



FINAL REPORT FOR THE
LABOUR FORCE PARTICIPATION AND SOCIAL INCLUSION
FOR PEOPLE LIVING WITH HIV AND OTHER EPISODIC DISABILITIES
PROJECT

March 2007

Final Report for the *Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities* Project

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The **Canadian Working Group on HIV and Rehabilitation** (CWGHR) is a national charitable organization working to improve the quality of life of people living with HIV/AIDS through rehabilitation research, education, and cross-sector partnerships. CWGHR members are individuals and organizations that have an interest in HIV, disability and rehabilitation. These include: community-based HIV/AIDS, disability and rehabilitation organizations; national professional associations; unions; government agencies; private-sector companies; people living with HIV; health care, social care and human resources professionals; and other people who are interested in HIV and rehabilitation.

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I. Executive Summary

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, multi-sector, multi-disciplinary, charitable organization of stakeholders involved in rehabilitation in the context of HIV in Canada. Since 2001, CWGHR has undertaken research which has shown that the episodic nature of HIV and other disabilities wreaks havoc with the work lives and income support for people with episodic disabilities. In addition, there are many systemic and practical barriers which prevent people with episodic disabilities from participating in the labour force in a meaningful way due to the episodic nature of their conditions.

In order to establish an ongoing platform for the exchange of ideas and collaboration with national disability organizations on issues specific to episodic disabilities, CWGHR has held the Secretariat role for the [Episodic Disabilities Network \(www.hivandrehab.ca/EN/episodic_disabilities/episodic_disabilities_network.php\)](http://www.hivandrehab.ca/EN/episodic_disabilities/episodic_disabilities_network.php)¹ (EDN) since 2003. In 2004, the EDN identified income support and labour force participation as key priorities.

In response, CWGHR coordinated a national multi-phase project on 'Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities', funded by Human Resources and Social Development Canada. The project has researched policies internationally, recommended models to accommodate episodic disabilities and implemented a cost-benefit analysis of these models. A pilot project was designed for consideration for implementation, to test and evaluate the models in a Canadian context. The purpose of these activities was to provide evidence-based recommendations for policy improvements that would contribute to labour force participation and social inclusion of people living with episodic disabilities.

- Project activities (with weblinks for more information)
 - Researched Canadian and international disability income support and employment policies and practices, and developed [recommendations \(www.hivandrehab.ca/EN/episodic_disabilities/documents/Policies_and_Programs_English.pdf\)](http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Policies_and_Programs_English.pdf)
 - [Costed \(www.hivandrehab.ca/EN/episodic_disabilities/documents/Population-Based_Economic_Analysis_English.pdf\)](http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Population-Based_Economic_Analysis_English.pdf) one recommendation, specifically, partial CPP(D) disability benefits
 - Surveyed certified Human Resources Professionals regarding their knowledge of episodic disabilities, analyzed responses and developed [recommendations \(www.hivandrehab.ca/EN/episodic_disabilities/documents/HR_report_English.pdf\)](http://www.hivandrehab.ca/EN/episodic_disabilities/documents/HR_report_English.pdf)
 - Presented findings from the above activities at a [National Summit \(www.hivandrehab.ca/EN/episodic_disabilities/documents/National_Summit_Report_English.pdf\)](http://www.hivandrehab.ca/EN/episodic_disabilities/documents/National_Summit_Report_English.pdf) on Episodic Disabilities in March 2006, which brought together relevant stakeholders to share research findings and collaborate on solutions
 - Coordinated the [Episodic Disabilities Network \(www.hivandrehab.ca/EN/episodic_disabilities/episodic_disabilities_network.php\)](http://www.hivandrehab.ca/EN/episodic_disabilities/episodic_disabilities_network.php), an ongoing platform for the exchange of ideas and collaboration on issues specific to episodic disabilities with national disability organizations
 - Established a stronger voice for people living with episodic disabilities by increasing their representation in the EDN.
 - Developed a critical path for moving forward on policy, research, government relations and communications.

Evaluation activities accompanied the core project activities in order to inform and improve sequential components of the project as it progressed.

¹ The *Episodic Disabilities Network* includes participation of the *Canadian Mental Health Association*, *Lupus Canada*, *Multiple Sclerosis Society of Canada*, and other national disability organizations. It provides a forum to exchange information amongst participant organizations to enhance the ability of Network participants to respond in a coordinated way to inform policies and programs to improve quality of life and promote inclusion for people with episodic disabilities.

II. Background

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, multi-sector, multi-disciplinary, charitable organization of stakeholders working on disabilities and rehabilitation in the context of HIV in Canada. Since 2001, CWGHR has undertaken research on episodic disabilities which has shown that the episodic nature of HIV and other disabilities wreaks havoc with the work lives and income support for people living with episodic disabilities. In addition, there are many systemic and practical barriers which prevent people with episodic disabilities from participating in the labour force in a meaningful way due to the episodic nature of their conditions.

In response to a call for proposals from the Social Development Partnership Program of the Office for Disability Issues, Human Resources and Social Development Canada, CWGHR submitted the proposal for the project called *'Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities'* in February 2004. The rationale for the project is clarified in the following excerpts from the proposal and other sources:

Rationale for Project

Although there are no statistics on the exact number of people living with lifelong episodic conditions, Social Development Canada (SDC)² stated in its November 2003 report that "recurrent and episodic disabilities³ are becoming more prevalent in Canadian society."⁴

While there had been little research undertaken on episodic disabilities, several government departments have supported a cross-disability approach to relevant policies and programming. For example, in a recent Public Health Agency of Canada⁵ (PHAC) document, PHAC "encourage[s] greater integration of HIV/AIDS prevention, care and treatment interventions with those of other diseases"⁶

The following example illustrates some of the challenges that people with episodic disabilities face. Although many people with episodic disabilities are eligible for coverage and/or currently receive disability benefits through Canada Pension Plan Disability (CPP(D)) Program and / or private insurance, current policies do not recognize and/or accommodate the needs of people with episodic disabilities for flexible income support nor do they recognize the concept of 'partial disability benefits'. According to some current definitions of disability, people are considered either *fully disabled* or *able to work*. However, some people with episodic disabilities may be able and want to work part time or during periods of good health, but are currently on full time disability benefits because there is no mechanism for partial disability benefits or they risk losing critical income and health benefits if they return to work. In fact, the experience of many people with disabilities is that these programs trap them in poverty by creating barriers to staying on the job or returning to work. For people who live with episodic disabilities, with periods when their health would permit them to work, this is especially true.

² In December 2003, Human Resources Development Canada divided into two departments: *Human Resources and Skills Development Canada* and *Social Development Canada*. In 2006, the two departments were combined to form Human Resources and Social Development Canada.

³ Episodic Disabilities is a term used to describe conditions such as multiple sclerosis, HIV/AIDS, some mental health conditions, cancers and forms of lupus and arthritis. One of the primary distinguishing features of episodic disabilities is their unpredictability, which can force people out of the workforce without warning, and then resolve to once again allow people to return to work.

⁴ 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.

⁵ As of September 1, 2004, the HIV/AIDS Division of Health Canada moved to the new *Public Health Agency of Canada*

⁶ Public Health Agency of Canada. *The Federal Initiative to Address HIV/AIDS in Canada: Strengthening Federal Action in the Canadian Response to HIV/AIDS*. 2004. p. 7

In addition to the research that CWGHR has undertaken on this issue, other organizations have published their findings of barriers to labour force participation by people with episodic disabilities. Other initiatives included:

- CWGHR, in collaboration with the Canadian AIDS Society, presented a brief to the *Parliamentary Sub-Committee on the Status of Persons with Disabilities* outlining the challenges for people with episodic disabilities such as HIV in the existing Canada Pension Plan – Disability Program, such as: the unpredictability of recurring episodes; resulting difficulty maintaining long-term work and contribution requirements; location of supports; differing definitions of ‘disability’.⁷
- The Institute for Work and Health undertook research in 2003 exploring the impact of fluctuating disability on labour force participation for people living with HIV. Recommendations clearly indicate the need for further exploration of flexible models of labour force participation to lessen the risk and provide greater options for people to engage in the labour force.⁸
- Research related to vocational rehabilitation has found that “people look to the workplace to meet their needs for primary social interaction and as a surrogate family system.”⁹ This same report found that long term unemployment may have a devastating impact on self-esteem.¹⁰
- Systemic and practical barriers within disability income support programs prevent people with HIV/AIDS who are able to work from participating in the labour force in a meaningful way.¹¹

As access to income security and appropriate employment are key determinants of health¹², the above issues require further investigation in the context of episodic disability.

⁷ Canadian AIDS Society and CWGHR. HIV as an Episodic Illness: Revising the CPP(D) Program, 2003.

⁸ Ferrier, S. and Lavis, J. *With Health Comes Work? People Living with HIV Consider Returning to Work*. AIDS Care. Vol 15 (3). June 2003, 433-434.

⁹ Harder, Henry. *Early Intervention in Disability Management: Factors that Influence Successful Return to Work*. International Journal of Disability, Community and Rehabilitation. Vol. 2 2003, p2.

¹⁰ Ibid, p4.

¹¹ Anderson, Joan & Glen Brown. HIV & Disability Insurance in Canada: An Environmental Scan, 2005. CWGHR.

¹² Wellesley Central Hospital and Health Canada. *Rehabilitation Services: A Comprehensive Guide for the Care of Persons with HIV Disease: Module 7*, p79. 1998.

III. The Project – Goal, Objectives and Four Stages

Goal

Contribute to social inclusion for people living with episodic disabilities in Canada by:

- building sustainable relationships among key stakeholders and promoting the development of comprehensive coordinated approaches
- through research findings, providing the basis for the development of comprehensive policies and programming that support flexible and appropriate options for meaningful labour force participation. This, in turn, will promote more inclusive communities and workplaces and improved quality of life for people with HIV and other episodic disabilities.

Objectives

1. To develop new knowledge on lifelong, episodic disabilities and the implications for labour force participation and social inclusion by:
 - a. Building on and developing a body of new knowledge to inform policy and programming related to labour force participation and social inclusion for people living with HIV and episodic disabilities;
 - b. Identifying barriers, strengths, and models that promote labour force participation and social inclusion;
 - c. Developing strategies to promote models that address barriers.
2. To promote translation and uptake of new knowledge related to inclusion of people living with HIV and other episodic disabilities in social and labour contexts by:
 - a. Developing tools and disseminating resources;
3. To strengthen relationships among episodic disability groups, to promote coordination and to increase episodic disability stakeholder involvement in shared issues by:
 - a. Energizing partners to become involved and use the Episodic Disabilities Network as a resource for other initiatives;
 - b. Building strong coordinated alliances among episodic disability groups.
4. To enhance the capacity of CWGHR to take leadership on issues related to episodic disabilities for people living with HIV and other episodic conditions

As mentioned above, the 28 month project spanned the period from December 1, 2004, to March 31, 2007. Details of the activities within the four stages of the project and their outcomes follow. Many of the activities within each stage overlap. For example, those that are related to relationship-building and networks span the entire project and have built momentum and sustainable strategies beyond the funded period. This sustainability beyond the funded period is detailed in “Next Steps”.

Stage 1: Development and Support of Partnerships and Project Structure

Activities

- Management plans, project structure, terms of reference were developed. Time lines were reviewed.
- The engagement of the Episodic Disabilities Network (EDN), established by CWGHR in 2002, was sustained (See Appendix I for list of EDN participants).

Two face-to-face meetings of the EDN occurred during this stage, resulting in numerous project-relevant contacts. Strategic alliances were developed for exchanging knowledge and ideas, in order to increase capacity for episodic disability groups to understand and inform policy and program issues from an episodic disability perspective.

- The Episodic Disabilities Network (EDN) employed mechanisms to engage key stakeholders and gather their input throughout the project. The EDN provided input into the project through several mechanisms: EDN members were included on the National Advisory Committee; the EDN was consulted during the project design, and; the EDN provided feedback and analysis of research findings on each aspect of research
- Utilizing CWGHR’s extensive national contacts, the National Advisory Committee was formed, with representation from the EDN and other identified stakeholders. (See

Acknowledgements for list of members and their associations.) One conference call, one in-person meeting, and numerous other contacts were made on project-related issues. The National Advisory Committee reviewed and updated the work plan and its timelines. Evaluation goals and strategies were confirmed.

- Strategic alliances on related national initiatives were developed:
 - Collaborated on a joint press conference with HIV/AIDS Legal Network (See Appendix II for *Statement of Common Agenda*).
 - Participated on the National Advisory Committee of the *Income Support Research* project, sponsored by the Canadian AIDS Society. (See [http://www.hivandpoverty.ca/web/isssetup.nsf/\(ActiveFiles\)/Consultation_Report_En/\\$file/Consultation_Report_En.pdf](http://www.hivandpoverty.ca/web/isssetup.nsf/(ActiveFiles)/Consultation_Report_En/$file/Consultation_Report_En.pdf).)
 - Participated on the National Advisory Committee of the *Chronic Illness, Disability and Workplace Policies* project, sponsored by the Interagency Coalition on AIDS and Development. ([Interagency Coalition on AIDS and Development \(ICAD\) \(www.icad-cisd.com/content/home.cfm?lang=e\)](http://www.icad-cisd.com/content/home.cfm?lang=e))
- An Evaluator was contracted to monitor and evaluate project activities, outputs and outcomes.

Outcomes

- The EDN provided a coordinated comprehensive approach to provide input and feedback, share information and more effectively reflect and integrate the issues of people with episodic disabilities throughout this project.
- The strategic alliance on related national initiatives resulted in increased awareness, knowledge exchange and integration about episodic disabilities.
- Comprehensive evaluation increased responsiveness of input from stakeholders into the project.

Stage 2: New Knowledge Development

Activities

- In consultation with National Advisory Committee and EDN, research questions were refined, resulting in a focus for policy analysis research.
- The EDN was surveyed for input into models and gaps.
- Knowledge about episodic disabilities was discussed within CWGHR's Strategic Planning process and has been integrated into the work of CWGHR.
- Partners were identified and educated to collaborate with the next steps of project.
- Interim Project Evaluation Report was produced.
- In-depth policy analysis was undertaken on key policy issues related to labour force participation and social inclusion of people living with HIV and other episodic disabilities, to identify and analyse strengths, barriers and models in policies, programmes and practices related to labour force participation and social inclusion of people living with HIV and other episodic disabilities.
- Cost-benefit analysis of various flexible employment/income support options (i.e. identifying models that accommodate episodic conditions and promote labour force participation, such as partial disability benefits with part-time work or automatic reinstatement of disability benefits to facilitate going in and out of labour force; examining the economic viability, challenges and benefits of those models) was undertaken.
- Survey was undertaken to identify learning needs of human resources professionals and vocational professionals related to episodic disabilities

Outcomes

- Increase awareness of various models to inform policies and programming and set the stage for undertaking pilot projects to test these models and evaluate their benefit for key

stakeholders (e.g. people with episodic disabilities, public and private insurance providers, employers).

1. Effective models included:

- multi-sector coordination among all relevant private & public sector stakeholders;
- flexibility in policies & programs to accommodate episodic participation in the labour force with sustainable income and benefit support regardless of employment status.
- partial disability income support integrated with employment earnings when a person with an episodic disability works part time

2. These flexible models can result in significant cost savings to the insurance carrier & in more labour force participation options for people with episodic disabilities.

3. There is a need for a core body of knowledge and training on episodic disabilities for human resources professionals.

4. Insurance options needed that remove the disincentives to participate in the labour force to one's potential.

- Increase evidence that current disincentives to employment must be replaced by flexible policies to enable people with episodic disabilities to participate effectively in the workforce. Policies must promote income security regardless of employment status.
- Increased evidence that human resources professionals, disability case workers, employment counsellors and employers need education and training about episodic disabilities.
- Increased evidence that more private insurance options are needed.
- Increased evidence that further research is needed to evaluate the recommendations in real-life situations.

Stage 3: Knowledge Translation

Activities

- Presentations were made in several locations in Canada to several sectors about the project, and participants were invited to contribute to the project.
- Newsletter with the theme "episodic disabilities" was produced and disseminated.
- Two Fact sheets - one on Episodic Disabilities, the other on the project, and with contact information and the invitation to participate (See Appendix III) - were developed and reviewed by the Education and Practice Advisory Committee. These Fact Sheets have been updated and disseminated at numerous presentations.
- Poster on new knowledge from the international policy analysis (See Appendix IV) was developed for presentation at a conference.
- With other members of EDN, information about project was disseminated to policy makers at SDC and to MPs and the Statement of Common Agenda was disseminated.
- A review committee of disability and rehabilitation policy experts from the National Advisory Committee was struck to select recommendations for costing from the international policy review.
- An economist with expertise in national disability care costing was contracted to complete an economic analysis of the primary recommendation.
- Presentations made in Toronto to key stakeholders (i.e. University of Toronto Rehab students; Ontario HIV Treatment Network, Wellesley Health Centre, CWGHR membership, etc.) about the project. Participants always invited to contribute to the project resulting in increased awareness, engagement and capacity of stakeholders to respond to episodic disability issues.
- National Survey of Human Resource professional regarding episodic disabilities complete and disseminated on-line via the Canadian Council of Human Resource Professionals.
- HR researcher contracted to analyze survey responses to above-described survey
- Prepared and disseminated a pre-budget submission on behalf of the EDN (Appendix V); disseminated information about disincentive in CPP-D plan to return to work to CPP-D.

- Discussion paper developed and further presented to private sector to increase awareness and engagement about the issue. (i.e. Two foundations, two financial institutes, two pharmaceuticals)
- Presentations at: the Ontario HIV/AIDS Treatment Network Conference, Canadian AIDS Society's Skills Building Conference, two CPP-D meetings, CWGHR Members, CWGHR Development Committee and Office for Disability Issues.
- Discussion paper presented to additional targets in private sector resulting in increased awareness, engagement and capacity of stakeholders to respond to episodic disability issues.

The Summit Planning process was taking place during this Stage with the actual National Summit occurring in Ottawa in March 2006. The planning process involved:

- Contracting and working with facilitators on agenda;
- Developing invitation list, circulating invitations and processing registrations;
- Coordination of multiple details, including travel and accommodation arrangements, for the event;
- Preparing presentation materials;
- Implemented outreach to people living with episodic disabilities.
- Preparing evaluation.
- Partnering with Algonquin College for development and implementation of media plan. Roger Cable in Ottawa covered the Summit.

In addition to the Summit-specific activities:

- The EDN met 3 times during this stage.
- A work plan for the newsletter was developed and implemented. The theme was Summit activities.
- Submissions were developed and accepted at Canadian Association of Nurses in AIDS Care, Canadian Association of HIV/AIDS Research and Canadian Association of Rehabilitation Professionals Conferences, as well as the International AIDS Conference.

The National Summit on Episodic Disabilities on March 2 and 3, 2006 in Ottawa was the point at which research findings/ new knowledge gained from the project to this point was disseminated, and the relationships and partnerships established from the previous stages of the project presented another opportunity for multi-sector consultation. The research findings were presented, and all participants were engaged in the developments of the next stage of the project.

After the Summit, tangibles such as the Final Report of the Summit, the DVD of the Summit, the writing, translation and printing of reports on each of the areas of research, the Evaluation of the Summit, and the Spring Edition of *backtolife.ca*, are examples of the tangibles that came out of the Summit. The month ended with the annual face-to-face meeting of the Advisory Committee, in which plans for the next quarters of the project were enhanced and endorsed. All reports were translated, printed as well as posted on CWGHR's website. A dissemination strategy for the wider HR sector was developed and implemented.

- With input from the EDN, developed and implemented mechanisms for knowledge translation, including:
 - a) workshops and presentations to policymakers
 - b) national multi-sector summit on labour force participation and social inclusion related to HIV and other episodic disabilities to develop coordinated strategies to address identified barriers with key stakeholders (e.g. employers, employees, human resource professionals, vocational rehabilitation counselors, private and public disability income support programs, employee assistance programs, policymakers)
 - c) educational resources and communication tools (e.g. newsletters, fact sheets, workshop guides, e-learning resources)

Outcome

These knowledge translation activities increased awareness and built and strengthened alliances among key stakeholders using different mechanisms to accommodate the learning needs of various stakeholders. For example: meetings with policymakers provided information and input on specific policy issues; the National Summit provided an opportunity for stakeholders to collaborate on coordinated strategies in priority areas; workshops provided the opportunity for relevant stakeholders to increase their ability to respond to episodic disabilities.

Stage 4: Pilot Project Development

Activities

Building on the foundations established in the first half of the project funding period, culminating in the successful National Summit on Episodic Disabilities in March 2006 in Ottawa, activities focused on the strategizing necessary to design pilot sites, as well as to sustain research beyond the funding period of this project.

To provide input into the development of Pilot Site protocol, a Pilot Site Steering Committee was struck. This committee met monthly from April 2006 until February 2007. Some of the outcomes include:

- Greater engagement of the stakeholders
- Greater awareness of the issues
- Development of shared vision and shared priorities
- Terms of Reference and Work Plan
- The June meeting was a collaboration with researchers to develop research question.
- In addition, options for securing partners and funding for long term national demonstration project were developed.

At their February 2007 meeting, the Committee determined it will continue its mandate beyond the funded period.

Workshops, meetings and presentations on key research areas to stakeholders from various sectors and disability groups, including policy makers, were held to

- increase awareness about the issues
- gain input from various stakeholders
- develop partnerships across Canada to support and participate in the design of pilot project (e.g. people living with episodic disabilities, insurance companies, employers with various companies and organizations, human resource professionals)

Outcomes

- Employers' Forum provided an excellent opportunity to disseminate information about the project to potential employers of people with episodic disabilities
- Network of Atlantic research institutes expanded the national reach of the project
- Presentation at *Opportunities Fund for Persons with Disabilities* annual staff meeting increased interdepartmental awareness of a government funding body of ODI-funded projects
- International AIDS Conference allowed for international exchange of information on employment, disability, and income support policy
- The continuity of meetings of the EDN resulted in greater capacity of episodic disability groups to exchange knowledge and to ensure that the project activities continually reflect the issues and priorities of people living with episodic disabilities.

- With private sector collaboration, developed memorandum of understanding, protocol, case scenarios and financial streams for private sector pilot site to test and evaluate new models for flexible employment and income support. As stated in the government response to the Sub-Committee report:
 “Pilot projects could be especially effective in determining what reforms work and what do not work in helping people with disabilities to reintegrate into the workforce and in identifying effective preventative strategies which might reduce future CPP Disability program costs.”¹³
- Developed partnerships with potential funders
- In partnership with a private funder and with support from ODI, developed a multi-year comprehensive strategy.

Features of the Project

- Its purpose was to improve the economic and social opportunities of people with episodic disabilities by not only identifying, but also addressing the systemic labour-force participation disincentives.
- Its goal was to progress towards reducing disincentives to labour force participation for people living with episodic disabilities. The intent was to complement income support benefits with earned income, thereby increasing total income and preventing even greater poverty.
- Community-input mechanisms, specifically for people living with episodic disabilities, were the foundation of the project and integrated throughout.
- It was cross-disability in its scope and its application of the research findings and multi-sectoral in its representation (human resources, labour, private insurers, public insurers, researchers, disability communities, HIV community). This cross-disability and multi-sectoral representation is essential to ensure that relevant stakeholders understand, as well as benefit from, each others’ perspectives, ultimately enriching the project.
- It was international in its review of policies.
- The need for more effective interjurisdictional (federal, provincial and territorial) collaboration was identified as an important issue. A strategy to address this was designed.
- Knowledge exchange was integrated into the project through workshops and presentations throughout the course of the project. One of the key activities was a National Summit in March 2006, the purpose of which was the dissemination of the new knowledge gained from the research, and the development of collaborative models which will form the foundation of the design of the pilot projects.
- New knowledge gained will be applied in demonstration projects.
- The project innovatively utilized the existing relationships with key stakeholders such as the Canadian Council of Human Resources Professionals, and the Canadian Life and Health Insurance Association to effect systemic change in attitudes and approaches, and has developed new partnerships with private employers who are positioned as champions and partners in the solutions.

¹³ Government of Canada Report. p21.

IV. Evaluation¹⁴

The evaluation for the project was guided by the objectives that were set by CWGHR and the National Advisory Committee (NAC). Comprehensive evaluation of each project stage and outcome helped to ensure that process lessons became integrated into the ongoing project activities. The primary objective of the project was to develop new knowledge regarding episodic disabilities, income support and labour force participation. The evaluation was also assessing the following objectives:

1. The project's development and support of partnerships between episodic disability groups at a national level;
2. The extent to which targeted Episodic Disability Network (EDN), CWGHR members and other stakeholders have gained knowledge on labour force participation and social inclusion for people living with HIV and other episodic disabilities;
3. The effectiveness of knowledge sharing and dissemination activities;
4. The capacity of Advisory Committee members and partners to design and implement the pilot project; and,
5. The extent to which the project's outcomes are disseminated to EDN and CWGHR members.

Tools

- Periodic self-assessment tool and consultation to measure partnership development progress from project staff, Episodic Disability Network members, CWGHR members and PAC
- Document review template
- Pre- and post-self assessment tool to measure knowledge change amongst workshop and summit participants
- Participant evaluation forms to gather feedback from meetings
- Participant observation at meetings
- Periodic self-assessment tool and consultation to measure progress on awareness and capacity of EDN, CWGHR and researchers with respect to pilot project design and implementation

Process

CWGHR engaged a program evaluation consultant early in the project in order to establish evaluation processes and tools that would be implemented throughout the project. The same evaluation consultant followed the project throughout the project, providing interim evaluation feedback and measuring changes over time. From the perspective of the program evaluator, this was a very effective way to design the evaluation component of the project, ensuring a close fit between the project activities and the evaluation of those activities. It also provided a useful blending of an internal evaluation perspective being brought by an external evaluator, in contrast to the more typical hiring of a program evaluator at the conclusion of a project.

Each evaluation objective was linked to project activities at each of the project stages and relevant program outcomes and, in turn, to indicators and data collection strategies. The evaluation plan and findings were delivered to the NAC members for approval and review throughout the project's implementation.

The NAC members were asked to complete three repeats of the self-assessment tool to measure their baseline, interim and final levels of knowledge and awareness with respect to the project outcomes and processes. The Project Manager also provided extensive evaluation data throughout the project, including periodic conversations providing an update on activities, and written reports of activities. Excerpts from the interim evaluation reports were inserted into some of the project deliverables such as presentation materials and CWGHR newsletters.

¹⁴ Section IV was written by External Project Evaluator, San Patten.

Key Findings

1. *Partnerships*

An important outcome of the project is the strengthened relationships among episodic disability groups and CWGHR's enhanced role as a national leader on issues related to episodic disabilities for people living with HIV and other episodic conditions. The success of the project was due in large part to a very skilled Project Coordinator and a supportive and engaged Project Advisory Committee. There was also ongoing coordination with the EDN, building new and stronger relationships by sharing information and collaborating on advocacy efforts and policy analysis. The Episodic Disabilities Project was well-managed, with a meaningfully engaged National Advisory Committee that provided in-depth analysis and guidance to the key activities of the project during through all project phases, particularly the policy analysis, planning of the National Summit and planning of the Pilot Sites. It is expected that ongoing EDN activities will create new and stronger alliances and knowledge-based relationships regarding episodic disability groups at the national level.

2. *New Knowledge*

EDN members experienced an average increase of 36% (or 1.8 points on a 5-point Likert scale), and PAC members a 38% increase (or 1.9 on a 5-point scale), over the duration of the project in their capacity in the following areas:

- Partnerships between episodic disease groups at a national level;
- Knowledge of labour force participation and social inclusion for people living with HIV and other episodic disabilities;
- Capacity to design the pilot project; and
- Effectiveness of knowledge sharing and dissemination activities.

New knowledge gains were also reported by individuals who participated in the National Episodic Disabilities Summit. In particular, Summit participants became more familiar with episodic disability partners across Canada and they gained knowledge of the labour force participation constraints faced by people living with other episodic disabilities.

3. *Knowledge Exchange*

CWGHR and its EDN partners continue to share information about related projects and initiatives, building a coordinated approach to activities, and have successfully integrated people living with episodic disabilities in order to provide a consumer perspective.

4. *Capacity Development*

EDN and NAC members have increased capacity to promote awareness in key areas with increased engagement and capacity of multi-sector stakeholders to respond to episodic disability issues in a coordinated way.

The policy analysis component of the project developed a clear focus for subsequent efforts to improve policy and programming around episodic disabilities, social inclusion and labour force participation. CWGHR gained substantial knowledge on the policy and program environment affecting labour force participation and social inclusion for people living with HIV and other episodic disabilities, and then applied this knowledge to develop relevant research questions that will continue to be pursued by CWGHR and the EDN.

5. *Knowledge Dissemination*

CWGHR's new knowledge of key policy and program issues faced by people with episodic disabilities has already been, and will continue to be, integrated into the design of future projects (including policy pilot projects), research projects, workshops, network building and information resource development.

Overall Conclusions

CWGHR's "*Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities*" project was successful in two important ways: 1) the project processes were collegial and beneficial for all involved; and 2) the project met each of its four objectives. Most importantly, and related to the project's primary objective, CWGHR led the development of new knowledge on lifelong, episodic disabilities and the implications for labour force participation and social inclusion, and has developed networks that will promote the translation and uptake of this new knowledge.

V. Identified Systemic Gaps in Supports for People with Episodic Disabilities

Identified systemic gaps fall into two categories:

- A. Identified policy gaps that resulted from research and consultations activities of the project
- B. Other identified systemic gaps that fall under federal, provincial and territorial jurisdictions

A. Identified Policy Gaps

Income Support and Benefits

1. Increased flexibility in the degree of workplace participation for CPP(D) recipients, which includes part-time work with partial CPP(D) benefits.
2. A Canada Pension Plan Disability Drop-Out Provision for those persons whose illness causes them to move in and out of the workforce.
3. A working income tax benefit (WITB) for low-income working persons with disabilities.
4. To encourage disabled employee hiring practices, a progressive tax refund or benefit subsidy to employers to address the costs of accommodations and of 'sick days' of employees with episodic disabilities.
5. Federal incentives provided to private health insurers to underwrite the premiums for employers to facilitate the employment of persons with pre-existing episodic disability conditions.
6. A federal plan to subsidize private insurers for the equivalent of the increased premiums paid by employers for employees with episodic disabilities.
7. A federal plan to continue the payment of premiums to the insurer for persons with episodic disabilities with comprehensive plans considering self-employment or employment without access to a benefits plan.
8. Portable prescription drug and health benefits provided through private insurers for workplaces covered by the same insurer.
9. A continuous federal extended health benefits plan for disability claimants.
10. Extended drug benefits for persons with disabilities, including episodic disabilities provided through federal funding supports, coordinated with the provinces and territories.
11. *Structure increased flexibility into the 'units' of EI Sickness Benefits. Traditionally, 'weeks' are the units of benefits for an EI recipient. However, the episodic nature of many disabilities means that, for some, working half days, or having a four day work week, facilitates a longer engagement in the labour force. Therefore, conceptualizing fifteen 'weeks' of EI benefits, as seventy-five days or one hundred and fifty half-days, may result in longer engagement in the workplace, without jeopardizing benefit weeks, with no additional expense to the Department.
12. *Extend EI Sickness Benefits for people not able to return to work for health reasons who need extra time before being able to participate again in the labour force. This may take the form of extensions of EI Sickness Benefits to the maximum length of claim for regular employment benefits. This would have particular significance and security for people with episodic disabilities who require a lengthier period of recuperation in order to regain the capacity for work.

Workplace Environment

13. Workplace Policy changes (legislative or voluntary) that
 - a. Result in continuous employee assistance that allow persons to work to their potential as their health permits, and
 - b. Provide income support and benefits coverage when not able to work.
14. A comprehensive employee support model, such as the NIDMAR model, for those who are employed.

Disability Management Centres

15. A unified system of structural supports that more fully addresses the needs of persons having episodic disabilities and their employers.
16. Accessible Disability Management Centres that provide individualized comprehensive case management support to both employers and employees through consulting and various other services designed to maintain disabled employees in the workplace to the largest extent possible.

*Note: Identified Policy Gaps 11 and 12 were developed subsequent to the March 2006 Summit.

B. Other identified systemic gaps that fall under federal, provincial and territorial jurisdictions

There are several opportunities for the federal, provincial and territorial jurisdictions to contribute to increasing accessibility of labour market for Canadians living with episodic disabilities. Identified opportunities for knowledge exchange and increased responsiveness on episodic disabilities have been grouped into themes and appear on the following chart.

Mobilizing an Action Plan for Inclusion of People Living with Episodic Disabilities

Themes	Action
To ensure awareness	<ul style="list-style-type: none"> • Education on Episodic Disabilities of federal, provincial and territorial staff working on disabilities • Development of internal Champions on episodic disabilities
Interministerial and Interjurisdictional Linkages	<ul style="list-style-type: none"> • Development of a proposal for an Integrated Strategy on Episodic Disabilities • Development of a feasibility study for a federal Interministerial Committee on Episodic Disabilities • Linkages with FPT Disability Advisory Committee • Linkages with PHAC Integrated Strategy Link
Stakeholder Supports	<ul style="list-style-type: none"> • Education of consumer groups and public on episodic disabilities • Coordination of programs and services for people with episodic disabilities • Employer education
Engagement of people living with episodic disabilities in the educational strategy of stakeholders	<ul style="list-style-type: none"> • Development of workshops by people living with episodic disabilities • Education and training of federal, provincial and territorial staff, employers, hr professionals and managers by people living with episodic disabilities
Building the Evidence in Episodic Disabilities	<ul style="list-style-type: none"> • Prevalence and Incidence Studies • Demonstration Projects • Develop clearing house on Episodic Disabilities resources • Evaluation of new and current initiatives

VI. Next Steps

Based on needs identified in consultation with relevant stakeholders a multi-year comprehensive strategy has been developed through which all stakeholders can collectively work toward increasing the accessibility of the labour force to people living with episodic disabilities.

In order to further this agenda, it will be critical to ensure that the education, policy, research, demonstration project and networking activities which CWGHR has developed in partnership with other NGOs, governments, public institutions (e.g. universities), professional associations, the private sector, and the public at large, are sustained.

VII. Appendices

Appendix I – List of National Episodic Disabilities Network Participants (Past and Present)

Michael Bach, Canadian Association of
Community Living

Carole Barron, Canadian Council on
Rehabilitation and Work

Laurie Beachall, Council of Canadians with
Disabilities

Glenn Betteridge, Canadian HIV/AIDS
Legal Network

Pamela Bowes, Lupus Canada

Dina Brooks, Canadian Lung Association

Ainsley Chapman, Canadian AIDS Society

Teren Clarke, Muscular Dystrophy
Association

Nichole Downer, Canadian AIDS Society

Judy Farrell, Lupus Canada

Judy Gould, Sunnybrook and Women's
College Hospital

Deanna Groetzinger, Multiple Sclerosis
Society

Kelly Grover, Institute for Work and Health

Francine Knoops, Canadian Psychiatric
Association

Deidre Lall, Arthritis Society

Chantale Lavoie, Canadian Breast Cancer
Network

Laurie Letheren, ARCH Disability Law
Centre

Heather Logan, Canadian Cancer Society

Jackie Manthorne, Canadian Breast
Cancer Network

Penny Marrett, Canadian Mental Health
Association

Tim McClement, Hepatitis C Society of
Canada

Marg Otter, Muscular Dystrophy
Association

Rowena Pinto, Canadian Cancer Society

Norma Ricker, Canadian Council on
Rehabilitation and Work

John Stapleton, Open Policy

Kim Thomas, Canadian AIDS Society

Glenn Thompson, Canadian Mental Health
Association

and 4 representatives from Consumer organizations

Statement of Common Agenda on Disability, Full Participation & Work

In Canada today, many people live with recurrent or episodic disabilities that are characterized by alternating periods of illness and wellness. As stated in the Government of Canada response to the 2003 report *Listening to Canadians: A First View of the Canada Pension Plan Disability Program*: “recurrent and episodic disabilities are becoming more prevalent in Canadian society”.

There are many systemic and practical barriers which prevent people with episodic disabilities from participating in the labour force, in communities, and in society in a meaningful way.

People living with disabilities have a right to participate fully and equally in Canadian society. Adequate income is an integral part of full participation.

People living with disabilities have a right to participate fully and equally in Canadian society.

Many people with disabilities rely on federal, provincial and private income support and replacement programs during periods when they are unable to participate fully in the workforce. However, certain aspects of these programs can act as disincentives to full participation.

In fact, the experience of many people with disabilities is that these programs trap them in poverty by creating barriers to staying on the job or returning to work. For people who live with episodic disabilities, this is especially true.

It is time that both public and private disability income support and replacement programs were reformed to meet the needs and aspirations of people living with disabilities.

We call upon the federal and provincial governments and private insurance companies to work with each other and with people living with disabilities to bring about long-overdue reform.

Signed,

- | | |
|--|--|
| ▪ ARCH: A Legal Resource Centre for Persons with Disabilities | ▪ Canadian Mental Health Association |
| ▪ Canadian Association of Nurses in AIDS Care | ▪ Canadian Working Group on HIV and Rehabilitation (CWGHR) |
| ▪ Canadian Association of Physical Medicine and Rehabilitation | ▪ COCQ-sida |
| ▪ The Canadian Association of Rehabilitation Professionals | ▪ Hepatitis C Society of Canada |
| ▪ Canadian Breast Cancer Network | ▪ Lupus Canada |
| ▪ Canadian Cancer Society – Ontario | ▪ Multiple Sclerosis Society of Canada |
| ▪ Canadian HIV/AIDS Legal Network | ▪ Muscular Dystrophy Canada |
| | ▪ Ontario Breast Cancer Research Initiative |

Appendix III – Fact Sheets on Episodic Disabilities

[An International Policy Review and Analysis Fact Sheet](#) (Microsoft Word: 142 KB)

[Program and Policy Recommendations for Episodic Disability Support Fact Sheet](#) (Microsoft Word: 142 KB)

[A Population-Based Economic Analysis of Episodic Work Benefits Fact Sheet](#) (Microsoft Word: 144 KB)

[An Analysis of Responses of Human Resources Professionals on Supporting Persons with Episodic Disabilities](#) (Microsoft Word: 145 KB)

Appendix IV – Posters on the Project Presented at Conferences

Pages 19a – 19e



Canadian Working Group on HIV and Rehabilitation

Groupe de travail canadien sur le VIH et la réinsertion sociale

An Analysis of International Support Policies & Programs for People with HIV & other Episodic Disabilities

BACKGROUND

The Canadian Working Group on HIV and Rehabilitation (CWGHR) has undertaken research on HIV and other Episodic Disabilities. The Episodic Disabilities Network (see box below) identified income support and workplace participation as priorities. project objectives to identify effective models, policies and programs that facilitate the optimal labour force engagement, as well as provide disability income and other support when not able to work, for people with HIV and other episodic disabilities. As part of the Episodic Disabilities Project, CWGHR undertook an international review of workplace and income support policies and programs, both public and private, in order to identify the disincentives to labour force participation for people with HIV and other episodic disabilities and develop recommendations to address the disincentives, while ensuring income and benefit supports when not able to work. A cost-benefit analysis will be undertaken on the recommended models, and form the basis for pilot sites that will be developed to test the effectiveness of models in the Canadian context.

1. RESEARCH QUESTIONS

1. 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?
2. What recommendations could 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?

2. METHOD

1. Key Guiding questions developed by multi-sectoral national advisory committee for policy and program analysis
2. International (Canadian, U.S., British, European and Australian) income support and policy and program analysis

What is the Episodic Disabilities Network (EDN)?

This network is comprised primarily of national organizations that represent or can embrace the interests of people living with disabilities and support issues related to episodic disabilities.

3. RESULTS

COMMON CHARACTERISTICS OF EFFECTIVE MODELS

- multi-sector coordination - incentives / legislation for employers to participate
- flexibility to accommodate episodic participation in the labour force
- income and benefit support when disability did not allow for labour force participation

The final report includes recommendations for incorporating aspects of models in Germany, the Netherlands, British and Scandinavian countries, into the Canadian market system. These recommendations target the private and public sector for policies and programs that will be created to better enable people with episodic disabilities to participate in the labour force to their potential.

4. CONCLUSIONS

The cross-disability approach resulted in a larger collection of models and programs to review than if it was HIV-specific.

Further research is needed to determine the effectiveness of models, or components thereof, that are effective in other jurisdictions when implemented in the Canadian context.

The planned cost-benefit analysis and the impact on participants with episodic disabilities at the pilot sites will enhance the new-knowledge gained in this study.

The multi-sectoral consultation ensures engagement of relevant sectors.

What are Episodic Disabilities and their challenges?

The unpredictable nature of HIV and other episodic disabilities, such as multiple sclerosis, mental illness and cancer, can present challenges to active labour force participation, stable income and social inclusion as fluctuations occur in a person's ability to participate in the labour force. Disability workplace and income support policies and programs may be well-designed for people who can no longer take part in the labour force, but do not meet the needs of those who can participate episodically in the labour force.

Contact Information

Eileen McKee, Canadian Working Group on HIV and Rehabilitation (CWGHR). 600-1240 Bay Street, Toronto, ON M5R 2A7. TEL: (416) 513-0440 x.234, EMAIL: emckee@hivandrehab.ca



A STRATEGY FOR POLICY CHANGE: ADDRESSING RETURN TO / STAY AT WORK DISINCENTIVES

By Eileen McKee and Ken King, Canadian Working Group on HIV and Rehabilitation

What are Episodic Disabilities and their challenges?
 The unpredictable nature of HIV and other episodic disabilities, such as arthritis, asthma, mental illness and cancer, can present challenges to active labour force participation, stable income and social inclusion as fluctuations occur in a person's ability to participate in the labour force. Disability workplace and income support policies and programs may be well-designed for people who can no longer take part in labour force, but do not meet the needs of those who can participate episodically in the labour force.

Background
 The Canadian Working Group on HIV and Rehabilitation (CWGHR) has undertaken research on HIV and other Episodic Disabilities. As part of the Episodic Disabilities Project, CWGHR undertook an exploratory research project to identify barriers to labour force participation and develop recommendations to address the disincentives, while ensuring income and benefit supports when not able to work. A cost-benefit analysis on the recommended models has been completed and these two reports form the basis for the results from an online survey analysis of Certified Human Resources Professionals are also discussed.

Research Questions
 1. What are the key findings of international policies and programs that facilitate or inhibit income support and meaningful labour force participation of people living with HIV and other episodic disabilities?
 2. What recommendations could be made regarding the implementation of policies that promote the development of meaningful labour force participation of people living with HIV and other episodic disabilities?

Methods
 A. Key Guiding questions developed by multi-sectoral national advisory committee for policy and program analysis
 B. International (Canadian, U.S., British, European and Australian) income support and policy and program analysis
 C. Developing a model for the Canadian disability support context
 D. Coding Analysis of a key research finding
 E. A survey of Certified Human Resources Professionals on understanding of and support mechanisms used in providing workplace supports

Step 1

An International Policy Analysis
 The Social Program Evaluation Group (SPEG) at Queen's University was contracted to conduct an international literature-based review of key aspects and rigour of legislative or enforceable labour policies and programs affecting people with Episodic Disability & made primary policy recommendations.

Key Points
 • Disability is not only a medical condition. Legislators, professionals & business leaders should adopt a 'social' approach to defining disability and commit to making income assistance & employment policies integrated, flexible, & timely.
 • Governments should create tax incentives or grants for groups trying to achieve better services.
 • Everyone including case managers, legislators, community support groups, lobby groups, physicians & employers, needs to be better informed on the advantages of involving people with episodic disabilities more equitably in our social systems.

Conclusion
 What will work in Canada must accommodate the complexities of our federal/provincial and municipal levels of government, each with its own legislation and structures for administration of income assistance and employment programs. Foremost among the recommendations is an incremental process in which stakeholders work to streamline & coordinate systems, under the leadership of the federal government.

Step 2

Model Recommendations for Persons with Episodic Disabilities in the Canadian Context
 National projects as well as information obtained directly from persons with episodic disabilities were evaluated to produce the recommendations below for a model that addresses the income and health care needs of persons with episodic disabilities in the Canadian context.

Income Support and Benefits

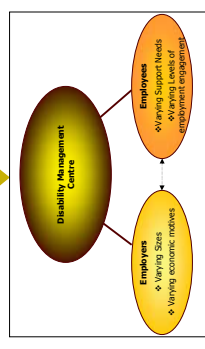
- Increased flexibility, including part-time work with partial CPP(D) benefits, for CPP(D) recipients.
- A CPP(D) Drop-Out Provision for disabilities which decrease CPP contributions
- A working income tax benefit (WITB) for low-income working persons with disabilities.
- A progressive tax refund or subsidy to employers for costs of accommodations & 'sick days'.
- Federal plans
 - For private insurers to underwrite the premiums for employers to facilitate the employment of persons with pre-existing conditions.
 - to subsidize private insurers for the equivalent of the increased premiums paid by employers.
 - to continue the payment of premiums to the insurer with comprehensive plans considering self-employment or employment for persons without access to a benefits plan.
- Portable prescription drug and health benefits provided through private insurers for workplaces covered by the same insurer.
- A continuous federal extended health benefits plan for disability claimants.
- Extended drug benefits provided through federal funding supports, coordinated with the provinces and territories.

Workplace Environment

- Workplace Policy changes (legislative or voluntary) that result in continuous employee assistance that allow persons to work to their potential as their health permits, provide income support and benefits coverage whether or not able to work.
- A comprehensive employee support model, such as the National Institute for Disability Management and Research model, for those who are employed.

Disability Management Centres

- A unified system of structural supports that more fully addresses the needs of persons with episodic disabilities and their employers designed to facilitate the recruitment and retention of employees with episodic disabilities in the workplace to the largest extent possible.



Step 3

An Economic Analysis of Income Support Benefits

Goal
 To provide an economic assessment of a more flexible proposed hypothetical CPP-D benefit program to allow disabled persons who resume work to retain a portion of their CPP-D benefits.

Method
 The Life at Risk™ platform incorporates demographic, chronic disease and economic models to yield an assessment of policy decisions by estimating the change in key economic variables based on a 28 year simulation period, from 2006 to 2033. The diseases included in this analysis are cancer, circulatory diseases, mental illness, HIV/AIDS & chronic obstructive pulmonary disease. The primary CPP-D factors used to derive the gross economic value of the proposed hypothetical CPP-D policy include:

- The portion of usual CPP-D entitlement that could be retained if a CPP-D recipient partially returned to work.
- The percentage of currently eligible CPP-D recipients that can be induced to enter back into the Canadian workforce by virtue of the hypothetical CPP-D policy.
- The percentage of work that CPP-D recipients could work if they choose to under the hypothetical CPP-D policy. The modelled average of work ranges between 0% and 43.3%, with an expected average of 20%.
- The percentage of CPP-D recipients that would be able to return to work under the hypothetical CPP-D policy would be able to work 20% of normal working hours.

Note: The results are for the gross economic gain expected from a hypothetical CPP-D policy.

Results and Conclusion
 The table below summarizes the results of the Life at Risk™ simulations for the hypothetical CPP-D policy scenario.

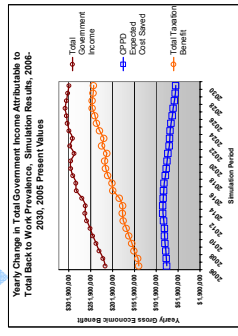
The number of disabled people going back to work under the hypothetical CPP-D policy will have a significant positive impact on the economy in every year of the forecast period due to:

- higher labour force participation;
- higher total tax revenues for the federal and provincial governments;
- lower cost of CPP-D payments (partial to those CPP-D recipients that go back to work).

The results of the most conservative estimate show that there are gross economic benefits derived from the proposed hypothetical CPP-D policy. The total cumulative benefit expected to accrue to the government from incremental taxation revenue and a reduction in CPP-D payments from 2007 to 2011 is \$32 million, in 2006 dollars. The total cost of the program, from 2007 to 2011, is \$10 million, and the net benefit is \$22 million, or 20% of total program costs.

Estimated CPP-D Recipients Going Back to Work from proposed hypothetical CPP-D Policy Scenario

Range	Cumulative from 2007 to 2011	Cumulative from 2007 to 2016	Yearly Average 2007 to 2010
95% Lower Bound	214,391	462,256	97,020
Expected	262,150	569,835	69,762
95% Upper Bound	318,965	720,890	85,447



An Analysis of Certified Human Resources Professionals' (CHRP) Responses to a Survey about Episodic Disabilities

Rationale and Method
 Human Resources (HR) professionals can play a pivotal role in maximizing the work potential of employees, including employees with episodic disabilities.

- What is the level of knowledge of HR professionals regarding episodic disabilities?
- What additional training do HR professionals need to more effectively support employees with episodic disabilities?

CWGHR implemented a national survey to determine the knowledge and training needs of HR professionals regarding episodic disabilities. Responses from 482 CHRPs were analyzed.

Results

- > 60% of the respondents report having little to no knowledge on managing cases of episodic disabilities.
- Part-time work arrangements & continuing salary are the most common forms of income support offered by HR professionals.
- 70% of HR professionals report that the workplace accommodation policies at their organizations need review.
- > 75% of all return-to-work programs involve part-time work.
- Almost 70% of respondents report inability to identify episodic disability cases within their caseload.
- > 50% of respondents report that their training was not useful with respect to episodic disabilities.
- 56% of CHRPs interviewed express interest in training specific to episodic disability issues.

Recommendations

- Expand existing income support mechanisms available to HR professionals, such as partial CPP(D) benefits.
- Demonstrate leadership through the Canadian Council of Human Resources Associations & its affiliated associations to
 - create solutions to systemic & legislative barriers,
 - develop resources for CHRPs to provide appropriate support for employees with episodic disabilities,
 - foster opportunities for communication between HR professionals to exchange ideas & insights,
 - develop curriculum content specific to episodic disabilities.

Conclusion

- The cross-disability approach resulted in a larger collection of modes and programs to review than a single-disability, HIV-specific approach.
- Further research is needed to determine the effectiveness of models, or components thereof, that are effective in the workplace for these models are implemented in the Canadian context.
- Future cost-benefit analyses including the impact on participants with episodic disabilities at the pilot sites will enhance the new knowledge gained in this study.
- The multi-sector consultation enhances engagement of relevant sectors.



Canadian Working Group on HIV and Rehabilitation

Groupe de travail canadien sur le VIH et la réinsertion sociale

Using a Multi-Sector & Episodic/Cross-Disability Design for Policy Change: An Integrated Employment/Income Support System

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ON M5R 2A7. TEL: (416) 513-0440 x 234, Email: emckee@hivandrehab.ca

Issue

Today, people living with HIV who have access to treatment are living longer, but also with intermittent disabilities. There are many disabilities that are similar to HIV, such as multiple sclerosis, mental illness, hepatitis C, lupus and some forms of cancer, in that they are lifelong and episodic in nature. As fluctuations occur in a person's functioning and health, the unpredictable nature of HIV and other *episodic disabilities*, present challenges to active labour force participation, stable income and social inclusion.

Objectives

1. Develop progressive solutions for optimal labour force engagement, income and benefit supports for people with episodic disabilities
2. Determine the cost of the primary recommendations
3. Determine knowledge, skills and training needs of human resources professionals about episodic disabilities

Description of Research

Implementing a multi-sector and cross-disability perspective (see charts below), CWGHR undertook:

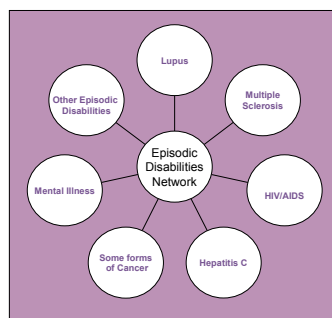
- an international review of private and public workplace and income support policies and programs, to develop progressive solutions for optimal labour force engagement, income and benefit supports for people with episodic disabilities
- a cost-benefit analysis of the primary recommendations
- a survey/analysis of the knowledge, skills and training needs of human resources professionals about episodic disabilities

Lessons Learned

1. Common themes of effective models include:
 - multi-sector coordination among all relevant private & public sector stakeholders;
 - flexibility in policies & programs to accommodate episodic participation in the labour force
 - sustainable income and benefit support regardless of employment status.
2. Policy changes that allowed for partial disability income support when a person with an episodic disability worked part time would result in significant cost savings.
3. There is a need for a core body of knowledge and training on episodic disabilities for Human Resources professionals.
4. There is a need for more disability plans offered through the private sector.



Multi-Sector Perspective



Cross-Disability Perspective on Episodic Disabilities

Conclusions

- Current disincentives to employment must be removed from policies and programs. Flexible policies must be implemented to enable people with episodic disabilities to participate effectively in the workforce and promote income security regardless of employment status.
- Human Resources professionals, disability case workers, employment counselors and employers need education and training about episodic disabilities.
- More insurance options with incentives to participate in the labour force to one's potential are needed.
- Further research is needed to evaluate the recommendations in real-life situations.



Using a Multi-Sector & Episodic/Cross-Disability Design for Policy Change: An Integrated Employment/Income Support System

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Issue

Today, people living with HIV who have access to treatment are living longer, but also with intermittent disabilities. There are many disabilities that are similar to HIV, such as multiple sclerosis, mental illness, hepatitis C, lupus and some forms of cancer, in that they are lifelong and episodic in nature. As fluctuations occur in a person's functioning and health, the unpredictable nature of HIV and other *episodic disabilities*, present challenges to active labour force participation, stable income and social inclusion.

Purpose

To research and develop flexible policy and program options for accommodating people living with episodic disabilities in the labour force.

Description of Research

Using multi-sector and cross-disability perspectives (see charts below):

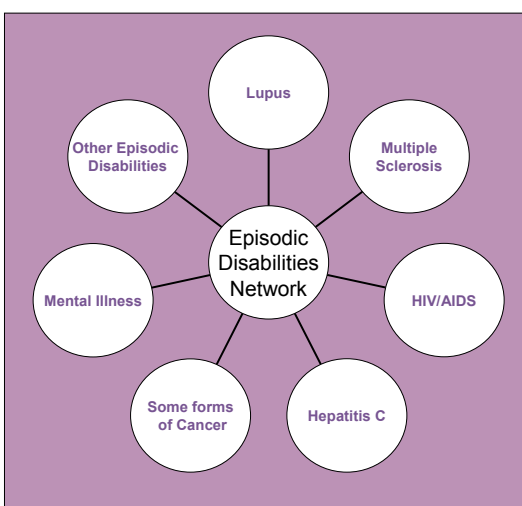
- Undertake an international review of private and public workplace and income support policies and programs
- Recommend progressive solutions for optimal labour force engagement, income and benefit supports for people with episodic disabilities
- Undertake a cost-benefit analysis of the primary recommendation
- Complete a survey/analysis of the knowledge, skills and training needs of human resources professionals about episodic disabilities

Lessons Learned

1. Effective models included:
 - multi-sector coordination among all relevant private & public sector stakeholders;
 - flexibility in policies & programs to accommodate episodic participation in the labour force with sustainable income and benefit support regardless of employment status.
 - partial disability income support integrated with employment earnings when a person with an episodic disability works part time
2. These flexible models can result in significant cost savings to the insurance carrier & in more labour force participation options for people with episodic disabilities.
3. There is a need for a core body of knowledge and training on episodic disabilities for human resources professionals.



Multi-Sector Perspective



Cross-Disability Perspective on Episodic Disabilities



Conclusions

- Current disincentives to employment must be removed from policies and programs. Flexible policies must be implemented to enable people with episodic disabilities to participate effectively in the workforce and promote income security regardless of employment status.
- Human Resources professionals, disability case workers, employment counselors and employers need education and training about episodic disabilities.
- Further research is needed to evaluate the recommendations in real-life situations.

Next Steps

With all relevant stakeholders:

- Design pilot sites in workplaces to implement the recommendations and reduce risk for people living with episodic disabilities to engage in the workforce
- Evaluate the implications of the policy and program changes on workforce participation, health, quality of life, economic and social variables



Canadian Working Group on HIV and Rehabilitation

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A National Voice for People Living with Episodic Disabilities

Authors: Eileen McKee, MSW, MBA; Ken King, Episodic Disabilities Initiatives
The Canadian Working Group on HIV and Rehabilitation (CWGHR)

Background: Research undertaken by the Canadian Working Group on HIV and Rehabilitation (CWGHR) since 2001 has shown there are many disabilities similar to HIV in that they are lifelong with unpredictable episodes of wellness and impairment. Examples include Hepatitis C, Lupus, multiple sclerosis, some forms of mental illness, cancer and arthritis. This episodic component can negatively impact labour force participation, care plans, stable income and social inclusion. Over the past three years, CWGHR has been coordinating a group of organizations representing people living with Episodic Disabilities, called the Episodic Disabilities Network (EDN).

Objectives: To determine the need and format for including the voice of people living with HIV and other episodic illnesses.

Methods: Needs assessments were conducted with existing groups familiar with CWGHR's episodic disabilities initiatives: the National Advisory Committee for CWGHR's "Episodic Disabilities Project" ¹, the project's Pilot Site Steering Committee and the EDN. These groups, including 30 individuals and organizations, were asked about the need for, purpose of and format to integrate the voice of people living with episodic disabilities.

Results: The respondents unanimously supported strategies that will

- integrate the voice of people living with HIV and other episodic disabilities
- provide a forum for knowledge exchange
- inform decisions affecting people living with HIV/AIDS and / or other episodic disabilities
- lessen isolation
- provide a source for cohorts for research or consultations.

The respondents also supported the inclusion of people living with episodic disabilities in the existing national EDN as the format of first choice for implementing these strategies.

Conclusions: In addition to organizations working on support and other issues related to episodic disabilities, a national voice for and of persons living with episodic disabilities is a critical component in a comprehensive strategy to enhance the care and treatment of persons living with HIV and other episodic illnesses.

Next Steps:

- Revise the Terms of Reference for the organizationally based EDN to include persons living with episodic disabilities.
- Determine the structures that will facilitate attaining the objectives, such as knowledge exchange, participation in cohort studies and participation in policy activities.

¹ In response to this issue, CWGHR coordinated a national multi-phase 'episodic disabilities' project funded by Human Resources and Social Development Canada. The project has researched policies internationally, recommended models to accommodate episodic disabilities and implemented a cost-benefit analysis. It will be important to implement demonstration projects to test and evaluate the models in a Canadian context. The result will be evidence-based recommendations for policy improvements that will contribute to labour force participation and social inclusion of people living with episodic disabilities.

Appendix V – Pre-Budget Submission (September 2005)

Pages 20a – 20n

**ENHANCING PRODUCTIVITY GROWTH IN CANADA:
REMOVING BARRIERS TO WORK FOR PEOPLE WITH EPISODIC
DISABILITIES**

A Submission to the House of Commons Standing Committee on
Finance

Submitted by: Episodic Disabilities Network

Date: September 2005

For additional information, please contact: emckee@hivandrehab.ca.

EXECUTIVE SUMMARY AND RECOMMENDATIONS

The Episodic Disabilities Network* supports the priority that the Standing Committee on Finance has placed on productivity growth and human capital in Canada. In order to enhance productivity in Canada, we need to realize the potential of our greatest asset – our human resources. For too long the human resource potential of people with episodic disabilities has gone unfulfilled. People with episodic disabilities are left on the margins of the labour force by programs which do not do enough to facilitate their participation in the labour force. In fact, many of the programs, either individually or in the interaction among them, act as a disincentive to labour force participation. This is in sombre contrast to Canada's human rights obligations, under both international law and Canadian law: specifically the right to equality, and the need for measures to actively secure and promote equality.

Towards this end, and in response to the request for input on the Federal Budget, the Episodic Disabilities Network provides the following recommendations to increase the productivity growth of the Canadian labour force by facilitating the participation of people living with episodic disabilities:

- 1. Provide enhanced funding to the Federal / Provincial / Territorial Benefits and Supports for people with Disabilities Committee to address the incompatibility of income support and benefits** plans.**
- 2. Increase financial support to episodic disabilities communities and organizations to participate in consultations, training opportunities and partnerships that are related to benefits and supports for people with episodic disabilities.**
- 3. Facilitate a process for preserving extended health care, housing and other supports for CPP-D recipients who wish to participate in the labour force to their potential.**
- 4. Increase the flexibility in the degree of participation in the workplace for CPP-D recipients, which includes part-time work with inversely proportional CPP-D benefits.**
- 5. Provide resources for pilot programs aimed at implementing these recommendations**
- 6. Provide the resources for the education and training of those key stakeholders in the fields of rehabilitation and human resources regarding episodic disabilities, as it relates to their professional roles in assisting individuals to work to their potential.**

*Appendix I contains the list of organizations which endorse these recommendations.

** Throughout this document, the term "benefits" and "supports" are inclusive of extended health benefits, assistive devices, housing subsidies and other supports that are basic to one's quality of life.

What is the Episodic Disabilities Network?

The Episodic Disabilities Network (EDN) is a network of national associations that promote and advocate for people with episodic disabilities. The secretariat for this network is supported by the Canadian Working Group on HIV and Rehabilitation (CWGHR). Since 1998, CWGHR has coordinated a national response to rehabilitation issues in the context of HIV disease through research, education and multi-sectoral partnerships. As HIV is experienced as a lifelong episodic condition for many people, characterized by alternating periods of disability and wellness, there are many similarities between the experiences of people living with HIV and those living with other episodic conditions. CWGHR has been exploring these issues by undertaking research and developing alliances with other disability groups to build a knowledge base on issues related to HIV and other episodic disabilities.

What are Episodic Disabilities?

During the last decade or more, episodic disabilities, characterized by distinct periods of illness and wellness, have become more prevalent in Canadian society. Increasing numbers of Canadians are living with episodic disabilities, which include: cancer, HIV/AIDS, lupus, muscular dystrophy, multiple sclerosis and mental illnesses such as schizophrenia and mood disorders. One of the key distinguishing features of an episodic disability is its unpredictability, which can force people out of the workforce without warning, and then, over time, resolve itself and allow people to return to work.

Systematic barriers like inflexible workplace practices and rigid disability pension requirements often prevent people with episodic disabilities from participating fully in the workforce and in their communities in a meaningful way.

A Cross-Disability Perspective

The Episodic Disabilities Network has identified a number of shared issues. All groups agree on the importance of the need for further investigation into barriers to stable and adequate income support, labour force participation and social inclusion. As income support and labour force participation are inextricably linked for most people with episodic disabilities, barriers to and models for stable and adequate labour force participation and social inclusion must be critically examined in order to facilitate labour force participation for those living with episodic disabilities.

THE ISSUE

The Statement of Common Agenda, endorsed by twelve disability-related organizations who are participants of the EDN, calls for:

...long-overdue reform to both public and private disability income insurance and support programs. ... Although there is currently some flexibility for people with episodic illnesses in public and private disability income support and replacement programs, these programs include disincentives that make it difficult for people with episodic disabilities to return to the workforce. In addition, the programs and their requirements are often communicated poorly to those who need them the most. The rules and decision-making processes are complex, not well publicized, and lack transparency.

The federal government is to be applauded for its efforts to recognize that people with disabilities face a number of challenges when re-entering the workforce; however, more needs to be done. Although many people with episodic disabilities are eligible for coverage and/or currently receive disability benefits through Canada Pension Plan Disability Program or private insurance, current policies do not recognize and/or accommodate the needs of people with episodic disabilities for flexible work options and income support nor do they recognize the concept of part-time work. For example, In *Listening to Canadians*, the *Standing Committee on Human Resources and the Status of Persons with Disabilities* recommended that “the terms ‘severe and prolonged’ [be] amended to take into account cyclical and degenerative conditions.”¹ Current legislation does not provide access to the CPP-D program on an as-need basis, based on the fluctuating level of a person’s functioning and disability.

Not only do existing policies provide disincentives for individuals with disabilities to return to work / stay at work, they contradict basic principles inherent in international documents. The following, from the 1993 United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities*, addresses the right to equality, and the need for measures to actively secure and promote equality:

“States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment . . . they must have equal opportunities for productive and gainful employment in the labour market.”²

¹ *Listening to Canadians. A First View of the Future of the Canada Pension Plan Disability Program.* Standing Committee on Human Resources and the Status of Persons with Disabilities. June 2003.

² 1993 United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities.* Fuller version in Appendix I

The United Nations *Standard Rules* further adds that states should recognize their responsibility to provide income maintenance to persons with disabilities. *Standard Rules* related to employment and income for people with episodic disabilities include:

- *actively supporting the integration of persons with disabilities into open employment.... through a variety of measures, such as vocational training, incentive-oriented quota schemes, reserved or designated employment, loans or grants for small business, exclusive contracts or priority production rights, tax concessions, contract compliance or other technical or financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities.*
- *Cooperating with organizations of persons with disabilities to create training and employment opportunities, including flexible hours, part-time work, job-sharing, self-employment and attendant care for persons with disabilities.*
- *ensuring the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities, including the costs frequently incurred by persons with disabilities and their families as a result of the disability.*
- *Providing incentives to restore the income-earning capacity of persons with disabilities by contributing to the organization, development and financing of vocational training and placement services.*
- *Providing incentives for persons with disabilities to seek employment in order to establish or re-establish their income-earning capacity.*³

The *Committee on Finance*, in its invitation for views on policy changes to enhance Canada's productivity, has recognized the importance of human capital and productivity as areas for action. The Committee on Finance has an opportunity to also recognize the right of people with disabilities to participate in the labour force to their potential. For these reasons, policies that result in disincentives to participation in the labour force demand careful examination.

The federal government has a unique opportunity to demonstrate its belief in the importance of the people of Canada to contribute to the country's economy to the best of their ability by ensuring that the people of Canada have a well-coordinated strategy, with collaboration from all levels of government, to maximize employment potential, including the employment potential of those with episodic disabilities, while at the same time, increasing the productivity of all of its human capital.

³ 1993 United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities*. Fuller version in Appendix I

RECOMMENDATIONS

Recommendation:

1. **Provide enhanced funding to the Federal / Provincial / Territorial Benefits and Supports for people with Disabilities Committee to address the incompatibility of income support and benefits plans across jurisdictions.**

The Federal government should take a leadership role, and provide funding for provincial participation with the intent to coordinate programs that people with disabilities rely upon for income and other support to increase their ability to participate in the labour force, as is well-articulated in *In Unison*⁴. The Federal Government should provide the resources for this FPT Committee to develop and implement the process that would result in an integrated income support and benefits system that allows persons with episodic disabilities to participate in the labour force to their potential. This leadership can be demonstrated in numerous ways:

- Facilitate the creation of one entry point for applicants to federal, provincial and private plans. The individualized needs of each recipient may be met by more than one plan;
- Provide funding for case managers / advocates to inform a recipient of benefits, entitlements and return-to-work / stay-at-work incentives. This speaks to the need for a *case management approach* that crosses all three types of plans to:
 - Inform the recipients of entitlements and the employment incentives;
 - Address the perception accurately that ‘employment means loss of benefits’;
 - Ultimately maximize the recipient’s potential to participate in the labour force;
- Provide funding for a comprehensive and effective communications plan that results in people with episodic disabilities making informed decisions regarding labour force participation. *Improving the Odds* provides insight on factors that can be addressed to improve the employment and income situation of people with disabilities, such as return-to-work and stay-at-work incentives.

The following are comments from focus group participants:

“...when coverage is needed but not available through the workplace, people may have few practical options but to remain out of - or exit – the labour force in order to get the publicly funded supports that in many cases are not sufficiently available to employed people....people with disabilities considering entering paid employment, “... may withdraw from opportunities offered. It [work] would mean a loss of non-cash benefits ...As well, there are less and less jobs with [any] benefits, so work may not provide the benefits that people with disabilities need.”⁵

These comments speak to the real or perceived risk when considering employment. If perceived, this speaks to the need for a more comprehensive and effective communication strategy to inform recipients about available benefits. But perhaps even more than this, it may speak to the need for greater coordination in a very complex, multi-plan, multi-jurisdiction approach to the provision of income support and benefits that may or may not be at risk when a recipient considers returning to or staying at work.

⁴ *In Unison: A Canadian Approach to Disability Issues*. Federal/Provincial/Territorial Ministers Responsible for Social Services, 1997.

⁵ *Improving the Odds: Employment, Disability and Public Programs in Canada*, Roeher Institute, 2004. p.63

Recommendation:

2. Increase funding to support episodic disability communities and organizations to participate in consultations, training opportunities and partnerships that are related to benefits and supports for people with episodic disabilities.

Local non-governmental organizations (NGOs) are strategic partners for disability program administrators and communications personnel promoting and processing policies. This right of persons with disabilities to participate in consultations is recognized in Rule 18 of the 1993 UN Standard Rules:

“States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.”⁶

Unfortunately many episodic disability communities and organizations are underfunded and have limited ability to provide extensive training and education sessions, as well as staff time to contribute to partnerships.

Recommendation:

3. Facilitate a process for preserving extended health care benefits, housing and other related supports for CPP-D recipients to participate in the labour force to their potential.

The link between extended health care benefit entitlement income level and income is one of the strongest disincentives to return to work.

“HALS 1991 showed that many thousands of people with disabilities (120,000) did not seek employment out of concern about losing medical or other benefits....In recent research... full or partial withdrawal of supplemental benefits ... may discourage recipients from attempting to mix short-term employment and social assistance with the result that they may leave the labour force and rely on social assistance full time.”⁷

Efforts should therefore be made to preserve extended health benefits and other social assistance for people with episodic disabilities who attempt to stay at or return to work. This is central to their sense of well-being and security and a key component of their well-being and ability to participate to their capacity in the labour force.

To address this disincentive, the federal government should explore its role in the provision of extended health care benefits and other social assistance to CPP-D recipients who wish to participate in the labour force to their potential. Preservation of extended health care benefits may be in the form of a federal ‘pharmacare’, or a federal role in ‘pharmacare’.

⁶ 1993 United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities*. Fuller version in Appendix II

⁷ *Improving the Odds*, Roeher Institute, p. 63

Recommendation:

4. Increase the degree of flexibility of workplace participation for CPP-D recipients, with part-time work with inversely proportional CPP-D benefits.

Although CPP-D is to be lauded for introducing *automatic reinstatement* as an incentive, it does not address the needs of those individuals who are not able to work full-time because of health restrictions. CPP-D does have a non-reportable \$4100 earning allowance; however, this is not a policy that is an incentive to return to or stay at work. We therefore recommend inversely proportional CPP-D benefits for CPP-D recipients in less-than-full-time work due to health restrictions. Such support for part-time work and job-sharing would offer financial, health and social benefits: social inclusion, paying CPP-D premiums and taxes, and contributing to the labour force. At the same time, it would be reasonable that CPP-D payments proportionally decrease as the earned income increased. In summary, part-time work complemented by partial CPP-D payments for CPP-D recipients who are unable to work full-time, is a return-to-work / stay-at-work incentive. Without incentives to participate as fully as possible in the labour force, people with episodic disabilities will be leaving the workplace entirely to become entitled to CPP-D income support, and face life-long poverty when they have the capacity to return to / remain in the workplace

Information obtained from a service provider in the community provided insight on some of the challenges faced by individuals with episodic disabilities:

“Clients who are CPP-D recipients who are preparing themselves for work are in need of flexible schedules that accommodate their physical limitations. This often means declaring their availability for part-time work. This may be with the intention of transitioning to full-time work, or it may remain at part-time, or change to unemployment, dependent upon health status. There is the perception that CPP-D does not understand this need for flexibility.”⁸

⁸ Quote from a service provider.

Recommendation:

5. Provide resources for pilot programs aimed at implementing these recommendations.

From a fiscal point of view, increased coordination of income security benefits and support programs for people with disabilities is assumed to be a positive scenario from all perspectives. Increased labour force participation results in less reliance on benefits from federal and provincial programs, therefore a cost savings to programs like CPP-D. People with disabilities, with increased financial independence, will have a higher standard of living. Canadian society will have increased productivity when people with disabilities participate in labour force based on skills and abilities.

Further research is required that includes a comparison of the cost of the medical benefits and supports for the CPP-D recipient who returns to the labour force part-time with the contributions they make, such as premiums to CPP, Employment Insurance, Workers' safety Insurance Board and other plans, health and income taxes, as well as the increased purchasing power that is generated by increased income. Also included in the analysis are the long-term implications on retirement income, since the earned income, used to determine RRSP contribution allowances and CPP rates, will be higher.

In addition, there are assumed benefits that go beyond income levels, such as social inclusion and integration, self-esteem and mental health. These are all assumptions that need to be well-evaluated. Pilot programs aimed at implementing these recommendations need to be supported.

Recommendation:

6. Provide the resources for the education and training of those key stakeholders in the fields of rehabilitation and human resources regarding episodic disabilities, as it relates to their professional roles in assisting individuals to work to their potential.

The role of Rehabilitation professionals in supporting individuals with episodic disabilities to participate to their fullest potential in the labour force cannot be emphasized enough. CPP-D needs to investment in human capital by funding a co-ordinated approach to training and education of rehabilitation professionals on the implications of episodic disabilities. Such an investment in human capital will result in rehabilitation professionals understanding the specific implications of, barriers to, and supports for, episodic disabilities. With this enhanced care, CPP-D beneficiaries, as well as others with episodic disabilities, will have greater participation levels in the labour force, resulting in future cost savings for programs such as CPP-D.

CONCLUSIONS

The recommendations include but are not limited to:

- 1. Enhanced funding to the Federal / Provincial / Territorial Benefits and Supports for people with Disabilities Committee to address the incompatibility of income, housing and related-support and benefits plans for people with episodic disabilities. –**
- 2. Increase funding for non-government organizations of people with episodic disabilities to participate in consultations, training opportunities and partnerships with disability programs.**
- 3. A process for preserving extended health, housing and related benefits for CPP-D recipients who wish to participate in the labour force to their potential.**
- 4. Increased flexibility in the degree of participation in the workplace for CPP-D recipients, which includes part-time work with inversely proportional CPP-D benefits.**
- 5. Resources for pilot programs aimed at implementing these recommendations**
- 6. Resources for the education and training of those key stakeholders in the fields of rehabilitation and human resources regarding episodic disabilities, as it relates to their professional roles in assisting individuals to work to their potential.**

National leadership is needed to establish strong and coherent policies that prioritize early intervention, comprehensive treatment, vocational rehabilitation and labour force participation incentives to address the episodic experiences of people with disabilities.

Actions that reduce the disincentives to returning to work and/or support an employee to stay at work are not a trade-off, but an investment in human capital, in human rights, in productivity and in labour force participation.

APPENDIX I

The Submission has been circulated to participants of the Episodic Disabilities Network.

Endorsing Organizations as of September 6, 2005

Canadian AIDS Society

Canadian HIV/AIDS Legal Network

Canadian Mental Health Association

Canadian Working Group on HIV and Rehabilitation

Lupus Canada

Multiple Sclerosis Society of Canada

Schizophrenia Society of Canada

APPENDIX II

Exerpts from Rules 6, 7 and 18 of the The 1993 United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities*

The 1993 United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities* recognizes the rights of persons with disabilities to equal opportunities for employment, as well as the responsibility of states to provide income maintenance to persons with disabilities:

Rule 6: Employment

States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment . . . they must have equal opportunities for productive and gainful employment in the labour market. [*Bullets have replaced numbers because not all of the Rules are listed.*]

- States should actively support the integration of persons with disabilities into open employment. This active support could occur through a variety of measures, such as vocational training, incentive-oriented quota schemes, reserved or designated employment, loans or grants for small business, exclusive contracts or priority production rights, tax concessions, contract compliance or other technical or financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities.
- States, workers' organizations and employers should cooperate to ensure equitable recruitment and promotion policies, employment conditions, rates of pay, measures to improve the work environment in order to prevent injuries and impairments and measures for the rehabilitation of employees who have sustained employment-related injuries.
- States, workers' organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create training and employment opportunities, including flexible hours, part-time work, job-sharing, self-employment and attendant care for persons with disabilities.

Rule 8: Income maintenance and social security

States are responsible for the provision of social security and income maintenance for persons with disabilities.

- States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities. States should ensure that the provision of support takes into account the costs frequently incurred by persons with disabilities and their families as a result of the disability.
- Social security systems should include incentives to restore the income-earning capacity of persons with disabilities. Such systems should provide or contribute to the organization, development and financing of vocational training. They should also assist with placement services.
- Social security programmes should also provide incentives for persons with disabilities to seek employment in order to establish or re-establish their income-earning capacity. Income support should be maintained as long as the disabling conditions remain in a manner that does not discourage persons with disabilities from seeking employment. It should only be reduced or terminated when persons with disabilities achieve adequate and secure income.

Rule 18: Organizations of persons with disabilities

States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.

- States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy.
- States should establish ongoing communication with organizations of persons with disabilities and ensure their participation in the development of government policies.
- The role of organizations of persons with disabilities could be to identify needs and priorities, to participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, and to contribute to public awareness and to advocate change.
- The role of local organizations of persons with disabilities should be developed and strengthened to ensure that they influence matters at the community level.

Appendix VI – List of Presentations and Consultations

CONFERENCE PRESENTATIONS AND CONSULTATIONS

November 2006 '*Using a Multi-Sectoral and Cross-Disability Design for Policy Change*' – Ontario HIV/AIDS Treatment Network Annual Conference, Toronto, Ontario.

November 2006 '*The Episodic Disabilities Project: Recommendations for EI Flexibility for People with Episodic Disabilities*'. To Director General, Employment Insurance Commission, Government of Canada, Ottawa, Ontario.

November 2006 '*Back to Life*'. Central West Opening Doors Conference. Hamilton, Ontario.

November 2006 '*New Perspective – New Solutions: Partnering on Episodic Disabilities*'. To Federal / Provincial / Territorial AIDS Advisory Committee, Government of Canada.

October 2006 '*Episodic Disabilities: New Perspectives – New Solutions*'. Opportunities Fund Annual Conference, Government of Canada.

October 2006 '*Episodic Disabilities Project: No One Left Behind*'. Canadian Labour Congress, Health, Safety and Wellness Committee Annual Meeting, Ottawa, Ontario.

October 2006 '*Episodic Disabilities: New Perspective – New Solutions*'. Strategic Employment Solutions Conference, Toronto, Ontario.

September 2006 – '*Increasing Labour Force Participation Opportunities for People with Episodic Disabilities*'. Atlantic Interdisciplinary Research Network for HIV and Hepatitis C, St. John's, Nfld.

August 2006 '*Using a Multi-Sector & Episodic/Cross-Disability Design for Policy Change: An Integrated Employment/Income Support System*'. International AIDS Conference, Toronto, Ontario.

July 2006 '*Evaluating the Effectiveness of an Innovative Income Support and Workplace Policy Model*'. AIDS Committee of Toronto.

July 2006 '*HIV as an Episodic Disability and Implications to Labour Force Participation*'. University of Toronto Physiotherapy Course, Toronto.

June 2006 '*Shifting Policy for Optimal Work Participation*'. Canadian Association of Rehabilitation Professionals Annual Conference, Montreal, Quebec.

June 2006 '*Just Do It!! From Policy to Reality – A Tool for Change in your Community*'. Community Action Forum. St. Joseph's Health Centre, Toronto, Ontario.

May 2006 '*A Strategy for Policy Change: Addressing Return to Work Disincentives*'. Canadian Association of HIV Research, Quebec City, Quebec.

April 2006 '*Increasing Labour Force Participation Opportunities for People with Episodic Disabilities*'. Canadian Association of Nurses in AIDS Care, Montreal, Quebec.

March 2006 –National Summit on Episodic Disabilities, Ottawa, Ontario. See <http://www.hivandrehab.ca/episodic/episodic.htm> for complete coverage of Summit. DVD available on request.

November 2005. '*Labour Force Participation Opportunities for People Living with Episodic Disabilities*'. Canadian AIDS Society Skills Building Conference, Montreal, Quebec.

November 2005 '*An International Analysis of Support Policies and Programs for People with HIV and other Episodic Disabilities*'. Ontario HIV/AIDS Treatment Network Annual Conference.

July 2005 '*Labour Force Participation Opportunities for People Living with Episodic Disabilities*'. Department of Physical Therapy, University of Toronto.

May 2005 '*Back to Life: Canada Pension Plan and Private Insurance Disability Policies and Practices affecting People Living with HIV/AIDS (PHAs)*'. Canadian Association of HIV/AIDS Research Annual Conference. Vancouver, B. C.

April 2005 '*Episodic Disability and Labour Force Project*'. Canadian Association of Nurses in AIDS Care Annual Conference. Banff, Alberta.

April 2005 '*Episodic Disabilities*'. Committee on Disability Issues, Canadian Life and Health Insurance Association.

April 2005 '*Episodic Disabilities and Labour Force Participation.*' Disabilities Task Group, CUPE, Ottawa, Ontario.

Appendix VII – Responses to ODI Questions

Responses to ODI Questions

Who is using the product / knowledge generated by this project?

The products and knowledge generated by this project is accessible to all members of

- the EDN - national disability organizations
- the Project Advisory Committee (cross-sector, including private sector)
- Pilot Site Steering Committee members (cross-sector)

In addition, multiple presentations have been made to organizations and at conferences, where project materials have been disseminated. Project products and knowledge is available via the website.

A list of 2006 presentations is appended to demonstrate the scope of audiences, from governments of different jurisdictions, to professional associations.

What is the reach of the products / knowledge developed?

Nature of Organizations	Number of Organizations reached with product / knowledge	Number of products / knowledge distributed / shared to organizations
<i>Communities – Disability, Human Rights, Human Resources,</i>	<i>Summit: 50 participants (people living with episodic disabilities, professionals working with people who have episodic disabilities, policy makers, employers and insurance companies)</i>	<i>4 research reports, 4 fact sheets, 7 posters; 10 Meetings: 8 PAC; 12 PSSC. Episodic Disabilities Web pages with 12,779 hits since July 2006, National Summit</i>
<i>Municipal</i>	<i>Ontario Works municipal case workers</i>	
<i>Regional</i>	<i>Opportunities Fund Regional Office Ont Gov't – Ministry of Community and Social Services – Ontario Works and Ontario Disability Supports Program</i>	
<i>National</i>	<i>EDN - Approx number of meetings: 10 Episodic Disabilities Network; 10 in Ottawa with ODI, CPP-D, EI and elected representatives; 50 presentations to national organizations. 20 ppt presentations developed.</i>	
<i>International</i>	<i>AIDS Conference</i>	
<i>Educational Institutions</i>	<i>UoT</i>	<i>40 x 2 presentations to physiotherapy students</i>

Did your project achieve / exceed its intended results? Please provide a statement of how? 100 words maximum

Overall, the Episodic Disabilities project was well managed through a Coordinator, a multi-sector Advisory Committee and EDN which guided and monitored all project activities. New and stronger knowledge-based relationships and alliances were forged at a national level between CWGHR and other episodic disability groups. The project built capacity of episodic disability groups to understand and inform policy and program issues from an episodic disability perspective. The project also developed an increased knowledge base to inform policy and programming through policy analysis research. The resulting increased knowledge base of policy and programming barriers and models will inform future research, policy and programming directions. The project implemented effective knowledge translation mechanisms such as the Episodic Disabilities Summit, workshops and the initiation of a pilot project. Comprehensive evaluation of each project stage and outcome helped to ensure that process lessons became integrated into the ongoing project activities.

How has the funding for this project benefited the target population / improved the lives of individual Canadians? 100 words maximum.

The project benefited the target population, directly or indirectly, in several ways:

- New and stronger knowledge-based relationships and alliances with episodic disability groups at national level
- Increased capacity for episodic disability groups to understand and inform policy and program issues from an episodic disability perspective
- Increased awareness, engagement and capacity of stakeholders to respond to episodic disability issues
- Direct benefit to individuals living with episodic disabilities who participated in the knowledge translation activities (Summit, workshops and pilot site) as well as those who participated in the EDN
- The multi-stakeholder collaboration represented by the EDN participants has resulted in a better understand each others' issues resulting in a strong cross-disability approach

What would have been the impact had this project not been funded? 100 words maximum.

If this project had not been funded, little if any progress would have been made with respect to understanding and addressing the many systemic and practical barriers which prevent people living with episodic disabilities from participating in the labour force in a meaningful way due to the episodic nature of their conditions. The episodic nature of HIV and other disabilities wreaks havoc with the work lives and income support for people living with episodic disabilities. Without this project, Canada would be no further ahead in addressing income support and employment policy barriers (e.g., with respect to workplace, Canada Pension Plan Disability Program, Employment Insurance and / or private insurance) which do not recognize and/or accommodate the needs of people with episodic disabilities for flexible income support nor recognize the concept of 'partial disability benefits'. This, in turn, would continue to be a primary barrier to accessing employment.

Although there is more work to do, this project has built on and expanded the foundation of knowledge on episodic disabilities that CWGHR has developed since 2001.