

The Path Forward

Addressing Episodic Disabilities in Canada

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RECOMMENDATIONS

Although there is a confluence of opinion towards inclusivity, there remain a number of barriers that impede the full integration of persons with episodic 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 and that create incentives and reduce barriers for increased labour force participation for people with episodic disabilities. Steps towards this end would include:

1. Making Employment Insurance Sickness Benefits more flexible—making it easier for people with lifelong episodic disabilities to stay in the work force 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, to the well-being of Canada.
2. Developing a pan-Canadian 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.
3. 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.

The interjurisdictional complexities of these issues require the participation of all sectors (e.g. government, public, and private) 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 and for Canadian society as a whole.

NEXT STEPS

A critical next step will be to convene a national policy dialogue of key disability stakeholdersⁱⁱⁱ to discuss the longterm 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 would 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 that often result from conditions including arthritis, Crohn's disease, diabetes, hepatitis C, HIV/AIDS, mental illness multiple sclerosis and some forms of cancer and rare diseases. The Episodic Disability Network (EDN) serves as a pan-Canadian forum for episodic disability. The EDN collaborates on research, advances public policy on employment and income support and promotes broad integration to strengthen episodic disabilities activities in Canada.

People with lifelong episodic disabilities may face barriers to employment and income support, despite their ability to participate in the workforce. Canadians with episodic disabilities have varying capacities to contribute to the Canadian economy. Sometimes people with an episodic disability can work full time for an extended period; however other times they are able to work reduced hours or may need a period away from the work force. Most want to work to their full capacity to complement the disability income support they receive when they cannot work.^{iv} However, many current policies and legislation are disincentives to labour force participation for people with episodic disabilities and currently there is no mechanism for partial disability benefits or to accommodate periodic absences from the workforce.

Research and consultations by the EDN and the Government of Canada 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.

THE ISSUE

Everybody has been touched by episodic disability. Episodic disabling conditions or diseases are lifelong, but unlike permanent or progressive disabling conditions, they result in episodes of disability. Even with the best possible medical management people may experience episodes of disability. The periods of disability can vary in severity and duration. There may be advance warning or the episode may come on unexpectedly. Examples of conditions that are episodically disabling are mental illness, arthritis, HIV/AIDS, multiple sclerosis, Crohn's and colitis, asthma, psoriasis, and some forms of cancer and rare diseases. All too often, these conditions have a negative impact on workforce participation and income security. In many instances, this impact can be lessened, if not prevented, through adjustments to existing programs.

Advances in medical technologies mean that many diseases and conditions are no longer imminently fatal, and disabling symptoms can often be reduced, managed or delayed. However, as a result, more and more Canadians are living longer with lifelong episodic disabilities, and overall women have a higher rate of episodic illness than men.^v While the specific prevalence of episodic disability is not known, millions of Canadians live with diseases /conditions linked to episodic disability. The majority of the people affected are in their prime working years and are women.^{vi}

The price of excluding people with disabilities from the world of work is an economic loss—for the individual, for the family and for Canada. 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.”^{vii} The Mental Health Commission of Canada reported: “The economic burden of mental disorders in Canada has been estimated at \$51 billion per year, with almost \$20 billion of that coming from workplace losses.”^{viii} In the coming decades, fewer young people will be entering the workforce and growth in the population traditionally considered to be of working age is projected to slow or even reverse. This employment trend necessitates programs which bolster full inclusion for all Canadians. People living with episodic disabilities tend to be experienced workers, many at the peak of their work life. Many people living with episodic disabilities may be able and want to work, but remain on full disability benefits because there is no mechanism for partial disability benefits or to accommodate periodic absences from the workforce. 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 participate in the labour force.^{ix}

LACK OF INTEGRATION OF INCOME SUPPORT PROGRAMS

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. Government, private and quasi-government bodies spent approximately \$28.2 billion (in 2008/2009) in direct income support benefits^{x xi} to individuals with disabilities without any comprehensive oversight respecting what the programs do as a whole or purport to achieve for Canadians with disabilities.^{xii} 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 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.

By design, some income programs interact well and some interact 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 coordination. 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.^{xiii} 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, e.g. CPP, support for veterans, workers’ compensation, EI sickness and Long Term Income Protection (LTIP) compensate based on workplace attachment. Only social assistance, the Registered Disability Savings Plan (RDSP) and disability tax credits do not.

According to some current definitions of disability within income support programs, people are considered either fully disabled or able to work. Also, most of these programs do not recognize the episodic nature of many disabilities. 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. Many of the existing programs and services use definitions that exclude or are perceived to exclude people living with conditions that result in episodic disabilities.

Some programs insure against having a disability, meaning they do not pay when the “disability” is not manifesting itself (i.e. when the person is asymptomatic). This is what happens most often to persons living with lifelong conditions that are episodically disabling, 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, fluctuating 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 income supports.

Canada, like other OECD countries, has made reform of sickness and disability policies a priority (OECD, 2010), and there have been recent legislative changes to make eligibility criteria for disability income benefits more flexible. The impetus for this reform stems from two areas: on the one hand, a desire to promote social and economic inclusion and social justice, and on the other, to capitalize on the potential contributions of an under-utilized labour force (Statistics Canada, 2006; OECD, 2010; Williams, 2006).^{xiv}

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 have been introduced for recipients of

disability income support to participate in the labour force. For example, CPP-disability incentives include automatic reinstatement,^{xv} 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 these 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.^{xvi}

THE UNINTENDED CONSEQUENCE: STAYING OUT OF THE LABOUR FORCE

Although most 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. The result is 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 economically 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

MAKING A CASE FOR CHANGE: A WIN-WIN SOLUTION

The opportunity to participate in the labour force to their ability and to have timely access to disability benefits only when unable to work could facilitate greater independence, contribute to the Canadian economy by paying income tax, CPP premiums 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.^{xvii} 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 help address the needs of people living with an episodic disability.

RECOMMENDATIONS

In order to address current barriers and promote the financial independence and social inclusion of people living with “lifelong episodic disabilities,” 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:

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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 would be pleased to collaborate with the federal government and all key stakeholders to further explore and implement the above set of approaches.

ENDNOTES

ⁱ An episodic disabling condition or disease is lifelong, but unlike permanent or progressive disabling conditions; these all too often result in episodes of disability. The periods of disability can vary in severity and duration. There may be advance warning or the episode may come on unexpectedly. Examples of conditions that are episodically disabling are mental illness, arthritis, HIV/AIDS, multiple sclerosis, Crohn's and colitis, asthma, psoriasis, and some forms of cancer and rare diseases.

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 Taken from <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007003-eng.pdf>

^{vi} Taken from <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007003-eng.pdf>

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

^{viii} Taken from Mental Health Commission of Canada, 2011,

http://www.mentalhealthcommission.ca/SiteCollectionDocuments/Workforce_2011/MHCC_ENG_PR_FINAL.pdf

^{ix} For example: Bert, 42, was diagnosed with multiple sclerosis in his mid-30s. When first diagnosed, Bert had a short period of time off because 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 CPP-D benefits. Rehabilitation and new medication has afforded Bert greater mobility and he is keen to return to work. However, he is concerned about 1) Getting by if he is unable to sustain a full work schedule (note: CPP-D offers a range of return-to-work supports—beneficiaries can earn up to \$4,400 in 2008 without having to contact CPP-D, 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; and 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.

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

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

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

^{xiii} 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.

^{xiv} Smith-Fowler, H. (2011). Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario?, pg. 6.

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

^{xvi} 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.

^{xvii} 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>.

^{xviii} 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.

^{xix} 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.