

# **CWGHR**

Canadian Working Group on  
HIV and Rehabilitation

# Module 7: Rehabilitation Services of the Comprehensive Guide for the Care of Persons with HIV Disease

- Developed by the Wellesley Central Hospital, Toronto in 1998
- Highlighted a number of issues including the need for a shared/common language and a national strategy
- Connected many of the founders of CWGHR

# What is the Canadian Working Group on HIV and Rehabilitation?

- a unique, national, autonomous and multi-sectoral working group
- members represent many disciplines addressing rehabilitation issues in the context of HIV disease
- CWGHR's work is centred on the needs of people living with HIV

# What is CWGHR's mandate?

- To co-ordinate a national response to, facilitate and support the development of, and provide advice on, rehabilitation issues in the context of HIV disease
- To raise and distribute funds for rehabilitation projects in the context of HIV

# CWGHHR's Stakeholder Groups

- People living with HIV disease
- Community based organizations working on HIV
- National associations of health and social service professionals
- Employment sector representatives
- Government funders
- Private sector funders

# What are CWGHR's goals?

- To facilitate the development of rehabilitation programs and resources for people living with HIV disease
- To promote innovation and excellence in the field of rehabilitation in the context of HIV disease and for disabilities episodic and cyclic in nature

# What are CWGHR's goals?

- To generate awareness of and access to rehabilitation services for people living with HIV disease in all regions of Canada
- To address the needs and concerns of families, caregivers, communities and people living with HIV-related disabilities

# What are CWGHR's activities?

- To develop, maintain, and expand collaboration and partnerships among the various stakeholders in HIV and rehabilitation
- To provide opportunities for the stakeholders to dialogue through two national meetings each year
- To develop and coordinate strategies for identifying and addressing areas for change
- To fund research projects in the community

# CWGHR's Position Paper

- June 2000, Russel Ogden - researcher

- Provided background on policy issues concerning rehabilitation in the context of HIV disease
- Identified key players and guided CWGHR's planning in addressing these issues
- Informed potential research and project areas

# Goals of CWGHR's Cross Disability Project

- Bring people together to define common 'disability' and 'rehabilitation' issues for people with lifelong episodic conditions
- Initiate dialogue between disability groups
- Explore future partnerships between organizations
- Discuss policy issues

# Process

- Environmental scan: lit review and key informant interviews
- Multi-sectoral advisory committee
- Phase One: interviews with non-HIV groups
- Phase Two: national consultation
- Phase Three: meeting with federal policy maker

# Emerging Themes

- New definitions of ‘disability’ and ‘rehabilitation’
- Care, treatment and support
- Workplace accommodation and employment
- Income security and support
- Legislation and policy
- Stigma and prejudice
- Need for education regarding episodic illness

# Model of Cross Disability Issues

- **‘Permanent disability’** (lifelong and relatively consistent) issues: legislation, employment equity, income security, long term care and support, independent living
- **‘Episodic disability’** issues: working, unpredictability, insurance, vocational rehab
- **HIV & rehab**: share concerns with both permanent and episodic disability groups

**CWGHR  
HIV & Rehab**

**Permanent Disability**

- Blindness
- Cerebral Palsy
- Down's Syndrome
- Stroke
  - Spinal Cord Injury
  - Amputation
  - Traumatic Brain Injury
  - Invisible

**Episodic Disability**

- Multiple Sclerosis •
- Cancer •
- Mental Illness •
- Chrohn's & Colitis •
- Arthritis •
- Diabetes •
- Fibromyalgia •
- Cystic Fibrosis •

# Episodic Disability Research Project

- To examine the reality of living with HIV/AIDS in relation to the uncertain, unpredictable and fluctuating nature of this disease, and the “roller-coaster”-like trajectory of that reality
- Focus groups across the country in March
- Recommendations for rehabilitation policies and programs

# Research Projects

1. Dr. Peter AIDS Foundation - Issues of Engagement in Rehabilitation among persons with HIV/AIDS who are at High Risk for Declining Health (completed spring, 2001)
2. Canadian AIDS Society - AIDS in the Workplace Manual Development Phase I (completed November, 2000)
3. Canadian AIDS Society - Capacity Building and Training Strategy on Benefits Counselling Issues for Canadian AIDS Service Organizations (completed November, 2000)

# Research Projects

4. HIV/AIDS Interagency Coalition on Mental Health Issues - The Challenging Depression and HIV Project (completed October, 2001)
5. McMaster University, School of Rehabilitation Science - Development and Evaluation of an Interprofessional Educational Programme on Rehabilitation of Clients with HIV/AIDS for Students in the Health Sciences Professions (completed December, 2002)

# Research Projects

6. AIDS Committee of Toronto - Employment ACTION Program: Needs Assessment Study (began March, 2002)
7. University of Toronto - Development of a National Survey of Rehabilitation Professionals on Services for People living with HIV Disease (began January, 2002)
8. McMaster University, School of Rehabilitation Science - Persons with HIV/AIDS (PWHA's) as Educators in the Health Sciences: Impact of a Training Program on Learners and PWHA's (began January, 2002)