



A recommendation to address Episodic Disabilities in Canada Contribution to the Pre-Budget Consultations – August 14 2009

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RECOMMENDATION

In order to address current barriers and promote the financial independence and social inclusion of people living with “lifelong episodic disabilities”,¹ it is necessary to research, identify and develop policies and programs that promote overall coordination and governance among disability support programs, create incentives and reduce barriers for increased labour force participation for people with episodic disabilities.

Steps towards this end would include the federal government hosting a national policy dialogue² to explore, among many topics:

1. The financial implications of increasing coordination among the eight disability support programs and five service areas³ to include options for people with episodic disabilities within disability benefit programs.
2. Developing a program or combination of programs that provides partial disability income support to complement earned income from part time work for people who are living with lifelong episodic disabilities and who have a partial capacity to work. Workers with partial capacity to work should be supported to find employment and enter or remain in the workforce.
3. The option of changing disability income support programs such as the Employment Insurance (EI) sickness program [and other relevant disability income support programs] to a different kind of “unit” system. E.g. A “unit” system that would allow people to work part time and/or intermittently and receive partial sickness benefits for up to 150 half-days as needed, instead of the current 15 consecutive weeks or 75 full-days. This would encourage people to remain attached to the work force by working part-time or intermittently when their health permits while receiving part-time benefits.

The interjurisdictional complexities of these issues require the participation of all sectors to promote a comprehensive and coordinated approach to income security and labour force participation for persons with episodic disabilities. This will result in financial and social advantages, both for Canadians living with episodic disabilities as well as for Canadian society as a whole.

¹ Episodic disabilities are lifelong and chronic conditions such as HIV, multiple sclerosis, lupus, arthritis, cancer, diabetes, mental and mood disorders. People living with episodic disabilities may experience periods of good health that may be unpredictably interrupted by periods of illness or disability. Resulting consequences can force people out of the labour force without warning for indeterminate lengths of time. This in turn, can have significant impacts on health and income stability.

² A dialogue on existing Canadian programs in an employment context would serve to especially highlight the particular issues faced by persons with episodic disabilities.

³ The Eight (8) Income Programs are Canada Pension Plan disability (CPP-D), Employment Insurance Sickness (EI sickness), Veterans’ Benefits for Disability, Disability Tax Credits, Personal/Family Resources Registered Disability Savings Plan (RDSP) (calling this a program for purposes of discussion); Provincial social assistance for disability, Workers’ Compensation, Employers’ Long Term Income Protection (LTIP). The 5 services areas are: Disability Supports, Caregiver supports, Employment and Training, Social Services and Medical Services.

EXECUTIVE SUMMARY

Despite a global shift towards labour market integration and inclusivity, the number of people with disabilities returning to work remains low.⁴ Approximately one million working age Canadians with disabilities are either unemployed or out of the labour force (Dunn, 2006). There are a number of barriers that inhibit the full integration of people living with disabilities in society such as employment and income support challenges. These barriers are further exacerbated during the current economic crisis as people with disabilities have to compete for jobs with the increasing numbers of unemployed.⁴

Among people with disabilities, people with lifelong episodic disabilities¹ with a partial capacity to work, may face even greater barriers to employment and income support notwithstanding having a partial capacity to work. Canadians with episodic disabilities have varying capacities to contribute to the Canadian economy. Many want to work to their capacity to complement disability income support when they cannot work.⁵ However, current policies and legislation are disincentives to labour force participation for people with disabilities who can participate in the labour force intermittently or part time when their health permits.

For example, most income support programs are designed for people with disabilities who need to fully disengage from the labour force. Some programs insure against having a disability, meaning they don't pay when the disability is not there (i.e. Asymptomatic). This is what happens most often to persons with episodic disabilities who are particularly vulnerable to income security programs that 'compensate the disability' and not the person – what they pay is based on “the biography of the disability”. This type of compensation program may address needs of people with more permanent and predictable lifelong disabilities than people with lifelong and often unpredictable disabilities that go through various degrees and episodes of illness. Creative solutions are needed in order to accommodate the person with the episodic disability and not only the disability itself, and help retain existing workers with episodic disabilities who otherwise prematurely exit the labour force in order to qualify for and access required disability supports.

Research and consultations by **The Canadian Working Group on HIV and Rehabilitation**⁶ (CWGHR), the Government of Canada and others, have identified a policy gap related to income and employment for people with lifelong, episodic disabilities and have resulted in the development of recommendations for strategies to address these disincentives. To address these gaps, it is important to convene key stakeholders to discuss the long term future of disability income and service programs in the new economy, including programs and policies that affect people with episodic disabilities.

THE ISSUE

In 2006, approximately 4.4 million Canadians living in households reported having an activity limitation. This translates to a disability rate of 14.3%.⁷ “Having a job is fundamental to social inclusion and integration, but employment opportunities of people with health problems or disability are limited”.⁸ On average across countries within the Organization for Economic Cooperation and Development (OECD), employment rates of people with disabilities are just above 40% which is just over half of the rate for people without disability, which stood close to 75% in the mid-2000s.⁸ People with disabilities have limited employment opportunities and income and are among the poorest of poor. In Canada, approximately one million working age Canadians with disabilities are either unemployed or out of the labour force (Dunn, 2006). More than 55% of adults with disabilities live below the low income cut-off as compared to 19% of adults without disabilities (Bach, 2003). The majority of adults with disabilities have incomes below \$15,000 per year (Bach, 2003). The profound poverty of people with disabilities has been found to be both a cause and consequence of exclusion from social, economic and political life. (Bach et al, 2003) Disability income programs are critical supports for people living with disabilities. Government, private

⁴ OECD (2009), *Sickness, Disability and Work: Addressing Policy Challenges in OECD Countries*. High-Level Forum, Stockholm, 14-15 May 2009.

⁵ Anderson, Joan & Glen Brown *HIV & Disability Insurance in Canada: An Environmental Scan*. CWGHR 2005

⁶ The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national charitable organization whose mandate is to bridge the worlds of HIV, disability and rehabilitation

⁷ See Statistics Canada, *2006 Participation and Activity Limitation Survey: Analytical Report: Prevalence of Disability in Canada in 2006*: <http://www.statcan.ca/english/freepub/89-628-XIE/2007002/prevalence-en.htm>

⁸ OECD (2009), *Sickness, Disability and Work: Keeping on Track in the Economic Downturn*, Background Paper. High-Level Forum, Stockholm, 14-15 May 2009. Pg.11

and quasi government bodies spent approximately \$26 billion dollars in direct income support benefits^{9,10} to individuals with disabilities without any comprehensive oversight respecting what the programs do as a whole or purport to achieve for Canadians with disabilities.¹¹

By design, some income programs interact well, some poorly, creating major income inequities. Disability services associated with income programs are often cancelled when income programs offset each other. In this program environment, it is extremely difficult to forge a comprehensive disability income program as the programs are oriented very differently and run in isolation without any overall governance.

Among people with disabilities, people with lifelong, episodic disabilities may face even greater barriers to employment and income support while having a partial capacity to work. People with lifelong episodic disabilities often experience periods of good health which are interrupted by periods of disability. Increasing numbers of Canadians are living with lifelong episodic disabilities, social Development Canada (SDC)¹² stated in its November 2003 report that “recurrent and episodic disabilities are becoming more prevalent in Canadian society.”¹³ Often it is difficult to predict when these “episodes” of disability will occur or how long they will last. This can force people out of the workforce without warning for indeterminate lengths of time. This in turn can have significant impacts on health and income stability.

According to some current definitions of disability within disability income support programs, people are considered either fully disabled or able to work. However, some people living with episodic disabilities may be able and want to work part-time or during periods of good health, but remain on full disability benefits because there is no mechanism for partial disability benefits. In fact, the experience of many people living with disabilities is that these programs trap them in poverty by creating barriers to staying on the job or returning to work. For people living with episodic disabilities who have periods when their health permits them to work, this can be especially true.¹⁴ “The financial impact of HIV [and other episodic conditions] is often exacerbated by the lack of flexible employment opportunities or disability plans that can accommodate the needs of people who will go through periods of ill health when they cannot work. As a result, a growing number of people with HIV [and other disabilities] in Canada are trapped in poverty.”¹⁴ While some people with disabilities may receive benefits from multiple income support programs and live above the low income cut-off (LICO) few people living with episodic disabilities live in this category.

The Government of Canada is to be commended for its attention to date in addressing the needs of people with episodic disabilities through ongoing income support policy and programmatic change. An example of these efforts includes the federal response to the issues raised in *Listening to Canadians*¹⁵ that pertain to, not only an individual program, but also the *interrelationships* amongst Canada Pension Plan – Disability (CPPD) and other disability income support programs, including private insurance, provincial disability income support programs and how income support payments are impacted by the policies of other disability support programs.

There are significant and important incentives and opportunities for recipients of disability income support to participate in the labour force. For example, CPPD incentives for its recipients include automatic reinstatement¹⁶, three-month work trials, allowable earnings, fast track and vocational supports. Provincial programs, such as Ontario Disability Support Program, also have return-to-work incentives for recipients. However, ironically, in a number of cases, these incentives become disincentives for people with lifelong episodic illnesses who may be able to work at many various points throughout their life and illness. While we commend the government for these

⁹ For the purposes of this discussion paper, Motor Vehicle Injury Insurance and Personal Injury Insurance are not included.

¹⁰ This number is compiled from the individual websites of the various disability income support programs.

¹¹ Stapleton, John and Anne Tweddle, Open Policy. Review of Current Canadian Disability Income and Employment Policies and Programs. CWGHR. 2008.

¹² In December 2003, HRDC divided into two departments: Human Resources & Skills Development Canada & Social Development Canada.

¹³ Government of Canada. Government Response to ‘Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program. The Fifth Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities’. November 2003. p22.

¹⁴ Canadian Public Health Association (2005). Leading Together: Canada Takes Action on HIV/AIDS (2005-2010).

¹⁵ Standing Committee on Human Resources Development and the Status of Persons with Disabilities. (2003) *Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program*. Retrieved from <http://cmte.parl.gc.ca/cmte/CommitteePublication.aspx?COM=3269&Lang=1&SourceId=213424>.

¹⁶ Automatic reinstatement can occur if the same or a related condition occurs within two years of a recipient returning to work. For more on CPPD return-to-work incentives, see <http://www1.servicecanada.gc.ca/en/isp/pub/factsheets/vocrehab.shtml>.

incentives, it is important to ensure that people living with lifelong, episodic disabilities are able to utilize these benefits throughout their lives as well as participate to their capacity in the labour force, and in this manner, contribute to Canada's labour force.

There is growing anecdotal evidence but little formal research that identifies the number of Canadians with episodic disabilities, and of those, how many are out of the labour force because of the disincentives or challenges related to working part-time and maintaining disability income support for those times when not able to work.

The Government of Canada has acknowledged that this limitation exists. In 2008, The Office for Disability Issues (HRSDC) commissioned research on episodic disabilities to increase the "understanding of the prevalence of Canadians with disabilities who have episodic absences from work and/or work part-time to accommodate their disabilities".¹⁷ This research should help identify some of the barriers faced by people who have episodic disabilities, to staying attached to the work place and accessing current income support programs as well as identify concrete ways to increase opportunities for all Canadians to participate in the labour force. The results will contribute significantly to the growing body of knowledge on episodic disabilities.

THE UNINTENDED CONSEQUENCE

Disability income programs are critical supports for people living with HIV and other episodic disabilities. However, most of these programs do not recognize the episodic nature of many disabilities and when they do, there are varying definitions, policies and practices due to the fact that these are designed for different purposes and by different jurisdictions. This results in a lack of integration and coordination amongst programs and services which makes it challenging for people living with episodic disabilities to navigate the maze of policies and programs.

Although people with episodic disabilities are able and eager to contribute to the labour force intermittently and/or part time as their health permits, most disability income support programs do not provide partial disability benefits to complement part-time earnings. This results in the unintended consequence that people living with episodic disabilities may be in a worse financial position if they return to work part-time or work intermittently, with only their part-time income, than if they completely disengage from the labour force and remain on full disability income. Therefore, many Canadians are forced to disengage completely from the labour force, in order to access disability income and the needed stability it provides.

"Ideally, people with a partially-reduced work capacity should not [have to] leave the labour force and should be supported to find, or remain in, an appropriate job. This would help ensure social integration, raise the living standards of the individuals in question and maintain effective labour supply in the face of an ageing population."¹⁸ Disability policy should help include rather than exclude people from work. "This includes looking at what persons with partial work capacity can do so as to help them either stay in work or get back to work – and transforming the disability benefit system from pure income replacement to a labour-market-oriented intervention."⁴

This is exacerbated further by the fact that some programs insure against having a disability. This means that they don't pay when the disability is not there (i.e. Asymptomatic). This is what happens most often to persons with episodic disabilities who are particularly vulnerable to income security programs that 'compensate the disability' and not the person – what they pay is based on "the biography of the disability". Creative solutions are needed in order to accommodate the person with the episodic disability and not only the disability itself, and help retain existing workers with episodic disabilities who otherwise prematurely exit the labour force in order to qualify for and access required disability supports.

More work needs to be done to ascertain the net benefits of a more flexible program that facilitates the labour force participation of Canadians with episodic disabilities to their capability. Notwithstanding, the results of independent economic analysis led to the conclusion that, using the most conservative of disability communities' estimates of the projected number of disabled people going back to work within a more flexible program, a national disability support program that provides partial or intermittent disability support benefits will have a significant positive

¹⁷ November 2008, Request for Proposals issued by Service Canada on behalf of Human Resources and Social Development Canada (HRSDC). 7613-08-0002

¹⁸ OECD (2007). New Ways of Addressing Partial Work Capacity: OECD Thematic Review on Sickness, Disability and work. Issues Paper and Progress Report. Pg.4

impact on the economy in every year of the forecast period, 2007 to 2030. The annual average savings is estimated to be \$89 million.¹⁹

MAKING A CASE FOR CHANGE – A WIN-WIN SOLUTION

The opportunity to participate in the labour force to their ability and to have access to partial disability benefits when unable to work, could facilitate greater independence, contribute to the Canadian economy by paying income tax and reduce the need for full disability benefits for some people. At the same time, the person would gain the social inclusion benefits and satisfaction derived from being involved in employment.²⁰ Both the financial and social implications of partial disability benefits could be a win-win for these Canadians as well as for disability income support programs. Addressing these issues will not only help address the needs of people living with an episodic disability in the post recession economy but also address the potential skilled labour shortage challenges that will result from the upcoming demographic shift of 2011 when a large number of Canadians will be retiring.

Given the interjurisdictional complexities of these issues, how can all stakeholders (governments, insurers, and employers) come together to ensure that people living with lifelong, episodic disabilities are able to contribute significantly to the labour force when they are able to work without jeopardizing or losing their livelihood and benefits when unable to work? How can governments structure, implement and coordinate disability income and extended health care benefits in a way that promotes opportunities for people whose disability can and will return to participate part-time or intermittently in the labour force?

RECOMMENDATION

In order to address current barriers and promote the financial independence and social inclusion of people living with “lifelong episodic disabilities”,¹ it is necessary to research, identify and develop policies and programs that promote overall coordination and governance among disability support programs, create incentives and reduce barriers for increased labour force participation for people with episodic disabilities.

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NEXT STEPS

CWGHR will be pleased to collaborate with the federal government and all key stakeholders to further explore and implement the above set of approaches. For example, CWGHR will assist with planning a national policy dialogue with governments, the private sector, public institutions (e.g.: universities), professional associations, other non-government organizations, people living with episodic disabilities and the public at large, to further this agenda.

¹⁹ RiskAnalytica, A Population-Based Economic Analysis of Episodic Work Benefits, CWGHR, 2006. Expected number of people who qualify for CPPD benefits that will have an episodic disability arising from cancer, circulatory diseases, mental illness, HIV/AIDS and chronic obstructive pulmonary disease.

²⁰ Australian Medical Association. Social Determinants of Health and the Prevention of Health Inequities - 2007. Retrieved August 1, 2008 from <http://www.ama.com.au/web.nsf/doc/WEEN-73U6YS>.