Improving; Soc Dev Canada, Multilateral; Torjman.

#### D. Problems in the System

- *Inadequate Funding*
- *Eligibility Criteria*
- *Unclear Jurisdictions*
- *Uneven Implementation and Coordination*
- *Lack of Integration*

##### *Inadequate Funding:*

Through an array of programs and initiatives, public and private, Canada spends considerable money and devotes substantial time and energy to providing assistance to people with disabilities. However, Canada is lagging in this area of social policy funding. According to a recent OECD study (2003)<sup>20</sup>, federal expenditures in Canada on all disability programs in 1999 were 1.28% of the gross domestic product (provincial data were not included). By comparison, federal expenditures in Australia were 1.44% of GDP (in 1999), 1.40% in the U.S., 1.54% in the U.K., 2.70% in the European Union, and 2.40% for the twenty OECD nations in the study.

Despite this expenditure level, the consensus of opinion among disability specialists, who have looked closely at the real-world effects of financial and social assistance on the lives of people with disabilities in Canada, is that the basic strategy does not work consistently or well – for people with disabilities in general, and especially for people whose disabilities are episodic in nature. This is certainly true in the area of financial assistance, where an array of specific problems have been identified, not only in Canada but also in Australia, the nations of the European Union, the United States and other developed and developing nations around the world.

For example, CPP-D has limited its direct financial support for vocational rehabilitation, without commensurate new employability programming becoming available on provincial and territorial levels. Partial benefits, which can be effective for the development of employability especially for people with a wide range of episodic disabilities, have not yet been made available on the federal level. Thus, the situation facing a disabled person in Canada is characterized by less adequate benefits than fifteen years previously, tighter eligibility criteria, increasingly fragmented jurisdictions and administrative complexity. (We have noted that eligibility criteria for general social programs have been tightened. The social impact on those at the marginal end of employability, essentially

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<sup>20</sup> Organization for Economic Cooperation and Development (OECD), *Transforming Disability into Ability*, Paris, 2003, section 6.1, "Assessing policy approaches", pp. 124-8.

those with disabilities, has been significant). In addition, eligibility criteria are inconsistent across programs, as are definitions of 'disability' (which vary even among national surveys of the prevalence of disability in Canada).

***Eligibility Criteria:***

When disabilities are episodic in nature, eligibility criteria appear even more confusing and discouraging. The situation leads to contradictions in program operations, widespread confusion and misinformation, discouragement by potential applicants, late referrals, insufficient follow-up and gaps in service. It can be difficult for people with disabilities to comprehend which financial assistance programs exist and how they interact, which programs they can qualify for and how to gain access. At the same time, program staff caseloads are high, and staff attention and expertise are typically focussed within the jurisdictions of particular support programs, rather than across the entire landscape of possible assistance that claimants might need and for which they might indeed qualify.

***Unclear Jurisdictions:***

Despite the recent establishment of two re-named and re-focused federal departments (Human Resources and Skills Development Canada and Social Development Canada), the delegation of increased responsibility to provinces and territories has weakened the leadership role of the federal government and decreased its ability to set and enforce national disability directions and standards. Responsibility for the social integration of people with disabilities, especially in employment, is highly fragmented among national and provincial/territorial levels, divided between departments and agencies and across policies, laws, regulations and programs. Inter-jurisdictional discrepancies are commonplace, making coordination difficult to accomplish. (In Canada, as in many other countries, anti-discrimination and duty-to-accommodate legislation has not demonstrably improved the overall employment prospects of people with disabilities).

***Uneven Implementation and Coordination:***

Combined with new limits placed on social assistance in Canadian provinces and territories nationwide, the net effect of revised administrative arrangements has not been favourable for the social integration of people with disabilities. Provincial funding for social services has not kept pace with increased responsibilities. The actual delivery of such services has typically become more restrictive in operation and more limited in scope.

People with disabilities still encounter numerous barriers and disincentives when seeking to retain their jobs or return to work after the onset of impairment:

- Overly restrictive and inflexible eligibility criteria
- Inadequate job-search information and assistance
- Lack of access to comprehensive vocational rehabilitation
- Insufficient financial support for work-related supports
- Potential loss of benefits when work, re-training or volunteer activities are pursued
- Poorly-informed employers and inflexible working environments, and
- Limited employment opportunities, especially for people with episodic disabilities.

Most workplaces, large and small, still have no formal policies or programs regarding disability and return-to-work.

Canada is not alone in its failure to achieve administrative coherence, program coordination and the removal of financial and other disincentives to remain working. Few European Union nations, for example, operate targeted job retention and re-integration programs for people with disabilities in other than formal employment settings. This contributes to a two-tier system for assistance and support, creating needless complexity and delays for claimants who must wait for jurisdiction and responsibility to be established. Inter-program coordination is greater in Germany than in most other European countries<sup>21</sup>.

***Lack of Integration:***

With limited exceptions, the Canadian system of disability assistance essentially treats income support and employment as discontinuous options that people with disabilities must confront. Income support is only made available when employability is deemed to be absent. Therefore, in order for a disabled person to consider, assert and pursue employability, financial security must be jeopardized. Considerable research has confirmed that this is a strong fear for many people with disabilities, especially for people whose disabilities are episodic in nature. Program analysis has shown that, despite the existence of some exceptions to this essential pattern, the fear is entirely justified. People with episodic disabilities, as much or more than many other workers with disabilities, experience a strong and persistent financial disincentive to attempt to find, retain or return to jobs, either at their current or former workplaces or in new places or fields of employment.

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<sup>21</sup> Sources see Appendix C – Austr HREOC, National Inquiry; Baanders et al; Burt Perrin; CAS, Force for Change; Roehr, Improving; Soc Dev Canada, Multilateral; Torjman; WCG.

For example, the OECD study (2003) found that the rate of movement of people with disabilities off benefits to employment of some sort is low (around 1% per year) in most countries (including Canada), despite an array of financial assistance and employment support arrangements. Significant revisions to strategies and programs of delivering assistance to people with disabilities in Canada are clearly in order<sup>22</sup>.

## E. Policy Principles

The preceding information and trends are yielding consensus in the field about overall directions in the future. This section discusses a number of policy principles or criteria to be used in assessing potential:

- *Diversity of disabilities*
- *Citizenship rights*
- *Equality*
- *Quality of life*
- *Central role in planning and decision-making*
- *Non-coercive*
- *Confidentiality*
- *Transparency of information*
- *Eligibility criteria*
- *Early intervention*
- *Program flexibility*
- *Integrated approach*
- *Employment emphasis*
- *Responsibility and accountability*
- *Mutual obligations*
- *Program funding*
- *Monitoring and evaluation*

### ***Diversity of Disabilities:***

Impairments, disabilities and handicaps are diverse along many dimensions. Major variations include:

- Nature and physical site of the impairment
- Original cause and precipitating factors for improvement
- Predictability of prognosis
- Stability recurrence or decline
- Likelihood of secondary symptoms and complications (physical and emotional)
- Treatment possibilities and regimens
- Side-effects of medications and other treatments
- Generation of current handicap(s) and possible/likely occurrence of future handicap(s)
- Public visibility of the impairment and the handicap(s) it generates
- Nature and extent of stigma attached to the disability
- Effects on self-image, self-confidence, and
- Current expectations and plans for the future.

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<sup>22</sup> Sources see Appendix C – Austr HREOC, Second Submission; Bambra; BCPWA; Berkowitz; Burt Perrin; CAS, Force for Change; CAS, Income Security; Dept of Work & Pensions, Disabled; CMHA, Position Paper; Disability & Info Tech; Legal Network and CWGHR; OECD, Transforming; Parliamentary Library; Prince; Roher, Improving; Torjman; Zeitzer.

Other than variability, no single or uniform conception of disability is adequate to summarize such a variety of conditions and effects. This presents a challenge in forming the basis for policies and programs to assist people with episodic disabilities<sup>23</sup>.

***Citizenship rights:***

People with disabilities are entitled to services and support as a full citizen, equal in rights to every other Canadian. Prejudice and stigma based on disability should be counteracted, and discrimination based on disability should be prohibited. Employers have a duty to accommodate employees living with disabilities, including episodic disabilities<sup>24</sup>.

***Equality:***

The ability of people with disabilities to gain access to needed financial assistance, employment assistance and related supportive services should never be limited because of gender, age, race, ethnicity (including Aboriginal status), sexual orientation or kind of disability<sup>25</sup>.

***Quality of Life:***

Everyone has the right to personal security, social inclusion and access to needed services in the face of sickness or disability. Programs to assist people with disabilities should emphasize quality of life as they conceive it, themselves, and should focus on personal independence and social inclusion. Financial supports should be appropriate to maintain financial security at a reasonable level, and to assist people with disabilities to enter, remain in, or return to the workforce if they choose. Financial assistance should include access to partial disability benefits, in situations where impairment temporarily or permanently prevents full-time work<sup>26</sup>.

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<sup>23</sup> Sources see Appendix C – Australian HREOC, first submission; BCPWA; Berkowitz; Burt Perrin; CAS, Force for Change; CAS, Providing Benefits Counseling; deBruyn, Plan of Action; Eur Foundation; ILO Manual; Manitoba Human Rights; Neufeldt; Nixon & Renwick; OECD, Transforming; Return, Policy Guidelines; Roehrer, Improving; Soc Dev Canada, Advancing; Wellesley; Wittenburg.

<sup>24</sup> Sources see Appendix C – Australian HREOC, First submission; Baanders et al; BCPWA; CMHA, Position paper; Disability and Info Tech; Eur Foundation; ILO Manual; Prince; Roehrer, Improving; Roehrer, Policy; Ross-Van Dorp; Royal Netherlands Embassy; Return, Policy Guidelines.

<sup>25</sup> Sources see Appendix C – ILO Manual; Roehrer, Improving; Torjman; Wittenburg.

<sup>26</sup> Sources see Appendix C – Austr HREOC, second submission; BCPWA; Berkowitz; CAS, Force for Change; CAS, Providing Benefits Counseling; CMHA, Position Paper; Eur Foundation; ILO Manual; OECD, Transforming; Prince; Return, Policy Guidelines; Roehrer, Improving; Roehrer, Policy; Roehrer, Toward a Common Approach; Ross-Van Dorp; Royal Netherlands Embassy; Wittenburg.

***Central role in planning and decision-making:***

People with episodic disabilities must be at the center of all planning and decision-making related to financial support, employment and supportive services. They should be expected and encouraged to identify personal needs and goals and to have these honoured within any planning for services and assistance. Primary among such possibilities should be the opportunity to retain a job or return to work, even when faced with an episodic disability. Whatever their choices and decisions, people with disabilities should never need to face financial hardship because of lack of access to assistance and supports<sup>27</sup>.

***Non-coercive:***

Planning and delivering assistance to people with disabilities should be consultative and characterized by negotiation rather than coercion. When disability requires interruption of employment, there should be no undue pressure to return to work, and no penalties (including withdrawal of financial support) during the period when return-to-work may be attempted (successfully or not)<sup>28</sup>.

***Confidentiality:***

Information about impairments that is provided by people with disabilities, in order to gain access to financial support, employment assistance and other needed services should be kept confidential and only disclosed with their informed consent<sup>29</sup>.

***Transparency of information:***

People with disabilities have a right to complete and understandable information about all factors involved in program alternatives and decisions that must be made<sup>30</sup>.

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<sup>27</sup> Sources see Appendix C – BCPWA; CAS, Providing Benefits Counseling; Eur Foundation; ILO Manual; Prince; Roehrer, Improving; Royal Netherlands Embassy; Wellesley.

<sup>28</sup> Sources see Appendix C – CAS, Force for Change; CAS, Providing Benefits Counseling; ILO Manual; Neufeldt; OECD, Transforming; Wellesley.

<sup>29</sup> (Sources see Appendix C – CAS, Providing Benefits Counseling; ILO Manual; Wellesley)

<sup>30</sup> (Sources see Appendix C – CAS, Providing Benefits Counseling; Eur Foundation; Return, Policy Guidelines; Roehrer, Improving)

***Eligibility criteria:***

Programs of support and assistance to people with episodic disabilities should operate on the basis of clear, appropriate and equitable eligibility criteria. Except for specialized programs like workers' compensation, program eligibility should not depend on distinction between work- and non-work-related causes or sources of aggravation of a disability.

***Early intervention:***

Timeliness is crucial in the provision of assistance and support to people who become disabled or experience an episodic disability. In the case of people already employed, this should include early and proactive assistance, workplace accommodation and vocational rehabilitation, as well as protection of financial security and other measures for social inclusion<sup>31</sup>.

***Program flexibility:***

Flexibility should be at the core of programs of assistance and support for people with episodic disabilities, in ways appropriate to the variability of disabilities and the unpredictability of their prognosis. Program planning should be individualized, tailored to specific and changing situations and needs of each individual, in order to encourage effective planning for employment (including return-to-work) and other avenues of social inclusion. Disability status should be re-assessed on a regular basis, in a non-threatening way and without unfairly jeopardizing financial assistance<sup>32</sup>.

***Integrated approach:***

Provision of assistance to people with episodic disabilities requires a continuum of financial security and social inclusion programs that are effectively integrated. Fragmentation of jurisdictions and responsibilities needs to be kept to a minimum, because of the confusions, contradictions and gaps it can generate. Programs should be established and run on principles of community development and partnership between people with disabilities and their organizations, governments of various levels, employers and their associations, workers and their unions, service providers and their agencies and associations, and communities and their representatives. The value of full and

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<sup>31</sup> Sources see Appendix C – Bambra; CWGHR, Early Intervention; Eur Foundation; OECD, TRANSFORMING; Return, Policy Guidelines.

<sup>32</sup> Sources see Appendix C – BCPWA; CAS, Providing Benefits Counseling; deBruyn, Plan of Action; ILO Manual; OECD, Transforming; Office of the Commissioner; Wellesley; Wittenburg.

informed participation by people with disabilities and their associations applies to the development of social policies and programs on all levels<sup>33</sup>.

***Employment emphasis:***

Access to employment should always be available as a primary option in a continuum of assistance provided to people with episodic disabilities, along with supports that make employment possible. Whenever feasible, the major goal should be to sustain current employment after the onset of the disability or episodic problem. Intervention needs to be proactive, coordinated and comprehensive, incorporating an array of ingredients: prevention of injury and illness, financial and work-related supports, workplace accommodation, vocational rehabilitation, career counselling, job search assistance, access to education and training and self-employment. The choice of finding, retaining or returning to employment should never jeopardize access to needed financial benefits<sup>34</sup>.

***Responsibility and accountability:***

In government departments, at workplaces, in social agencies and community-based groups, responsibilities in programs of assistance to people with disabilities need to be clearly defined, along with the designation of roles to fulfill them. Training should be made available, to provide relevant knowledge and skills about the situations of people with episodic disabilities and other special handicaps. Mechanisms should be in place to ensure accountability, as well as fair and effective avenues for appeal<sup>35</sup>.

***Mutual obligations:***

When effective work-retention or return-to-work programs or plans are established for people with disabilities, they should participate actively and responsibly to meet obligations identified within program procedures<sup>36</sup>.

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<sup>33</sup> Sources see Appendix C – BCPWA; CAS, Providing Benefits; Disability and Info Tech; Durand; Eur Foundation; ILO Manual; Neufeldt and Albright; OECD, Transforming; Prince; Return, Between Work and Welfare; Return, Interim Report; Return, Policy Guidelines; Roehrer, Improving; Soc Dev Canada, Advancing; Wellesley.

<sup>34</sup> Sources see Appendix C – Bambra; BCPWA; Berkowitz; CAS, Providing Benefits Counseling; Eur Foundation; ILO Manual; OECD, Transforming; Prince; Return, Policy Guidelines; Roehrer, Improving; Soc Dev Canada, Multilateral; Wittenburg.

<sup>35</sup> Sources see Appendix C – BCPWA; Eur Foundation; OECD, Transforming; Prince; Roehrer, Improving; Wellesley.

<sup>36</sup> Sources see Appendix C – OECD, Transforming.

***Program funding:***

Since society benefits from full and active participation by people with episodic disabilities in economic and social life, society must share the costs of assistance, rather than force people with disabilities and employers to carry the financial burden separately. Programs of financial and employment-related assistance for people with disabilities should be funded at levels adequate to need, and with a view to keeping staff caseloads at a reasonable level for effective functioning<sup>37</sup>.

***Monitoring and evaluation:***

Programs to assist people with episodic disabilities should be regularly monitored and evaluated. Attention should be given to the relationship and balance between initiatives for financial assistance and social inclusion (employment in particular), and how programs to achieve these two goals may impact upon each other<sup>38</sup>.

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<sup>37</sup> Sources see Appendix C – Austr HREOC, second submission; Eur Foundation; ILO Manual; Rocher, Improving; Torjman.

<sup>38</sup> Sources see Appendix C – Return, Policy Guidelines.

## NEW DIRECTIONS FOR CANADIAN POLICIES AND PROGRAMS

In recent years, researchers, analysts and program planners in Canada and elsewhere around the world have investigated the many values of social integration for people with disabilities, and they have identified effective ways to accomplish it. In doing so, they have invariably stressed the crucial roles of financial assistance and employment. Increased attention has been paid to special issues facing people with episodic disabilities, because of growing awareness that existing policies and programs are often poorly suited to their particular needs, interests and circumstances, especially in the area of return-to-work:

For example, the OECD study of employment assistance strategies for people with disabilities<sup>39</sup> identified several key aspects of social integration policies:

- Relative consistency of coverage
- Structures and processes for assessing eligibility
- Articulation of employer roles and responsibilities
- Contexts for delivering employment assistance (e.g., supported, subsidized or sheltered work)
- Avenues for incorporating vocational rehabilitation into the integration process
- Relationship to the provision of financial benefits, and
- Additional work-related incentives for employers and other stakeholders.

In our view, a number of strategic and programmatic changes are necessary.

### A. **Definitional/Conceptual**

#### **A1 – More Inclusive Definition of Disability**

The purpose of defining disability should be to indicate ‘whom’ the policy is intended to address. Despite variations in specific wording, most nations rely on a medical model to define disability in their programs of financial assistance. Typical definitions, in Canada as elsewhere, require people with disabilities to see themselves as *different* and to present themselves in the worst possible light – that is, in terms of pathology rather than recovery. They become stigmatized by the system at its most basic level of self-identity, causing personal discouragement and substantially reducing their motivation for successful rehabilitation and social inclusion.

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<sup>39</sup> Organization for Economic Cooperation and Development (OECD), Transforming Disability into Ability, Paris, 2003, section 6.1, "Assessing policy approaches", pp. 124-8.

**RECOMMENDATION**

**A broad and inclusive common definition of disability needs to be established in Canada across diverse government programs of assistance (financial, social, legal, etc.).**

The strict use of a medical model for dichotomous decision-making needs to be replaced with a definition which more broadly reflects the variability and unpredictability of impairment progression, and that also respects interactions between particular impairments and the real-world contexts (including work and other avenues for social inclusion) in which impairment gets translated into barriers. The definition should view people with disabilities as full citizens rather than as passive recipients of services, and should allow for validation of the self-reports that they can provide about limitations in particular activities and areas of their lives. The concept of disability should be regarded as dynamic, reflecting not only a current circumstance, but also the possibility of a condition that may have occurred in the past and might appear again in the future.

**RECOMMENDATION**

**Widespread restrictions based on the use of two key terms, 'severe' and 'prolonged', need to be revised, to permit increased access to financial assistance by people experiencing episodic disabilities.**

These terms are rooted in a medical and prognostic framework of diagnosing sickness, rather than a social framework of identifying and overcoming barriers in the environment. Such basic change was suggested by the content of the Villani Supreme Court<sup>40</sup> decision in 2001. The process of generating a new and more appropriate definition of 'disability' should include active participation and input by people with disabilities and their organizations<sup>41</sup>.

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<sup>40</sup> Villani v. Attorney General for Canada, Federal Court of Appeal, 2001, cited in Office of the Commissioner of Review Tribunals, "Report of the Panel Member Task Force on Core Policy Issues", Commons Sub-Committee on the Status of Persons with Disabilities, Ottawa, March 2003; Prince, Michael, "The Canada Pension Plan Disability Program: Values and Solutions", submission to the House of Commons Sub-Committee on the Status of Persons with Disabilities, Victoria B.C., February 2003; Multiple Sclerosis Society of Canada, "A Fair and Effective Disability Tax Credit", Submission to the Technical Advisory Committee, Toronto, August 2003.

<sup>41</sup> Sources see Appendix C – Austr HREOC, second submission; Boyce; Brands; Burt Perrin; CAS & CWGHR; deBruyn, Plan of Action; Disability and Info Tech; People with disabilities International; Legal Network and CWGHR; MS Society, MS & CPP-D; Neufeldt; Office of Commissioner; Prince; Proctor, Looking Beyond; Roehrer, Improving; Soc Dev Canada, Definitions; Torjman; Weir; Wittenburg.

## **A2 – More flexible eligibility criteria**

Whether people are disabled or able-bodied, whether disabilities are persistent or episodic, everyone needs basic financial safety and security. The purpose of specifying eligibility criteria should be to identify the ‘conditions’ under which a defined target group requires program assistance. These criteria should be related to the goal (i.e., secure income) of the program. Establishing program eligibility should be different from identifying the target population; eligibility criteria should not be confused with definitions of disability. Criteria need to address the concepts of diminished ability, minimum work disruption, and social context.

### **RECOMMENDATION**

**Eligibility criteria should be framed as continua, on a broad range of factors rather than as simple dichotomies in the permanence of medical conditions.**

Access to income support should not be treated as an all-or-nothing process, reserved essentially for 'unemployable' people and thus unavailable to people whose ties to employment remain – or can readily become – active. When eligibility for financial assistance and employability is specified, more than a medical diagnosis is required. Attention also needs to be given to the social context, to real-world factors such as skills, education, geographic location and local labour market conditions.

The idea of a minimum qualifying period (MQP) for contributions to CPP needs reassessment and revision. CPP-D eligibility criteria need to be returned to mid-1990's standards for the required number of contribution years (5 out of 10 rather than 4 out of 6). This would provide people with limited or interrupted work histories due to episodic disabilities to have greater access to benefits. Similarly, people with disabilities who seek training or education while temporarily away from regular jobs should not be penalized for attempting to improve their employability. MQP calculations need to be made more flexible under certain conditions.

Working people with episodic and recurring disabilities should be exempt from waiting periods and MQP eligibility requirements applied to new entrants to the workforce, and be given ready access to short-term earnings-replacement options<sup>42</sup>.

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<sup>42</sup> Sources see Appendix C – Berkowitz; Boyce; Burt Perrin; CAS & CWGHR; CMHA, Employment; Prince; CMHA, Position Paper; MS Society, MS & CPP-D Issues; OECD, Transforming; Office of Commissioner; Proctor, Looking Beyond; Roehrer, Improving; Torjman; Weir.

## **B. Policy/Legal**

### **B1 – Government Policy Coherence**

Worldwide studies, including many in Canada, have concluded that, to achieve significant benefits for the social integration of people with disabilities, federal governments must establish strong and coherent policies in the area of employment. National leadership is essential, if provincial and territorial policies and programs regarding social welfare, social services, education and training, rehabilitation, health and social research are going to generate a substantial vision for return-to-work when people become disabled. This is especially true for people whose disabilities are episodic in nature.

Return-to-work has increasingly become a core disability policy emphasis in several European Union nations. Germany, for example, uses a 'social discourse' model<sup>43</sup> developed by the Canadian disability consultant, NIDMAR. This model aims to combine active involvement by business and labour in federal policy and program planning, proactive employer contact with workers with disabilities, early assessment with a rehabilitation focus, assistance programs which encourage return-to-work, and provision of financial assistance (including partial benefits) compatible with such policy ingredients.

Sweden also places early intervention, vocational rehabilitation and coordinated stakeholder involvement at the centre of its national disability policy. Employers are expected to play key roles in early identification of worker disability, fast referrals to appropriate sources of diagnostic expertise and financial assistance, and development of individualized rehabilitation plans that encourage return-to-work. Temporary financial benefits are available prior to formal diagnosis of disability, to encourage immediate pursuit of rehabilitation. The emphasis is on preventing disabled employees from needing to leave the workforce in the first place.

High priority is given in the Netherlands to workplace adjustment and support, to enable disabled employees to retain or return to jobs. Government-funded incentives are made available to employers, to enable them to play a strong, proactive role in early identification of employee disability, planning for rehabilitation and immediate protection of financial security.

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<sup>43</sup> European Foundation for the Improvement of Living and Working Conditions, Employment and Disability: Back to Work Strategies, Dublin, 2004, pp. 43-5 and Chapter 6, "Policies and initiatives in Germany", pp. 59-64.

**RECOMMENDATION**

**A policy goal of “employable, if and when able” should be explored**

Because the active involvement of employers and workplaces in the re-integration process is vital for effective implementation of disability policy, Canada needs to develop more effective policy emphasis on this particular goal of return to work. Three general approaches are in use worldwide:

- Rights-based anti-discrimination legislation
- Obligations-based employment quotas and
- Incentives-based voluntary action.

Each aims to achieve a balance between promoting employment of workers with disabilities and imposing undue hardship on employers.

Anti-discrimination laws, moral suasion, quotas, financial incentives, mandated obligations, provision of technical assistance, and temporary wage subsidies are all potential strategies available to Canada to increase employer involvement in the social integration process. Whenever specific obligations are identified for employer responsibilities, incentives must be provided to assist their compliance, and sanctions for failure to do so. Effective mechanisms for enforcement are discussed in the pages ahead.

**B2 – Collaborative Program Funding**

Better integration with return-to-work initiatives would reduce long-term dependence on benefits by many claimants. Program funding is currently inadequate to meet this need for those with episodic disabilities. The public sector (through taxation revenue), private employers (through assessment and private insurance costs) and employees (through contributions, taxes and private insurance fees) can all be involved in the funding of disability financial assistance. When people become disabled, they should be able to access a robust program of financial assistance that is funded equitably, adequately and from a variety of sources.

**RECOMMENDATION**

**Available funds could be spent more efficiently if administrative complexity was reduced, integration across programs was increased and costs were shared more widely.**

In recent years, community-based disability organizations have experienced increased demand for services and advocacy, and at the same time faced decreased access to government funding. The result has been a decline in their ability to participate effectively in the provision of counselling and advocacy, with a consequent magnification of gaps and inconsistencies in the delivery of financial assistance to people with disabilities whose needs and personal circumstances (episodic disabilities) are non-routine<sup>44</sup>.

### ***Greater income security***

Income security is a broad but vital area of concern for people with disabilities, regardless of their current employment status. Such security provides for an array of specific needs, each of which is vitally important in its own right: shelter, food, transportation, medical care, disability supports, maternity and childcare expenses and support for dependents.

Because of the complexity and variety of factors and contexts, it is difficult to assess how adequately the financial security of people with disabilities is being met in Canada. People with disabilities can theoretically receive income from both work and public benefits. According to the OECD study, the proportion receiving both kinds of income in 1999 was between 5% and 15% in most countries (the highest rate was in Sweden, over 33%; the lowest rate was in Australia, due to means testing). No figures were available for Canada.

Among recipients of disability benefits worldwide, about one-in-three was employed in 1999; in Sweden, the rate was more than one-in-two; in three countries with no partial disability benefits (Australia, Austria and Spain), the rate was only one-in-nine. Again, no figures were available for Canada.

In 1999, the average personal income for people with disabilities in Canada was approximately 85% of the average personal income of people without a disability; by comparison, the comparative figure in Australia was 44%. On the other hand, the average federal disability benefit in Canada in 1999 was 29% of per capita wages (down two percentage points from 31% in 1990) for those eligible; the

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<sup>44</sup> Sources see Appendix C – Boyce; OECD, Transforming; Return, Policy Guidelines.

comparative figure in Australia was 74% (up eleven percentage points from 63% in 1990). Thus, Canada has a broad, but modest, income support system.

**RECOMMENDATION**

**Financial assistance that provides a reliable and adequate level of income security should be readily available throughout the entire disability experience.**

Financial assistance which provides a reliable and adequate level of income security should be readily available throughout the entire disability experience: on a temporary basis even before applying for particular benefits programs, throughout the application process, after qualifying and during attempts at return-to-work. To determine appropriate level of financial support, programs should investigate all the actual costs of living with a disability. Benefits should be indexed to rises in the cost of living.

In Canada, the Disability Tax Credit (along with the Medical Expense Tax Credit) is an important first step toward addressing the personal costs of disability. When appropriately structured, tax credits and deductions can be used to top-up wages for people with disabilities who attempt return-to-work, and to help pay the added costs of special supports and re-training.

However, as currently formulated, the Disability Tax Credit is too complex and confusing in its application. It excludes episodic disabilities, because intermittent impairments are not considered 'prolonged' and the 'daily life' criterion is too ambiguous in its application. The tax credit needs to be made refundable, so that people with insufficient income to pay tax can also derive important financial benefits. The time required for appeals is far too slow. Reconsideration should be also given to the requirement to include CPP-D as taxable income<sup>45</sup>.

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<sup>45</sup> Sources see Appendix C – BCPWA; Burt Perrin; Caledon, Disability Supports; deBruyn, Plan of Action; CAS & CWGHR; CMHA, Employment; ILO Manual; MS Society, Fair and Effective; OECD, Transforming; Office of Commissioner; Proctor, Looking Beyond; Return, Interim Report; Wittenburg.

### **B3 – Anti-discrimination legislation**

Although many nations around the world, including Canada, have anti-discrimination legislation, little evidence exists anywhere to demonstrate that, as currently structured and administered, it is widely used or notably effective in increasing the employability of people with disabilities, especially people with episodic disabilities.

Laws and regulations prohibiting discrimination in employment based on disability are intended to address an array of employment barriers:

- Discriminatory attitudes
- Lack of awareness
- Decisions about hiring and promotion
- Physical barriers and communication problems, and
- Workplace rules and procedures that are implicitly or explicitly unfair.

Such legislation typically covers two kinds of employment discrimination: treating a disabled worker or job applicant less favourably because of an impairment, without appropriate justification, and failing to make reasonable adjustments (the 'duty to accommodate') to a disability without appropriate justification. It mandates that the hiring, assignment, promotion and evaluation of all employees be based solely on work-related merit rather than on disability status, and that workplace circumstances allow all employees an equal chance to perform the requirements of their jobs and to enjoy work-related benefits.

Despite the potential benefits of such legislation for people seeking to find or retain jobs or return to work in the case of intermittent and episodic disability, disadvantages are also apparent. One common problem in employment discrimination law is unclear standards for application. In this regard, the Americans with Disabilities Act has been more successful than similar legislation in many other places (including Canada), because its criteria and application standards are expressed more clearly and its allocation of responsibilities for enforcement is more specific.

People with disabilities are often unaware of their rights under such legislation and unsure how to achieve redress. Many are reluctant to risk the barriers of cost and time that are inherent in enforcement. Employers, as well, can incur added costs from legal advice, litigation, delegated staff time and punitive damages.

## **RECOMMENDATION**

**Legislation should oblige employers and other employees to be aware of their duty to accommodate, within reasonable limits, to the needs of employees with episodic disabilities.**

The duty to accommodate should apply to work schedules, task assignment of tasks and job design, time-off for medical appointments, leave policies, and, especially for people with episodic disabilities, the opportunity to shift back and forth between part-time and full-time work.

Notably different from the essentially medical definitions of disability commonly used in financial assistance and other employment support programs, anti-discrimination legislation often uses a definition based on the social model. The Manitoba Human Rights Code section on disability, for example, refers to some of life's major activities, including employment, and mentions that disability can be permanent, ongoing, episodic, or of some persistence. The Code also identifies specific circumstances in which discrimination can occur: indirect discrimination (e.g., policies regarding sick leave or disability planning), unfair treatment based on episodic disability, and job loss following application for workers' compensation. Similarly in the U.K., the definition of disability under the Disability Discrimination Act mentions substantial and long-term adverse effect on a person's ability to carry out normal, day-to-day activities. It covers progressive and episodic conditions from the onset of their noticeable effect on activities, and people are still protected by the Act if they have recovered from a past disability.

In general, because of inevitable tension between a mandated 'duty to accommodate' and the protection afforded to employers by the limit of 'reasonable justification', the application of anti-discrimination legislation in employment can result in substantial dependence on administrative discretion and court procedures to make workplaces more accessible to people with disabilities. Often there is confusion about interactions between anti-discrimination legislation and other related laws – occupational health and safety and workers' compensation, for example.

It is not surprising that studies<sup>46</sup> have found that the employment situation of people with disabilities in most places, including Canada, has not so far been markedly improved by such legislation. The Australian government currently provides an array of information sources (including on-line resources, pamphlets and community-based offices) about anti-discrimination laws relevant for people with disabilities seeking to retain or return to jobs. Even so, the Australian Disability Discrimination Act has not clearly achieved its goals in employment, and additional mechanisms are needed. The same is true for Canada.

## **C. Administration**

### **C1 – Effective assessment process**

Application of disability definition and eligibility criteria to claimants requires an assessment process. Assessment should be treated as a professional rather than a bureaucratic responsibility, be comprehensive in nature, and be done by people trained in rehabilitation and financial planning skills, in addition to medical expertise. People responsible for assessment require clear and consistent guidelines and specialized preparation for their role.

Assessment of disability should be de-linked from determination of need for financial assistance. It should be a two-step process:

- First, a diagnosis of functional limitations (regardless of permanence) on medical grounds, and
- Second, an analysis of financial situation and capacity to work (and to participate in other forms of social inclusion), based on personal reports, context data and input from vocational rehabilitation and other specialists.

Claimants should always have ready access to advocates from outside the process, for consultation during applications and appeals.

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<sup>46</sup> See for example, Burt Perrin Associates, "Lessons Learned from Evaluations of Disability Policy and Programs", Evaluation Services, Human Resource Development Canada, Ottawa, 1999, Section F, "Vocational Rehabilitation"; Australian Human Rights and Equal Opportunity Commission, "Productivity Commission review of the Disability Discrimination Act – First Submission", Sydney, November 2003; European Foundation for the Improvement of Living and Working Conditions, Employment and Disability: Back to Work Strategies, Dublin, 2004, pp. 6-7 and 13-14; Baanders, A. N. et al, "Work adjustments among the chronically ill", International Journal of Rehabilitation Research, March 2001; the Roeher Institute, Improving the Odds: Employment, Disability and Public Programs in Canada, Toronto, 2004, Chapter XI, "Summary of Findings".

## RECOMMENDATION

**Financial assistance programs in Canada should be more proactive in providing for earlier and faster eligibility assessment (and appeals).**

OECD<sup>47</sup> (2003) found that early, individualized intervention is the single most effective measure to protect against long-term benefit dependence. This is true particularly for people who become disabled while employed, as well as for disabled adolescents finishing their education and becoming independent from parents, and for disabled adults who have not yet successfully entered the labour force.

Lengthy time periods for processing their applications pose a substantial problem for many disabled claimants. Short-term earnings replacement should be immediately available. In Sweden, rapid investigation of possible disability is initiated by employers (or employees who request it), with quick referral to appropriate programs for assessment and intake. Income support is made immediately available. In Germany, provision of early assistance is a guiding principle of its disability policy. In several EU countries (Netherlands, Sweden and Germany among them), it is not unusual for people with disabilities to immediately receive short-term benefits and then to transfer to longer-term benefit arrangements if impairment warrants.

Through its program, 'Australians Working Together', Australia attempts to provide increased work opportunities for people with disabilities, thus decreasing their reliance on income supports. This includes earlier and better assessment of their capacity to retain or return to jobs – focusing less on what they cannot do, emphasizing more what they are able to do, and following up such assessment with proactive support for return-to-work (rehabilitation, financial assistance, education and re-training).

Information provided in the application and assessment process should be treated with strict confidentiality. Considerable stigma is associated with disability in general, even more so with particular impairments. The anticipation of prejudice and discrimination understandably prevents some people with disabilities from disclosing their conditions at work, thus reducing their initial

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<sup>47</sup> Organization for Economic Cooperation and Development (OECD), *Transforming Disability into Ability*, Paris, 2003, p. 162

access to support programs. Ethical dilemmas are involved with the disclosure of health information, when employers, family doctors and social agencies can all be asked to function as gatekeepers. In every case the privacy and security of the claimant should be considered paramount without jeopardizing eligibility, and information should only be disclosed with the informed consent of claimants<sup>48</sup>.

**C2 – Improved coordination between government departments and levels, and with employers and private insurance schemes**

Provision of financial assistance in Canada is currently characterized by inconsistent applications, administrative complexity and widespread confusion on the part of claimants. The current patchwork quilt of disability programs, assessment processes and administrative structures needs to be replaced with a better integrated scheme, which takes into account various forms of financial support programs on federal and provincial/territorial levels as well as private LTD insurance, and which harmonizes their operations. In Sweden, for example, the same government department administers short-term and long-term benefits.

In the 1990's, the Netherlands moved substantially away from public programs and toward privatized schemes for short-term financial security. Employers were assigned increased responsibility to provide employees with financial security during the first year of incapacity to work, along with increased emphasis on accident prevention and return-to-work policies. In turn, government offered incentives to workplaces for developing effective retention and reintegration policies and for retaining and hiring greater numbers of workers with disabilities, and it filled gaps that the private insurance sector did not cover.

**RECOMMENDATION**

**A clearer order of jurisdiction in responsibility for the provision of benefits needs to be established across various government levels (and with private insurance plans)**

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<sup>48</sup> Sources see Appendix C – Berkowitz; Burt Perrin; CAS & CWGHR; CMHA, Employment; CMHA, Position Paper; CWGHR, Early Intervention; OECD, Transforming; Prince; Proctor, Looking Beyond; Roher, Improving; Soc Dev Canada, Definitions; Torjman.

A more coherent multi-lateral strategy should be developed for federal, provincial and territorial programs of financial assistance to people with disabilities everywhere. Shared standards should apply to eligibility criteria, assessment procedures and appeal processes. Portability of one's personal information, eligibility status, and coverage must be more readily available for people who change their residence (and has already been successfully accomplished in the fields of education and health care). This requires inter-provincial agreements that could be facilitated by the federal level, in the same way that health insurance programs are portable and coordinated<sup>49</sup>.

**C3 – Clearer program information and local access to advocacy support**

Formidable information and paperwork challenges face people with disabilities who are trying to obtain, remain on, or return to financial assistance. They need access to comprehensive, understandable and accurate information regarding income maintenance programs, employability and related supports and potentially beneficial tax benefits.

**RECOMMENDATION**

**An array of local 'one-stop' sites to acquire user-friendly information should be made widely available**

Such local sites should provide user-friendly information along with in-person support and assistance, in a variety of languages and using an array of technologies, sufficiently comprehensive and transparent for all claimants whatever their backgrounds. Ready access to independent, trained advocates should be automatic during initial application and appeals processes.

In addition, disability advocates and community-based support groups need more substantial, in-depth information, as well as in-service training about financial assistance policy analysis, program development and evaluation, relevant background research, population characteristics and recent income support innovations – as part of an increased role for them in policy development and program implementation<sup>50</sup>.

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<sup>49</sup> Sources see Appendix C – Berkowitz; Burt Perrin; CAS, Force for Change; De Vos, Case Studies; CMHA, Position Paper; Torjman; Wellesley)

<sup>50</sup> Sources see Appendix C – BCPWA; CAS, Income security; CAS & CWGHR; CMHA, Position Paper; deBruyn, Plan of Action.

#### **C4 – Individualized case management with community agencies**

Direct, personal encouragement and ongoing, active links with the workplace during vocational rehabilitation are key to successful re-integration. Coherent and systematic case management delivered by trained professionals would be more effective for return-to-work and protection of clients' quality of life than the strategy most often used in Canada today – namely, bureaucratically disjointed administration of large caseloads by government departments, brief encounters by clients with health professionals, often followed by impersonal, high-tech medical interventions. The current situation reinforces the idea that 'something is wrong' with the disabled person.

People with disabilities are facing very difficult decisions: Whether to disclose a disability and to whom? Where to seek support? Whether to plan an absence from work? Whether to consider withdrawal from the labour market entirely, and if so, in what status and for how long? Eventually, whether to consider return-to-work? These are all crucial questions of which people with disabilities need to seek impartial advice, not judgment.

Australia and Germany have already taken steps toward active involvement by community partners, and the decentralized Ticket-to-Work program<sup>51</sup>. In the U.S. is another community-focused initiative based on a case-management model.

A proactive, holistic and individualized case-management approach would be more effective for financial planning, return-to-work and protection of quality of life than the current fragmented strategies typical of financial assistance programs on all government levels. The responsibilities of these two roles should only be combined if a case management system was set up to operate at arm's length from government authority – for example, under the direction of community-based disability groups. Otherwise such consolidation would concentrate too much information and influence into the same case management position, and could jeopardize the ability of disabled claimants to identify, clarify and pursue their personal interests.

Case-management should be delivered by staff who are well-trained in all the variations and implications of disabilities – including episodic disabilities. Standards of professional expertise for benefits counselling should be identified, and funding for pre- and in-service training should be

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<sup>51</sup> Zeitzer, Ilene, "Nothing About Without Us' – People with disabilities as managers of their own rehabilitation", presentation to International Forum on Disability Management, Maastricht, Netherlands, 2004.

provided. Physical, cognitive, affective and functional characteristics of claimants need to be taken into account by case-managers, along with the financial, employment and social contexts of claimants' lives, much more thoroughly and systematically than is currently the practice in most programs.

### RECOMMENDATION

**Case management needs to be holistic, addressing physical and psychological qualities of clients and their social contexts and personal relationships, as well as relevant characteristics of the workplace and the people who work there.**

To address choices of such complexity and personal significance with confidence and insight, clients must establish ongoing and stable contact with trained, well-informed and sensitive case managers. Trust needs to build in both directions.

Disability management<sup>52</sup> is an alternative model that emphasizes building disability infrastructures at worksites. This model places increased responsibility on employers for policy development and program planning to assist workers with disabilities to maintain financial security while they seek medical diagnosis and treatment, vocational rehabilitation and ways to retain jobs or return to work. Small and medium-sized workplaces often need outside assistance (financial and technical) to develop disability management strategies<sup>53</sup>.

### **C5 – Faster, clearer and more equitable appeal procedures**

In financial assistance programs available to disabled Canadians, decisions from the appeals process can carry extreme significance for the lives of claimants. The overall system, as currently structured, is doubly flawed. It deflects too many people from application to the appropriate assistance program in the first place, and it forces too many others into lengthy, confusing, costly and

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<sup>52</sup> International Forum on Disability Management (IFDM), "What is disability management?", "International survey of disability management practices", and "Regional strategies to achieve DM in small enterprises", online resources at IFDM website ([www.ifdm.nl](http://www.ifdm.nl)), 2004; European Foundation for the Improvement of Living and Working Conditions, Employment and Disability: Back to Work Strategies, Dublin, 2004, see especially Chapter 3, "New initiatives in retaining jobs and return to work"; Burt Perrin Associates, "Lessons Learned from Evaluation of Disability Policy and Programs", Human Resource Development Canada, Ottawa, 1999, Section B, "Disability Management and Return to Work".

<sup>53</sup> Sources see Appendix C – Anderson and Brown; Burt Perrin; CAS, Force for Change; CAS, Providing Benefits Counseling; Eur Found; Int Forum on Disability Management; Loisel; Parliamentary Library, Disability Support; OECD, Transforming; Proctor, Looking Beyond; Return, Between Work and Welfare; Return, Interim Report; Return, Policy Guidelines; Roehner, Improving; Torjman; Zeitzer; Weir.

unnecessary appeals that delay the eventual delivery of vital financial assistance. Some private insurance and provincial assistance programs require people to apply first to CPP-D, even though it is clear they would not qualify there. All this accomplishes is to transfer initial disability assessment to CPP-D auspices. It is not surprising that two-thirds of initial applicants to CPP-D are denied eligibility, and that nearly two-thirds of these do not apply for reconsideration.

Reforms are needed to make appeal adjudication more transparent, consistent and claimant-friendly. Procedures should be described and implemented in formats and language which are more easily understandable to people with disabilities of diverse cultural and educational backgrounds. In CPP-D, appeal backlogs and lengthy delays are common, as are personal reports of confusion and intimidation. Appropriate timeline standards should be established, published and implemented. Even when the case management process functions at an administrative distance from government departments, clients need ready access to outside advocates from disability organizations and other community-based groups, to assist them to clarify their own expectations and pursue their interests. Most people who appeal, accompanied by an advocate, win the appeal. Groups advocating for the needs and interests of people with disabilities should have a clear voice and strong presence in all appeal situations<sup>54</sup>.

### **C6 – Effective accountability and more substantial program evaluation**

Recent Canadian federal policy initiatives in the area of social integration for people with disabilities typically mention research and program evaluation as major objectives. Canada is not alone, however, among nations currently devoting limited time and resources on any level to the evaluation of strategies and programs that would increase the employability of workers with disabilities and improve their possibilities for successful rehabilitation, job-retention and return-to-work. This is especially true regarding the needs of people with episodic disabilities, whose particular circumstances and challenges have only recently begun to be appreciated by governments and many employers, although people with disabilities and community-based support groups have advocated on their behalf for decades.

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<sup>54</sup> Sources see Appendix C – CAS, Force for Change; CAS & CWGHR; CMHA, Position Paper; CWGHR; MS Society, MS & CPP-D.

Not enough is currently known about the comparative effectiveness of approaches and programs for financial assistance to people with disabilities in Canada. Few cost/effectiveness studies have been done, here or around the world, about various administrative and funding models, and about the relationship between providing benefits and encouraging return-to-work. People with disabilities and their advocacy groups currently receive insufficient support for involvement in planning and evaluation of such benefit programs.

### **RECOMMENDATION**

**Pilot projects need to be initiated, sufficiently funded and thoroughly evaluated, in order to investigate various models and methods of delivering financial assistance to people with disabilities.**

Programmatic research needs to be undertaken, for example, about:

- Effects of revised definitions of 'disability', based on a social model
- Techniques of application of eligibility standards, in the assessment process
- Outcomes from wider availability of partial benefits
- Program alternatives for delivering case management to claimants with disabilities.
- Models for better coordination of financial assistance across government levels
- Ways to establish faster outreach to workers with disabilities
- Methods to increase the roles of community-based disability organizations; and
- Strategies to improve the availability and transparency of information for potential claimants, as well as for employers and other stakeholders.

These pilot projects could ask key questions:

- What percent of people needing financial assistance are aware of it and actually getting it?
- What are their characteristics?
- Who are the people not getting the assistance they need?
- Which disabilities are better served, and which worse?
- How adequate and comprehensive is the assistance that is provided?
- How well is financial assistance integrated with employability and return-to-work?
- At what levels of training and expertise do program staff operate?

From analysis, valid and relevant conclusions could be reached upon which policy development depends:

- How do people with disabilities assess their own impairments and the effects on their employability?
- How does the employment rate of disabled adults compared to the rate for able-bodied adults?

- What percent of workers who become disabled actually accomplish return-to-work, and in what kinds of jobs (compared to their earlier employment)?
- Which factors encourage people with disabilities to attempt job-retention and return-to-work, and which factors inhibit such attempts?
- What percent of employers have been requested to undertake workplace accommodations, and what percent have actually done so?
- How many workplaces have established effective disability policies, and what are their characteristics?
- How often are such policies actually implemented?
- How are the experiences of people with episodic disabilities similar to, or different from, those of people with more permanent and stable impairments?

To stimulate *program development*, the effectiveness of innovative social integration strategies needs to be compared with the application of more traditional formats. Which kinds of case management and contexts for its delivery, for example, are most helpful to people with disabilities in the vocational rehabilitation process? How will the availability of partial benefits, the extension of work-trial periods or the increase of earnings limits affect rehabilitation outcomes? What are effective ways to provide and deliver appropriate assistance to self-directed business ventures run by people with disabilities? Do people with episodic disabilities require special program options to meet their particular needs, or do well-constructed integration programs function equally well for people with various kinds of impairments? In all cases, how do the economic costs and benefits of job-retention and return-to-work programs compare with the costs and benefits of providing financial assistance directly?

#### **RECOMMENDATION**

**On the workplace level, disability policies should be monitored on an ongoing basis, assessed regularly and revised when necessary.**

Attention should be given to the effects of policy implementation on workplace productivity and morale. To accomplish this kind of program support and effectiveness, responsibilities for policy implementation need to be allocated in clear and specific terms. The same is true for agencies and institutions that have been delegated particular responsibilities in the vocational rehabilitation process, including diagnosis, treatment, re-training and case-management<sup>55</sup>.

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<sup>55</sup> Sources see Appendix C – Austr HREOC, First submission; Burt Perrin; ICAD; Mental Health Foundation, Welfare to Work; Rocher, Improving; Return, Employers; Return, Policy Guidelines; Rocher, Policy; Soc Dev Canada, Multilateral.

## **D. Income Benefits**

### **D1 – Partial benefits**

Provision of partial benefits should be standard in all financial assistance programs at all levels for people with disabilities whose employability is significant but incomplete, and should function on a pro-rated basis relative to loss of earnings capacity.

#### **RECOMMENDATION**

Canadian programs, especially on the federal level, need to be more supportive of the many people with episodic disabilities who want to do part-time or periodic work.

Currently CPP-D provides no access to partial benefits; making partial benefits available would support many persons' rehabilitation and social inclusion. Appropriate disability supports that encourage employment (e.g., transportation, personal care, medications, etc.) should be maintained for claimants throughout the transition-to-work process, whether or not it proves successful on any particular attempt. Too many disabled Canadians still fight for access to supplementary supports.

It should be easier for people with disabilities to move in and out of re-employment programs. The earnings exemption in Canada should be increased. The length of time for trial work periods should be extended, permission granted for people with disabilities to hold part-time jobs, and partial benefits made more readily available, all without jeopardizing benefits – to provide sufficient time and opportunity for more adequate assessment of return-to-work possibilities. If re-integration fails or needs to be postponed, financial assistance should be immediately reinstated, without any delay for reassessment.

The reality is that most people with disabilities are on a continuum somewhere between total financial dependence and total independence, rather than existing at the all-or-nothing extremes of a dichotomy. A wide range of physical and mental conditions should be accepted as justifications for partial benefit claims. The fact that administration of partial benefit programs can sometimes be difficult and contentious does not contradict their importance and value. In countries with multiple levels of benefits for partial disability, one in three new awards is for partial benefits. Sweden, the Netherlands, Austria and Germany, for example, all make effective use of partial benefit schemes.

Current claw back provisions and earnings exemption rules for people with disabilities who attempt to re-establish ties to the workforce need to be substantially revised, so that they do not function as disincentives to finding, retaining or returning to work. A scaled approach should be established, whereby financial assistance declines as earnings increase. The current level of 'allowable earnings' under CPP-D (\$3900 yearly) is clearly insufficient, especially for people with episodic disabilities who can manage part-time or occasional employment on a regular basis.

Two additional schemes for encouraging employment should be considered:

- Top-up payments (to compensate for lower earnings from a lower-level job or reduced working hours after disability) and
- Wage subsidies (to employers as an incentive to hire or retain workers with disabilities).

Both are potentially effective; neither replaces the value of making partial benefits more widely available<sup>56</sup>.

## **D2 – Revised delivery of private LTD schemes**

The legal and administrative context within which private LTD insurance operates needs revision. Incentives should be established to extend the use of LTD policies to smaller workplaces (including self-directed businesses run by people with disabilities, individually or collectively), and to tap the potential advantages of group-based premiums for workers who are, or will, become disabled.

### **RECOMMENDATION**

**Private insurance coverage should be accessible to a greater variety of workplaces –for-profit and not-for-profit, corporate and cooperative.**

It should be more difficult for private insurers to disqualify applicants to LTD on the basis of particular disabilities or specific 'pre-existing conditions'. Quebec and the U.S. are examples of locations where private disability coverage is portable for workers with disabilities who already have it, and where 'pre-existing condition' clauses are less likely to prevent a disabled person from changing from one workplace to another.

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<sup>56</sup> (Sources see Appendix C – Bambra; BCPWA; Berkowitz; Burt Perrin; CMHA, Employment; CMHA, Position Paper; CWGHR, Early Intervention; deBruyn, Plan of Action; Dept of Work and Pensions, Disabled; MS Society, MS & CPP-D; Neufeldt & Albright; OECD, Transforming; Return, Interim Report; Roher, Improving; Soc Dev Canada, Advancing; Torjman)

Members of group plans should have ready access to the terms and conditions of their policies. Employers should be required to maintain the LTD coverage of employees on disability leave. Persons formerly on LTD should have a period of time (perhaps a year) to attempt return-to-work and, if unsuccessful, should be able to return immediately to LTD benefits without penalty.

The insurance industry has shown itself very able to develop a wide variety of financial products to address and cover an array of customer contexts and concerns. With appropriate direction, encouragement and assistance from government, it can make short- and long-term disability insurance more readily available to workplaces and individuals<sup>57</sup>.

## **E. Employment**

### **E1 – Workplace policy**

Because employment is central to the social integration of people with disabilities, active involvement by employers and workplaces is critical for the success of the entire process. Awareness has grown among disability experts around the world about the importance of workplace policies that address job retention and rehabilitation of workers with disabilities. Investigators have found that, when such policies exist, are implemented and regularly reviewed, they provide a useful structure for accommodation and rehabilitation, reduce negative attitudes and fears and help sustain workplace productivity. Such policies can generate an organizational culture which supports job retention and return-to-work by disabled employees, clarifies the importance of confidentiality and increases supervisor skills in disability issues.

However, various barriers prevent many Canadian employers from developing disability policies:

- Fears and stereotypes and those of their employees
- Insufficient understanding of disability issues and of the benefits of retaining or hiring workers with disabilities
- Inadequate expertise and information about accommodation and return-to-work strategies
- Perceived pressures from a competitive business environment, and
- Lack of familiarity and contact with relevant community-based agencies and services.

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<sup>57</sup> Sources see Appendix C – Anderson & Brown, Final Report; Austr HREOC, first submission; deBruyn, Plan of Action; Legal Network, Current Issues; Burt Perrin.

## RECOMMENDATION

**Workplace policies that address job retention and rehabilitation of workers with disabilities, should be implemented, reviewed and updated regularly.**

Research in the U.S. and the U.K. has found that costs of accommodation, along with related training and supervision, actually do not pose significant barriers. The most substantial workplace change, and also the most difficult to accomplish, is improvement in the attitudes of supervisors and fellow employees toward retaining or hiring workers with disabilities.

Emerging consensus among disability experts about workplace disability policy suggests that it should include the following ingredients:

- Statement of concern about workplace health and safety issues
- Acknowledgement of diversity among employees
- Reference to relevant legislation
- Prohibition of discrimination based on disability, along with indication of parity among disabilities
- Commitment to retain disabled employees whenever possible, assist their vocational rehabilitation and participate in plans for return-to-work
- Support for the principle of reasonable accommodation and for the removal of workplace barriers (explicit and implicit, physical and procedural)
- Identification of a significant role for the disabled employee in activating and implementing the policy
- Description of all aspects of work (including task assignments, work schedules, job security, benefits and retraining options) to which the policy applies
- Presentation of an action plan which outlines concrete steps to be taken when an employee becomes disabled and which clarifies responsibilities on the parts of management, supervisory staff, fellow workers and union locals (where appropriate)
- Provision for workplace education regarding the policy and its implications
- Protection of the confidentiality of private information; establishment of avenues for appeal
- Provision for regular policy review and revision, and
- Agreement to delegate sufficient funds to implement the policy.

Studies in the Netherlands have shown that, although companies typically generate informal approaches to accident prevention, occupational health and safety, absenteeism and disability among their employees, most workplace responses remain ad-hoc and unsystematic, and are not formally articulated as policies. In a survey of integration practices among small and medium-sized firms, not one had a specific policy about recruitment or retention of workers with disabilities. Firms gave the explanation that they anticipated high absenteeism among workers with disabilities and increased

workplace problems from their recruitment. Investigators, however, identified factors making it more likely for smaller firms to retain and recruit workers with disabilities:

- A facilitating role played by community-based agencies,
- Awareness of government-funded incentives
- Prior awareness training for management
- Active support by supervisors, and
- Sensitivity to corporate social image, especially in smaller communities.

In recent years more workplaces around the world, including many in Canada, have begun to develop policies which focus on hiring disabled applicants, retaining employees who become disabled and assisting their return-to-work. Not all address the social integration of workers with disabilities comprehensively, and most make no specific mention of episodic disabilities. Despite variations in workplace characteristics, policy formats and local community contexts, they show similar recognition of the significance of disability issues in employment and shared commitment to the social inclusion of workers with disabilities. Together they suggest directions in which more Canadian workplaces need to move, in order to support job retention and return-to-work. Some demonstrate that particular attention can be given to special challenges faced by people whose disabilities are episodic in nature.

In Germany, the Ford Corporation has begun a comprehensive initiative to prevent losing the expertise and experience of its workers with disabilities. This represents a shift away from its earlier view, generated in part by a government quota system, that disability is a workplace nuisance, toward the idea that re-integrating workers with disabilities into production makes good business sense. The Ford policy combines prevention and rehabilitation strategies. Ability profiles focus on disabled employees' abilities rather than on their limitations. In cases of disability, a multidisciplinary team (psychologists, health and rehabilitation professionals and job production specialists) is directed to implement rehabilitation plans, matching worker abilities to job requirements along several dimensions.

The Vancouver Island Health Authority has more than 16,000 employees and sixteen unions. A special division oversees disability issues, in which staff are trained in occupational health and safety, ergonomics, wellness and claims management. Early intervention is emphasized. When disabilities are disclosed during performance reviews or through self-disclosure at other times, employees contact their own physicians to diagnose the problems, complete an assessment and offer work-

related recommendations. A team of stakeholders is then convened including insurance carriers, unions, labour relations staff and management. The team considers job modifications and re-training possibilities. An external rehabilitation agency is consulted to plan return-to-work. Attention is also given to financial security and other necessary supports. However, after the six-month window for LTD coverage has passed, disabled employees sometimes report feeling 'tied' to this employer for the protection of ongoing financial security and other supports, because assistance is seldom portable.

MKB Benefits, a private insurance corporation in the Netherlands, provides insurance (sickness, absence and disability) for its membership of five hundred smaller firms. According to current Dutch law, employers are responsible for paying workers during the first two years of absence from work, and they must provide appropriate rehabilitation support during this period. (They are given financial incentives to do so, and they face sanctions if they fail to comply.) Employers are required by law to intervene early when disability is disclosed, but small businesses often do not have the expertise for such responsibility. A federal agency exists to assist employers, but its effects in this regard are currently mixed. MKB tries to fill the void, by using a panel of specialized service-providers for a full range of supports, including job placement for claimants who cannot return to their original jobs. The general approach is flexible and participative.

Since 1995, the Royal Bank of Canada has attempted to increase hiring and retention of employees with disabilities, using guidelines suggested by the federal Employment Equity Act. Stressing workplace accommodation and viewing it as a partnership between the corporation, management and employees, the RBC originally set up a disability advisory council to plan a two-year initiative and to establish a budget for accommodation and other expenses. An internal survey of employee disabilities was undertaken, along with in-service staff education. Contacts were established with community-based disability organizations. Eventually a disability action plan and operational guidelines were produced, along with the allocation of specific responsibilities for implementation and the clarification of a proactive process for internal communication.

Victoria University and Kangan Batman TAFE (Technical and Further Education), located in Victoria, Australia, have each developed policies to support students with episodic disabilities. Their definitions of disability mention episodic disabilities specifically and give examples. Areas for 'reasonable adjustment' are identified: class attendance, workload management, course delivery and

assessment. Medical certificates are not always needed to support students' claims. Individualized adjustment plans are suggested. Disability services staff are trained and made available for consultation, planning and referral.

In Ireland, a joint initiative of the Business and Employers Confederation and the Congress of Trade Unions focuses on workplace safety as well as the rehabilitation and re-integration of workers with disabilities. A voluntary code of practice has been generated, which can operate nationally and locally to assist injured employees to formulate individualized plans for return-to-work. In Ireland, the legislative context requires employees to take legal action against employers to gain financial compensation for disabling injuries. The voluntary code identifies a flowchart of steps toward rehabilitation and re-integration. In it, early contact is encouraged, along with appropriate medical intervention. The code recommends that long-term treatment should be funded by employers, without admission of liability.

Two particular disabilities have been especially fertile ground for the development of comprehensive workplace disability policies that acknowledge the realities of episodic disability: mental health and HIV/AIDS. Mental health problems are commonly episodic in nature. With the discovery and more widespread distribution of anti-retroviral medications, the same is now also true in wealthier countries for HIV/AIDS.

In the U.K., the Department for Environment, Food and Rural Affairs (DEFRA) has produced a guide for 'reasonable adjustment' to the special needs of departmental employees with mental health problems. The DEFRA policy acknowledges that the Disability Discrimination Act requires 'reasonable adjustment' in the event of any 'long-term' disability which is 'recognized by a respected body of medical opinion'. Employees are encouraged to contact line managers, talk privately to a member of the workplace 'disability team' and fill out a confidential disability questionnaire, so that workplace adjustments can be considered. Examples of 'reasonable adjustments' are listed:

- Rearrangement of job responsibilities to increase flexibility
- Permission for healthcare professionals to attend adjustment planning meetings
- Restructured workspace
- Permission to work at home, and
- Consideration of side-effects of medications and time-outs for medical appointments.

Overall, it is management's responsibility to develop increased awareness of mental health issues among staff.

The policy of one frozen food manufacturer in the U.K. encourages rehabilitation and re-integration of employees who have been absent because of work-related stress. It emphasizes increased staff awareness of the importance of return-to-work and rehabilitation for employees with mental health problems, early intervention, professional diagnosis, reasonable work adjustments and support for appropriate interventions including psychotherapy delivered either inside and outside the workplace.

The Ottawa-based Inter-agency Coalition for AIDS and Development (ICAD) has produced a template for disability policy<sup>58</sup> which could well serve as a model for other workplaces, public and private, especially with reference to episodic disabilities. The title of the policy, itself, refers to 'life-threatening, chronic and episodic disability'. Reference is made to relevant Canadian legislation, as well as to international human rights documents. The policy mandates staff training and broader workplace education to increase employee awareness of the nature of episodic and other disabilities. It acknowledges the employer's duty to accommodate in a wide array of workplace practices and contexts. It affirms that 'staff with a life threatening or chronic illness will continue in employment as long as they are medically fit for available, appropriate work.' Specific employee rights and corresponding employer obligations are listed, along with encouragement for employees to contact appropriate community-based agencies when necessary. Confidentiality is protected.

In South Africa, the multi-national mining corporation, Anglo American plc, has produced an HIV/AIDS policy which is based on non-discrimination, consultation and the full participation of all stakeholders. Its major goals are to eliminate stigma and discrimination based on this disease, protect confidentiality, ensure gender equality and encourage social dialogue between management, employees, PHAs, unions and government. The policy mandates that job applicants should not be specially tested for HIV infection, and that HIV status is not a permitted basis for decisions about hiring or about maintaining employment. PHAs can continue to work until medically unfit to do so. The company's group retirement policy includes ill-health applications irrespective of cause, and

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<sup>58</sup> Interagency Coalition on AIDS and Development (ICAD), "Development of a Workplace Policy for Life Threatening or Chronic Illness", "Fact Sheet 1: Life threatening, Chronic and/or Episodic Disability & HIV/AIDS in the Workplace – Benchmarking Organizational Policy Development and Implementation", and "Fact Sheet 2: A Rights Based Approach to Workplace Policy Development – Employment Related Challenges: Discussions and Decisions...Are you Prepared?", Ottawa, 2004-5.

PHAs are entitled to the same sick leave, pension, disability and medical benefits as all other employees. HIV prevention strategies are indicated, including voluntary counseling and testing, early intervention, care and support. The policy is intended to be reviewed regularly and revised as necessary.

The approach of the International Labour Organization (ILO) to workplace disability policy in the area of HIV/AIDS is based on principles of non-discrimination, gender equality, healthy work environment, social dialogue, confidentiality and continuation of employment. Based on its Code of Practice regarding HIV/AIDS, the ILO policy stresses parity across disabilities for all workplace policies and employee benefits, an open and supportive workplace environment, reasonable accommodation when requested by disabled employees, protection of job security, state guarantee of financial security, education to increase awareness by co-workers, access to various kinds of counselling inside and outside the workplace, active input by community-based groups and provision of financial support or re-training for people who lose employment.

These examples of successful employment initiatives are by no means representative of the numerous disability policies produced by workplaces of all kinds, in Canada and elsewhere. They reflect the variety of job retention and return-to-work formats presented in the much larger sample of initiatives located during the preparation of this report. It is therefore possible to highlight from these examples the kinds of steps already being taken, as well as some areas where additional work still remains to be done.

With some notable exceptions many employers – like most government disability programs – still rely heavily on a medical model to define and assess disability, even though work is itself such a context-dependent reality. It remains easier for most employers to visualize long-term disability as a permanent condition, than for them to recognize how often it can be episodic in nature. This limits the likelihood that employers will generate workplace policies and programs to address the special challenges and interests of people with episodic disabilities – especially without being assisted, encouraged or mandated to do so. Regarding the problem of ongoing financial security for disabled employees, employers typically have little reason or inclination to play an active role in providing solutions beyond private LTD policies they might decide to purchase, except in those few countries (like the Netherlands, in recent years) where legislation has assigned them greater responsibility. Neither are they likely to consider it their concern whether such LTD policies are portable to other

workplaces, thus making it more likely for their disabled employees to feel limited in re-integration planning.

Canadian research<sup>59</sup> indicates that an employer's willingness to retain and assist disabled employees will reduce the duration and cost of their rehabilitation. A number of incentives can encourage employers to be proactive in this regard:

- Awareness of financial support from government
- Perception of economic benefits from retaining the skills and experiences of existing employees who have become disabled
- Easier access to disability management expertise
- Genuine concern for corporate reputation and morale
- Fulfilment of legal obligations; and
- Considered response to leadership from government as well as from business and professional associations.

Whether workplaces are large or small, local, regional or multi-national in scope, public or private in auspices, profit-oriented or non-profit, they can move from informal and ad-hoc reactions to individual workers' disabilities towards the development of formal disability policies for all employees. Employers are able to recognize the importance of work for the social integration process of people with disabilities, and thus the potential significance of active workplace involvement in its accomplishment. They can appreciate that job retention and return-to-work programs for existing employees can produce demonstrable benefits for their own workplaces as well as for their workers with disabilities, including values relating to sound business practice, competitiveness and sustained workforce productivity. They can move attention from what their workers with disabilities cannot do, to what they can do well. They understand that re-integration is a complicated process, and that planning often works best in teamwork and partnership formats. They can begin to see the need for early intervention and ways to accomplish it. They can commit to protection of worker confidentiality. They can respond well to relevant information and expertise provided by outside agencies and consultants, especially when it is easily accessible and readily applicable. Finally they can become prepared to make effective use of financial incentives from government to support workplace accommodation.

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<sup>59</sup> Loisel, Patrick et al, "Disability Prevention – New paradigm for the management of occupational back pain", Disease Management and Health Outcomes, No. 7, 2001.

## **E2 – Incentives**

For large numbers of employers to subscribe readily to the idea of a 'duty to accommodate', especially in small and medium-sized workplaces, federal, provincial and territorial governments need to provide an array of financial incentives for them to do so, as well as information and technical support. When this is done, legislation can be extended to apply to smaller workplaces.

### **RECOMMENDATION**

**Federal, provincial and territorial governments need to provide an array of financial incentives as well as information and technical support to encourage employers to subscribe readily to the idea of a 'duty to accommodate'.**

Europe has established a considerable variety of incentives for employers to be active in return-to-work programming. In the U.K., for example, the Disability Rights Commission Act (2004) provides incentives to employers with fewer than 15 employees. Incentives in Germany are delivered through a quota system. The Netherlands has been more successful in providing incentives outside a quota context. As well, many Dutch laws directed at the social integration of people with disabilities are designed as financial incentives for employers to retain disabled employees, by compensating for accommodation expenses and sick-leave costs. However, Dutch businesses (especially small and medium-sized) actually make little use of these measures.

The Ticket-to-Work program<sup>60</sup> in the U.S. is a federally funded pilot-project intended to enable workers with disabilities to decide which community-based agencies to approach for comprehensive rehabilitation planning and assistance. The beneficiary receives a voucher and can decide how, when and where to use it. Service-providers get paid when clients are successful in generating employment income greater than the basic level of government-based financial support to which they would otherwise be entitled. The goal of the 'Projects with Industry' program in the U.S. is to provide financial incentives to employers in order to encourage them to partner with unions and rehabilitation agencies in the delivery of supportive services and in workplace training to employees with disabilities.

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<sup>60</sup> Zeitzer, Ilene, "Nothing About Without Us' – People with disabilities as managers of their own rehabilitation", presentation to International Forum on Disability Management, Maastricht, Netherlands, 2004.

In Australia, the rate of development of workplace accommodation action plans has been highest among local governments and universities, but low for most other kinds of workplaces, including private businesses (large and small).

Employers typically prefer subsidies to quotas. Subsidies work best for people who are difficult to employ, but they can generate stigma, resentment, displacement of other workers and disproportionate access to low-wage, low-skill jobs. Investigations in Australia have found no evidence that quota systems work effectively for the employment of people with disabilities, including return-to-work for people with episodic disabilities. Canadian research has found mixed effectiveness for wage subsidy incentives to employers to hire or retain disabled employees. Subsidies work best when coordinated with other forms of employer support, such as tax exemptions for workplace accommodations, assisted access to community-based expertise about accommodation and return-to-work, and grants to retain, hire or retrain disabled employees<sup>61</sup>.

### **E3 – Vocational Rehabilitation**

In many nations around the world, the average per capita cost of vocational rehabilitation is low compared to the cost of providing disability benefits<sup>62</sup>. Vocational rehabilitation attempts to address several issues:

- The client's physical and emotional health
- Availability of personal support networks
- Likelihood of experiencing prejudice and discrimination at work and elsewhere
- Ability to cope with job changes and workplace relocation
- Risk of job-loss when attempting return-to-work, and
- ongoing protection of income security.

Key issues must be addressed during vocational rehabilitation planning: Has the client been placed at the centre of the process? Does the program provide gradual transition to work? Can the client access relevant support services? What plans are in place to protect financial security, especially if

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<sup>61</sup> Sources see Appendix C – Austr Dept, JobAble; Austr HREOC, first submission; Austr HREOC, Second Submission; Baanders et al; Bamba; Bruyere; Burt Perrin; Canadian HIV/AIDS Legal Network, Employment; Canadian HIV/AIDS Legal Network, Examples; CAS & CWGHR; Canadian Human Rights Comm; CAS, Guide; de Vos, Case Studies; Disability Rights Commission, UK; Disability Unit, Disability; Eur Found; Eur Indus Relations Observatory; ICAD; Int Forum on Disability Management, Disability; Manitoba Human Rights; OECD; Parliamentary Library, Disability Support; Return, Between Work and Welfare; Return, Policy Guidelines; Rocher, Improving; Rocher, Policy; Soc Dev Canada, Multilateral; Zeitzer.

<sup>62</sup> Organization for Economic Cooperation and Development (OECD), Transforming Disability into Ability, Paris, 2003, "Summarizing the findings of the integration policy analysis", p. 122

return-to-work is unsuccessful? Are service-providers in effective contact with each other? Are all stakeholders familiar with the special needs and circumstances of people with episodic disabilities?

The Netherlands is one nation where comparatively greater emphasis has been placed on the idea that community-based groups and agencies should have a prominent role in the re-integration process. For example, RCW is a Dutch reintegration agency set up jointly by employers and employees within the transport sector. Its goal is to support disabled employees and employers in job-retention and return to work initiatives. RCW focuses on three aspects of re-integration: medical, workplace and private life. Contacts are established with outside agencies, and case-managers are provided to facilitate workplace consultation and planning. Positive Approach is another independent Dutch agency, run by and for persons with HIV/AIDS. Its major goal is return-to-work for people living with HIV/AIDS. It provides information and training for employers, unions and rehabilitation professionals, and tries to combat workplace prejudice and discrimination.

In Vancouver Canada, North Island College is a unionized workplace with 400 employees. The Director of Human Resources originally brought to her position considerable prior experience in integration issues and disability management. She helped the school to realize that its investment in the development of its employees' skills and expertise required the development of a disability policy which emphasized job-retention and return-to-work for disabled employees. Human resource staff now attempt to involve insurance providers, medical experts, community rehabilitation consultants, ergonomic specialists and union representatives in the implementation of workers with disabilities' rehabilitation plans. Specific attention is given to protection of insurance benefits and pensions.

Although Thrifty Foods in British Columbia has no formal disability hiring policy, an informal workplace culture of support for employees with problems has emerged over the years. When an employee becomes disabled, a team is put together to devise a plan for return-to-work. The team consists of the employee, the disability manager, insurance company representatives, medical experts and community-based rehabilitation professionals. Steps are currently underway for earlier initiation of the rehabilitation and return-to-work process.

## RECOMMENDATION

**To make the varied kinds of re-integration assistance viable, increased encouragement for multi-sectoral partnerships is essential at the community level.**

Vocational rehabilitation should routinely include work-experience components. It is especially important that the client's original workplace provides opportunities for people with disabilities to gradually re-integrate themselves into job demands, routines and schedules. More needs to be done to extend employer cooperation, along with community-based rehabilitation and job counselling agencies, primary care physicians, labour unions and the private insurance industry. This, however, will require governmental policy frameworks and program strategies which mandate greater stakeholder involvement, and which give service-providers sufficient access to information, training, financial resources and other incentives to make it happen<sup>63</sup>.

### **E4 – Self-directed employment**

One potentially valuable format for the employment of people with episodic disabilities is self-directed business. This includes individually run enterprises, small firms, worker cooperatives, subsidiaries of organizations of people with disabilities and partnerships with other businesses. The type of enterprise may vary, depending on local and regional market forces and other circumstances. When they are staffed and run by people with disabilities, such self-directed businesses are likely to demonstrate increased awareness of, and sensitivity to, the special accommodation needs of workers with an array of impairments, including those that are episodic in nature.

Self-directed business in a partnership or cooperative context is based on four foundations:

- Identity or self-concept which attracts participants and encourages sufficient solidarity for them to work together
- The right 'know how' (technical and business skills)
- Accessible and appropriate resources (advice and training, financial assistance, marketing networks, subcontracts), and
- An enabling social context (disability laws which prohibit discrimination, community development initiatives).

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<sup>63</sup> (Sources see Appendix C – Bambra; Boyce; Brands; CAS, Force for Change; CAS, Providing Benefits Counseling; CAS & CWGHR; deBruyn, Plan of Action; Eur Found; Int Forum on Disab Management; Loisel; Mental Health Foundation, Welfare to work; OECD; Roher, Improving; Torjman; U.S. Dept of Health and Human Services, Research; WCG; Wellesley)

## RECOMMENDATION

**Income and other disability supports should be available without penalty to people with disabilities who decide to pursue self-directed employment and business development.**

Key elements facilitate emergence of this kind of enterprise: awareness-raising activities, community development processes, provision of appropriate training and access to business, financial and material resources.

A recent global study<sup>64</sup> found that people with disabilities, individually or in groups, undertake self-directed business for several reasons. In low-income countries, it can be chosen for social reasons (other people with disabilities already do it), economic reasons (a way to earn a living) or because it generates a more favourable working context than many salaried workplaces (less discrimination, greater accessibility and accommodation). In high-income countries, people with disabilities choose this employment option to avoid discriminatory attitudes and practices, compensate for inability to secure wage employment elsewhere, gain the self-satisfaction of being one's own boss and achieve a more flexible and accommodating work schedule. Self-directed businesses are successful when they enable people with disabilities to generate meaningful income (without penalty regarding financial benefits and other supports), when they can achieve stability (at least two years of operation), when they hire significant numbers of workers with disabilities and when they generate economically viable businesses with innovative.

With some exceptions, people with disabilities and their organizations in Canada have been hesitant to consider this option – perhaps because of a lack of awareness of its possibilities, perceived risk of losing personal income support when it is undertaken, or the lack of genuine encouragement from disability policies and programs of governments at all levels. Worldwide analysis has shown that one major factor for success in pursuit of self-directed employment by people with disabilities is maintenance of financial assistance during the business development process<sup>65</sup>.

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<sup>64</sup> Neufeldt, Aldred and Albright, Alison, *Disability and Self-directed Employment: Business Development Models*, Toronto: Captus Press and Ottawa: International Development Research Centre, 1998, pp. 279-80.

<sup>65</sup> Sources see Appendix C – Anglo American plc; Austr HREOC, *Disability Rights*; Austr HREOC, *First submission*; Brands, *Positive Approach*; Bruyere; deBruyn, *Plan of Action*; Caledon, *Abled Initiative*; Caledon, *RBC Financial Group*; Can Human Rights; CAS Guide; CMHA, *Employment*; DEFRA, *Guide*; de Vos, *Case Studies*; Eur Foundation; Govt du Quebec; Int Forum on Disability Management, *Disability Management*; ICAD; ILO Manual;

## F. Integration Strategies

### **F1 – Effective integration of financial assistance with employment initiatives and vocational rehabilitation**

Investigators have found that employment – including job retention and return-to-work for people already employed when impairments occur – should be viewed as the major focus of a continuum of care for most people with disabilities. When they have access to vocational rehabilitation, related counselling and job search assistance, disability supports, appropriate education and training and protection of financial security during the re-integration process goals of job retention and return-to-work can be more readily accomplished, and the employment gap with able-bodied people can be significantly narrowed. People with sufficient financial security to attempt to retain or return to current jobs or to seek new ones are more likely to improve their earnings and thereby reduce their long-term dependence on benefits.

#### **RECOMMENDATION**

**Support programs in Canada should provide financial security to people with disabilities who have recovered sufficiently to consider and attempt return-to-work.**

Too often in Canada and elsewhere, barriers prevent such holistic programming from occurring. Workers with disabilities – especially people with episodic disabilities whose circumstances do not fit conveniently into existing program categories – cannot always locate effective and appropriate counselling. Many prefer to consult community-based rehabilitation services rather than government agencies, a fact confirmed by increases in demand for the services of disability organizations even as they experience decreases in government funding. Opportunities for re-training can be restricted by cost, physical inaccessibility, restrictive eligibility requirements, lack of awareness and poor coordination with income supports. Blurred and inconsistent lines of responsibility between various financial assistance schemes contribute to lower employment rates for people with disabilities and high benefit dependence. Older workers with disabilities are especially inhibited in this way from participation in work, because of the more limited job market they often face. Existing financial incentives and information resources are often insufficient for employers too, discouraging them from taking a more active and effective role in planning for job retention and return-to-work, in partnership with their disabled employees.

Employment planning needs to be an early and essential ingredient in the operation of all income support programs. However, it should never be operated as one form of claims control, jeopardizing potential financial support. In the U.S., the Early Intervention program (under Social Security Disability Insurance) allows claimants to seek work and still collect benefits, by providing temporary financial assistance to people with disabilities attempting to return to their jobs. In Germany, the clear emphasis is on reintegration into the workforce, even as financial benefits are used to support an appropriate standard of living. The U.K. has established an array of financial support programs (Disability Working Allowance, Disability Living Allowance, Working Tax Credit, Travel-to-work Grants, Jobseeker's Allowance) that are integrated with employability and return-to-work initiatives.

Canada is the only country with a 'fast-track' reapplication process, for repeated access to federal disability pension benefits when return-to-work attempts do not succeed. (The U.K., Sweden and Denmark have similar, although less substantial, initiatives.) The current fast-track process in CPP-D, however, does not guarantee reinstatement for claimants, and it can actually take months to accomplish.

**RECOMMENDATION**

**Reinstatement of benefits for people with episodic disability  
should be guaranteed and immediate.**

Studies in Australia have identified effective ways to integrate financial and employability assistance. An essential step is the removal of disincentives to participation in vocational rehabilitation. As is currently the case in Germany and Sweden, financial assistance programs must establish early, proactive contact with workers with disabilities, and individualized, flexible formats must be available for the provision of income support. Where related programs exist simultaneously on several levels of government, their operations must be effectively coordinated. People with disabilities and employers each need to be given more prominent and active roles and responsibilities in the return-to-work process, as well as sufficient information about the importance of return-to-work and the steps required to accomplish it.

Studies in the U.K. have shown that the availability of a continuum of options increases favourable re-integration outcomes for people with mental health problems and other episodic disabilities. Effective employability programs are based on communication among local stakeholders, adequate funding, built-in flexibility and procedures that support the kind of sound business practices which employers understand and appreciate.

Overall, the number of people with disabilities in Canada who are not currently working, but can work and would like to do so, depends on two factors: procedures in the operation of financial assistance programs and the nature of workplace circumstances. The negative interaction of these two factors can effectively 'disable' someone from working. When people develop impairments that prevent them from continuing their employment, often on a temporary or episodic basis, their first attempts at return-to-work will not always be successful or permanent. Disability management needs to be ongoing, while financial assistance remains continuously available.

## SUMMARY OF RECOMMENDATIONS

### A. Definitional/Conceptual Changes

- A broad and inclusive common definition of disability needs to be established in Canada across diverse government programs of assistance (financial, social, legal, etc.).
- Widespread restrictions based on the use of two key terms, 'severe' and 'prolonged', need to be revised, to permit increased access to financial assistance by people experiencing episodic disabilities.
- Eligibility criteria should be framed as continua, on a broad range of factors rather than as simple dichotomies in the permanence of medical conditions.

### B. Policy/Legal Changes

- A policy goal of “employable, if and when able” should be explored.
- Available funds could be spent more efficiently if administrative complexity was reduced, integration across programs were increased and costs were shared more widely.
- Financial assistance that provides a reliable and adequate level of income security should be readily available throughout the entire disability experience.
- Legislation should oblige employers and other employees to be aware of their duty to accommodate, within reasonable limits, to the needs of employees with episodic disabilities.

### C. Administration

- Financial assistance programs in Canada should be more proactive, providing for earlier and faster eligibility assessment (and appeals).
- A clearer order of jurisdiction in responsibility for the provision of benefits needs to be established across various government levels (and with private insurance plans)
- An array of local 'one-stop' sites to acquire user-friendly information should be made widely available
- Case management needs to be holistic, addressing physical and psychological qualities of clients and their social contexts and personal relationships, as well as relevant characteristics of the workplace and the people who work there.
- Faster and more efficient appeal procedures should be available to applicants who are denied or disqualified from benefits.

- Pilot projects need to be initiated, sufficiently funded and thoroughly evaluated, in order to investigate various models and methods of delivering financial assistance to people with disabilities.
- On the workplace level, disability policies should be monitored on an ongoing basis, assessed regularly and revised when necessary.

#### **D. Income Benefits**

- Canadian programs, especially on the federal level, need to be more supportive of the many people with episodic disabilities who want to do part-time or periodic work.
- Private insurance coverage should be accessible to a greater variety of workplaces –for-profit and not-for-profit, corporate and cooperative.

#### **E. Employment**

- Workplace policies that address job retention and rehabilitation of workers with disabilities, should be implemented, reviewed and updated regularly.
- Federal, provincial and territorial governments need to provide an array of financial incentives as well as information and technical support to encourage employers to subscribe readily to the idea of a 'duty to accommodate'.
- To make the varied kinds of re-integration assistance viable, increased encouragement for multi-sectoral partnerships is essential at the community level.
- Income and other disability supports should be available without penalty to people with disabilities who decide to pursue self-directed employment and business development.

#### **F. Integration Strategies**

- Support programs in Canada should provide financial security to people with disabilities who have recovered sufficiently to consider and attempt return-to-work.
- Reinstatement of benefits for people with episodic disability should be guaranteed and immediate.

## **UNRESOLVED ISSUES IN PLANNING POLICY INITIATIVES FOR EPISODIC DISABILITIES**

These new directions and recommendations on improving the income-employment situation of those with episodic disabilities are intentionally forward looking. They illustrate the very broad scope of the problem and the need for coordinated action. The fact that numerous countries are attempting to integrate this group into general income and support programs and specific disability initiatives, makes an important point.

However, there are also four concerns that do not seem to be covered in the literature on episodic disabilities, and will need to be addressed in such a project. These concerns are addressed below:

### **Philosophy and Policy Principles**

CW/GHR needs to decide the degree to which it proceeds with:

- a) Individual pilot projects that test various program options outlined in the earlier chapters,  
AND
- b) Its participation and advocacy within larger policy environments for improving social security in Canadian society.
- c) It is likely that both are necessary, but they need to be balanced if quick action for those with episodic disabilities is to occur, at the same time as fostering necessary public support for more comprehensive changes in the labour market. Definitional issues, eligibility criteria and assessment procedures would vary considerably in these different policy strategies.

### **Resources and Stakeholders**

Fundamentally, domestic social support programmes involve a transfer of resources between economic stakeholders, at least in the short term. Tensions often arise in this transfer when the units involved become larger than the family, or occasionally the neighbourhood, which may have an appreciation for individual disadvantage and the benefit to all of a positive income and work environment. The challenge of resource generation for policy development in episodic disability is to personalize the problem of 'intermittent dependence' so that it has familiarity for other taxpayers. At the same time, there is a need to address the issue of work productivity for employers. A balance needs to be found between the personal and social good achieved by an individual's participation at work and the economic good achieved for the business. If these issues are addressed, resource generation and social support from other Canadian stakeholders may be more forthcoming.

### **Implementation Concerns in an Inclusive Approach**

Implementation and case management issues tend to decrease when a social support programme is generic and addresses broad populations under easily recognizable conditions. The field of episodic disabilities faces a unique challenge in this regard. As the term ‘disability’ becomes more inclusive of various chronic illnesses (including HIV/AIDS), developmental conditions and mental states, it becomes increasingly difficult to utilize a unique medical definition for eligibility purposes or to implement specific assessment procedures for identifying the need for assistance. This is probably a good thing, and may lead to quicker adoption of a social definition of disability, although it also creates difficulties in defining the assessment skills of those empowered to make decisions.

Furthermore, with respect to identifying needs for support in the current work environment, how should one measure job insecurity in a time of massive changes in the workplace, especially for those with episodic disability? Besides the obvious objective measures of reduced employment and income, there are also more subjective, but still useful measures of insecurity – the likelihood of becoming more functionally disabled; the likelihood of losing one’s job in a particular type of business; the likelihood of finding another job in a particular labour market; the value of the current job; and the value of the future job, or period of unemployment. The more inclusive the social support program becomes to all disabilities, the more pressure there will be to answer these questions.

### **Integration of Income and Employment Supports in Episodic Disability**

There is considerable unanimity on the issue of whether to integrate, or provide a continuum for, employment with fair pay and financial assistance without employment. This balance is increasingly accepted in many general programs on disability support. Since episodic disability is a situation of repeated time periods with reduced functional abilities, the issue, technically, is one of frequency and length of this problem. This situation is likely to be highly variable across individuals, although predictable to a certain degree according to diagnosis, severity, age and secondary problems. The management issue for social support programs is how to balance the individual’s episodic needs with the administrative input required to assess and to maintain the continuum of supports that are required. There is a need for standards of a ‘minimum length’ (at least  $xx$  days) and ‘maximum frequency’ (not more than  $yy$  times per year) of reduced function if cases are to be handled with efficiency by a support system. These standards may vary across provincial jurisdictions, as well as across business types, depending on availability of administrative resources.