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Welcome to the Spring 2005 issue of *backtolife.ca*. The theme for this issue is episodic disabilities. More and more we have heard the term 'episodic disability'. Although we still don't have the "best" term, 'episodic' seems to be a useful term to describe the experiences that people go through.

An episodic disability differs from a permanent disability in that it is marked by fluctuating and unpredictable periods and degrees of wellness and disability. In some cases, people live with both permanent and episodic disabilities. The article from the StarPhoenix, included in this newsletter, provides an example of some of the implications of having an episodic disability.

The implications of an episodic disability cross several disabilities - multiple sclerosis, cancer, diabetes, hepatitis C, mental health and many others. This cross-disability perspective is captured in the article by Deanna Groetzinger, Vice-President of Communications at the Multiple Sclerosis Society of Canada. Deanna and representatives from five other episodic disability organizations met with staff in Ottawa from Social Development Canada and the Office of Disability Issues to discuss recommended changes to the CPP-Disability Program to reduce the existing barriers to people with episodic disabilities.

Over the past few years, CWGHR has worked with a group of other organizations working on episodic disabilities. The resulting *Episodic Disabilities Network* was created to exchange information within its membership to enhance the ability of Network participants to respond in a coordinated way to issues of mutual concern and improve quality of life while promoting inclusion for people with episodic disabilities. For a comprehensive description of participating organizations and their respective links, check www.hivandrehab.ca and click Episodic Disabilities.

In the spring of 2004, *income support* and *labour force participation* were identified as the priority items of concern to all participants. These income-support challenges affect not only people living with various disabilities, but also several sectors: employers; public and private insurance providers; unions; health and vocational professionals; the human resource sector; and policy makers. These are some of the sectors that need to collaborate to result in a system that is more effective and comprehensive. Richard Weston, from the Canadian Council of Human Resource Associations (CCHRA), has written an article from the heart, from a human resources perspective. →



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CWGHR is very excited about two recently-funded projects that will serve to inform the work on episodic disabilities. The Office for Disability Issues, Social Development Canada (SDC) has funded, until March 2007, a 28-month national project to explore policy and programming options to promote greater opportunities for labour force participation and social inclusion for people living with episodic disabilities. The profiles of the cross-sectoral members of the Project Advisory Committee are inside.

Prevention, Care and Treatment Programs Unit, HIV/AIDS Policy, Coordination and Programs Division, Public Health Agency of Canada, has generously funded another exciting project at CWGHR. "Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building" is a two-year project that will work to develop and evaluate interprofessional curriculum resources on HIV, ultimately to enhance and increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV/AIDS in Canada. These exciting two projects, with further details inside, will inform each other with the new knowledge developed by each project.

In addition to CWGHR, other organizations have undertaken initiatives that are addressing specific implications of episodic disabilities. Read about two such projects in this newsletter.

Each article in this issue of backtolife.ca brings a specific perspective to the income-support, labour force participation and social inclusion challenges faced by people living with episodic disabilities.

Eileen McKee is Project Manager for the "Labour Force Participation and Social Inclusion for People Living with HIV and other Episodic Disabilities" Project, and is the Editor for this edition of 'backtolife.ca'.

"The day-to-day management is tough – with no predictability. Each day can be a totally different experience. It is difficult to make any plans."

*Kris McDonald, person living with MS
Multiple Sclerosis Society From 'Looking
Beyond the Silo', May 2002*

What is an Episodic Disability?

By Eileen McKee

Before discussing the term episodic disability, let's first look at a definition of disability. To be eligible for benefits under the Canada Pension Plan Disability (CPP-D) program, a person must have a disability that is both 'severe and prolonged'. "If persons return to work inside 12 months, their disabilities do not meet the criterion of being prolonged." (*Listening to Canadians: A First View of the Future of the Canada Pension Plan (CPP) Disability program*, Fifth Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities. 2003).

An example of not meeting the legislated disability definition of 'severe and prolonged' appeared in The Saskatoon StarPhoenix and is reproduced in this issue. Similar experiences have also been cited by people with episodic disabilities such as multiple sclerosis, HIV/AIDS and mental health challenges.

What makes an episodic disability different from a permanent disability?

A person can simultaneously live with both permanent and episodic disabilities; however, there are clear distinctions. An episodic disability is marked by fluctuating and unpredictable periods and degrees of wellness and disability. One potential consequence is that a person may move in and out of the labour force in an unpredictable manner.

What are some of the challenges of living with an episodic disability?

- **Definitions:** Definitions used in legislation, by medical and rehabilitation providers, by insurance providers and by government benefit programs can differ, can have an inherent bias towards physical disabilities and can create barriers to accessing and coordinating programs and benefits for people with episodic disabilities who need access to various income support programs.
- **Care, Treatment and Support:** Goals can be difficult to set. Depression is common. The need for support can change in an unpredictable manner, and care is often difficult to plan. Care and treatment can

be compromised when it is dependent upon income-support and benefits programs that do not address the episodic nature of some disabilities.

Workplace Accommodation / Employment Issues:

Flexibility is very important in an income support program that is going to address episodic disabilities. Part-time work and flextime are critical components. Employer associations, insurance industry representatives, governments, unions and disability communities need to coordinate, collaborate and contribute to plans that accommodate the needs of those living with episodic disabilities.

• **Income Support and Security:** If your main source of income is a disability pension that is tied directly to your health status, and your health condition fluctuates, disability benefits may be "cut off" during periods of improved health. Complicated claim procedures may need to be repeated. These benefits are then difficult to reinstate when required later during periods when the health status declines. This all-or-nothing approach may be a disincentive to return to work. Loss of benefits and challenges around reinstatement can evoke fear.

• **Legislation and Policy:** Legislation needs to be barrier-free for people with episodic disabilities. Trial periods, automatic reinstatement of benefits, part-time work and job sharing, and benefit coverage while earning an income are all features of a flexible and comprehensive set of policies.

• **Education:** Greater awareness is needed for people living with an episodic illness, for their caregivers, for care providers, for employers, for insurance companies and funders, and for policy makers.

Need more information?

For more information on episodic disabilities, the Episodic Disabilities Network or the 'Episodic Disability' project, please contact emckee@hivandrehab.ca.

"My patient is feeling better right now, and would like to return to work... If he does return, however, he will be cut off from his long-term disability benefits. [Consequently] he has decided not to return to work because the fear is too great... I think return to work would help his self-esteem - he has suffered from depression - if going back to work doesn't work out, there's a real sense of failure."

Dr David W. Grossman
College of Family Physicians of Canada
From 'Looking beyond the Silo', May 2002

Why a project on Episodic Disabilities, Labour Force Participation and Social Inclusion?

There are many issues faced by people living with episodic disabilities in Canada. Two priority issues identified by the participants of the Episodic Disabilities Network are *income security* and *labour force participation*. There are also clear links between labour force participation and social inclusion. For a comprehensive overview of social inclusion, see the *2003 Social Inclusion and Research Conference* proceedings on the *Canadian Council on Social Development* website at www.ccsc.ca/events/inclusion.

In response to the priority placed on income security and labour force participation, the Canadian Working Group on HIV and Rehabilitation (CWGHR) is sponsoring the project "Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities".

There are four stages to this project:

Stage 1: Network Development

The first stage involves the engagement of episodic disability groups for input on project activities.

Stage 2: New Knowledge Development

The New Knowledge Development Stage includes identification and analysis of policies, programmes and practices of public and private disability income support and workplace issues to determine strengths, gaps and barriers. The research includes:

- Identification, then in-depth policy and program analysis, of various flexible employment/income support options in Canada and other countries to determine best practice models
- A cost-benefit analysis of selected models of employment/income support options
- Identification of learning needs, strengths, models and gaps of HR and vocational professionals related to episodic disabilities

Stage 3: Knowledge Translation

This stage involves:

- Workshops and presentations to policymakers, employers, human resource professionals, labour representatives, insurance providers and other relevant stakeholders

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The Advisory Committee for the Episodic Disabilities Project



Deanna Groetzinger
Vice-President, Communications
Multiple Sclerosis Society of Canada

Deanna Groetzinger is vice-president of communications for the Multiple Sclerosis Society of Canada. She works with volunteers and staff across the country in meeting the goal of informing people about MS and the work of the MS Society and in ensuring that people with MS have the opportunity to participate fully in all aspects of life.

Deanna works with the National Public Education Committee and the Ontario Division PALMS Committee to develop public awareness campaigns and other activities to inform Canadians about MS as well as numerous publications for people with MS, research publications for lay audiences and the Society's web site. She works with the National Government Relations Committee on a wide variety of social action activities including equitable access to treatments for MS, income support and pension reform, the need for accessible transportation and barrier free design. Deanna has worked with several project groups within the International Federation of MS Societies.

Richard Weston MBA, CHRP

Richard Weston has been a leader in both line and staff management functions in the Hospitality industry, and in Human Resource leadership positions, providing strategic direction, advice and guidance to Line Management. He has an MBA from the Ivey School of Business with specialization in management of service operations, organizational behaviour, and labour relations. Richard is a Past Member on the Board of Directors, Human Resources Professionals Association of Ontario, and a member of the Professional Development Steering Committee. He is a consultant with expertise in areas such as strategic planning, organization design and culture, job design and constructive performance management processes. He is a hands on person, with the drive to work with others to define goals and achieve them. He is a volunteer with the Canadian Council of Human Resource Associations (CCHRA)



Irene Klatt
Assistant Vice President, Health Insurance
Canadian Life and Health Insurance Association (CLHIA)

As CLHIA's Assistant Vice President, Health Insurance, Irene currently monitors developments in the health, and dental field in Canada. She advises the member insurance companies of the Canadian Life and Health Insurance Association of significant trends, regulations and issues that have a potential impact on the health insurance industry in Canada.

In her role, she answers questions from member companies, the news media and the public on a broad range of insurance issues. She works with insurance companies and health and dental associations to address various concerns and to develop acceptable industry standards in Canada.

Irene is the author of *"Health Services Across Canada at a Glance"*, a detailed comparative chart that outlines the intricate relationship between Canada's provincial health and hospital plans and private insurance. She has also written for publications like Benefits Canada, The Journal of Financial Service Professionals, The Globe and Mail, and Reader's Digest, including contributions to three health-related textbooks.

She is a Certified Financial Planner (CFP), a member of the Canadian Pension and Benefits Institute, and a registered lobbyist. She is a past member of the CEBS Advisory Board, the Canadian Institute of Law and Medicine, the Canadian Health Economics Research Association, and the International Health Economics Association, among other organizations.

She is a graduate of the University of Toronto. In 1988, she received her Associate Life and Health Claims – with Distinction from the International Claim Association. In May 2001, the International CFP Council awarded Irene first prize for Best Paper for her work, "Understanding the Canadian Health Care System".

Carole Barron

Carole Barron commenced her vocation as an Intensive Care Nurse working with open heart surgery and organ transplant patients, progressing to Assistant Executive Director, Canadian Cancer Society, NL Division. In 1988 Carole was seriously injured in a motor vehicle accident. Believing that the challenge of recovering from this accident provided opportunity for understanding ability, Carole accepted the Executive Director position with the NL Society for the Physically Disabled (Easter Seals and March of Dimes). Carole moved to Toronto to accept her current position as President & CEO with the Canadian Council on Rehabilitation and Work. She has held a number of volunteer board appointments in leadership capacities such as Volunteer Centre, Community Services Council, Easter Seals and March of Dimes National Council, and the Canada Career Consortium.

Muriel Westmorland

Muriel Westmorland is an Occupational Therapist and a Fellow of the Canadian Association of Occupational Therapy. She is an Associate Professor at McMaster University's School of Rehabilitation Science and has had 40 years of experience in occupational therapy practice, education and research in England, Australia and Canada. Muriel's area of research is disability and employment. In Australia and Canada she established vocational rehabilitation programs to assess persons with disabilities (PWD) and worked with government departments to assist in the employment process. Muriel is active locally (working with a PWD advocacy group re housing), provincially (on the Roundtable on Return to Function/Return to

Work), nationally (as an invited expert to assist Social Development Canada with their Disability Research Agenda and a member of the National Institute of Disability Management and Research [NIDMAR] Board), and internationally (as a member of the International Forum on Disability Management).

Cameron Crawford

Cameron Crawford is President of The Roeher Institute, a research and development organization focused on issues of public policy, disability, human rights and socio-economic inclusion. The Institute has published extensively on issues of disability and labour force integration, social security, social services, health care planning and service delivery, literacy and education, issues facing children with disabilities and their families, violence/abuse, the justice system, emerging technologies and inclusive approaches to service delivery in the private sector. Cameron's work has spanned all of these areas, and he has conducted research on contract for various federal and provincial government departments, the Organisation for Economic Co-operation and Development, and a range of non-government organizations including NGOs in the disability sector and corporate clients.

Ken King

Ken King has extensive experience in the HIV+ community, as a PHA himself, as a counselor and therapist, and as a volunteer with ASOs. He currently is involved in research on lessening depression as experienced by PHAs. He has also worked with innovative projects integrating individuals into society.

Francisco Ibanez-Carrasco

Francisco Ibanez-Carrasco has been living with HIV for 20 years and experienced many of the return-to-work, income security, and rehabilitation issues that drive this project. He is one of CWGHR Co-Chairs and works as an HIV/AIDS Research Technical Assistant at the Community Based Research Capacity Building Program housed at the B.C. Persons With AIDS Society. He is also a faculty member at Goddard College, Vermont, US. He specializes in curriculum design and implementation, participatory qualitative methodologies, popular education, and health education.



Penny Marrett
Chief Executive Officer,
National Office, Canadian Mental Health Association

Penny Marrett is responsible for strengthening the relationships at all levels of the Canadian Mental Health Association (CMHA): cultivating relationships with government departments; broadening the organization's revenue base; strengthening its communications; developing and strengthening its public policy work; strengthening its capacity

to work with other organizations to achieve common aims and provide leadership and support to the organization to achieve its vision of *mentally healthy people in a healthy society*. She brings extensive experience with the operational issues faced by multi-tiered organizations with a pan-Canadian focus in creating and implementing national policies and monitoring strategic directions. She has held a number of leadership positions within the voluntary health and arts sectors including Chief Operating Officer of The Arthritis Society, Director of the Health Charities Council of Canada, Director of the Health Issues Division at the Coalition of National Voluntary Organizations, and Executive Director of the Schizophrenia Society of Canada.

Penny holds a Masters in Public Administration from Queen's University and a Bachelor of Music from McGill University.

Peggy Proctor

Peggy graduated from the University of Saskatchewan with a B.Sc.(PT) in 1984. During the first 10 years of her career she gained experience as a physiotherapist in many different clinical areas and in many geographic locations, across Canada and abroad. In 1997-98 she worked as a Program Coordinator with the Canadian Physiotherapy Association in the office of Education, Practice and Research in Ottawa — and since returning to the prairies in 1998 she has been on faculty at the School of Physical Therapy at the University of Saskatchewan, Saskatoon. Peggy is a sessional lecturer, teaching the final-year 'Professional Issues' course, and is the Assistant Clinical Coordinator in the Physical Therapy program. She has been instrumental in many initiatives relating to the areas of Interprofessional Learning and Aboriginal Equity in the undergraduate curriculum at the School of Physical Therapy. She has a special interest in HIV and rehabilitation, and also does physiotherapy consulting for the Saskatchewan Workers' Compensation Board, along with other project-based work.



Penni Richmond

Penni is the Director, Human Rights Branch, Canadian Labour Congress. For Penni's full bio, please check the Episodic Disabilities webpage at www.backtolife.ca/episodic/episodic.htm

The project is very fortunate to benefit from the knowledge, experience and perspective of representatives from the Canada Pension Plan:

Marcel Lariviere
Senior Manager
Disabilities Benefits & Appeals Department of Social Development, CPP

and

Barbara Farber
Policy Analyst/Analyste de politique
CPP Disability Policy/Politique de l'invalidité du RPC

It is increasingly recognized that workplace policies and income support policies must be coordinated in order to address people's needs. Not only do they need to be coordinated when people are able to work, but also when a person is unable to work during periods of disability. In the article that follows, Mary Alderwood talks about the impact of the 2004 Forum on HIV and Rehabilitation, and the recent initiative by the Interagency Coalition on AIDS and Development (ICAD) on workplace policies. This initiative dovetails beautifully with CWGHR's project on episodic disabilities which addresses both workplace policies and income support policies for people with episodic disabilities.

Workplace Policy Development and Training - A Project of the Interagency Coalition on AIDS and Development

By Mary Alderwood

In January 2004, I attended the CWGHR National Forum on HIV and Rehabilitation and had the opportunity to present information about the work being done by ICAD in the area of policy development and training. Participating in this forum increased my awareness of HIV/AIDS as an episodic disability, and I learned about some of the challenges that are similar to other episodic disabilities such as intermittent and varying degrees of wellness and illness, unpredictability and the need for awareness and education in the workplace about the challenges and requirements facing employees and employers today.

Following the forum, our work has continued and in October 2004, ICAD, in partnership with the Coalition des organismes communautaires Québécois de lutte contre le sida (COCQ-Sida), received funding from Health Canada via the National HIV/AIDS Capacity Building Fund. This funding will support a project aimed at assisting ICAD members, and others, with policy development and training for life threatening, chronic and/or episodic disabilities in the Canadian workplace. An Advisory Committee, representing ICAD's national membership and sector expertise has been formed to guide the implementation process. For complete project details, workshop dates across Canada and resource material, please refer to www.icad-cisd.com

One of the important features of this project is the rights-based approach applied to policy development and the practical considerations for implementing employee rights and employer obligations in the workplace. Identifying and responding to specific requirements for individuals who have been diagnosed with an episodic disability will also be a component of this project. To that end, policy training and resource material will include information about the following:

- Characteristics of an episodic disability
- Understanding the challenges: employee and employer experiences
- Disability awareness and education
- How complementary workplace policies and practices, such as flexible work arrangements, can assist in responding to the unpredictable nature of an episodic disability
- Understanding the duty to accommodate and the practical steps that can be taken to best support the employee while at the same time respond to organizational requirements
- Income replacement, gradual back to work programs and staff planning
- Working together to identify responsive and effective options in the workplace

As a complement to policy development and training, a number of regionally based AIDS Service Organizations will also be supported with employment related resource material. This material will be available for employers and employees and will provide critical information about employee rights, employer obligations and the practical considerations in the Canadian context. In addition, successful workplace models will be identified throughout the course of this project and posted onto the ICAD website.

For further details, please contact Rosemary Forbes at rforbes@icad-cisd.com or 613-233-7440 extension 14.

Mary Alderwood provides Training and Education and Human Resources Consulting services and is the Project Consultant for the ICAD Workplace Policy Development and Training Project. Mary can be reached at 613-825-7582.

The unpredictability of living with HIV, as with other episodic disabilities, can have a significant impact on income support. The Canadian AIDS Society (CAS) is developing a compendium of provincial and federal income and health benefit programs. While the article below, by Ainsley Chapman, Income Security Project Coordinator at the CAS, is addressed specifically to the caregivers for people living with HIV, much of the information is also relevant to caregivers of people with other episodic disabilities. CAS participates in the Episodic Disabilities Network.

Income and Health Benefit Information for caregivers, medical personnel, therapists for people living with HIV/AIDS - A Project of the Canadian AIDS Society By Ainsley Chapman

As part of a 27 month project (to be completed in March, 2006), the Canadian AIDS Society (CAS) is taking to the streets to find out what is really happening when people living with HIV/AIDS (PLWHIV/AIDS) try to access provincial and federal income supports and health benefit programs. This information, along with research conducted by a legal consultant into benefits PLWHIV/AIDS are legally entitled to, will be available to all visitors on the CAS website. This is an important resource for anyone who provides emotional, physical, psychological, social or any other kind of support and care. Why? Because, for the many PLWHIV/AIDS who do not have private insurance, these programs provide the coverage and supports that they need to increase their quality of life and personal success. Unfortunately, discrimination, poorly understood policies and overflowing caseloads have made it difficult for many people to access these programs. Many PLWHIV/AIDS may not know that coverage for a service exists, they may not know how to ask about it, or they may need evidence before they can apply.

You could help your clients and increase access to your service by knowing information such as:

- How to fill out a form or record medical information on an application with special wording that benefits your client's case;
- Contact numbers in the community of agencies, AIDS Service Organizations, advocacy groups, etc. that can support your client when applying for coverage for your service;
- Basic information about the conditions under which the province will cover your service, so that you can let clients know that coverage may exist for them;

- Contact information of someone in the program who is familiar with your service and can provide your client with the details that they need to apply.

Through this online information you will be able to easily access information about:

- Medical criteria included in the eligibility requirements
- Supportive living devices, tools and programs area available to people who are eligible
- Income someone can receive from an income support program
- Earning limits through paid work before it is deducted from their support cheque

This initiative not only summarizes legislation that governs each program, but *red flags* the pitfalls and provides suggestions on how to get around barriers from people who have already used the program! Local AIDS Service Organizations often look for partnerships and contacts with people in other fields who are sensitive to the unique needs of their clients, and welcome a phone call or request for more information about how they can support you (and vice versa!).

New Resource available from CAS! - HIV and Poverty Information Sheet Series

Seven easy to read information sheets outline the link between HIV and poverty. They describe:

- how poverty makes PLWHIV/AIDS vulnerable to HIV;
- why PLWHIV/AIDS are vulnerable to poverty;
- the barriers that PLWHIV/AIDS face when attempting to gain economic security; and
- the public income support accessed by PLWHIV/AIDS

These sheets are a good introduction to the social and economic barriers faced by people at risk of and living with HIV disease, and illustrate the variety of factors that need to be addressed by the different sectors and occupations that are active in the field of Rehabilitation/Active Living. To order these free resources, for a list of local AIDS Service Organizations in your area, or for more information about CAS's project, visit the CAS website: www.cdnaids.ca, or phone Ainsley Chapman, Income Security Project Coordinator. 1-800-499-1986 x116, ainsleyc@cdnaids.ca. You may contact the Canadian HIV/AIDS Information Centre at www.aidssida.cpha.ca/ 1-877-999-7740, or download a PDF copy from the Canadian AIDS Society Website www.cdnaids.ca.

Episodic Disabilities: A Human Resources Perspective

By Richard Weston

The Human Resources Manager approached the Production Manager to say the Lead Hand is able to return to modified duties from extended sick leave: in this case the medications are working and the person is not only able to but has a strong desire (need) to contribute once again. The Production Manager asks the following questions:

1. Why do I need to worry about it? I have enough issues keeping the production lines running with healthy staff!
2. How do I tell the staff? You can imagine their response after what happened before.
3. What work can be safely assigned?
4. How long do I have to keep the person around?
5. What do the staff and I have to be careful of?
6. How will my budget be impacted?
7. What should I be looking for in terms of warning signs of recurrence?

As the Production Manager walks away, the closing comment is: "And these are just the questions off the top of my head!"

To what extent are the Human Resources Staffs of our organizations prepared to successfully tackle the return-to-work issues of staff who have been diagnosed with an Episodic Disorder? Return to work from an injured back, an amputation or heart attacks are events typically managed in relatively routine fashion. There is precedent, experience, knowledge and comfort in dealing with such situations. For Episodic Disabilities, while there may be precedent, there will likely be less experience, less knowledge and therefore more discomfort, not to mention the negative attitudes and behaviours of co-workers. There need not be. However, the workplace reality is the ongoing issues with which HR people deal day in and day out:

- juggling multiple service requests, some of which conflict;
- preparing for and attending many meetings;
- delivering what some view as unpleasant news, and;
- having to continually demonstrate delivery of value-added services.

Where does the time come from to address the needs of one person?

Having been in such a position, I DID ask that question. The answer for me as it is for many others in the HR Profession, is: "I will find the time, and other issues will be put on hold. But where do I start?"

I have dealt with HIV, narcolepsy, epilepsy, mental illness, blindness, cerebral palsy, amputations and cancer in the work place. The last two were easy to deal with: I knew what to do, there were no "questions" about working with them, albeit some people, for other reasons, may not have been happy to see the employees return. The other disabilities were not so easy to address. As the HR Consultant, I met with and processed the long-term disability paperwork for the first employee with HIV in the organization. I was surprised that not one of his co-workers stopped to say Hi. They all knew he was there - word spreads. I had no idea what HIV was all about. I had no idea where to go for information. The insurance carrier was not helpful.

As the quality of medications for episodic disabilities improves, providing increasing opportunities for people to return to work and contribute, a partnership is required with all groups involved (committed) in ensuring value-added return to work strategies and plans are in place. It is time for barriers to be brought down. The provision and sharing of information, services and support to each other is critical. In fact it is common sense. The partnership just needs to do it.

Since being asked to join CWGHR last fall, I have read a great deal of outstanding material, not the least of which was the guide to multi-sector workshops on rehabilitation in the context of HIV, developed in April 2003. No need to re-invent any wheels here. They are already round and rolling. The duty to accommodate return-to-work efforts is clear and, mostly, accepted. Increasing knowledge increases the confidence of those responsible for managing return-to-work efforts. Human Resource Professionals need to know the answers to THE 5 Ws': **Who, What, Why, When and Where**. How successful return to work plans will happen is equally important. We have the answers to address the above. It is time to make it happen.

All provincial HR associations have a necessary role to play supporting their members in providing value-added information as needed. Partnerships with these associations will achieve much: provide HR Professionals with concrete information to destroy workplace myths; help them to learn about the medications; their side effects and actions to take when necessary; understand, develop and imbed the return-to-work plans that capture the specific support network needs of the person while providing information that will assist co-workers to create a supportive environment.

Are there best practices that address these initiatives? Many companies already have them imbedded in their policies and procedures. However, the best companies ensure all parties know, understand, believe and live those policies: that they work equally for ALL employees.

As a Human Resource Professional I would be more effective if the information needed for a specific return-to-work program was readily accessible. Let's make it happen for our partners.

Richard Weston, MBA, CHRP, has been involved in human resource management in both the public and private sector at both Federal and Provincial levels. He is a past member of the HRPAA Board of Directors. Richard represents the Canadian Council of Human Resource Associations (CCHRA), which is a CWGHR member. CCHR is the national body for Human Resources Professionals in Canada. Richard also shares his expertise as a member of the Advisory Committee for the "Labour Force Participation and Social Inclusion for People Living with HIV and other Episodic Disabilities" project.

Deanna Groetzinger is Vice-President of Communications for the Multiple Sclerosis Society of Canada. The MS Society of Canada participates on the Episodic Disabilities Network. Deanna is also on the Advisory Committee for CWGHR's "Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities" Project. In the article below, Deanna describes behind-the-scenes work being done to change income-support policy to better meet the needs of people with episodic disabilities.

Taking the episodic disability case to Ottawa

By Deanna Groetzinger

Bringing the concerns of Canadians who have episodic disabilities to politicians and policy makers is one of the key objectives of the Episodic Disabilities Network. (For more information about the Episodic Disabilities Network, please read the article called "What is the Episodic Disabilities Network" in this newsletter.)

Many organizations within the network have worked individually to bring about changes to the disability tax credit, Canada Pension Plan disability benefits and other income support programs that could help people who have diseases or disorders that are episodic in nature. This means their signs and symptoms are intermittent and all too often they are disqualified from receiving tax breaks or benefits because they don't meet the criteria of having a disability that is 'severe and prolonged'. In November 2004, a number of organizations agreed there was strength in numbers and came together to meet with Social Development Canada officials. This meeting was followed by a second one in late January which included the head of the Office for Disability Issues.

Representatives at the meeting were from: MS Society of Canada; Canadian Working Group on HIV and Rehabilitation; Canadian Council on Rehabilitation and Work; Canadian Mental Health Association; Ontario Legal Aid Clinics; and Schizophrenia Society of Canada.

A wide range of topics were covered at the January meeting. These included:

- how organizations can have input into the federal-provincial-territorial review of CPP;
- moving forward from the recommendations from the recent report *Disability Tax Fairness*;
- anticipated activities of the Office for Disability Issues to look at a more comprehensive disability support program; and
- how we could work with Social Development Canada on an on-going basis to solve some of the administrative issues with CPP(D) that cause problems for people.

Moving ahead, a number of members of the Episodic Disabilities Network have asked that the Parliamentary Sub-committee on the Status of Disability Issues conduct a study of a comprehensive disability support program. The smaller group will continue to liaise with representatives from Social Development Canada and the Office of Disability Issues to keep communications open and ongoing.

Interprofessional Learning on Rehabilitation and HIV

By Eileen McKee

As the nature and impact of HIV/AIDS have shifted in recent years, many people are living longer with HIV, but also with impairments, activity limitations and participation restrictions.¹ As rehabilitation professionals have an increasingly important role to play in HIV care, treatment and support, there is a critical need for development and delivery of high quality curriculum resources and educational initiatives to address their specific learning needs.

How is CWGHR responding?

"Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building through Development of New Knowledge, Curriculum Resources, and Partnerships", is a two-year project that CWGHR is undertaking. This project builds on recent and current interprofessional education initiatives to enhance and increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV/AIDS in Canada. CWGHR will work with key university and rehabilitation stakeholders to develop, pilot test and evaluate interprofessional curriculum resources on HIV as well as other mechanisms to address the HIV-related learning needs of rehabilitation professionals. The funding for this project is provided by HIV/AIDS Policy, Coordination and Programs Division, Public Health Agency of Canada.

Who will be participating?

This project will have a broad-based capacity building impact by bringing together and drawing on the expertise of key stakeholders in rehabilitation and HIV from across Canada, including clinicians, educators and researchers. Primary partners with CWGHR in this project include:

- Canadian Physiotherapy Association (CPA)
- Canadian Association of Occupational Therapists (CAOT)
- Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) and
- College of Family Physicians of Canada (CFPC).

People living with HIV will play an integral role throughout the project, as will university site partners across Canada with whom educational initiatives will be developed and piloted. Due to the strong link between treatment issues and rehabilitation, the Canadian AIDS

Treatment Information Exchange (CATIE) will also be actively involved, providing important opportunities to share knowledge and expertise.

Project Coordinator

Gillian Bone steps out of the hospital environment into the national HIV and rehabilitation community as the Project Coordinator for this 'Capacity Building' project. Gillian trained as a physiotherapist in the UK and moved to Toronto in 1990 as a physiotherapist at what is now Bloorview MacMillan Children's Centre, the provincial children's rehabilitation facility for Ontario. After 4 years in community based rehabilitation she moved to the Hospital for Sick Children (HSC) where she worked with the Neurology Program, including the Stroke and Multiple Sclerosis Clinics and was a member for the Paediatric HIV Team, providing physiotherapy services to infants and children living with HIV. Her role at HSC also included team leadership within the Rehabilitation Department and a clinical lecturer position at the University of Toronto in the Department of Physical Therapy. Her Masters research area was of models of occupational therapy and physiotherapy service delivery for children with HIV.

Together with a dynamic interdisciplinary project advisory committee, including rehabilitation, HIV and interprofessional education experts, Gillian's experience and expertise will be critical in bridging the traditionally separate worlds of rehabilitation and HIV.

How we will keep you informed of progress?

The next issue will inform you about the progress of this exciting project, as will a webpage at www.hivandrehab.ca.

¹ World Health Organization's International Classification of Functioning, Disability and Health (ICF), 2001

A Request from CWGHR

As a first step for this project, we are developing a compendium of material and resources on HIV and Rehabilitation as well as interprofessional education. If you know of or have any articles or materials, please forward them to Gillian Bone by e-mail (jlondon@canada.com) or by regular mail to:

Gillian Bone, c/o CWGHR
365 Bloor Street East, Suite 301
Toronto, ON M4W 3L4.

Vellacott tries to help breast cancer patient

The StarPhoenix (Saskatoon)
 Monday, February 7, 2005
 Janet French

Saskatoon-Wanuskewin MP Maurice Vellacott is going to bat for a woman with breast cancer who can't claim disability benefits from the Canadian Pension Plan.

"We think this is something of a travesty and some injustice that's been done," Vellacott said. "My heart is out for those who in a bureaucratic system sometimes fall between the cracks."

Doctors diagnosed Cheryl Arcand, of Leask, with breast cancer last September. Following a mastectomy last October, she is in the middle of a six-month course of chemotherapy and is due for radiation treatment later. With no insurance or disability funds available through her employers, the single woman had only 15 weeks of Employment Insurance (EI) from Human Resources Skills Development Canada (HRSDC) to live off of.

The bell tolled on her EI payments on Saturday, just days after the Canadian Pension Plan rejected her application for prolonged disability payments. She was rejected, she said, because CPP doesn't see her cancer as a prolonged disability.

"It's a lot of stress because my financial situation is not the greatest," Arcand said. "They want you to eat properly and they want you to rest, but it's always in the back of my head, what am I going to do next month? I'm more worried about my finances than my health."

Jean Tessier, a communications advisor for Income Security Programs at Social Development Canada (SDC) said the department bases their CPP Disability decisions on more than a medical diagnosis. They also gather information on a person's ability to work from occupational therapists, physiotherapists and employers, he said.

"CPP recognizes that cancer can result in a severe and prolonged disability," he wrote in an e-mail. Approximately 17 per cent of individuals receiving CPP Disability have 'neoplasms,' which includes cancer, as their primary medical condition. It is not the diagnosis alone,

such as cancer, that is considered, but the impact of the medical condition on the applicant's ability to work."

The department cannot comment on individual cases or decisions.

Vellacott said he thinks Arcand does have a long-term disability and has written a letter to SDC telling them so. "I don't think people should be shunted aside just because somebody has too summarily or too (superficially) looked at the case and then just brushed it aside," he said.

Cancer is a complex disease and the date treatment is over isn't necessarily the day a patient is ready for work, he said. "You can't tell from one day to the next how the treatment is affecting you," Vellacott said.

Vellacott wants the department to re-assess Arcand's CPP application. If that fails, he thinks changes to EI could be in order. "Cheryl is being an honest upright kind of person," he said. "Instead, if she were to have stepped away from work or her employer would have let her go, she could have been on (EI) for 45 weeks. But she's an honest person with ethic and integrity."

Vellacott said he is willing to stand behind others in a similar position to Arcand, who have paid into federal programs for years and are denied access to their benefits during a prolonged illness.

"I see her as a courageous person," Vellacott said. "In a more weakened or tired condition, (she) is prepared to put some more effort into it and I think if she charts a course here, it's not only for herself but others as well."

Breast cancer is Arcand's second "kick at the cat" with cancer, she said. Twenty-two years ago she had uterine cancer. She said no one can predict how a patient with cancer feels or when they can work. "Yet CPP has it in their mind that they can see better than the medical team can," she said. "The chemo treatment has probably been simpler than all this paperwork."

Arcand wants other people, whether they have cancer or not, to lobby their MPs for longer sickness benefits through EI. If HRSDC can extend parental benefits, they can extend disability sickness benefits too, especially given the \$46-million surplus in EI coffers Canada's auditor general, Sheila Fraser, denounced in November, Arcand said.

Why a project on Episodic Disabilities, Labour Force Participation and Social Inclusion?

CONTINUED FROM PAGE 3

- A national summit on labour force participation and social inclusion related to HIV and other episodic disabilities
- Development and dissemination of educational and communications resources

Stage 4: Pilot Project

In this stage, a national pilot project will be designed that will facilitate labour force participation by testing and evaluating new models for flexible employment and income support to accommodate people with episodic disabilities. Partnerships to support and participate in the pilot project will be developed.

The Advisory Committee for the project is composed of a group of dynamic representatives from several sectors. The wealth of experience they bring to the project is described in further detail in this newsletter.

The Project Manager, Eileen McKee has her Masters in Social Work, with extensive clinical and supervisory expertise. She was Executive Director of an addiction

treatment program. Eileen has also designed and is the content expert for an on-line accredited course on 'addictions and the older adult'. Before joining CWGHR as the Project Manager for the "Episodic Disabilities" project, Eileen was a consultant for the Ontario Strategy to Combat Elder Abuse, and the training / implementation coordinator for a searchable database for rehabilitation services.

What other Research has been done on Episodic Disabilities?

Until recently, very little research had been done on Episodic Disabilities. However, new research is now emerging. A list of links related to episodic disabilities, labour force participation and social inclusion can be found on the CWGHR website at www.backtolife.ca, by clicking *Research*.

Need more information?

For more information on episodic disabilities, the Episodic Disabilities Network or the 'Episodic Disability' project, please contact emckee@hivandrehab.ca.

Eileen McKee is the Project Manager for the "Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities" Project.

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Disclaimer: While the content of these articles is, to the best of our knowledge, current and reliable, information is not a substitute for actual health care and treatment. Articles do not necessarily reflect the official policy of CWGHR or any sponsoring organizations.

Note: Acronyms to describe people living with HIV vary from community to community (PWAs, PHAs, PLHAs, etc). Wherever possible, we have kept these regional variations and used the acronym suggested by the author.

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