

**CANADIAN WORKING GROUP ON HIV AND REHABILITATION  
(CWGHR)**

**GROUPE DE TRAVAIL CANADIEN SUR LE VIH  
ET LA RÉINSERTION SOCIALE**

# **ANNUAL REPORT**

**2000 - 2001**

**CWGHR**

**June, 2001**

Approved by CWGHR Management Committee, July 17, 2001

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### **Acknowledgements**

The Canadian Working Group on HIV and Rehabilitation (CWGHR) gratefully acknowledges the financial support of:

Canadian Strategy on HIV/AIDS  
 GlaxoWellcome in partnership with BioChem Pharma  
 The Life and Health Insurance Companies in Canada

CWGHR also gratefully acknowledges the in-kind support of:

BC Centre for Excellence in HIV/AIDS  
 Human Resources Development Canada  
 St. Michael's Hospital, Wellesley Central Site

## **A. INTRODUCTION**

This Annual Report provides an overview of the key activities, accomplishments, issues and opportunities of the Canadian Working Group on HIV and Rehabilitation (CWGHR) from April 1, 2000 to March 31, 2001, as well as future plans and activities for fiscal year 2000-01.

### **Background /Context**

The Canadian Working Group on HIV and Rehabilitation is a national, multi-sectoral, multi-disciplinary working group of stakeholders involved in rehabilitation in the context of HIV disease. CWGHR was formed in 1998 in response to the emerging need for a national program to provide vision, leadership and coordination on HIV and rehabilitation across Canada.

Funds were provided for three years by AIDS Care, Treatment and Support Program of Health Canada and several private sector partners. The first year, 1998-99, was a developmental period, during which CWGHR focussed on membership and organizational development issues, including terms of reference and operational guidelines for CWGHR and its key committees. Fiscal year 1999-2000 was the first full year of funding and the first full cycle of activities.

There are several factors which contributed to the opportunities, activities and challenges of 2000-01:

a) CWGHR has two primary mandates:

- a coordinating and advisory role on issues of rehabilitation in the context of HIV disease
- a role in raising and distributing funds for projects in the field of rehabilitation in the context of HIV disease

CWGHR's activities in 2000-2001 fell within both these roles at a national level, as key activities were implemented and began to gain momentum

b) CWGHR's unique multi-sectoral, multi-disciplinary structure currently includes six stakeholder groups, including: community based organizations, health care providers, people living with HIV disease, employment-related representatives, government and private sector funders. Leadership, coordination and communication among all stakeholder groups have been essential to ensure that all CWGHR members understand each other's perspective on issues, and that everyone's expertise is recognized and utilized. The Management Committee, which includes representation from all stakeholder groups, has played a strong and significant role in ensuring that structures and systems operated effectively.

c) Resource and partnership development activities were undertaken, to reach out to new partners in addition to the three funding partners at the table. It was critical to strengthen CWGHR's relationship with its current supporters, as well as develop a plan for marketing and partnership development.

d) Fiscal year 2000-01 was the second year in which CWGHR provided funds for projects through its project review and funding allocation process. Systems for project review which had been implemented the previous year were evaluated and strengthened. See section B ii) below for more information on project funding.

## **B. ACTIVITIES**

Through a consultation process among CWGHR members ensuing from the development of our Position Paper on Policy Issues related to Rehabilitation in the context of HIV Disease (see B i

below) CWGHR determined that education/research and practice issues are a priority for CWGHR in beginning to implement the recommendations outlined in the document: i.e. in order to implement other recommendations effectively, significant research and education must be undertaken on the issues of disability and rehabilitation in the context of HIV disease. Activities of 2001 fall within this primary area in both aspects of CWGHR's dual mandate (coordination/advisory role and funding allocation for projects). Activities are outlined in the following broad categories:

- I) Program development, including resource and partnership development
- II) Project review and funding allocation
- III) Meetings and conference presentations
- IV) Administration and Organizational Development

## ***I Program Development***

### **a) Policy / Knowledge Development: CWGHR Policy/Position paper**

- In order to identify key areas to guide our work, CWGHR developed a position paper on policy issues related to rehabilitation in the context of HIV disease. The primary objectives of the paper were to provide a comprehensive overview of related policy issues in Canada, to determine work to be done on each issue and suggest potential partners to take leadership in addressing these issues. The research, which was begun in late 1999, was done through a literature review, key informant interviews and general consultation with CWGHR at its national meeting in March, 2000. The paper was completed in June 2000 and distributed to all stakeholders who had been consulted in the research, other CWGHR colleagues and associates, and is also housed/distributed by the National AIDS Clearinghouse in Ottawa.
- *Deliverable:* Position Paper on Policy Issues of Rehabilitation in the Context of HIV Disease, June, 2000 and summary version.
- The research and recommendations from this paper have guided CWGHR's priority areas for future work. CWGHR has determined that issues related to education/research and practice are priorities for 2000-01.
- Priorities for CWGHR's request for proposals/ funding allocation process in 2001 were drawn from this policy paper

### **b) Education/Practice Advisory Committee**

As education is a priority activity, CWGHR formed an Education Practice Advisory Committee (EPAC) in the fall of 2000. The initial role of this committee was to develop an overall framework for CWGHR's activities related to education, research and practice. At the March, 2001 national meeting, CWGHR agreed that EPAC would continue to meet, to oversee and guide the implementation of the framework

### **c) Resource/Partnership Development (RPD)**

- CWGHR devoted a great deal of time to this area over the past year. Early in 2000 CWGHR hired a Resource and Partnership Development Consultant to assist with development of promotional materials and approach new private sector funders to support CWGHR. This led to the contribution of new funds from two pharmaceutical

companies: DuPont Pharma and Hoffmann-LaRoche. In addition to contributing funds, representatives of both these companies have become members of CWGHR which furthers CWGHR's development as a multi-sectoral working group.

- Due to limited funds to pay the partnership development consultant, this work did not continue past September, 2000. It was critical to find resources to support continued partnership development activities. The fall of 2000 was spent searching for additional funds to support marketing and partnership development activities. This included a proposal to Human Resources Development Canada (HRDC) for a project focusing on partnership development. (see below for more information on this project).

*Deliverable:* SDPP Proposal: "Progress and Partnership: The Development of Rehabilitation for HIV-related Disability", September, 2000.

- A key activity in 2000 was the development of promotional materials, including a brochure outlining CWGHR's background, main objectives and activities. This brochure was completed in May, 2000 and is distributed widely as part of CWGHR's outreach at conferences, other meetings and events. The brochure will be updated on a regular basis, with the next update scheduled for the summer of 2001.

*Deliverable:* CWGHR brochure, 2000 (French and English versions)

- CWGHR submitted a proposal to the Social Development Partnerships Program (SDPP) of Human Resources Development Canada (HRDC). Funds for this project were approved in the spring of 2001. The objectives of this project are to develop partnerships with other groups addressing issues of disability and rehabilitation related to chronic or episodic illnesses, as well as education and research in this area. Funds were approved and the project will begin in June, 2001.
- In addition to the above proposal to HRDC, CWGHR receives donated support from HRDC for translation services for CWGHR materials and communication.
- Links with US government  
During CWGHR's first year, 1998-99, CWGHR worked with Dr. Elaine Daniels of the US Department of Health and Human Services (DHHS), to facilitate communication between US and Canadian work in rehabilitation. Dr Daniels acted as a liaison with the US government. As CWGHR's work moved forward, CWGHR members decided to focus primarily on rehabilitation issues in Canada and then link with other countries at a later date. At the same time, Dr. Daniels left her position in DHHS. CWGHR still sees international linkages/collaboration as being critical to effective work in this field and plans further international outreach/collaboration in the future.

#### **d) Evaluation of CWGHR**

- This is a key area of work. An initial plan for evaluation was developed in the summer of 1999. At the September, 1999 national meeting of CWGHR, there was discussion on 7 key areas of CWGHR's work as a first step in identifying two priority areas. That initial process informed the decision to begin work on "new knowledge development" (see section on policy paper). This model for evaluation is being developed further to relate objectives and proposed 'benchmarks/outcomes' in key areas to CWGHR's accomplishments. In the fall of 2000, CWGHR began to develop a logic model to be used in the development of a comprehensive evaluation of its activities and structure. Results of the evaluation will

inform and guide CWGHR's future direction and activities. Evaluation will be undertaken in the next year, after the logic model has been developed and benchmarks for evaluation have been determined. Certain aspects (e.g. process evaluation) will be evaluated on an ongoing basis; others (e.g. evaluation of the multi-sectoral model) will be done on a periodic basis.

**e) Symposium Feasibility Committee**

- At its national meeting in March, 2000, CWGHR formed a committee to explore the feasibility of a symposium on rehabilitation in the context of HIV disease. As an initial component, this committee has been planning for CWGHR to host/facilitate a one-day satellite workshop on rehabilitation in the context of HIV disease at the 3<sup>rd</sup> Canadian HIV/AIDS Skills Building Symposium in July 2001. This may be used as a pilot for planning and implementing a more extensive symposium some time in the next 2 or 3 years.
- In addition to the Satellite workshop in July 2001, CWGHR has been working on development of a workshop on rehabilitation issues in the context of HIV, which was presented in February 2001 in partnership with the Ontario AIDS Network. This workshop has formed the basis of the satellite workshop in July. CWGHR has received additional requests for this workshop /presentation in a variety of settings during 2001-02.

*Deliverable:* "generic" workshop on rehabilitation in the context of HIV, to be adapted for a range of participants and settings.

**f) Dissemination of Module 7**

At the CWGHR national meeting in the fall of 2000, there was agreement that as part of its education activities, CWGHR would take on the dissemination of *Module 7: Rehabilitation Services in the context of HIV*. This document was developed in 1998 and has not had pro/inter-active distribution across Canada. As the module is still relevant, CWGHR will work with the national AIDS Clearinghouse in 2001-02, (where Module 7 is housed), to disseminate the module by providing educational presentations or workshops where Module 7 is distributed as a resource/tool for further learning.

**g) Prevalence Study**

In February, 2001, Health Canada provided funds for a small pilot study on the prevalence of impairments, disabilities and handicaps among people living with HIV. This information is important to determine issues and needs regarding rehabilitation services. This project is being implemented by researchers at the BC Centre for Excellence in HIV/AIDS in Vancouver, in partnership with BC PWA Society. The data/results of this pilot study will provide initial information which may lead to further (i.e. in greater depth) research on disability and rehabilitation issues.

**h) Ontario HIV/AIDS Treatment Network (OHTN) Priority Initiatives Working Group on Return to active living, work and health.**

Early in 2001, OHTN approached CWGHR to work with them on developing a provincial working group on rehabilitation issues in the context of HIV. Later this year, OHTN will be working with several CWGHR members and others from Ontario to take on work at the provincial level. There is potential for this model of provincially coordinated work on rehabilitation to be adapted in other provinces.

**II. Project Review and Funding Allocation**

In addition to undertaking its own research and other activities, CWGHR provides funding for projects in the field of rehabilitation in the context of HIV disease. CWGHR has developed a

Request for Proposals which is sent out annually across Canada. Funds are allocated by CWGHR (through recommendations of the Project Review Committee - see below) for a one year period.

*Deliverable:* Request for Proposals (RFP), 2000

#### **a) Funded Projects**

In 2000, there were two key priority areas for project funding (see RFP, 2000 for more information):

- Track 1: Projects which focused on:
  - Professional Education
  - Professional Practice
- Track 2: Projects which focused on
  - Income Security issues
  - Maintenance of employment

Unfortunately, most of the proposals which were submitted did not focus on these priority areas and were not eligible for funding. CWGHR allocated funds for only one project in 2000-01: "Development and Evaluation of an Interprofessional Educational Programme on Rehabilitation of Clients with HIV/AIDS for Students in the Health Sciences Professions", sponsored by the School of Rehabilitation Science at McMaster University. This project began in February, 2001 for a 12 month period.

#### **b) Status of Projects funded in 1999**

- At the November, 2000 CWGHR meeting, there were reports from two completed projects which had been funded in 1999, sponsored by the Canadian AIDS Society. (CAS). Final reports have been submitted and will be distributed through CAS networks/colleagues as well as CWGHR associated organizations.
- The projects of the Dr. Peter Centre in Vancouver and Coalition on HIV and Mental Health in Toronto will be completed in 2001.
- When CWGHR develops its web site in 2001, there are plans to post reports from all funded projects on the web site, to facilitate the sharing of information.

#### **c) Evaluation of 2000 Project Review process**

- The Project Review Committee (PRC) completed its evaluation of the 2000 project review process. Recommendations were brought forward to the CWGHR meeting in November, 2000 for discussion/ approval. Changes have been integrated into the 2001 RFP and project review process.

#### **d) 2001 Project Review Process**

- With the revised priorities and processes for funding, the 2001 Request for Proposals will be developed in the spring and distributed in June, 2001. The deadline for submission of proposals for 2000 is September 7, 2001.

- As in previous years, the Project Review Committee will review, evaluate and recommend projects to be funded. CWGHR will make final decisions re: funding allocations at CWGHR national meeting in October, 2001

### ***III. Meetings/presentations***

- CWGHR has completed development of promotional materials, including a brochure in both French and English, to assist CWGHR in its outreach activities.
- CWGHR frequently presents at meetings and conferences to exchange information on rehabilitation in the context of HIV disease, and discuss CWGHR's multi-sectoral model. These presentations provide a valuable opportunity to exchange information and ideas on the range of issues related to rehabilitation and HIV disease.
- In 2000-01, CWGHR members presented at several meetings and conferences, including the International AIDS Conference, Durban, South Africa (July, 2000), Canadian Association for HIV/AIDS Research (CAHR) conference (April 2000) Centre for Health Economics and Policy Analysis (CHEPA) Values in Health Policy conference (May, 2000), National Tri-Joint Rehabilitation conference (May, 2000); University of Toronto/Toronto Hospital HIV/AIDS Conference, December, 2000, Toronto; Ontario AIDS Network provincial meeting of people living with HIV, February, 2001, Toronto; Ontario AIDS Network panel to discuss research proposals and grant writing, March, 2001. In 2001-02, CWGHR will be hosting/facilitating a one day satellite workshop at the 3<sup>rd</sup> Canadian HIV/AIDS Skills Building Symposium in July 2001, as well as many workshops /presentations as part of the dissemination plan for Module 7.

### ***IV. Organizational Development and Administration***

#### **a) Office**

- As of September, 1999, CWGHR has had donated office space at St. Michael's Hospital, Wellesley Central Site in Toronto. As St. Michael's Hospital is a leader in HIV work in Canada, this location has enabled CWGHR be in close contact with other work related to HIV disease.
- As the Wellesley Central Site will be closing in June, 2001, CWGHR will be moving to Sherbourne Health Centre, a newly developed community health centre close to St. Michael's Hospital in downtown Toronto. This new location will enable CWGHR to continue to work with other organizations who have links with rehabilitation and HIV issues, as well as education, clinical practice and research.

#### **b) Structure**

During 2000-01, CWGHR's activities grew and the potential for additional government (HRDC) funds meant that additional staff would be hired to implement the growing work plan. To accommodate these changes as effectively and efficiently as possible, CWGHR revised its overall structure in March, 2001, to ensure more effective use/utilization of CWGHR members' time and expertise. There was agreement to move to a "governance model" where CWGHR members would guide the overall vision, policy/ mandate of CWGHR and staff would be responsible for implementation of activities related to the mandate. The staff Coordinator was moved to an Executive Director position, with overall managerial responsibility for operations, personnel and finance, including overseeing the work of two key new staff, to be hired in the new fiscal year (Resource/Partnership Development Coordinator and Education Coordinator).

There was also agreement that CWGHR members would still have the option of volunteering their time with “hands-on” activities, as some CWGHR members want to continue to be involved at the project or program level.

### **c) Membership**

- **Leadership:** In November, 2000, Tom McAulay resigned as co-chair of CWGHR and Greg Robinson took over as co-chair with Stephanie Nixon.
- CWGHR membership currently includes representatives from 6 stakeholder groups (see Section A b) - page 3)
- In October, 2000, representatives of the new private funders joined CWGHR: Sean Awalt of Hoffmann-LaRoche and John Brennan of DuPont Pharma. In addition, Dr. Gerry Bally took a leave from his position with the HIV/AIDS Division of Health Canada and Paul Lapierre has joined CWGHR as the contact person/representative from Health Canada.
- Tracey Donaldson of Health Canada is representing FPT-AIDS on CWGHR until a provincial representative of FPT-AIDS is able to join.
- Francisco Ibanez-Carrasco, a researcher who works with the Dr. Peter Centre and teaches at Simon Fraser University in Vancouver, joined CWGHR in the fall of 2000.
- Funding agreements (3 year commitments) from Canadian Life and Health Insurance Companies in Canada (CLHIA) and GlaxoWellcome/Biochem Pharma (GW/BP) were completed in March, 2001. Lorne Fox of GW/BP has continued to participate in CWGHR as member of the Resource and Partnership Development Committee.
- As mandated in 1999-2000 meeting, Management Committee is moving forward with the development of a new “employment-related” stakeholder group in CWGHR. As new members for this stakeholder group are identified and approached to join CWGHR, this stakeholder group will continue to develop.
- CWGHR is working to address the need for additional representation from a national cross-disability organization.

### **d) Health Canada funds for 2001-04**

During the fall of 2000, CWGHR met with representatives of the HIV/AIDS Division of Health Canada to discuss CWGHR’s work to date and future funding possibilities. CWGHR developed and submitted a proposal to Health Canada for renewal of the first contribution agreement and funding was approved in February, 2001 for three years (“CWGHR: Phase II” 2001-04). This funding will enable CWGHR to build on the momentum developed during the first three years. Reports on the activities over the next three years will provide regular updates on new development and issues.

## **C. ACCOMPLISHMENTS AND KEY MILESTONES**

In addition to the deliverables described with the above activities, the key accomplishments of 2000-01 fall within CWGHR’s two primary mandates; 1) advisory role, including research and coordination, and 2) the successful completion of the second cycle of project review and funding allocation. CWGHR activities gained momentum as partnerships with existing stakeholders were solidified and new members/partners were invited to participate. Specific highlights include:

- In discussion of the wide range of activities and issues in HIV and rehabilitation, CWGHR determined that it would focus on two key areas: 1) new knowledge development (including Education/Practice and Research) and 2) resource and partnership development. This decision informed priorities for other work in 2000-01.

- The completion and distribution of the Policy Paper in June, 2000 was key in CWGHR taking a leadership role in the area of rehabilitation in the context of HIV disease. Implementation of recommendations from the policy paper related to Education was determined to be a priority and led to the development of CWGHR's Education /Practice Advisory Committee (EPAC) and the EPAC framework to guide the education strategy. This plan will be essential to promote policy changes which will improve programs and services for people living with HIV disease.
- CWGHR received and reviewed projects and provided funding to one key project in the field of HIV and rehabilitation, intended to advance the field and promote new knowledge.
- Agreements with two new funding partners were developed and finalized.
- Resource and partnership development activities moved forward with the development of a marketing plan, hiring of a consultant to develop a proposal to pharmaceutical companies and other potential funding partners.
- Presentations on CWGHR and issues of rehabilitation were key to informing other stakeholders about CWGHR's unique structure and role and raising awareness on rehabilitation issues
- CWGHR's proposals to Health Canada for funds for a second phase of our work and to HRDC Social Development and Partnerships Program (Office for Disability Issues) have been key steps for CWGHR to play a leadership role in the area of disability, rehabilitation, employment and quality of life issues.
- Changing structure and involvement/participation of CWGHR members in areas of CWGHR's policy, governance and operations have been essential in 2000-01, as new activities were undertaken and gained momentum.
- In December, 2000, Elisse Zack, then CWGHR staff Coordinator and currently Executive Director, was accepted into the McGill-McConnell Management Program for National Voluntary Sector Leaders, co-sponsored by McGill University and the McConnell Foundation. This specialized program for national non-profit organizations is integrated into the work of each participant's organization and will provide many opportunities for organizational development and partnerships across Canada. The program runs from April 2001- September, 2002. Further information will be provided over the next 18 months as new activities take place.

#### **D. ISSUES AND OPPORTUNITIES**

The many and varied activities over the past year have presented challenges and opportunities for CWGHR:

- As the field of rehabilitation in the context of HIV disease is very broad, it became clear that CWGHR must focus on one or two key areas. This determination has enabled CWGHR to move forward with the current priority of education with all stakeholder groups.
- It continues to be important to clarify the different understanding and perspective that each member and stakeholder group may have on the wide range of issues involved in CWGHR's activities. This multi-sectoral partnership is one CWGHR's greatest strengths. Consultation among CWGHR members provides an opportunity for comprehensive leadership on key issues.
- CWGHR's two primary mandates must be balanced so that CWGHR plays a leadership role in new knowledge development/education, including a coordination and an advisory role, as well as in raising and distributing funds for projects through the project review process. Having clarified a focus on key issues, these two areas present many opportunities.

- The second cycle of project review and funding allocation was important not only in that an excellent project was funded, but also that the process provided important insights into issues of project review and funding allocation. An evaluation of the 2000 process led to several changes which were to be integrated in the 2001 project review process.
- Resource and partnership development is a priority for CWGHR as new funding partners must be developed to enable CWGHR to fund projects and undertake its own “internal” projects. With the addition of funds from HRDC in 2001-02, CWGHR will be able to increase its outreach and marketing activities, to facilitate greater understanding and support for CWGHR’s work. The multi-sectoral model provides an opportunity to reach out to a wide range of potential partners /stakeholders

## **E. FUTURE PLANS/ACTIVITIES**

CWGHR has a busy agenda in 2000-01, and its work continues to gain momentum. In addition to moving forward with activities, it is time to evaluate activities and developments to date, including CWGHR’s structure and priorities, in order to determine future directions. CWGHR will further develop a work plan based on the upcoming evaluation, priority recommendations of the Policy/Position paper, and activities in resource and partnership development.

In 2000-01, CWGHR will focus on the following activities:

- Continued distribution of the policy paper
- Implementation of priority recommendations from the Policy/position paper
- Implementation of key activities from the Education/Practice Activities framework including dissemination of Module 7 and related workshops
- Continuation and/or completion of 2000 funded projects
- Pilot study on the prevalence of HIV related impairments, disabilities and handicaps
- Review and rating of projects submitted through the 2001 RFP process, for funding allocations at the October 2001 CWGHR national meeting
- Continued development of CWGHR membership, including employment related stakeholder group and cross-disability representation
- Planning and implementation of a satellite workshop on rehabilitation at the 2001 Canadian HIV/AIDS Skills Building Symposium
- Continued research for “new knowledge” development on rehabilitation in the context of HIV disease
- Expanded implementation of CWGHR’s resource and partnership development plan, including negotiations with pharmaceutical companies and approaches to other potential new funders (private and public sector)
- Implementation of Social Development Partnerships Program project with funds from HRDC (focusing on education and partnership development activities)
- Development of CWGHR web site and other information systems
- Evaluation of aspects of CWGHR model and activities
- Work with Canadian Treatment Advocates Council (CTAC) on programs and policy issues
- Continued presentations at meetings and conferences as outlined in Section B. *III* above.
- Move to new office space at Sherbourne Health Centre

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