

Episodic Disabilities Network (EDN)
Addressing Episodic Disabilities in Canada
Contribution to the Pre-Budget Consultations – August 13 2010

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RECOMMENDATION

Although there is a confluence of opinion towards inclusivity, there remain a number of barriers that impede the full integration of persons with disabilities. In order to address current barriers and promote the financial independence and social inclusion of people living with “lifelong episodic disabilities”ⁱ, it is necessary to research, identify and develop policies and programs that promote overall coordination and governance among disability income support programs, create incentives and reduce barriers for increased labour force participation for people with episodic disabilities. Steps towards this end would include:

1. Developing a body (e.g. commission, ministry, department or level of government) to oversee and report on the coordination between the eight disability support programs and five service areasⁱⁱ and establish 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. Making Employment Insurance Sickness Benefits more flexible - making it easier for people with lifelong episodic disabilities to stay in the work place by allowing people to work part time and receive partial sickness benefits for 150 half-days instead of the current 15 weeks or 75 full-days. This modest step would contribute to the health and well-being of people with lifelong episodic disabilities and, ultimately, of Canada.

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.

NEXT STEPS

A critical next step would be to convene a national policy dialogue of key disability stakeholdersⁱⁱⁱ to: discuss the long term future of disability income and service programs in the new economy, develop a narrative on the role of the eight income and the five disability service areas under a comprehensive governance model, discuss the emergent and resistant problems, and encourage a citizen centred strategy for administration and policy. The Episodic Disability Network will be pleased to collaborate with the federal government and all key stakeholders to further explore and implement the above set of approaches.

EXECUTIVE SUMMARY

An increasing number of Canadians are living with lifelong episodic disabilities, including arthritis, Crohn's disease, diabetes, hepatitis C, HIV, multiple sclerosis, and some forms of cancer and mental illness. The Episodic Disabilities Network (EDN) brings together a wide range of key stakeholdersⁱⁱⁱ to collaborate on research, advance public policy on employment and income support and promote broad integration to strengthen episodic disabilities activities in Canada.

People with lifelong episodic disabilities may face barriers to employment and income support, notwithstanding being able to work intermittently or part time. Canadians with episodic disabilities have varying capacities to contribute to the Canadian economy. Many want to work to their capacity to complement the disability income support they receive when they cannot work.^{iv} However, current policies and legislation are disincentives to labour force participation for people with episodic disabilities who can participate in the labour force intermittently or part time when their health permits.

Research and consultations by the EDN, the Government of Canada and others have identified a policy gap related to income and employment for people with lifelong episodic disabilities. To address the policy gap, it is important to convene key stakeholdersⁱⁱⁱ 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.

A SNAPSHOT OF DISABILITY IN CANADA

There are roughly 4.4 million children and adults with disabilities in Canada. This translates to a disability rate of 14.3%.^v This represents an increase in the overall population reporting a disability from 12.4% in 2001 to 14.3% in 2006.^{vi} The disability rate is projected to increase further to between 15.8% and 16.4% of the population by 2026.^{vii}

There are a number of barriers that inhibit the full integration of people living with disabilities, such as employment and income support challenges. People with disabilities have limited employment opportunities and income, and are among the poorest Canadians. On average, adults with disabilities earn a lower annual salary than adults without disabilities. The average salary for employed working-age adults with disabilities has not increased since 2001: the average salary was \$30,380 in 2006, as compared to \$30,490 in 2001. In contrast, the average salary for employed working-age adults without disabilities was \$38,150 in 2006, an increase from \$35,670 in 2001.^{viii}

Also, 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.^{ix} In Canada, approximately one million working age Canadians with disabilities are either unemployed or out of the labour force (Dunn, 2006). 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)

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. Increasing numbers of Canadians are living with lifelong episodic disabilities. A recent study by Human Resources and Skills Development Canada^x noted that:

- According to the Participation and Activity Limitation Survey (PALS) 2006, 46.4% or 1,140,500 of the adult population with disabilities reported at least one of the 27 conditions associated with “episodic” disability. Among those individuals, 49.9% indicated that they were “often” or “sometimes” limited in the workplace.^{xi}
- Among the adult population with disabilities who indicated that they were “often” or “sometimes” limited at work or at school:
 - More than one third (35.8%) of persons with disabilities who report being “often” limited at work or at school and 26.4% of persons with disabilities who report being “sometimes” limited live in a household where the income in 2005 was less than \$35,423 (the lowest of the quintiles).
 - With respect to intermittent labour force attachment, there were 268,200 or 19.4% of adults with disabilities who had employment in the 12 months previous to the PALS 2006 interview who reported some breaks in their employment.

THE ISSUE

Major trends towards societal integration of persons with disabilities emerged in the post war period. Although there is a confluence of opinion towards inclusivity, there remain a number of barriers that impede the full integration of persons with disabilities. In fact, people with disabilities face barriers to employment and income support. 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 illness or disability. 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 and can have significant impacts on income stability.

Disability income programs are critical supports for people living with disabilities at the times when they are unable to work. Many of these disability income support programs have been developed over the past 45 years and include a range of programs with specific and distinct, sometimes conflicting mandates, provided by different departments in different jurisdictions. These can mean one or more of eight income support programs and five areas of disability services. The eight support income programs include: 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); Provincial Social Assistance for disability; Workers’ Compensation and Employers’ Long Term Income Protection (LTIP). The five services areas include: Disability Supports, Caregiver Supports, Employment and Training, Social Services and Medical Services.

Government, private and quasi government bodies spent approximately \$28.2 billion dollars in direct income support benefits^{xii xiii} to individuals with disabilities without any comprehensive oversight respecting what the programs do as a whole or purport to achieve for Canadians with disabilities.^{xiv} In fact, currently there is no coordinating body, commission, ministry, department or level of government to oversee and report on the: service coordination of each of the eight income support programs and five service areas; overall system of disability benefits (taken as a whole) in Canada; policy coordination among each of these benefit areas; differences in philosophies between the program areas; interaction of the programs; funding and value for money presented by these program areas; and program and policy areas taken as a whole. Accordingly, the full array of programs although they work well in various positive ways, cannot easily come together in ways that make the whole system accessible to all persons with disabilities.

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, in many cases disability supports may be jeopardized if/when a person undertakes paid work on a frequent but intermittent or part-time basis. In these cases, many Canadians remain on disability income support, rather than participating in the labour force^{xv}.

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.

Also all of the eight income support programs and five service areas, depending on the how a person became disabled and the type of disability they have, either ‘stack’ - meaning that they all pay without deducting each other- or they interact, deduct, or ‘cannibalize’ each other.^{xvi} This happens because programs either define themselves as ‘first payer’ or a ‘last payer’. Programs that are ‘last payer’ purport to pay people with disabilities who have no other resources. ‘First payer’ programs pay without regard to who else pays. Most disability programs compensate based on workplace attachment e.g. CPP, veterans, workers’ compensation, EI sickness, Long Term Income Protection (LTIP). Only social assistance, the Registered Disability Savings Plan (RDSP), and disability tax credits do not.

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 making them particularly

vulnerable to income security programs that 'compensate the disability' and not the person: these programs pay based on "the biography of the disability". As currently designed, this type of compensation program addresses the needs of people with more permanent and predictable lifelong disabilities than people with lifelong and often unpredictable disabilities that are characterized by degrees of severity and episodes of illness. Creative solutions are needed to accommodate persons with the episodic disability and not the disability itself. Creative solutions are also needed to help retain existing workers with episodic disabilities who otherwise prematurely exit the labour force in order to qualify for and access needed disability supports.

The Government of Canada is to be commended for work to date that is helping to address the needs of people with episodic disabilities. Significant and important incentives and opportunities for recipients of disability income support to participate in the labour force have been introduced. For example, CPP-disability incentives include automatic reinstatement^{xvii}, three-month work trials, allowable earnings, fast track and vocational supports. Provincial programs, such as the Ontario Disability Support Program, also have return-to-work incentives for recipients. However, while there are very important features of programs that allow for intermittent earned income and return-to-work supports, the demand placed on people to navigate these various and often confusing programs makes program and policy coordination a fundamental requirement to ensuring income stability for all Canadians with disabilities who can work.^{xviii}

THE UNINTENDED CONSEQUENCE: STAYING OUT OF THE LABOUR FORCE

According to some current definitions of disability within income support programs, people are considered either fully disabled or able to work. 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 since the programs 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 they are able, 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. At present, the "all-or-nothing" nature of most disability income supports leaves these individuals with no realistic alternative to long-term dependence on disability income programs, and no realistic opportunity to contribute to society. If a better system of short-term income supports were available during temporary periods of disability, people would be more encouraged to remain in the work force – a "win-win" solution which benefits everyone.^x

The International Labour Organisation report "The Price of Exclusion: The economic consequences of excluding people with disabilities from the world of work" stated that "summing up the productivity losses in the respective disability level groups yields a total economic loss of US\$28.6 billion in 2001 for Canada"^{xxix}. "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."^{xxx} 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."^{xxxi}

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 impact on the economy in every year of the forecast period, 2007 to 2030. The annual average savings is estimated to be \$89 million.^{xxii} Creative solutions are needed in order to accommodate the person with the episodic disability 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.

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 living with episodic disabilities. At the same time, the person would gain the social inclusion benefits and satisfaction derived from being involved in employment.^{xxiii} 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.

The EDN has worked collaboratively with Human Resources and Skills Development Canada to research the impact that episodic disabilities have on workforce participation and to identify and promote opportunities to address the needs of Canadians with episodic disabilities. The EDN has also worked to raise awareness of the need for reforms to Employment Insurance and federally provided income support programs to better support Canadians with episodic disabilities.

RECOMMENDATION

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ENDNOTES

ⁱ Episodic disabilities are lifelong and chronic conditions such as arthritis, HIV, multiple sclerosis etc. 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.

ⁱⁱ The Eight 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 five Services Areas are: Disability Supports, Caregiver Supports, Employment and Training, Social Services and Medical Services.

ⁱⁱⁱ Key stakeholders include: governments, the private sector, public institutions (e.g.: universities), professional associations, other non-government organizations, think tanks, civil society, people living with episodic disabilities and the public at large.

^{iv} Anderson, J. & Brown, G. (2005). HIV & Disability Insurance in Canada: An Environmental Scan. CWGHR 2005

^v 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>

^{vi} Human Resources and Skills Development Canada. (2009). Advancing the Inclusion of People with Disabilities 2009. Pg. 6

^{vii} Human Resources and Social Development Canada. (2005). Advancing the Inclusion of People with Disabilities 2005. Pg. 76

^{viii} Human Resources and Skills Development Canada. (2009). Advancing the Inclusion of People with Disabilities 2009. Pg. 38

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

^x Adele Furrrie Consulting Inc., Human Resources and Skills Development Canada. (2010). Towards a better understanding of the dynamics of disability and its impact on employment. March 31, 2010.

^{xi} An additional 704,800 adults who reported other underlying health conditions not associated with "episodic" disability also indicated that they were either "often" or "sometimes" limited at work or at school by their disabilities.

^{xii} For the purposes of this discussion paper, Motor Vehicle Injury Insurance and Personal Injury Insurance are not included.

^{xiii} This number is compiled from the individual websites of the various disability income support programs.

^{xiv} Stapleton, J. & Tweddle, A., Open Policy. (2008). Review of Current Canadian Disability Income and Employment Policies and Programs. CWGHR. 2008.

^{xv} For example: Bert, 42, was diagnosed with multiple sclerosis in his mid 30s. When first diagnosed, Bert had a short period of time off as he was attending medical appointments and receiving treatment. Bert continued to work until he was 39 when his MS progressed; he was unable to walk and needed personal care. For the last few years he has received CPPD benefits. Rehabilitation and new medication has afforded Bert greater mobility and he is keen to return to work. However, he is concerned about: 1) Managing if he is unable to sustain a full work schedule (note: CPPD offers a range of return to work supports). Beneficiaries can earn up to \$4,400 in 2008 without having to contact CPPD, and can in some circumstances earn beyond that level without having their benefits stopped. Those who are able to return to work on a regular basis receive a paid work trial, and automatic reinstatement of benefits is available if their disability recurs. 2) Changing the times that he requires his care. 3) Managing his regular hospital and other health appointments, all of which occur during office hours and will quickly use up his paid leave, and not being able to afford to take unpaid leave.

^{xvi} For example: A veteran who gets military disability, CPP, Workers' Compensation has benefits that 'stack'. Another worker who gets LTIP has LTIP that is reduced by CPP and social assistance has benefits that 'cannibalize'. At the one end of the continuum, the person with a disability gets a livable income from three sources

that do not deduct each other – e.g. a person could get \$30,000 a year. At the other end, the person with a disability could get benefits from three programs but the first program reduces the second and the third leaving the person with a poverty level income –e.g. a person could get \$12,000 a year because the programs deduct each other.

^{xvii} 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>.

^{xviii} Stapleton, J. & Tweddle, A., Open Policy. (2008). Navigating the Maze: Improving Coordination and Integration of Disability Income and Employment Policies and Programs for People living with HIV/AIDS - A Discussion Paper. August 2008

^{xix} International Labour Organisation. (2009). The Price of exclusion: The economic consequences of excluding people with disabilities from the world of work. Pg.8.

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

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

^{xxii} RiskAnalytica. (2006). A Population-Based Economic Analysis of Episodic Work Benefits. 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.

^{xxiii} 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>.