CWGHR

Canadian Working Group on HIV and Rehabilitation
Groupe de travail canadien sur le VIH et la réinsertion sociale

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

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Welcome to the Fall 2005 issue of ***backtolife.ca***. It has been a busy summer for CWGHR. Since our spring issue of ***backtolife.ca*** focusing on issues of HIV and other "episodic disabilities", we have moved forward with several key initiatives in our ongoing efforts to bridge the worlds of rehabilitation and HIV. In June 2005, we held our Annual General Meeting where there was excellent discussion on CWGHR's key initiatives, including development of interprofessional learning opportunities on HIV for rehabilitation professionals and cross-disability policy research and education on episodic disabilities, labour force participation and social inclusion.

In July, we moved to a new office which we hope our colleagues and friends will visit if / when you are in Toronto. We are very happy to be sharing this office space with the Canadian HIV/AIDS Legal Network, and we look forward to developing and strengthening our HIV work together with the Legal Network over the coming years.

This issue of ***backtolife.ca*** focuses on our capacity building project in rehabilitation and HIV. What is the role of rehabilitation in the lives of people living with HIV? What do we know about the educational needs of rehabilitation professionals, and what can we do to meet those needs? What are the different roles of rehabilitation professionals? And how can rehabilitation professionals contribute to the care and support of people living with HIV?

We hear a lot about, and believe in, the importance and value of a comprehensive, coordinated approach to care and support for people living with HIV. CWGHR has been trying to break down the "silos" of sectors, disciplines, jurisdictions and services that we all know and experience every day. Through this project, CWGHR is developing opportunities for **sustainable interprofessional learning**, that is, to increase the knowledge, skills and overall capacity of rehabilitation professionals, beginning with physiotherapists, occupational therapists, and speech-language pathologists, to work in an **integrated** way with other care providers to provide high quality care for people living with HIV.

We'll keep you posted on the developments of the project over the next year and we hope this issue of our newsletter sparks your interest by providing a glimpse into the world of interprofessional education and rehabilitation.

by Elisse Zack,
CWGHR Executive Director

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What's in this issue of *backtolife.ca*?

By Gillian Bone

In the Spring 2005 issue of ***backtolife.ca*** you were introduced to CWGHR's new two-year capacity building project, which aims to enhance and increase the capacity of rehabilitation professionals to respond to the rehabilitation needs of people living with HIV/AIDS in Canada. In this newsletter you can read more about the ongoing activities and plans of this project. We also learn more about a key piece of research that helped inform this project about the needs within the rehabilitation professional community, in the article "HIV & Rehabilitation: An Update on the Canadian Providers Survey." Interested in evaluation, this is a vital component of all CWGHR initiatives. For more about evaluation of the capacity building project, turn to page 9.

Some of you may have had personal experience of rehabilitation services; the articles from three rehabilitation therapists, with experience working with people living with HIV, offer insight into the roles of three different rehabilitation disciplines. In this newsletter we have started with occupational therapy, physiotherapy and speech-language pathology as they are the target disciplines for the Interprofessional Learning Project. We hope to highlight more rehabilitation roles in our future newsletters, as well as adding the perspective of personal experiences and thoughts about involvement in rehabilitation - suggestions & submissions welcome.

You will also be able to catch up on the exciting activities and progress of CWGHR's Episodic Disabilities Project in the article from the Eileen McKee, Project Manager, who, along with the project advisory committee, has been very active since the spring newsletter.

Finally **thank you very much** to the editorial team for their guidance and suggestions, and to the willing contributors who together have produced yet another excellent issue of ***backtolife.ca***

Editorial Team: Gillian Bone,
Francisco Ibáñez-Carrasco, Tom McAulay,
Karen McVeigh, Sheila Thomas
Translation: Jean Dussault
Design: Paul Lowery

Interprofessional Learning on Rehabilitation and HIV Project

Project Objectives:

1. To develop new and enhance existing knowledge-based relationships between CWGHR, rehabilitation professionals and other key stakeholders, including learning institutions, professional associations, and people living with HIV
2. To increase awareness of existing and new curriculum resources, educational initiatives, programs and tools in rehabilitation in the context of HIV and interprofessional education
3. To increase knowledge and skills related to HIV among rehabilitation professionals

Through CWGHR's educational workshops and the National Forum on HIV and Rehabilitation, the need was identified for continued development of high quality curriculum and opportunities for sustainable learning on HIV for rehabilitation professionals. Several key recent research initiatives provided documented evidence of the need for this project: the BC Prevalence Study which you can read from a link on www.hivandrehab.ca in the Education and Research section; and "HIV and Rehabilitation: The Canadian Providers Survey" see page 4**.** Interprofessional education of health care professionals is a Health Canada strategy and a growing field internationally in the education of health and social care providers. Interprofessional education develops capacity for collaborative patient-centred practice - more about this in our next newsletter.

Who is involved ?

This project brings together, and draws on the expertise of key stakeholders, in rehabilitation, education and HIV from across Canada; including clinicians, educators and researchers, 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. Several universities and other educational programs across Canada have signed on as partners with CWGHR to try out the new curriculum that we will be developing over the coming year and we also are excited to continue our work with our current national partners through the Canadian Physiotherapy Association, Canadian Association of Occupational Therapists, Canadian Association of Speech-Language Pathologists and Audiologists, and the College of Family Physicians ➡

of Canada, to develop and implement this project together. People living with HIV play an integral role throughout the project, in both the development and implementation of educational initiatives. Other key project stakeholders include: the Canadian AIDS Treatment Information Exchange (CATIE) due to the strong link between treatment and rehabilitation issues; and the Canadian Association of Nurses in AIDS Care (CANAC) reflecting the key role nurses play in coordinating treatment and care for people living with HIV. All project partnerships provide important opportunities to share knowledge and expertise.

Project Progress:

In February 2005, this 21-month project officially began, funded by the Public Health Agency of Canada HIV Capacity Building Fund. Since that time, a national Project Advisory Committee has been established, project coordinator, Gillian Bone, and project evaluator, San Patten, have been working very hard on the project. A literature and web based review have been undertaken, with Kelly O'Brien, developing a first draft of a compendium, a collection of educational resources on rehabilitation in the context of HIV, which has been shared with the Project Advisory Committee members.

The Project Advisory Committee members are:

Advisory Committee Member	Organization represented
Lesley Bainbridge Associate Principal Interprofessional Programs, College of Health Disciplines, University of British Columbia (Physical Therapist background)	University of British Columbia
Dr. Deb Cameron, Occupational Therapist Assistant Professor & Field work Coordinator, Department of Occupational Therapy, University of Toronto	Canadian Association of Occupational Therapists (CAOT)
Geoff Lawrence and Michael Bailey Educators, CATIE Capacity Building Project: Integrating HIV Treatment Information, Prevention and Support	Canadian AIDS Treatment Information Exchange (CATIE)
Kelly O'Brien, Physical Therapist Department of Physical Therapy, University of Toronto Centre for Research on Inner City Health, St. Michael's Hospital	Canadian Providers Survey Research Team, University of Toronto
Penny Parnes Director International Centre for Disability and Rehabilitation, University of Toronto, Speech-Language Pathologist	International Centre for Disability and Rehabilitation, University of Toronto
Dr. Greg Robinson Family Physician	College of Family Physicians of Canada and Person Living with HIV
Lynne Sinclair, Director of Education, Toronto Rehabilitation Institute, Physical Therapist	Toronto Rehabilitation Institute
Dr. Patty Solomon, Professor, School of Rehabilitation Science, McMaster University, Physical Therapist	Canadian Physiotherapy Association (CPA)
Dr. Graham Smith, Family Physician	College of Family Physicians of Canada
Christopher Sulway , Physical Therapist Planning Department, St. Michael's Hospital	CWGHR's Education / Practice Advisory Committee
Stephen Tattle, Registered Nurse, Professor, UNB-Humber Bachelor of Nursing Program	Canadian Association of Nurses in AIDS Care (CANAC)
Janet Wu Speech-Language Pathologist, HIV Team Professional Practice Leader, St. Michael's Hospital, Toronto	Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA)

The project team is completed with Janet London, Project Administrative Assistant, San Patten, Project Evaluator, Elisse Zack, CWGHR Executive Director and Gillian Bone, Project Coordinator.

Future plans:

Over the coming year we will

- exchange and gather information for the compendium and conduct key informant interviews / group consultations to inform the development of educational curriculum
- complete an environmental scan including consultations with stakeholder groups to further develop the compendium and assist in curriculum development
- develop interprofessional HIV curriculum for rehabilitation professionals
- develop site partnerships with educational institutions to pilot test the curriculum

Gillian Bone is Project Coordinator for the "Interprofessional Learning in Rehabilitation in the Context of HIV" Project, and is the Editor for this edition of backtolife.ca. If you have information or ideas to share or if you would like more information please contact gbone@hivandrehab.ca

HIV & Rehabilitation: An Update on the Canadian Providers' Survey

by the Survey Team

People living with HIV/AIDS are living longer than at the onset of the HIV epidemic, but are living with significant levels of bodily impairments, functional limitations, and social participation restrictions. Rehabilitation - broadly defined as all services and activities that address or prevent impairments, activity limitations and participation restrictions experienced by an individual - can help address these issues of disablement.

With the support of the Canadian Working Group on HIV and Rehabilitation (CWGHR) and in collaboration with a national advisory group, a "Rehabilitation Framework in the Context of HIV/AIDS" was developed to provide a broad conceptual understanding of the domains, services and issues. This framework provided a basis for a nationwide survey to explore the knowledge, attitudes and practices of Canadian rehabilitation professionals and HIV specialists concerning rehabilitation services for people living with HIV/AIDS. Specific objectives of the study were to: 1) describe the extent and nature of involvement of different rehabilitation professionals in the provision of HIV services to people living with HIV/AIDS in Canada; and 2) describe the extent and nature of involvement of HIV specialists in rehabilitation in Canada.

With funding support from the Canadian Institutes of Health Research (CIHR), we surveyed a sample of selected rehabilitation professionals and the known population of HIV specialists. Rehabilitation professionals included physical therapists, occupational therapists, physiatrists, and speech-language pathologists who may or may not have been working in the area of HIV/AIDS. HIV specialists included physicians (general practitioners, infectious disease specialists, psychiatrists and other specialists), nurses, dieticians, pharmacists, social workers, and psychologists working in the field of HIV/AIDS. The mail survey, developed with the assistance of a national advisory committee, was pre-tested, and administered to the selected health care providers using the Dillman Tailored Design Method. Analysis focused on areas including: a) current practices in HIV rehabilitation, b) training, knowledge & workplace awareness in rehabilitation and HIV, c) views on professionals' roles in HIV rehabilitation, and d) HIV rehabilitation service delivery issues. Some descriptive results for the two provider groups are discussed.

Rehabilitation Professionals

For rehabilitation professionals, the overall response rate was 74%, with 1058 usable surveys produced. The majority of respondents were female (88%) and averaged 14 years in practice. 61% indicated that they had never knowingly served an HIV positive client. Of these, 27% indicated they would like to work with this client group (27% would not, and 46% were unsure). Of the 39% who had knowingly served an HIV positive client, the mean number of people living with HIV/AIDS served in the past year was 4. Only 27% had received training in HIV/AIDS as part of their rehabilitation education. Forty-eight percent reported no or little awareness of HIV rehabilitation within their workplaces. The majority of rehabilitation professional respondents indicated that their profession was somewhat (40%) or very important (46%) to people living with HIV/AIDS, but only 19% agreed that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat this client group. Fifty-three percent disagreed that serving people living with HIV/AIDS is more demanding than serving clients with other chronic illnesses or conditions. However, 50% agreed that many rehabilitation professionals are uncomfortable with the idea of working with this population. Forty-one percent indicated that there were service barriers specific to HIV that might prevent people living with HIV/AIDS from having their rehabilitation needs met such as stigma, lack of available funding, and lack of education among health providers.

HIV Specialists

Among the HIV specialists, the response rate was 63%, with 214 eligible surveys produced. Respondents included nurses, physicians, social workers, pharmacists, psychologists, and dietitians who had worked in an HIV clinical setting within the past 12 months. Respondents averaged 16 years in practice and had seen a mean of 53 HIV positive clients within the last month. Ninety percent were from metropolitan or urban areas. Sixty-two percent indicated that under half of their HIV caseload was rehabilitation-related, where rehabilitation was defined as services and activities that address or prevent impairments, activity limitations, and participation

restrictions. Within the last year, 86% had referred HIV positive clients to social workers, 85% had referred to community-based AIDS service organizations, 50% to physiotherapists, 35% to occupational therapists, 32% to physiatrists, and 10% speech-language pathologists. The most important rehabilitation issues in the context of HIV were seen to be income supports (85% indicated 'very important'), prevention (83%), chronic poverty (81%), housing (80%), employment (76%), and stigma (74%). The majority of reasons for referral to rehabilitation services were to address issues including: social service assistance (85%), income support (80%), drug coverage assistance (79%), psychosocial issues (76%) and housing support (74%). Seventy-five percent indicated that their profession was 'very important' in the rehabilitation of people living with HIV/AIDS. Ninety-four percent agreed or strongly agreed that rehabilitation professionals who provide service for people living with HIV/AIDS need specialized training, and only 44% agreed or strongly agreed that rehabilitation professionals currently possess adequate knowledge and skills to assess and treat people living with HIV/AIDS.

Despite the role that rehabilitation professionals may play in the care and treatment of people living with HIV/AIDS, only a minority currently serve HIV/AIDS clients. Of those who had served people living with HIV/AIDS, they saw only a very small number of HIV positive clients in the past year, and reasons for which they served these clients were primarily for rehabilitation issues unrelated to their HIV status. HIV specialists currently provide limited rehabilitation-related services for people living with HIV/AIDS; however, they refer to a range of services that do provide rehabilitation services for this population. HIV specialists refer HIV positive clients primarily for social participation restrictions and consider community-based supports and social workers to be crucial for people living with HIV/AIDS. Overall, there is a need for increased information for, and education of, rehabilitation professionals, HIV specialists, people living with HIV/AIDS, and other health providers who may refer to rehabilitation professionals on the role of rehabilitation in the context of HIV/AIDS. Also, there is a need for more collaborative practice among health care professionals to better meet the rehabilitative needs of people living with HIV/AIDS.

Complete study results will be available shortly on the HIV Social, Behavioural and Epidemiological Studies Unit, University of Toronto website at http://www.phs.utoronto.ca/hivstudiesunit/. Canadian Providers Survey Fact sheets will soon be available on CWGHR's website. For more information on rehabilitation in the context of HIV/AIDS, please see the Canadian Working Group on HIV and Rehabilitation (CWGHR) website at www.hivandrehab.ca.

Canadian Providers' Survey Team: Catherine Worthington, Ted Myers, Rhonda Cockerill, Stephanie Nixon (study investigators), Kelly O'Brien and Tarik Bereket (research staff).

Acknowledgements: This study was funded by the Canadian Institutes of Health Research (CIHR) and the Canadian Working Group on HIV and Rehabilitation (CWHGR). The research team would like to thank the national advisory committee for their guidance throughout the course of the survey including: Evan Collins, Louis-Marie Gagnon, Barney Hickey, Jim Marianchuck, Arlis McQuarrie, Christopher Sulway and Elisse Zack

Occupational Therapy in the context of HIV

A virtual interview with Todd Tran, CWGHR's representative from the Canadian Association of Occupational Therapy and occupational therapist working in the community in Toronto (with back up from Julie Giroux, occupational therapist at Women's College Hospital Foot Care Centre and part-time in the community)

Tell me, Todd, what is Occupational Therapy?
Many people mistake the word "occupation" for job but occupational therapists broaden this context further to mean "doing", helping people to perform life tasks or activities that are meaningful and purposeful for the individual. This can be anything from providing the proper adaptive device to play golf better, to energy conservation for making a meal. The Canadian Association of Occupational Therapy has a great definition: occupational therapy enables people to lead productive, independent and satisfying lives by assisting them in self-care, as well as activities that allow them to work or enjoy free time.

So how do Occupational Therapists make that happen?
We identify this through initial assessment by meeting with the individual in their chosen environment (i.e. home, office, etc.) and develop a client-centered goal to work on. This goal is based on the individual's challenges and how to compensate for or overcome their limitations. Some of the challenges and limitations an individual may face would include: physical limitations, strength and coordination; mental abilities, that includes memory, coping and planning skills; and the environments in which they spend time, such as school, work and home, including both the physical layout and the support one receives from others in each space.

Once you and your occupational therapist (OT) have decided what you want to work towards, then you may work on learning new ways of doing things, or activities to maintain and improve your skills. OTs can also make suggestions and adapt the things you use or where you use them (e.g. a modified keyboard to access the computer, equipment for the bathroom, changing the layout of your office). An OT may also help you to remove barriers to employment or to engage in recreational or community activities.

Todd, what does your job involve working with people living with HIV in the community in Toronto ?
Working in the community means I offer my services to people in their homes, or in community based long-term care environments including hospices. About 30% of the clients I visit are people living with HIV, who have a wide variety of needs and goals in their rehabilitation. I assess cognitive problems as with HIV dementia, carry out home safety assessments and provide modification or adaptive aids for their environment. I also provide discharge planning for some residents who are able to leave the hospice setting back to their homes. This includes assessment with their activities of daily living (i.e. self-care, household chores, finances etc.). Some of the strategies include energy conservation, and mobility devices (e.g. scooters and walkers).

How can someone access Occupational Therapy services?
Speak to your family physician and ask for a referral to occupational therapy, in Ontario that would be to the Community Care Access Centre (CCAC) or you can make a self-referral to them. For more information on occupational therapy services, you can contact the Canadian Association of Occupational Therapists www.caot.ca

How do you feel about working as an Occupational Therapist ?
It is rewarding, as an occupational therapist, to provide services that are uniquely tailored to an individual's circumstances to improve their day-to-day life. Even small interventions can have a large impact. For example, recommending installation of an automatic door opener to facilitate a person's mobility can improve their sense of independence and assist them in participating in their community.

The Role of the Physiotherapist

by Gillian Bone

The Ontario Physiotherapy Association describes a physiotherapist as "a graduate of a recognized university-based school of physiotherapy who is qualified to provide preventative, diagnostic and therapeutic services aimed at restoring function and preventing disability arising from disease, trauma or injury. Physiotherapists have a detailed understanding of how the body works, knowledge of disease, injury and the healing process and ability to distinguish what is normal from abnormal in posture, balance and movement and function. The physiotherapist is your partner in evaluating and restoring strength, endurance, movement and physical abilities affected by injury, disease or disability." Physiotherapists can help you achieve your highest level of physical functioning (at any stage of life) by providing you with a personalized treatment plan based on your specific needs. Physiotherapists can offer you:

- Assessment of movement, strength, endurance and other physical abilities;
- Assessment of the impact of an injury or disability on your physical functioning;
- Assessment of physical preparation for work and sports;
- Program planning and education to restore movement and reduce pain; and,

- Individualized treatment of an injury or disability based on scientific knowledge, a thorough assessment of the condition, environmental factors and lifestyle.

  Canadian Physiotherapy Association
  www.physiotherapy.ca

Accessing physiotherapy:
This is different in each province and territory. Talk to your doctor about your rehabilitation needs and discuss which rehabilitation professional(s) may be best suited to address those needs. Since the Regulated Health Professions Act of 1991, physiotherapists are considered primary care practitioners, so you do not need a referral from a doctor to be assessed and treated by a physiotherapist. However in hospitals, some provincially funded physiotherapy clinics, and most insurance programs (for the purpose of reimbursement) require a physician's referral - so that's a great place to begin !

Rehabilitation and children living with HIV
Having worked in the HIV program at the Hospital for Sick Children in Toronto for the past seven years - I have had the opportunity to understand much more about the rehabilitation needs of infants, children and adolescents living with HIV. Children living with HIV can present with a wide variety of rehabilitation needs: caused by the disease e.g. difficulty with movement or delayed development from HIV encephalopathy (brain problems); or from medication side effects e.g. muscle weakness or inadequate feeding from nausea, causing malnutrition and leading to poor growth. Rehabilitation professionals working with children with HIV must also consider the health of each child's care givers and other family members. Sometimes the diagnosis of the child is the first indication of HIV infection in the family and there may be more than one family member with medical and rehabilitation needs at one time.

HIV infection can affect children quite differently from adults and so their rehabilitation needs may also be different. The physiotherapist works as part of a rehabilitation team to meet the needs of each child and family. HIV in children may affect the brain so that a child's development is delayed, and they may not achieve or may lose developmental milestones. This is where rehabilitation becomes a vital treatment tool, in conjunction with medical management. The rehabilitation team, including the child's family and care givers, support, guide and facilitate development. The physiotherapist may help a child learn how to crawl, take their first steps or ride a tricycle in motor development. The occupational therapist may support a father and teacher helping a child with new learning at school, or adapt a child's chair to help them sit independently. The speech-language pathologist may facilitate communication for a child who is not yet speaking, or provide support to care givers to guide language development after hearing loss from recurrent middle ear infections. Dieticians, pharmacists, nurses, physicians, teachers, social workers, psychologists and many other health and social care providers are also involved in the rehabilitation process - we hope to highlight their perspectives in our upcoming newsletters.

Rehabilitation for infants and children is integrated into play activities. Play is a child's occupation and their way of learning new skills so rehabilitation integrates into that activity and also into activities of daily living and self care at an age-appropriate level. A therapist integrates the child's rehabilitation activities (exercises, positioning, modifications, language cues, feeding routine, etc) into the ordinary activities of home/day care/school life for the child with their care givers. Like any new activity it must be practiced and repeated for new learning to be integrated into ability and skill. Most importantly, rehabilitation with children living with HIV should be fun, perhaps challenging at times, and always leading to the next new skill or activity that the child and family want to achieve.

Gillian Bone is a physiotherapist who has been working in the field of paediatric physiotherapy for the past 16 years. She joined CWGHR as Project Coordinator for the Interprofessional Learning in Rehabilitation Project in May 2005. She can be reached at gbone@hivandrehab.ca

The Speech-Language Pathologist and People Living with HIV

by Janet Wu

For persons living with HIV/AIDS (PHA's), daily functioning may already be a challenge from dealing with overall health and nutritional issues. Imagine also having difficulties communicating with friends and loved ones, being unable to think clearly, or having difficulties eating or drinking safely in order to maintain your nutritional and respiratory health. Who can you seek help from to assist with these additional challenges?

The Speech-Language Pathologist is a health professional, trained at the graduate university level, who can provide assessment and management of such difficulties. Available through acute/continuing care hospitals, rehabilitation centers, community care access centres as well as privately, Speech-Language Pathologists can provide management recommendations and treatment programs for a wide range of communication and swallowing disorders that can arise from HIV/AIDS and their associated complications.

Communication difficulties can include slurred speech (dysarthria), weak voice (dysphonia), word-finding or comprehension difficulties (aphasia), concentration problems/verbal memory loss (cognitive-communication disorder), and reading/writing difficulties (dyslexia/ dysgraphia). These disorders can interfere not only with daily functioning and work, but can also significantly impact on quality of life for PHA's. (For children with HIV/AIDS, learning and academic performance can pose especially difficult challenges.) Swallowing disorders can include muscular or sensory disorders of the mouth and throat (oro-pharyngeal dysphagia), which can compound difficulties with painful mouth and digestive tract sores, can significantly compromise respiratory and nutritional health, and be especially life-threatening for PHA's.

A thorough assessment is usually provided to determine the nature of the communication or swallowing disorder. If necessary, instrumental assessment, such as dynamic imaging of the throat or swallowing mechanism, may be utilized to further assess the disorder. Management can include a variety of modes such as exercise or therapeutic programs, assistive devices, and environmental or provider-assisted modifications. Frequently, an interdisciplinary team is also involved to focus on common goals.

For further information or referral, speak to your family physician or contact the Canadian Association of Speech-Language Pathologists & Audiologists.

***Janet Wu** is the Professional Practice Leader and Speech-Language Pathologist at St. Michael's Hospital in Toronto. She is also an Advisory Committee member for the Interprofessional Learning in Rehabilitation Project, representing the Canadian Association of Speech-Language Pathologists & Audiologists.*

***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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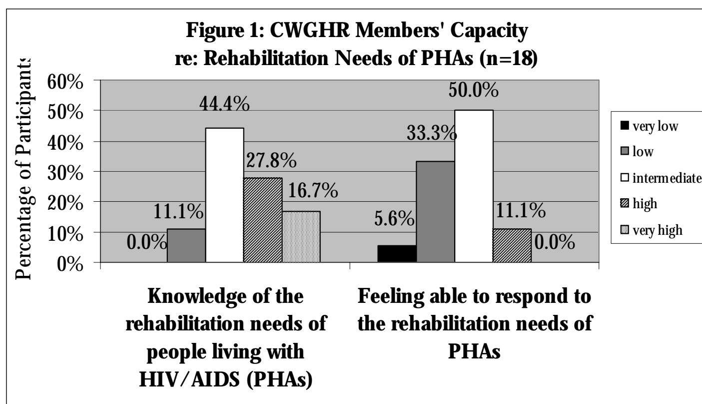
Rehabilitation in the Context of HIV: CWGHR Members' Understanding of the Issues

by San Patten, Interprofessional Learning Project Evaluator

Gillian Bone presented an overview of the project to the CWGHR membership at the annual general meeting on June 10, 2005. The project was met with enthusiasm, and CWGHR members provided helpful input to guide the project. A total of 18 CWGHR members completed a questionnaire to measure their baseline awareness, understanding and interest in the *"Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building Through Development of New Knowledge, Curriculum Resources and Partnerships"* project. The 18 respondents comprised a fairly representative sample of the CWGHR membership and worked in a wide variety of professional settings. The baseline survey is one component of the evaluation process led by San Patten for CWGHR's Capacity Building project.

As indicated in Figure 1, while the majority of the respondents had intermediate or higher knowledge of the rehabilitation needs of people living with HIV (PHAs), only 11.1% rated their ability in this area as high.



The majority of CWGHR members had relatively equal distribution of experience in partnerships between rehabilitation professionals and HIV professionals. With respect to experience in interprofessional learning amongst various rehabilitation professions, the majority of participants had very low (11.1%) or low (38.9%) experience. The majority of CWGHR members rated themselves as intermediate (50.0%) regarding their awareness of educational resources for rehabilitation professionals regarding HIV. The same proportion (50.0%) rated themselves as intermediate with respect to opportunities to disseminate curriculum or educational resources to colleagues.

Gillian Bone, Interprofessional Learning Project Coordinator and San Patten, Project Evaluator, discuss the project.

As indicated in Figures 2 and 3, most of the CWGHR members disagreed or strongly disagreed that rehabilitation professionals currently possess the necessary knowledge and skills to help PHAs with issues around employment. Also, the majority of CWGHR members disagreed or strongly disagreed that the majority of practicing rehabilitation professionals in Canada knowingly serve PHAs. The majority strongly agreed or agreed that there are opportunities for rehabilitation professionals to learn more about HIV/AIDS. There was quite a bit of variation in CWGHR members' agreement that rehabilitation professionals are currently knowledgeable about how to help PHAs with physical impairments, activity limitations, or participation restrictions due to HIV or medication side effects; the largest proportion rated neutral on this statement. While many of the CWGHR members strongly agreed or agreed with the statement: "I believe that most rehabilitation professionals are reluctant to work with PHAs because they feel they do not possess the knowledge and skills to work with this client group," a large proportion were neutral on the statement. One CWGHR member noted:

> *"Homophobia and viewing of gays, drug users etc. as curiosities is very widespread among health care providers outside of specialized facilities and needs to be part of training before rehab for PHAs is effective."*

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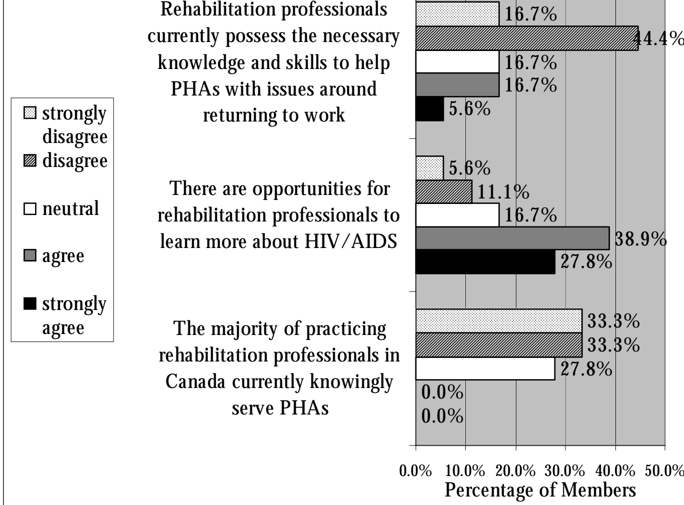

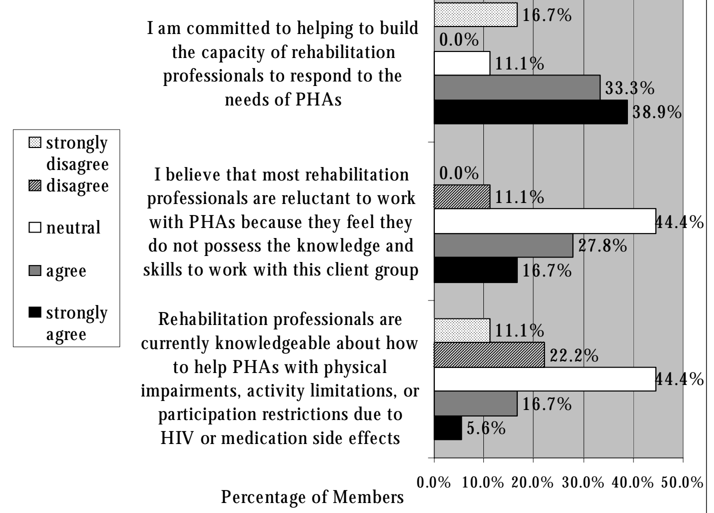

Finally, it is encouraging to see that the majority of CWGHR members strongly agreed or agreed that they are committed to helping to build the capacity of rehabilitation professionals to respond to the needs of PHAs.

In order to capture CWGHR members' vision for the Project, they were asked to complete the following sentence: *"I will know that CWGHR has been successful in building the capacity of rehabilitation professionals to respond to the needs of people living with HIV/AIDS if/when…"*

…people living with HIV indicate that their needs are being met, they know about and are able to access the full range of care and supports available to all people living with chronic illnesses, and they are able to play a vibrant role in their community/society.

…there is an increased proportion of health care and social services providers with the knowledge, ability and will to provide in a continuum of care for all persons living with HIV, and increased referrals from other health care professionals, such as family physicians, of PHAs to rehab professionals.

…there are transparent return to work policies, procedures and collaborative effort by all parties, including businesses.

These are three compiled vision statements based on all the responses from the CWGHR members.

Thanks very much to all of the CWGHR members who completed the baseline survey. The survey will be repeated with CWGHR members after the conclusion of the Capacity Building Project in order to assess changes created the project.

CWGHR's Episodic Disabilities & Labour Force Participation Project: An Update

by Eileen McKee, Project Manager

As you can imagine, there has been much activity in the past several months on the Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities Project.

We are analyzing the results of a report on policies related to income support, return to work as they relate to episodic disabilities. An economist will cost out key recommendations that are made in this report. These two products will be presented at the National Summit in March 2006 (see bullet below) and serve as the foundation on which we will design pilot sites for implementing the recommendations.

By year-end we will have completed an on-line survey of 15,000 Canadian human resources professionals to

determine their experience and their educational needs related to episodic disabilities. The result, due by March 2006, will inform continuing educational needs of this sector.

The Episodic Disabilities Network developed a Statement of Common Agenda, followed by a media release and lobbying campaign in Ottawa in May 2005. A workplan that builds on those advances has been developed. We will keep you advised as the workplan is implemented over the next few months.

The Standing Committee on Finance is holding its public hearing on the 2005 pre-budget consultations from Sept 26 – Nov 4. The Theme is 'Enhancing Productivity Growth in Canada'. On behalf of the Episodic Disabilities Network, a submission was made and is posted on CWGHR's website.

Exchanging knowledge with other projects is an important strategy of the project. Towards this end, the Episodic Disabilities Project Manager is on the National Advisory Committees of two other projects:

- Chronic Illness / HIV/AIDS and Workplace Policies is sponsored by The Interagency Coalition on AIDS and Development (ICAD). ICAD has funding from Health Canada via the National HIV/AIDS Capacity Building Fund until March 2006 for a project aimed at assisting ICAD members as employers (AIDS service organizations) with policy development and training for chronic and/or episodic disabilities in the Canadian workplace. 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. In fact, the conceptualization of the project was inspired by a CWGHR Forum on Episodic Disabilities in January 2004. Activities of this ICAD project included: Cross-Canada focus groups; train-the trainer workshops; the development of fact sheets; a submission to the CWGHR newsletter; a resource manual. CWGHR contributed a Fact Sheet on Episodic Disabilities.

- Canadian AIDS Society (CAS) Income Support Project Advisory Committee is developing a compendium that will be a searchable database for income support and benefit plans across provinces and Canada. Target audience is persons living with AIDS. Submission was made to the CAS newsletter regarding episodic disabilities and the project.

Plans are well underway for a National Summit, the purpose of which is to present the findings and engage stakeholders in a discussion of the policy analysis and the cost-benefit analysis, as well as to develop coordinated strategies to identify and address barriers with key stakeholders. We also will develop a strategy to design and fund the piloting of the recommendations that come from the policy analysis. Representatives from the following Stakeholder groups will be attending:

- researchers
- rehabilitation professionals
- vocational rehabilitation professionals
- insurance companies
- government policy makers
- employers (associations & champions)
- HR professionals
- people living with episodic disabilities
- the Episodic Disabilities Network

Fundraising is an important part of this project. Research funding and support for the Summit is being sought from both public and private sources. Your assistance in this endeavour would be greatly appreciated.

Episodic Disability Network representatives prepare for meetings with politicians in Ottawa

This project has been informed and influenced by many stakeholders from several sectors to make it the success it is. I am indebted to them for their cooperation and contributions. Please contact me at any point with questions or inputs into the project. I can be reached at emckee@hivandrehab.ca.