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## Income Support and Employment Issues for People Living with HIV

By Francisco Ibáñez-Carrasco

In Canadian society, we value both paid work and unpaid volunteer work. However, we are only beginning to understand the challenges people living with HIV face when attempting to participate in public life. Obstacles to enter the workforce include treatment issues (side effects and adherence) and self-esteem erosion due to lipodystrophy from long-term use of anti-HIV medications. Other barriers are the limited opportunities to return to work given the *episodic* nature of HIV-related disabilities and the often uncooperative social services that make it difficult for HIV+ people to overcome poverty, substandard housing conditions, and fear of peer and societal rejection.

Going back to work full-time is not an option for *all* individuals living with HIV in Canada. The experience and expertise of some HIV-positive individuals proves that participating in public life is feasible when appropriate, flexible and creative conditions are worked out between various sectors. Private organizations, insurers, health care professionals, governmental assistance organizations, AIDS service organizations, and most importantly, HIV+ individuals are finding new arrangements. Moffatt Clarke's article in this issue is courageous and exemplary. Knowing that

there *really* are new ways of participating in public life drives our current educational and research work at CWGHR.

The articles and updates in this issue provide useful information and inspiration to health workers, employers, insurers, advocates, and persons with HIV. They are intended to support all your work on both *disability* (due to HIV and other episodic and lifelong conditions) and *rehabilitation*. While CWGHR defines rehabilitation as a broad multi-sector venture to promote participation in active living, we focus this issue of the newsletter on income support and employment issues. We introduce the solid work being done by the HIV/AIDS Legal Network, CAS and CWGHR. We show our proactive stance by launching the National Forum project that will build capacity, strengthen networks and provide encouragement to many. Also, we want to remind you to check our website, [www.backtolife.ca](http://www.backtolife.ca), our virtual connection to the world, as well as our useful glossary at the end of this issue – new ideas call for a new language.

*Francisco Ibáñez-Carrasco is one of CWGHR's Co-chairs. After years of medical and employment disability he has formed a family and works as the BC Health Canada Research Technical Assistant for the community-based research program at the BC Persons With AIDS Society.*



## On the Job: Living and Working Full-time with HIV

by Moffatt Clarke

So, what's it like for HIV-positive people who work full-time? It's a great question - one, however, that doesn't seem to get asked very much, let alone answered.

As a person living with HIV (PWA) working full-time for a large national organization, here are some of my key issues and concerns, along with a few ideas to make our lives on- and off-the-job fuller and more manageable.

### 1. Creating a Healthy Workplace

Many organizations, including my own, are concerned with an aging workforce, poor employee retention, and many employees taking stress leave. Organizations are looking to address these issues by implementing a variety of initiatives including health promotion and healthy living programs that their employees, including those living with HIV and other episodic conditions can benefit. Some examples include:

- **Supporting disclosure of health conditions, when appropriate**

Although anyone with a knowing eye will recognize the protease-inhibitor induced lipodystrophy that I wear like a badge of honour on my face and body, at the top of the list concerns is the question: do I disclose my HIV status to my manager, my co-workers, my clients and customers? The answer is always very situation-specific. Being open is prudent in some cases; much of the time, however, if I'm feeling well and productive, it doesn't need to be an issue in the workplace.

- **Promoting flexible work arrangements**

Efforts to modernize human resource policies to make working arrangements more flexible often benefit HIV-positive staff. Flexible arrangements include

- o compressed work-weeks
- o variable workday hours
- o self-funded leave
- o leave with income averaging
- o working from home

- **Responding to the duty to accommodate**

Increasing focus is being paid to "duty to accommodate" policies for employees with disabilities, with a view to removing barriers that prevent our full participation in the workplace. Such initiatives include identifying and removing barriers to employment, and supporting career development and promotion.

### 2. Addressing Issues Raised by Disability Insurance

Many group disability insurance (DI) plans, ours included, were designed decades ago when many diseases or conditions either did not exist or were not diagnosed (multiple sclerosis, some forms of cancer, fibromyalgia, etc.) and before we understood the implications of episodic conditions. Efforts need to be made now to revise DI plans so they are more compatible with the needs of people with episodic conditions like HIV. Flexible coverage would enable people to work when they are well enough, and know they will have coverage when they are not well.

See the boxes for stories of people living with HIV and their experiences with part-time disability insurance.

#### IAN'S STORY

FOR THE LAST SEVEN YEARS, I HAVE WORKED AT MY JOB ON A 40% BASIS. THIS WAS MADE POSSIBLE BY A PROVISION IN MY DISABILITY INSURANCE COVERAGE THAT ALLOWED FOR PARTIAL DISABILITY COVERAGE. FOLLOWING A PERIOD OF ABOUT FIVE MONTHS COMPLETELY AWAY FROM WORK I RETURNED, WITH THE CONSENT OF MY DOCTOR TO PART-TIME WORK. THIS ARRANGEMENT HAS NOW CONTINUED THROUGH TWO INSURANCE CARRIERS AND WILL PROBABLY CONTINUE THROUGH A THIRD.

THE DRAWBACK TO THIS SITUATION IS THAT I AM BEING PAID DISABILITY PAYMENTS BASED ON MY 1996 SALARY. ANY INCREASES IN FUNDS, SALARY INCREASES ETC. THAT MAY BE FORTHCOMING FROM MY EMPLOYER ARE DEDUCTED DIRECTLY FROM THE TAX-FREE PAYMENTS FROM THE DISABILITY PLAN. THE PARADOX IS THAT IF I GET A RAISE, I AM WORSE OFF FINANCIALLY. THE OTHER DILEMMA IS MY PENSION FUND: IT IS BEING CONTRIBUTED TO ON THE BASIS OF A 40% SALARY AND THEREFORE IS CORRESPONDINGLY SMALL. SO THE OPPORTUNITY TO KEEP MY HAND IN AND TO HAVE A REDUCED WORK WEEK, WHILE WELCOME FROM A HEALTH POINT OF VIEW, DOES HAVE SOME STRONG ECONOMIC DOWNSIDES. THESE ARE BECOMING MORE WORRISOME AS I CONTEMPLATE THAT I MIGHT MAKE RETIREMENT AGE, WHEN ALL PAYMENTS FROM THE DISABILITY INSURANCE WOULD STOP. I WOULD THEN BE REQUIRED TO RETIRE AND WOULD HAVE ONLY A VERY MODEST PENSION.

## BRUCE'S STORY

IN 1995, I SPOKE WITH MY DOCTOR WHO HAD EXPRESSED CONCERNS REGARDING THE AMOUNT OF STRESS MY JOB ENTAILED. I ASKED POINT BLANK IF HE WOULD SUPPORT ME IN A REQUEST TO EITHER TAKE TIME OFF OR TO WORK LESS. HE AGREED IMMEDIATELY SO I SAT DOWN AND DRAFTED A LETTER TO MY EMPLOYER. FOR FINANCIAL REASONS AS WELL AS A PERSONAL BELIEF THAT THE REGULAR ROUTINE OF WORK WAS A GOOD THING FOR ME, I DID NOT WANT TO GO OFF ON FULL TIME DISABILITY. SINCE MY PARTICULAR DISABILITY PLAN WAS NOT TAX FREE, I WOULD HAVE ENDED UP IN FINANCIAL DIFFICULTY HAD I PURSUED THAT AVENUE.

INSTEAD, I ASKED THAT I WORK A NINE DAY FORTNIGHT, WITH MY DISABILITY PLAN COVERING THE REMAINING ONE DAY EVERY TWO WEEKS. MY DOCTOR PROVIDED A SUPPORTING LETTER AND VERY SOON THEREAFTER THE PLAN WAS ACCEPTED. I HAVE NOTHING BUT PRAISE FOR THE HUMAN RESOURCES DEPARTMENT OF MY EMPLOYER IN ALL OF THIS. THEY HAVE BEEN AMAZING.

OVER THE PAST SEVEN YEARS I HAVE GONE TO A FOUR DAY WORK WEEK, WITH INSURANCE COVERING ONE DAY A WEEK, EXPANDING TO MORE DAYS AS NEEDED IF I HAVE A BOUT OF BAD DRUG REACTIONS. THIS HAS CONTINUED THROUGH SEVERAL INSURANCE COMPANIES.

THE HUMAN RESOURCES DEPARTMENT HAS EXPLAINED THAT, WITH MY 25 YEARS OF EXPERIENCE WITH THE COMPANY, I AM VALUABLE TO THEM. THEY KNOW FULL WELL I COULD BE OFF ON FULL TIME DISABILITY ANYTIME I CHOOSE.

### 3. Ensuring Access to Health Services

People with HIV need to support efforts to reform health care so that it remains public and accessible. For example, this can be accomplished by ensuring access to primary and specialty medical services on weekends or in the evenings for people who are working. Models such as community health centres serve us well: in these settings, general practitioners provide care in integrated community-based primary care settings alongside allied health care practitioners, including nurse practitioners, pharmacists, social workers, dieticians and others.

### 4. Re-orienting Community Services to Support Living Well

There are also ways that community-based organizations could better respond to the needs of their working clients by developing “healthy living” programs and services and by improving existing programs. Examples include:

- Ensuring that programs and services are available outside of the 9 to 5 time period
- Building partnerships with fitness and community centres to offer fitness classes and programs for PWAs, accessible to those who are working
- Exploring ways that busy single working people can eat better meals, through initiatives such as
  - o community kitchens for working PWAs who need to eat well but are too tired to shop and cook when they get home from work
  - o buyers clubs or co-ops for buying groceries, vitamins and supplements in bulk to lower costs

So, these are just some of the questions and a few of the answers that might contribute to an ongoing discussion about being on the job – living and working full-time with HIV.

Support for HIV positive people to stay at work is a win/win situation. Fewer people will be dependent on income security programs, employers will get to retain their investment in human resources and more positive people will continue to contribute to the workforce.

*Moffatt Clarke is an activist-bureaucrat who works for Health Canada's Population and Public Health Branch in the BC Regional Office in Vancouver. His interests include community action for social justice, international development, anything and everything Brazilian, gardening, yoga and chilling out on Third Beach in Stanley Park.*

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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.*

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## Accessing the Disability Tax Credit

By Ainsley Chapman

Current eligibility criteria for the Disability Tax Credit exclude a large number of individuals burdened with the high-costs of living with a disability, including many people living with HIV. We may soon see, however, some changes to these criteria. John Manley, Deputy Prime Minister and Minister of Finance and Elinor Caplan, Minister of National Revenue, recently appointed a Technical Advisory Committee on Tax Measures for Persons with Disabilities. The mandate of this committee is to explore the policy and administrative issues related to the disability tax credit and other federal tax assistance intended for persons with disabilities. The Canadian AIDS Society (CAS) was invited by the committee to provide input into these issues. In August, CAS prepared and submitted a brief outlining a list of key barriers that prevent people living with HIV to access the tax credit. Some of the recommendations that CAS made in this brief include:

- Coordinating federal definitions of disability
- Expanding eligibility criteria such as “prolonged impairment”, “basic activities of daily living” and “markedly restricted” to reflect the experience of living with HIV
- More effort by Canada Customs and Revenue Agency to promote the tax credit, and ensure that information about it is more accessible
- Patients should not be responsible for paying Medical Assessment Fees when applying for the credit
- Complementary and Alternative Medicine (including Medical Marijuana and related expenses) should be included as allowable expenses for the Medical Expense Tax Credit

To access a copy of “HIV and Disability Policy: Evaluating the Disability Tax Credit and Medical Expense Tax Credit”, please visit the CAS website, at [www.cdnaids.ca](http://www.cdnaids.ca).

*Ainsley Chapman is a National Programs Consultant at the Canadian AIDS Society*

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*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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## The Canadian HIV/AIDS Legal Network's Disability & Income Security Project

By Glenn Betteridge

The Canadian HIV/AIDS Legal Network's membership recently identified income security as a pressing and important issue for people living with HIV/AIDS. During periods of illness, many people living with HIV/AIDS are unable to work, and must rely on income security programs, both private disability insurance and government programs. Yet these programs often trap people living with HIV in poverty and unemployment because they ignore the "episodic" nature of HIV infection. Properly designed and implemented income security programs can facilitate reintegration into the workforce and alleviate poverty.

In 2002/2003, the Legal Network began research into the issue of HIV/AIDS, disability & income security. A draft discussion paper was written and circulated to key informants from the disability and HIV/AIDS communities. These people were brought together in January 2003 in Montreal for 2 days to provide feedback on the draft paper, and to plan an advocacy and follow-up strategy. The final paper is being drafted based on the input received. We anticipate that the Legal Network's paper on HIV/AIDS, Disability & Income Security will be released before the end of 2003.

The paper will review the interaction between federal and provincial income security programs and private disability insurance, including the ways these programs fail to meet the needs of people living with HIV/AIDS, and make recommendations for law reform. We will present a workshop based on the paper at the upcoming 4th Canadian HIV/AIDS Skills Building Symposium, in November in Calgary. The Legal Network will also publish a series of accessible, easier-to-read info sheets. For more information on this project, please contact Glenn Betteridge, at [gbetteridge@aidslaw.ca](mailto:gbetteridge@aidslaw.ca).

The Canadian HIV/AIDS Legal Network, based in Montréal, is the only national, community-based, charitable organization in Canada working exclusively in the area of policy and legal issues raised by HIV/AIDS. It was formed in November 1992 and has over 250 members across Canada and internationally. For more information, see website at [www.aidslaw.ca](http://www.aidslaw.ca).

*Glenn Betteridge is a Senior Policy Analyst at the Canadian HIV/AIDS Legal Network.*

## The Working Positive Summit Conference

*By Karen Escovitz*

The Working Positive Summit Conference, held on April 9-11, 2003 in Philadelphia, PA, was convened for the purpose of compiling information about evidence-based and experience-based best practices in employment services for people living with HIV/AIDS. In facilitated working sessions, the participants compiled the best current information about *effective* service strategies for helping people with HIV/AIDS with employment, and identified areas where there is particular need for improvement and development of resources. The conference was attended by approximately 35 of the U.S.'s leading service providers, researchers and educators on the topic of HIV and employment. We were pleased to be joined by Kate Reeve of CWGHR. In many ways, the U.S. lags behind Canada in incorporation of a rehabilitation approach to services and supports for PLWHA.

While we were able to identify and agree on some best practices, it was also helpful to note in each session the kinds of barriers we had encountered in our efforts to provide effective services. Perhaps foremost among these are the tensions between wanting to provide responsive and client-centered services, but being constrained by funding that is primarily concerned with narrowly defined outcomes. This is made more complicated by the diversity of employment experience and vocational development needs of PLWHA, and the decidedly non-linear paths that individuals take as they consider, prepare for, and make the transition to employment.

One of the results of the Working Positive Summit Conference was the formation of a committee that will work to establish a national coalition of individuals and organizations, similar to CWGHR but based in the US. This coalition will act as a hub for dissemination of effective practice information, research coordination and development, and policy level advocacy related to HIV and employment.

For more information about the conference, or to receive a summary of the proceedings, contact Karen Escovitz, MSS, The Matrix Center at Horizon House, 120 S. 30<sup>th</sup> St., Philadelphia, PA, USA. Phone: 215-386-3838  
Email: karen.escovitz@hhinc.org

*Karen Escovitz was the Co-ordinator of the Working Positive Summit Conference.*

## CWGHR's National Forum Project: New Knowledge on Rehabilitation in the Context of HIV

*By Kate Reeve*

For several years, CWGHR has been discussing the idea of holding a national forum on rehabilitation in the context of HIV as a way to bring together stakeholders and raise awareness of critical issues in the field. With the support of Health Canada's Capacity Building fund, and HRDC, CWGHR has been able to move forward with this initiative. The forum project is designed to engage stakeholders, facilitate the development of new knowledge on rehabilitation in the context of HIV and provide opportunities to form new partnerships. Partners in this initiative include Health Canada, Human Resources Development Canada, the Canadian Association of Occupational Therapists, and the Canadian Physiotherapy Association.

Key activities include:

- developing benchmarks for learning related to rehabilitation in the context of HIV for stakeholder groups through consultation with stakeholders
- holding a national forum at which stakeholders can exchange ideas, develop new knowledge and build their capacity to response to the diverse rehabilitation needs of people living with HIV - **January 31 & February 1, 2004**
- creating and disseminating resources (including the next issue of the newsletter) that explore issues raised throughout the project, for use in curriculum development and in the formulation of policy recommendations

The project marks an important step in the development of CWGHR, as an organization building cross-sector partnerships and as a national voice in rehabilitation in the context of HIV. The forum will also have profound implications for CWGHR's future work, particularly related to the new knowledge and partnerships developed over the course of the project.

For more information, to apply to participate or to find out about getting involved as a partner in this project, check our website, [www.backtolife.ca](http://www.backtolife.ca), or contact Kate Reeve at [kreeve@hivandrehab.ca](mailto:kreeve@hivandrehab.ca).

*Kate Reeve is CWGHR's Education Co-ordinator.*

## Report from the Rapporteur: A Look at CWGHR's Research Initiatives

By Robb Travers

When asked to 'rapporteur' CWGHR's 2003 Annual Meeting, I wondered whether I was the right individual for such a task - after all, I knew relatively little about the organization. What I had heard, however, was positive, so I rose to the challenge.

I reviewed many documents and interviewed individuals who headed up CWGHR-initiated or funded projects in 2002 including:

- an evaluation of a return-to-work program for people living with HIV<sup>1</sup>;
- a model for involving PHAs as educators for students in the health sciences<sup>2</sup>;
- a study about the unpredictable nature of life with an episodic disability<sup>3</sup>;
- an analysis of the prevalence of HIV-related disabilities and activity limitations among PHAs<sup>4</sup>.
- the formulation phase for a future analysis of the broad range of insurance issues facing PHAs,
- an initial look at the potential contributions CWGHR might make at an international level.

My role as "rapporteur" was to synthesize the various CWGHR-supported projects into some kind of whole, identifying the links between them and how they complemented each other. My other role was to assess their implications for CWGHR's future work.

### Stronger together

Common to many of the CWGHR projects was their ability to bridge the divide between the worlds of research, community-based services and activism, as well as their commitment to ensuring that PHAs' voices are regarded as expert in research. CWGHR's Insurance Committee adopted a guiding principle "to keep the ultimate interest of PHAs as our priority" while the PHAs as Educators study used the lived experience of PHAs as an innovative teaching tool for health sciences students. These projects empowered *PHAs through enhancing capacities and practical skills*.

### Raising the bar!

CWGHR-initiated projects were varied in their research methods and yielded rich data. Methods included program evaluations,<sup>1,2</sup> an in-depth, qualitative study,<sup>3</sup> and invaluable first 'hard' evidence of the prevalence of HIV-related activity limitations and impairments.<sup>4</sup>

### No stone left unturned

CWGHR projects enhance the understanding of disability in the context of HIV at multiple levels: HIV-related impairments (micro level),<sup>4</sup> activity limitations (meso level)<sup>3</sup>, and participation limitations facing PHAs in society (macro level)<sup>1</sup>.

### A social change agenda

CWGHR initiatives were committed to enhancing quality of life among PHAs through impacting public policy and programming, and learning benchmarks were established through several. For example, PHAs as Educators proved that PHAs are valuable teachers; Episodic Disability will provide a rich base of information for understanding life with a lifelong illness, and the Prevalence study provided a baseline learning benchmark that future prevalence studies can compare to. Together, these projects shed light on the challenges ahead of PHAs returning to work and facing financial and insurance insecurities.

### Looking forward

CWGHR's work in 2002 increased the understating of disability and rehabilitation in the context of HIV – indeed, a very complex puzzle. Future CWGHR initiatives should further the completion of the puzzle and continue to impact policy and enhance quality of life for PHAs.

How could the next year build on work to date? Further research could deepen the understanding of public and private insurance issues impacting PHAs as well as people living with other episodic illnesses. An additional research priority is deepening our understanding of the cross-disability framework in relation to issues of other disabilities and diseases.

CWGHR has much to share and learn through situating its work in a broader international context. Much can be learned from the success story that is CWGHR – a unique and talented organization that has created so much understanding with relatively humble resources. That in itself is a success story to share.

*Robb Travers is Director of the Resource Centre for Community-Based Research at the Wellesley Central Health Corporation*

## **CWGHR'S Episodic Disability Project: Phase II - Living with HIV: Experiences of Lifelong, Episodic Disability**

*By Kelly O'Brien*

This project was developed in response to the results of a previous project completed by CWGHR in 2001-2 entitled: *Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions*. Results of the Silo project identified a lack of understanding about the impact living with HIV has on people's lives, particularly given the unpredictable trajectory of the disease. A second phase of research was launched to examine the experiences of people living with HIV focusing on the uncertain, unpredictable episodic and fluctuating nature of this condition.

First, a literature review was conducted to investigate the current state of knowledge of how people living with HIV experience the changing course of the infection, the chronicity and uncertainty related to the disease, and its impact on all aspects of a person's life. Results from this literature review indicated a lack of understanding or description about the impact of living with HIV, and HIV-related disability, given the episodic and unpredictable nature of the illness.

Second, focus groups were held in partnership with local AIDS Service Organizations across Canada. Each focus group consisted of 5-8 participants and was led by a trained facilitator and co-facilitator. Participants were asked a set of questions to help elaborate on their experiences related to the episodic, unpredictable course of the illness. These discussions were audio taped, transcribed, coded and analysed. The final report will soon be available.

Results of this project will:

- provide an understanding of the experiences of people living with the uncertainty of HIV
- inform the development of effective programs and relevant public policies
- enhance the care, treatment and support of people living with HIV
- facilitate future partnerships with cross disability groups.

If you have any questions regarding this project, or would like to receive a copy of the final report of this project, please contact Kate Reeve, CWGHR's Education Co-ordinator at [kreeve@hivandrehab.ca](mailto:kreeve@hivandrehab.ca), or 416-324-4183.

*Kelly O'Brien, a graduate student at the University of Toronto, is the co-ordinator of this project.*

<sup>1</sup> Working positive: A needs assessment of Employment Action for people living with HIV/AIDS. Unpublished Report: CWGHR and AIDS Committee of Toronto

<sup>2</sup> Solomon, P. & Guenter, D. (2002). Persons with HIV/AIDS (PHAs) as educators in the health sciences: Impact of a training program on learning and PHAs. Patty Solomon and Dale Guenter, McMaster University

<sup>3</sup> Weir, R., Crook, J., Zack, E., Reeve, K., & O'Brien. Living with HIV: Experiences of lifelong, episodic disability. Unpublished report: CWGHR

<sup>4</sup> Rusch, M., Nixon, S., Schilder, A., Braitstein, P., Chan, K., Hogg, B. (2002). Summary of research on the prevalence of HIV related impairments, activity limitations, and participation restrictions. Poster presented at the Annual Canadian HIV/AIDS Research Conference, Halifax: 2003.

## Update on the Rehabilitation Stream at the Upcoming Canadian HIV/AIDS Skills Building Symposium (Calgary, Nov 20-23, 2003)

By Elisse Zack

For people who will be attending the upcoming Canadian HIV/AIDS Skills Building Symposium (Calgary, Nov. 20-23, 2003), there will be a new stream of workshops dedicated to rehabilitation issues. Workshops will help build skills related to a range of topics such as: rehabilitation issues for people living with HIV, innovative rehabilitation programs, issues of HIV as a lifelong, episodic disability, income support programs and policies, benefits counselling, and co-ordination of care among diverse stakeholders and health disciplines.

CWGHR will be presenting a workshop to introduce participants to our new training manual on multi-sector workshops on rehabilitation issues. Participants will learn how to use the manual to hold multi-sector workshops, raise awareness of rehabilitation issues, develop their referral base, and strengthen relationships with partners and allies in their communities.

CWGHR's training manual is available on our website: [www.hivandrehab.ca](http://www.hivandrehab.ca). For tips on using the manual to hold multi-sector workshops in your community, contact Kate Reeve, CWGHR's Education Co-ordinator, at 416-324-4183 or [kreeve@hivandrehab.ca](mailto:kreeve@hivandrehab.ca).

*Elisse Zack is CWGHR's Executive Director.*

## Other Initiatives Related to Income Security

- **CWGHR's Future Research on Income Security:** As we saw in Moffatt Clarke's article, flexible arrangements with disability insurance coverage play an important role within the continuum of care, treatment and support for PWAs who want to remain at work. CWGHR plans to explore this further in an upcoming research project that will look at income security issues for PWAs from the perspectives of the various stakeholders involved (PWAs, insurance companies, employers, policymakers, etc.).

- **Benefits Counselling Manual:** Following up on their successful benefits counseling workshops held across Canada in 2000, CAS is currently developing a train-the-trainer manual to support leaders in Benefits Counselling to transfer their expertise to ASOs interested in conducting Benefits Counselling activities. Watch for English and French copies this winter.
  - **Canadian AIDS Society's Active Living Networking Group:** In response to the growing concern expressed by people living with HIV/AIDS (PLWHAs) that services and programs at ASOs emphasize returning to work, CAS is exploring ways to incorporate active living into their advocacy and capacity building activities, including establishing a discussion group for their members to explore issues related to active living. The objectives of this group are to strengthen networking between member organizations, gather information on the work of ASOs related to active living, and ultimately guide and enhance CAS's work in the area of active living. For more information about this group, please contact Ainsley Chapman, at 1-800-884-1058, x116, or by email at [ainsleyc@cdnaids.ca](mailto:ainsleyc@cdnaids.ca).
  - **Canada Pension Plan – Disability Program Consultation:** CWGHR collaborated with the Canadian AIDS Society (CAS) to present a brief for the Canada Pension Plan - Disability Program consultation on issues for people living with HIV. Check the CWGHR website, [www.backtolife.ca](http://www.backtolife.ca), for both of these documents.
    - *HIV as an Episodic Illness: Revising the CPP(D) Program*, February 2003, Brief Prepared for the Sub-committee on the Status of Person with Disabilities by CAS and CWGHR
    - *Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program*, Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities by Judi Longfield, M.P.
- Next Steps:** Staff at CPP-D is currently developing a response to *Listening to Canadians* that will analyse the report's recommendations. This response will be presented to cabinet by November 1, 2003, and cabinet will then review these recommendations in order to make policy decisions.

## Update on CWGHR Workshop for Rehabilitation Professionals

By Kate Reeve

CWGHR recently had the opportunity to lead a workshop at the annual conference of the Canadian Association of Rehabilitation Professionals – Ontario (CARP-Ontario). This conference brought CARP members from across Ontario together to explore a range of issues related to vocational rehabilitation, including issues related to HIV. In keeping with our multi-sector approach to rehabilitation, we invited a range of presenters to share their experiences, including a support worker from the Hamilton AIDS Network, a physiotherapist, and a person living with HIV. As usual, this multi-sector format produced an exciting dialogue. In fact, for many of the workshop's participants, this was the first time they heard a personal account of the employment challenges experienced by a person living with HIV. The group generated a list of possible solutions to issues related to episodic conditions in the area of vocational rehabilitation. One clear message emerged: in the end, solutions to these complex issues will best be found through increased dialogue between employers, insurance providers, rehabilitation service providers and people living with HIV and other episodic conditions.

In addition to this workshop, CWGHR is pleased to announce that CARP has recently published an article on issues related to rehabilitation in the context of HIV in their journal *Rehab Review*. For copies, please contact CARP at [ssu@telus.net](mailto:ssu@telus.net).

*Kate Reeve is CWGHR's Education Co-ordinator.*

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### Glossary of CWGHR terms

By Kate Reeve and Francisco Ibáñez-Carrasco

**Rehabilitation:** To optimize an individual's choices to participate in active living through a range of services, programs, and policies.

**Holistic approach:** Culturally competent and client-centered health care delivery that fosters a cooperative relationship among those involved in order to facilitate optimal health: physical, mental, emotional, social and spiritual.

**Interdisciplinary approach:** Care providers working in an explicitly collaborative manner. Clients and their loved ones play a critical role in planning and influencing care plans and delivery.

**Multi-sector approach:** To bring together stakeholders in rehabilitation to work collaboratively. Stakeholders, including people living with HIV, health professionals (such as physical, occupational, and complementary therapists, nurses, physicians, etc.), private companies (insurance, pharmaceutical), employment sector (employers, unions), universities, and government (funders, policy-makers) are able to learn from each other, find creative solutions to rehabilitation issues and respond to the rehabilitation needs of people living with HIV.

**ICF model:** CWGHR uses the World Health Organization's International Classification of Functioning, Disability and Health 2001 (<http://www3.who.int/icf/icftemplate.cfm>) as a framework for understanding disability. The ICF deals with health-related experience beyond those covered by 'disease' and it has three levels of classification:

1. **Impairments:** significant deviation or loss in body function or structure
2. **Activity limitations:** difficulties in carrying out activities
3. **Participation restrictions:** social and environmental consequences of impairments and activity limitations or barriers to social involvement

**Lifelong, episodic disability:** Living with HIV means dealing with unpredictable fluctuations in physical and mental health and a range of activity limitations and participation restrictions (see above). This affects a person's experience of living, working, managing daily activities, and planning for a future.

**Cross-disability initiatives:** Collaborative multi-sector work with organizations dealing with other disabilities to promote awareness of common issues and create recommendations for policies that better address the needs of those living with HIV and other disabilities.

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