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Promoting quality of life through research, education and cross-sector partnerships

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Feature: Navigating the Maze

Addressing Integration and Coordination of Disability and Income Support Policies and Programs for People Living with HIV

Welcome to the Spring 2008 Edition of **backtolife.ca**. This issue focuses on recent developments at CWGHR including *Navigating the Maze* and other initiatives in research and knowledge exchange on rehabilitation in HIV and other episodic disabilities.

Since our last issue of **backtolife.ca** in Spring 2007, we have been sending regular “CWGHR e-updates”, containing short electronic updates and summaries of new developments. We hope these updates have been useful in keeping you informed on CWGHR’s activities throughout the year. **backtolife.ca** provides an opportunity to reflect on recent developments and their lasting impact.

Here are a few highlights of our activities that you can read about in this issue:

- CWGHR’s episodic disabilities initiatives continue to gain momentum. The enclosed update will provide an overview of accomplishments, future

directions and knowledge exchange opportunities.

- CWGHR is engaged in a project called *Navigating the Maze*, which is directed toward better coordination and integration of disability income support programs and policies for people living with HIV. Learn more about this exciting project and meet a member of the project’s advisory committee.
- CWGHR’s work in identifying key and emerging Research Priorities and developing Best Practice Principles and Guidelines on disability and rehabilitation in the context of HIV.
- CWGHR’s online course focusing on episodic disabilities that has been designed for Human Resources professionals. The course pilot is now underway.
- CWGHR is partnering with the University of Calgary in research to identify key factors related to employment for PHAs. ➔

Highlights of our other noteworthy initiatives include:

- CWGHR's AGM and Skills Building conference will be held in Ottawa on June 16 and 17, 2008. Please hold these dates and plan to join us.
- CWGHR membership renewals and new memberships are now being accepted. Membership information and a membership form are enclosed with this newsletter.
- We welcome three new staff to CWGHR: Melissa Popiel and Fiona O'Connor, who are working with us on piloting/evaluating our online course for Human Resource professionals on episodic disabilities, and Ruth Pritchard, our Coordinator of Communications.
- As in previous years, CWGHR participated in the consultation process by submitting a series of 'Suggestions for Consideration' for the 2008 federal budget.
- CWGHR collaborated with the Interagency Coalition on AIDS and Development (ICAD) and the Canadian HIV/AIDS Legal Network to develop a discussion paper on HIV, Disability and Human Rights. This paper will be discussed further at our AGM sessions in June 2008.
- CWGHR is collaborating with the Canadian Association of Occupational Therapists (CAOT), Canadian Physiotherapy Association (CPA) and the Canadian Association of Speech Language Pathologists and Audiologists (CASLPA) to run CWGHR's interprofessional course on HIV for rehabilitation professionals in Ottawa in September 2008.
- An update on CWGHR's *Closing the Gaps* project (HIV, disability and rehabilitation in Canada and Cameroon) will be sent in the next e-update and posted on our web site.

- CWGHR's website has been redesigned for your ease of knowledge exchange and navigation. Let us know what you think, and how we can make it better.
- Recently, there has been a range of professional publications about episodic disabilities in the following journals: the Canadian Arthritis Patients Alliance newsletter, *Voices*; the Canadian *HR Reporter*, for Human Resources professionals and the *Rehab Review* for Rehabilitation professionals. If you know of another relevant journal that may be interested in publishing an article about episodic disabilities, please let us know.



Discussions on the *Navigating the Maze* project. Shown are Elisse Zack (left front), Alison Symington (left rear), John Stapleton (right rear), and Eileen McKee (right front)

The list of highlights and updates continues to expand — an indication of growing interest and activities focusing on HIV, disability and rehabilitation and the need for continued knowledge exchange with our membership and other colleagues. As always, check our website at hivandrehab.ca and contact us if you would like more information. We need and value your input and participation as we undertake and promote research and knowledge exchange on HIV, disability and rehabilitation. More information will be forthcoming on other developments soon. Stay tuned!

Navigating the Maze: Addressing Integration and Coordination of Disability and Income Policies and Programs for People Living with HIV and Other Episodic Disabilities

By Eileen McKee, MSW, MBA

Eileen is the Manager of CWGHR's Episodic Disabilities Initiatives.

A 'maze' is how many people living with HIV/AIDS (PLWHAs) have described the various income support and benefits programs that are available through a range of jurisdictions and across departments. Lack of coordination/integration of disability income support and employment programs were identified through CWGHR's research as key barriers to income security and employment. Interjurisdictional challenges are also identified in many other documents. For example, *A National Portrait: A Report on Governments' Responses to the HIV/AIDS Epidemic in Canada* states "coordination and collaboration are considered to be vital given the clear benefits associated with engaging community-level knowledge and experience".¹

In response, and in collaboration with a national advisory committee, CWGHR is undertaking a project to:

- promote improved integration and coordination of income/benefits and employment policies and programs for PHAs; and
- identify and promote mechanisms for communication, in collaboration with relevant government departments/ministries.

The first step in the process, reviewing the relevant programs, has resulted in a report called *Review of Current Canadian Disability Income and Employment Policies and Programs* that:

- identifies that individual philosophies, definitions, funding, service standards, policies, practices and governance have led

to a lack of integration of current and relevant policies and procedures.

- makes a case for mechanisms to facilitate integration. The existing patchwork of programs and philosophies discourages work as they qualify recipients who are fully disabled and unable to work. In order to qualify, people with HIV and other disabilities who can work intermittently are prematurely disengaging completely from the labour force.
- provides an inventory of programs that provide financial support to PLWHAs, as well as other disabilities. One finding is that over \$26 billion was spent in Canada in 2005–06 on disability benefits without any comprehensive oversight respecting what the programs do as a whole or purport to achieve for Canadians with disabilities.
- proposes recommendations to resolve the fundamental policy issues.

Summary of Recommendations

Key Recommendation

All governments and the third sector in Canada should explore a new model of governance to reshape and augment existing private and public income security and employment policies and in-kind programs for people living with disabilities. The new model would include a transparent, equitable and adequate system of benefits that recognizes and promotes rehabilitation and sustained labour force attachment where appropriate and possible. This system of benefits would include (partial) income support benefits for people living with episodic disabilities during episodes when they are not able to work due to their medical condition.

¹ *A National Portrait: A Report on Governments' Responses to the HIV/AIDS Epidemic in Canada* can be downloaded from <http://www.phac-aspc.gc.ca/aids-sida/publication/index.html> p.10–11

Other Recommendations

- That the federal government renew its commitment to produce an **inventory of federal, provincial and territorial (F/P/T) disability programs**. Availability to the public could be enhanced through one common set of web resources.
- Consideration should be given to a **national approach** to:
 - generating a **vision** for labour force participation for people living with disabilities; and
 - developing a more effective **policy emphasis** on active involvement of employers and workplaces.
- Adoption and implementation of the Service Canada vision of **coordinated service delivery** to Canadians with disabilities is encouraged. This would necessitate the creation of a navigation tool for access to all existing programs with links to provincial and territorial programs.
- Meetings between the F/P/T Advisory Committee on HIV/AIDS with all relevant F/P/T disability and income support committees would facilitate the development of **communication networks** and **improve policy coordination**. This would require a review of all F/P/T committees throughout government that concern people living with disabilities, with a view to convening special purpose meetings on issues of interest between the committees.

The first special purpose meeting would study a **new model of governance** which would require reshaping and augmenting existing private and public income security, employment programs and in-kind programs for people living with disabilities, with a view to providing a transparent, equitable and adequate system of benefits that recognizes and promotes rehabilitation and sustained

labour force attachment where appropriate and possible.

All work must include PLWHAs and people with other episodic disabilities.

- The Council of the Federation has an opportunity to convene a new model of governance to reshape and augment disability programs. Accordingly, the best way to introduce the topic at the Council of the Federation would be to approach the current lead province and the federal government to raise the topic of a new governance model for disability programs to be on the agenda of the Council. Once accepted, it could begin to drive the work required by separate F/P/T committees and special purpose cross-sectoral meetings.
- The new **Working Income Tax Benefit for the Disabled (WITB-D)** and the **Registered Disability Savings Plan (RDSP)** announced in the 2007 federal budget offer opportunities for enhancements that could cover people living with episodic disabilities. For example, the definition of disabilities could incorporate the 'episodic' nature of disabilities, as the WITB-D already recognizes that a person with a disability may be capable of participating in the labour force. To maximize the labour force participation of people living with episodic disabilities, implementation of a new national disability insurance program with specific features, including partial disability benefits to complement part-time earnings, should be considered (see Key Recommendation).
- Building on the foundation created by the WITB-D and RDSP, **research** and **consultation** options include:
 - commissioning of pilot projects and/or additional studies;
 - parliamentary or Senate Committee Hearings;
 - a new Blue Chip Panel; and/or



- a Green Paper Option.

The above options could be combined or undertaken separately in conjunction with the Council of the Federation and the array of F/P/T committees related to people living with disabilities.

Conclusions

The report builds on the work that has been done by CWGHR and its Episodic Disabilities Initiatives to identify policy gaps that are deterrents to optimal labour force participation for PLWHAs and those with other episodic disabilities.

Building on that work, the report makes a case for mechanisms to facilitate integration, including templates and work plans, and for recommendations to resolve the fundamental policy discrepancies. In doing so, this report

has also quantified the public and private resources paid in disability income support and benefits annually, and presented arguments for a coordinated approach that would remove barriers to labour force participation for PLWHAs and those with other episodic disabilities.

The next steps in the project involve consultations with provincial HIV/AIDS and with provincial income support representatives on the findings and recommendations.

You can soon read the full report on CWGHR's website at hivandrehab.ca.

CWGHR continues to work on increasing the opportunities for optimal labour force participation for PLWHAs with security/continuity of needed supports. This, in turn, will have positive implications for people living with other disabilities.



Navigating the Maze: An Interview with an Advisory Committee Member

By San Patten

San Patten is an Evaluation Consultant for CWGHR.

On February 5th, 2008, San Patten (an evaluation consultant for CWGHR) spoke with Le-Ann Dolan (an Advisory Committee member for the *Navigating the Maze* project) to capture her perspective on the *Navigating the Maze* Project.

San: Tell me a bit about yourself and your role at ACT.

Le-Ann: I'm the Director of Programs and Services at the AIDS Committee of Toronto (ACT). I've worked in the HIV/AIDS field for about eight years and I've developed a passion for employment and related issues affecting people living with HIV/AIDS (PLWHAs). Employment issues have been an area of focus for me ever since I began working at ACT; with the Employment Action team I've been helping to

build back-to-work employment programming for PLWHAs.

San: Why was the *Navigating the Maze* project of interest to you? Why did you join the advisory committee?

Le-Ann: Well, there were really two reasons. The first is that I have a lot of respect for the work that CWGHR has been doing in the area of disability and HIV/AIDS communities. And I wanted a way to get involved with CWGHR. And second, I heard a lot of requests from our frontline staff working with employment and HIV/AIDS issues, requests that I get involved at the next level. Because at ACT we all see that it's important that we're involved at the policy change level as well as at the frontline service level. ➔

San: What impresses you about CWGHR's approach to HIV/AIDS issues, either within the *Navigating the Maze* project or in general?

Le-Ann: I just really like CWGHR's approach of addressing the issues from both an HIV/AIDS perspective and from a broader disability perspective. They've identified that there is overlap and opportunities for collaboration amongst disability groups. Also, the level of their approach is really important. In this project and their other areas of work, CWGHR really takes the time to consult with the community in meaningful ways, they pay attention to the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, and they really have a finger on the pulse of what's happening in the community. And then, CWGHR is good at taking that connection and bridging it to work with policy makers, looking at income and benefits systems and across various jurisdictions, like at provincial or territorial and federal levels.

We at the community level don't have as much opportunity to work at the policy level, because of the workload in providing our services. We definitely see the need for it, but we would have to divert a major part of our resources from our frontline day-to-day resources. So, we really rely on national organizations like CWGHR to represent us at the policy level.

San: Where do you think there is still room for improvement in the area of rehabilitation and HIV/AIDS?

Le-Ann: That's a good question. When I think of rehabilitation, I tend to think of employment first and foremost. And there have been two major areas we identify with clients. The first issue is that with private long-term disability insurance, you're either classified as disabled or not, and the rules don't allow for the episodic nature of HIV as a disability or illness. These benefits don't allow for part-time work and benefits.

Another major area needing improvement is the Canada Pension Plan Disability (CPP-D) benefit. Even though it does allow for part-time work, you have to put in a claim stating your income and after the first \$4200 earned at any point over the year, you're subject to lose that CPP-D income benefit. If you are able to work part-time, and for that time, have earnings that are higher than the CPP-D rate, CPP-D does not provide partial disability benefits for the time that you are unable to work. And then you're left with your part-time income and you can't survive on that. There is new legislation on CPP-D for rapid reinstatement if a person is cut off, and this goes a long way to recognize the episodic nature of some illnesses. But you're still either on benefits or cut off, and that's very problematic.

One thing that is working well is the Ontario Disability Support Program (ODSP) which does allow someone to work part-time and receive part-time benefits. As well, the health care benefits, so critically important for all of us, but especially for people with disabilities in need of rehabilitation and medications, now follow the ODSP recipient until an employer provides these resources. This is an example of how things can work to everyone's benefit, but this is only a provincial policy for Ontario, and only for ODSP recipients, who likely were not attached enough to the labour force to qualify for CPP-D benefits. We know that inter-provincial policies and programs need to be introduced, and we ➔

We at the community level rely on national organizations like CWGHR to represent us at the policy level.

need to aim for consistency across jurisdictions at the highest level, not consistency at the lowest common denominator.

San: How do you hope the outcomes of the *Navigating the Maze* project will have an impact on your work and/or the people you work with?

Le-Ann: The project has already impacted our work. Part of the impact is just from the review paper comparing the various provincial and territorial income programs for the disabled. We do work with people who are quite mobile, so this report was really helpful in practical ways in working with clients to see the implications

of moving between provinces or territories. The project is also helpful in promoting an integrated disability income system, bridging key stakeholders to create relevant inter-provincial programs and policies.

No single government department is accountable for these sometimes conflicting policies. But all of these policies feed into perpetuating the cycle of poverty. And these aren't new issues. I remember these conversations when I was a child in my own household. It's great that CWGHR is addressing these policy issues at the federal/provincial/territorial level.

Episodic Disability Initiatives at CWGHR

By Eileen McKee, MSW, MBA

Eileen is the Manager of CWGHR's Episodic Disabilities Initiatives.

CWGHR defines episodic disabilities as physical or mental illnesses that are unpredictably recurrent and impact on people's ability to actively engage in the social and employment environments. Research undertaken by CWGHR has shown there are many disabilities that are similar to HIV in that they are lifelong and episodic in nature. Examples of episodic disabilities include multiple sclerosis, HIV, lupus, hepatitis C and some forms of arthritis, cancer and mental illnesses.

In contrast, the predominant disability income security model that has emerged in Canada is based on our traditional understanding of disability:

- a severe and prolonged disability;
- a definition of disability that does not include the capacity to work; and
- benefit reductions and disqualifications if there is participation in paid employment.


Systemic and practical disincentives, specifically lack of partial disability income support if one

works part-time, leave few alternatives for recipients except to remain disengaged from paid employment in order to maintain critical disability income and health care supports.

Yet Canadians with episodic disabilities have varying capacities to work over time.

In order to establish an ongoing platform for the exchange of ideas and collaboration on issues specific to episodic disabilities with national disability organizations, CWGHR developed and has continued to coordinate and support the Episodic Disabilities Network (EDN) since 2003. (For further information on the EDN, see the article *Collaborating for Capacity* on page 8.) The EDN has identified income support and labour force participation as key priorities.

Some of the episodic disability initiatives at CWGHR include:

- with funding from the Government of Canada, CWGHR developed an online course for Human Resources (HR) professionals about episodic disabilities. Content includes 

discussion on incentives to recruiting or retaining employees with episodic disabilities. For information about the course, contact CWGHR at info@hivandrehab.ca and see the article *Learn About Episodic Disabilities From Your Own Computer!* on page 9;

- the HR course is being piloted with Human Resources professionals;
- assessments of educational needs regarding episodic disabilities were completed with rehabilitation professionals and with nurses in AIDS care;
- EDN collaboration on access to rehabilitation

services;

- submission to the pre-budget consultations on the need to remove systemic barriers which prevent Canadians with episodic disabilities from participating to their abilities in the labour market; and
- articles about episodic disabilities were published in VOICES, a newsletter for HR professionals and in the Rehab Review for rehabilitation professionals. If you know of other publications that would benefit from this information, please contact info@hivandrehab.ca.

Collaborating for Capacity

By Eileen McKee, MSW, MBA

Eileen is the Manager of Episodic Disabilities Initiatives at CWGHR.

Have you ever been fascinated by the enhanced learning that occurs when information is shared amongst partners? How do we benefit from the insight of others, while improving effectiveness and strengthening partnerships? This is the reasoning behind a new initiative at CWGHR, *Collaborating for Capacity*.

The concept of “episodic disabilities”¹ is an innovative approach to understanding many lifelong disabling conditions prevalent in today’s society. Many people experience similar challenges in care, treatment, support, social and economic inclusion, employment and other aspects of participation in society, due specifically to the episodic nature of their condition/disability. Several conditions/diseases

have national strategies (e.g. cancer, diabetes, mental health, etc.) requiring coordination among many jurisdictions, disciplines and stakeholders. Rather than working in silos, CWGHR developed the Episodic Disabilities Network (EDN)² in 2003 to facilitate a cross-disability approach to address these issues.

Through a cross-disability approach, with a specific focus on the episodic nature of many of these disabilities, and by utilizing the EDN as a proven innovative, collaborative mechanism within which to transfer the benefits of lessons learned between and among participating organizations, *Collaborating for Capacity* will:

- increase opportunities and enhance

¹ CWGHR understands lifelong episodic disabilities as characterized by fluctuating periods and degrees of disability over time. Examples include arthritis, multiple sclerosis, HIV, diabetes, muscular dystrophy, lupus, as well as some forms of cancer, mental illness, and arthritis. One of the primary distinguishing characteristics of episodic disabilities is their unpredictability. Income support, health benefits, workplace and care policies that do not address the episodic nature of many disabilities can present challenges to people living with episodic disabilities.

² The Episodic Disabilities Network includes participation of the Canadian Mental Health Association, Lupus Canada, Multiple Sclerosis Society of Canada, and other national disability organizations including people living with episodic disabilities. It provides a forum to exchange information amongst participants to enhance their ability to respond in a coordinated way to inform policies and programs in order to improve quality of life and promote inclusion for people with episodic disabilities.

mechanisms to promote broad-based integration among these disability strategies;

- address gaps and increase the benefits of new knowledge development; and
- develop and enhance structures and tools to facilitate the effective exchange of models, knowledge and approaches specific to national integrated strategies of EDN participants.

In addition to the outcomes described above, the innovative approach of the EDN to improve integration of policy, practice, research and education will be strengthened by the activities, tools and resources developed through this initiative, including the development of a framework for a national integrated strategy on

episodic disabilities.

Building on established, innovative collaboration among episodic disability groups, this initiative will:

- increase capacity to share information/best practices; and
- lead to a foundation/framework for development of a national, integrated strategy on episodic disabilities to guide coordinated research and knowledge exchange for care and support of people with episodic disabilities.

To find out more about *Collaborating for Capacity*, or to contribute to its development, contact emckee@hivandrehab.ca.

Learn About Episodic Disabilities From Your Own Computer!

CWGHR CAMPUS offers a web-based course on episodic disabilities for Human Resources professionals.

By Eileen McKee, MSW, MBA and Melissa Popiel

Eileen is the Manager of CWGHR's Episodic Disabilities Initiatives.

Melissa is the Piloting Project Coordinator for the course "Managing Episodic Disabilities".

Do you know a Human Resources professional who would benefit from learning about episodic disabilities? CWGHR is committed to increasing awareness about the employment barriers that some people face when they have a condition such as HIV, multiple sclerosis, some forms of arthritis and cancer that results in episodes when they are not able to work.

To determine their knowledge and learning needs about episodic disabilities, CWGHR developed and undertook a survey of Human Resources professionals across Canada in 2005. Results indicated that Human Resources professionals require further information about episodic disabilities as well as strategies to support the inclusion of employees with episodic disabilities in the workplace.

In response, CWGHR developed and delivered workshops, and has now developed an online course for Human Resources professionals on episodic disabilities. This course is *available now* online to Human Resources professionals. To read more about the course and how to access it, visit our website at hivandrehab.ca. If you know a Human Resources professional who would benefit from this course, please forward this information to them and encourage them to contact CWGHR.

CWGHR is building on its work with Human Resources professionals and is developing resources for other stakeholders who need information about episodic disabilities in order to collaborate on meaningful solutions. We look forward to sharing these new developments with you. ➔

**HR course
available
online now**

In addition, CWGHR is piloting and evaluating this course through August 2008. The piloting will help determine the best means to educate Human Resources (HR) professionals on episodic disabilities. We anticipate findings

on how best to support employees living with episodic disabilities in the workplace. For more information on this project, contact Melissa Popiel, Piloting Project Coordinator at mpopiel@hivandrehab.ca.

Developing Networking Potential

By Melissa Popiel

Melissa coordinated the design consultations for the PLWHA Employment Network.

Are you a person living with HIV/AIDS (PLWHA) who would like the opportunity to discuss employment issues and opportunities with other PLWHAs?

A new opportunity is on the horizon for people living with HIV/AIDS (PLWHAs) looking to connect with other PLWHAs on employment-related challenges and successes. This new initiative will assist PLWHAs to connect with other PLWHAs who are in the process of returning to work or face employment hurdles. When fully developed, the network will provide information and support to PLWHAs at any stage throughout the employment continuum.

In 2007, consultations were completed on the design of this employment network to obtain input into if and how PLWHAs would prefer to communicate on matters related to obtaining and maintaining employment. These consultations occurred in varying formats to maximize the number of voices that could be heard. Focus groups were held at eight sites across the country which provided an opportunity for group discussions on how the network should be structured. An electronic survey was also distributed to PLWHAs across Canada and follow-up phone interviews were completed. The information was analyzed and recommendations were developed.

The end result of these consultations was a report making recommendations on how

PLWHAs would prefer the network to be structured. Based on the feedback received, there are two preferred suggestions for communication. One involves the development of an electronic networking system using a website with opportunities for interaction with the website. A second major suggestion is for the creation of regional networks of PLWHAs, to facilitate face to face discussions regarding local issues and challenges related to HIV and employment. Further consultations will be completed to develop a system that will allow PLWHAs a strong voice in the plans to take the input received in 2007 and create a network based on those ideas.

CWGHR will soon be moving into the next phase of this project through initial funding from the Public Health Agency of Canada to develop the structure of the Employment Network. This network is being developed for and by PLWHAs and will include ongoing consultations with PLWHAs to develop a structure that meets the changing needs of PLWHAs in the labour market. Participants in the earlier consultations and other relevant stakeholders will be involved in these further discussions which will include the schedule to implement the development plans. →

We will keep you posted on new happenings as we enter this next phase of the PLWHA Employment Network development over the next year of the project. If you have further

comments on the development of the PLWHA Employment Network, please contact Project Coordinator Melissa Popiel at mpopiel@hivandrehab.ca.

Development of a Conceptual Framework to Enhance Labour Force Participation for People Living with HIV in Canada

By Brent Oliver

Brent Oliver is the Research Coordinator for a Project entitled "Development of a Conceptual Framework to Enhance Labour Force Participation for People Living with HIV in Canada". He is currently pursuing doctoral studies at the University of Calgary, Faculty of Social Work.

CWGHR is in the first phase of a two year research project which aims to better understand and enhance labour force participation for people living with HIV (PLWHAs). Funded by the Canadian Institutes of Health Research, the study is being conducted in partnership with the University of Calgary and the University of Toronto. Over the next two years the project will engage a broad cross-section of community stakeholders, including individuals living with HIV, insurers, employers, policy-makers, and HIV community organizations in Alberta and Ontario.

The project is guided by an advisory committee of community stakeholders. The project team includes Dr. Catherine Worthington from the University of Calgary, Elisse Zack and Eileen McKee from CWGHR, Kelly O'Brien from University of Toronto, and Brent Oliver, the Research Coordinator.

The overall purpose of the study is to develop a conceptual framework of labour force participation for PLWHAs. The first research phase will include a review of existing literature in the area of labour force participation and income support for PLWHAs. This review will determine what is known from the existing literature about labour force participation for PLWHAs as well as identify key factors related to labour force participation for PLWHAs in Canada.

The review will also identify any shortcomings or gaps in the evidence. This will lead into a consultation phase whereby stakeholders may further contribute their perspectives on facilitators and barriers of labour force participation for PLWHAs.

In the consultation phase of the project, we will conduct interviews and focus group discussions with stakeholders including people living with HIV, employers, insurers and policy makers. This will enable us to develop, refine, and build consensus around a labour force participation conceptual framework for PLWHAs. This framework will identify the facilitators and barriers of participation as well as key components to include in an intervention model.

Once completed, this framework should be of use to a wide range of individuals and groups interested in labour force participation for PLWHAs including policy makers, program planners and researchers as well as PLWHAs, employers, insurance companies and health care providers.

For more detailed information about the project, or if you would like to become involved please contact Brent Oliver, Research Coordinator: (403) 220-8676 or email at boliver@ucalgary.ca.

Guiding Principles for Best Practice Guidelines for Rehabilitation and HIV

By Annette Wilkins, Kelly O'Brien, Patty Solomon

Annette Wilkins is a research consultant with experience in the development, implementation and evaluation of evidence-informed practice and policy initiatives for chronic and infectious diseases.

Kelly O'Brien is a Lecturer in the department of Physical Therapy and a PhD Candidate in the Department of Health Policy, Management and Evaluation at the University of Toronto.

Patty Solomon is a Professor in the School of Rehabilitation Sciences and Director of Interprofessional Education for the Faculty of Health Sciences at McMaster University.

One of CWGHR's objectives is to develop best practice guidelines for HIV and rehabilitation. As this is a complex initiative, we are doing the work in two phases. The purpose of the first phase was to identify *Guiding Principles for Best Practice Guidelines for Rehabilitation and HIV*. It is anticipated that these guiding principles will be taken into consideration by groups who are involved in developing best practice guidelines¹ in the area of HIV and rehabilitation.



A group of consultation delegates in discussion.

We conducted a review of the published and grey literature followed by consultation with a wide range of stakeholders through focus groups, key informant interviews and informal consultation. Data were collected and analyzed throughout 2007 and resulted in a draft preliminary list of guiding principles.

The draft guiding principles for HIV and

rehabilitation best practices fell into three main themes.

Theme One included the unique characteristics and experiences of the people living with HIV/AIDS (PLWHAs) in society.

Best practices should:

- incorporate an understanding of the diversity of PLWHAs;
- incorporate the social justice issues PLWHAs may face because of social and economic circumstances, multiple vulnerabilities and stigma or discrimination; and
- recognize the importance of self-help and support networks.

Theme Two related specifically to approaches to rehabilitation practice, education and research.

Best practices should incorporate:

- a client-centred and holistic approach;
- the most current knowledge of HIV and its treatments; and
- the principles of evidence informed rehabilitation.

Theme Three addressed system level issues that impact greatly on the rehabilitation care that may be received by PLWHAs. ➔

¹ Guidelines for clinical practice: From development to use. Institute of Medicine, Washington DC: National Academic Press, 1992.

Best practices should:

- address access to care and include strategies to maximize access to rehabilitation services;
- acknowledge and address the role of rehabilitation as a component of optimal care;
- acknowledge the role of government policy and advocacy in the provision of services; and
- incorporate communication strategies to ensure that all stakeholders understand what rehabilitation is and its role in HIV prevention and care.

Best Practices and Research Priorities for HIV and Rehabilitation: A Consultation Workshop for Knowledge Exchange on Work-to-Date and Planning for Next Steps

By Annette Wilkins and Kelly O'Brien

On February 29, 2008, CWGHR hosted a consultation workshop aimed at obtaining feedback on and planning next steps for **Best Practices and Research Priorities for HIV and Rehabilitation** initiatives. People living with HIV/AIDS (PLWHAs), rehabilitation clinicians, HIV researchers, representatives from HIV research organizations, and other AIDS service organizations participated in the session.

Important considerations for best practices in rehabilitation and HIV were:

- an acknowledgement of the need for high quality research assessing rehabilitation interventions; and
- the need to develop and evaluate practical tools to allow people living with HIV and their care providers to begin to navigate access to rehabilitation services in the immediate future.

From a wide range of potential research priorities, six **priority areas** were identified:

- **Episodic Disabilities** — To document the prevalence and incidence of disabilities, the episodic nature of disabilities, and concurrent conditions experienced by PLWHAs.
- **Rehabilitation** — To explore the nature and extent of access to rehabilitation services by people PLWHAs in Canada, barriers and facilitators to accessing rehabilitation
- **Mental Health** — To explore the prevalence and incidence of mental health issues faced by PLWHAs and the effectiveness of rehabilitation interventions to prevent or reduce these types of disablement.
- **HIV and the Brain** — To document neurocognitive impairments experienced by PLWHAs and determine the effectiveness of rehabilitation interventions to prevent or reduce

and effectiveness of various rehabilitation interventions in preventing or reducing disability experienced by adults living with HIV.



A discussion during the Best Practices and Research Priorities consultation. Standing is Eileen McKee and seated are Francisco Ibáñez-Carrasco and Darryl Parry.

these types of disablement.

- **Labour Force Participation** — To determine the effect of flexible labour force and income support policies on the health and economic outcomes of PLWHAs in Canada.
- **Measurement Tools** — To evaluate the psychometric properties of new and existing HIV questionnaires used in clinical practice and research.

The Best Practices and Research Priority

Projects are funded through the *Public Health Agency of Canada (PHAC)*. The recommendations from this workshop will help to inform the next steps and shape short-term and long-term plans for new high quality research in rehabilitation and HIV as well as useful rehabilitation guidelines for PLWHAs and practitioners.

Your feedback on these guidelines is important!! For an up-to-date list of the draft guiding principles and other supporting documents please visit hivandrehab.ca.

Don't forget to mark your calendar!

Mark your calendar for our next members' meeting and skills building workshops.

These sessions offer important networking and information exchange opportunities. The opportunities are even greater this year — our meeting is being held in partnership with our colleagues at the Canadian HIV/AIDS Legal Network and the Interagency Coalition on AIDS and Development.

When: June 16 and 17, 2008
Where: Delta Ottawa Hotel, Ottawa, Ontario, Canada
Topic: HIV, Disability and Human Rights: Opportunities for Collaboration

To register, go to hivandrehab/EN/AGM.php

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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