

Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions

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Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions

EXECUTIVE SUMMARY

DESIRED OUTCOMES: The CWGHR Cross Disability Project was designed to bring people together to define some common ‘disability’ and ‘rehabilitation’ issues among people living with lifelong episodic conditions. The intent was to initiate dialogue among various Canadian disability groups and to explore the concept of future cross disability partnerships between organizations. Discussion with federal policy makers regarding the unique concerns of people living with episodic illness was also articulated as a desired outcome.

PROCESS: The research question emerged from an environmental scan involving a literature review and key informant interviews to determine emerging issues/gaps in knowledge of rehabilitation in the context of HIV. A multi-sectoral advisory team including people living with HIV, government, health care and academia guided the research. The timeframe for the project was November 1, 2001 – March 30, 2002, and was composed of three major components. Phase one involved interviews with non-HIV groups dealing with lifelong episodic illness/disability to identify areas of mutual concern. Phase two involved a national consultation with several key organizations to explore shared program/policy issues and potential collaboration. Phase three involved a face-to-face meeting with the Chair of the Sub-committee on the Status of Persons with Disabilities (Government of Canada) regarding cross disability concerns.

GUEST LIST: The following organizations participated in the project: Canadian AIDS Society / Canadian Physiotherapy Association / Multiple Sclerosis Society of Canada / Canadian Breast Cancer Foundation / Canadian Psychiatric Association / Canadian Mental Health Association / Canadian Association of Occupational Therapists / Canadian Diabetes Association / College of Family Physicians of Canada / Canadian Psychological Association / Canadian Centre on Disability Studies / Reach Nova Scotia Association / CWGHR.

EMERGING THEMES: There were a number of themes identified by participants in the key informant interviews and in the one-day forum including: the need develop new definitions pertaining to ‘disability’ and ‘rehabilitation’; concerns regarding provision of care, treatment and support for individuals living with episodic illness; workplace accommodation and employment; income security and support; legislation and policy; stigma and prejudice; and need for education at many levels regarding episodic illness. These themes were shared in a follow-up meeting with Dr. Carolyn Bennett, MP, Chair of the Sub-committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities.

FUTURE DIRECTIONS: Many organizations expressed their commitment to continue collaboration on cross disability issues, and project participants generated several ideas for possible next steps.

**The Canadian Working Group on HIV and Rehabilitation
(CWGHR)**

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- Dr. Carolyn Bennett, Member of Parliament, Government of Canada, for her willingness to meet and work with CWGHR on issues pertaining to lifelong episodic disability
- All the individuals and organizations mentioned in this report, who contributed to the project by sharing their time, energy and expertise in both the key informant interviews and the one-day cross disability forum
- Peter Crighton, for his administrative support throughout

Thank You

“Until recently, HIV was viewed as a disease which progressed from infection through AIDS to death. HIV disease is now considered chronic and cyclical, with periods of wellness and illness which provide multiple opportunities for disease prevention and rehabilitation interventions.”

*A Comprehensive Guide for the Care of Persons with HIV Disease
Module 7: Rehabilitation Services (1998)
Health Canada*

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sectoral and multi-disciplinary working group. CWGHR was formed in 1998 with a mission to enhance the quality of life for Canadians living with HIV disease by facilitating the development of rehabilitation programs and resources, promoting innovation and excellence in the field and by generating awareness of, and access to, rehabilitation services. The mandate of CWGHR includes two roles: a development and advisory role, and a project and research funding role.

CWGHR members include: people living with HIV disease; community based HIV organizations; national professional organizations working with HIV and rehabilitation; relevant divisions of government; and private sector organizations and businesses.

INTRODUCTION

Health care providers, institutions, and organizations often separate different disease groups into distinct “silos” (e.g., Multiple Sclerosis Society, Cancer Society, Arthritis Society, Canadian AIDS Society, etc.) and these groups tend to operate autonomously, despite overlapping experience and many shared concerns.

As HIV disease has evolved into a more chronic and medically manageable condition, CWGHR has had a growing sense that collaboration with other disability groups would be both informative and beneficial. It was felt that other “consumer” and “provider” groups with experience in episodic illness might make effective partners in the effort to affect change.

CWGHR conceived of a cross disability project that would engage various disability groups and service providers in a discussion of commonalities between their “silos” and allow groups to explore possible collaborative work. There was also the intent to meet with policy makers to share collective concerns pertaining to episodic illness, as part of the project.

PROJECT DESCRIPTION

As part of a larger CWGHR project funded by the Office for Disability Issues (ODI) through Human Resources Development Canada (HRDC), a parcel of funding was devoted to “targeted research.” The focus for this research was determined by an environmental scan of current and emerging issues in rehabilitation in the context of HIV disease, completed by CWGHR in October 2001 (see Appendix A: Environmental Scan Findings).

The proposal for a specific Cross Disability Project was approved by CWGHR in October 2001.

The timeframe for the project was established as
November 1, 2001 – March 31, 2002.

The purpose of the Cross Disability Project was to explore issues of similarity between people living with HIV related disability and people living with other chronic, episodic and unpredictable illness and/or disability.

A Cross Disability Project Advisory committee was formed to oversee and guide the research and was comprised of the following members:

- Stephanie Nixon; CWGHR Co-Chair
- Nancy Lawand; Director, CPP Program Direction (HRDC) and CWGHR member
- Tom McAulay; British Columbia Persons with AIDS Society, CWGHR member, and person living with HIV disease
- Elisse Zack; Executive Director, CWGHR

A project consultant, Peggy Proctor, was retained to coordinate the project under the direction of the Project Advisory Committee.

Terminology

The Advisory Group began the project using the descriptors “chronic, episodic and cyclical” to describe the illness or disease specific groups being invited to participate in the project.

During the course of the project, direction by participants led to a change in the use of the descriptors “chronic, episodic and cyclical” to “lifelong and episodic” illness.

There was a feeling that the word “cyclical” was misleading (and should be omitted) because it implied some sort of predictability or rhythm to the disease.

In fact, living with an episodic illness is an extremely UNPREDICTABLE experience, which participants felt should be reflected in the terminology.

Objectives

The CWGHR Cross Disability Project was designed to bring people together to define common ‘disability’ and ‘rehabilitation’ issues among people living with episodic conditions. There was a strong desire to initiate dialogue among various Canadian disability groups, and to explore the concept of future cross disability partnerships between organizations. Discussion with federal policy makers regarding the unique concerns of people living with episodic illness was also articulated as a desired outcome.

Method

The research question emerged from the environmental scan undertaken by CWGHR (see Appendix A) that identified emerging issues/gaps in knowledge of rehabilitation in the context of HIV. The project was organized into three phases:

- Phase One involved key informant interviews with primarily non-HIV groups dealing with lifelong episodic illness/disability to identify areas of mutual concern. These non-HIV groups were selected by brainstorming and discussion among Advisory Group members to identify a cross-section of “consumer” and “provider” groups that may be dealing with similar issues in terms of episodic and unpredictable illness.
- Phase Two involved a national one-day forum with invited key organizations to explore shared program/policy issues and potential collaborations.
- Phase Three involved a meeting with the Chair of the Sub-committee on the Status of Persons with Disabilities (Government of Canada) regarding cross disability concerns.

Participants

Ten (10) key informants were interviewed in Phase One including representatives from: The Canadian Psychological Association; Canadian Association of Occupational Therapists; Multiple Sclerosis Society; Reach Nova Scotia; Canadian AIDS Society; Canadian Mental Health Association; Canadian Psychiatric Association; College of Family Physicians of Canada; Canadian Breast Cancer Foundation; and the Canadian Centre on Disability Studies.

Thirteen (13) invited participants attended the one-day forum including representatives from: The Canadian Psychological Association; Canadian Association of Occupational Therapists; Multiple Sclerosis Society; Reach Nova Scotia; Canadian AIDS Society; Canadian Mental Health Association; Canadian Psychiatric Association; College of Family Physicians of Canada; Canadian Breast Cancer Foundation; Canadian Centre on Disability Studies; Canadian Physiotherapy Association; Canadian Diabetes Association; and CWGHR.

Many other invited organizations sent their regrets, and asked to receive copies of the final project report. A full list of invited participants (with contact information) is included in Appendix D.

PHASE I: KEY INFORMANT INTERVIEWS

Key informant interviews were conducted by telephone with representatives of various national organizations. A table containing the names of individuals interviewed and a copy of the interview discussion template can be found in Appendix B. Informants were asked to explain the terms ‘disability’ and ‘rehabilitation’ in the context of people living with various episodic conditions and to identify key issues/concerns/gaps or barriers in regards to same. Informants were also asked to share “success stories” in terms of projects, partnerships or initiatives on behalf of their organizations. A list of “success story” examples can be found in Appendix C.

Major themes emerging from the key informant interviews included:

- I a) **Definitions:** Many groups do not use the words ‘disability’ or ‘rehabilitation’ in their lexicon. For example, a woman with breast cancer would likely not consider herself as having a “disability”; likewise a person struggling with mental illness may not view appropriate care and services as “rehabilitation”. The word “disability” tends to imply permanent physical disability to most people, while the word “rehabilitation” tends to imply a one-time intensive treatment and recovery that is time-limited (for example, cardiac rehabilitation following a heart attack or physical rehabilitation following a spinal cord injury).

All informants stressed the need for new definitions pertaining to lifelong, episodic illness. For example, many conventional medical and insurance policy definitions do not “fit” the unique reality of living with episodic illness. Criteria for access to services, programs and support are often worded and interpreted with “permanent” disability as the standard.

- I b) **Access to Care:** All key informants raised critical issues relating to recognition of the unique needs of people living with lifelong episodic illness and the need to meet those needs with appropriate service and care. The need for national standards of care was emphasized, and the disparity across Canada in regards to programs and services was often mentioned. The issue of drugs and drug costs due to new and emerging drug therapies was also raised as a common concern.
- I c) **Workplace Issues:** Common themes pertaining to the right to meaningful employment and the need for flexible workplace policies and duty to

accommodate were consistently articulated. For example, a worker may be well for six months, then unwell for a period of time, then return to work, then need surgery and a regime of treatment, then feel well again, etc. The unpredictable health status of the worker poses a unique set of challenges for both employer and employee.

- I d) **Income Security:** There appears to be a shared frustration with public and private insurance programs/policies that make it very difficult for people to qualify for benefits while entering and re-entering the workforce. Policies are rigid and unresponsive to the unique and ever changing circumstances of people living with episodic illness. People voiced the need for income protection that will carry them through periods of being well/unwell, working/not working, and part-time work. Most disability insurance policies and benefits do not make allowances for variable work patterns.
- I e) **Need for “Barrier Free” Legislation:** Many informants raised a concern regarding lack of policy development in ensuring barrier free access to Canadians. The ‘Americans with Disabilities Act’ was mentioned as an effective piece of legislation that Canada should consider as a model. This is an example of policy that mandates the removal of barriers for people living with disabilities.
- I f) **Stigma and Prejudice:** There was a sense that people living with mental illness often face debilitating stigma and prejudice that are similar to persons living with HIV disease. Stigma and prejudice are huge barriers that limit human potential. Many people with episodic illness attempt to “hide” their condition due to the stigma involved in disclosing it, and struggle to maintain their “healthy person” image at all costs, despite the up and down nature of their health status.

PHASE II: ONE-DAY CROSS DISABILITY FORUM

The one-day forum was held Monday, February 11, 2002, in Toronto. Of those invited, there were twelve participants in attendance, along with three CWGHR members, the executive director of CWGHR, and the project consultant. The participant list with contact information can be found in Appendix D.

The one-day forum provided an opportunity to discuss issues related to ‘disability’ and ‘rehabilitation’ for people living with lifelong, episodic and unpredictable conditions. An interactive approach was used to facilitate dialogue and idea sharing.

The morning session involved asking participants to identify the barriers (boulders) and facilitators (canoes) in the Canadian environment (the river) affecting the ability of people living with episodic illness to reach their potential. The group identified a wide assortment of issues, many of which were “big picture” issues relating to health and social service policy and delivery.

The early afternoon session was designed to have participants respond to the following question:

“What are specific issues that are UNIQUE to living with a lifelong episodic condition?”

The themes which emerged over the course of the day included: the need for common definitions; concerns regarding care, services and support; workplace accommodation and employment issues; income support and insurance issues; and, policy implications.

II a) **Definitions of ‘Disability’:** Current definitions tend to be based on “continuous disability” versus “episodic disability” and often have an inherent bias toward “physical disability.” Definitions used in legislation and policy are sometimes written and/or interpreted differently by various government departments. Terms and definitions used by medical and rehabilitation providers are sometimes different from definitions used by insurance providers or government benefit programs.

A ‘Federal Definitions Project’ is soon to be initiated across several federal government departments, and it was suggested that some cross disability advocacy on behalf of those living with episodic illness would be timely and appropriate, in terms of providing input.

II b) **Care, Treatment, and Support Services:** The health care system and service providers are often not well equipped to handle the unique and complex needs of people living with lifelong episodic illness. There is a need for integrated interdisciplinary care and services delivered in a community context. A concern was voiced regarding disparate access to care and services in various geographical regions across Canada, and between rural and urban settings.

Individuals living with episodic and unpredictable illness face a unique set of challenges in regards to their everyday life. The analogy of a “roller-coaster” was used – that is, one never knows what is coming around the next bend. The personal identity and body image of the person is often shifting (well vs. unwell) and this is very hard on self-esteem and concept

of self. Life goals are difficult (or impossible) to set, and a sense of failure often ensues. Depression was mentioned as common to the experience of living with lifelong episodic illness.

Although the importance of “support systems” is well recognized in the management of chronic illness, this also poses difficulties in the context of episodic disability, where the need for more or less support is often unknown, unpredictable and ever changing. In the words of one participant, “It’s the difference between knowing you’re on a roller coaster and cannot see what’s around the corner vs. not seeing that next week you’re going to be on a different roller coaster altogether.”

“The day-to-day management is tough – with no predictability. Each day can be a totally different experience. It is very difficult to make any plans.”

*Kris McDonald
person living with MS
Multiple Sclerosis Society*

Furthermore, basic determinants of health such as nutrition, poverty and homelessness must be considered -- these issues were raised repeatedly, especially by those participants representing mental health related organizations around the table.

- II c) **Workplace Accommodation / Employment Issues:** Flexibility is very important in regards to workplace environment and accommodation. Policies to support part-time work and flextime for workers with health issues are seen as critical. There is a need for employer associations, insurance industry representatives, governments, unions, and disability organizations to come together and explore/encourage means of accommodation for the unique health needs of workers living with episodic illness.

“Our society is now working around the clock -- 24/7/365 -- 24 hours/day, 7 days/week, 365 days/year – it’s hard to work or go to school without committing to it everyday.”

*Tom McAulay
person living with HIV*

II d) **Income Support and Security:** The long-term economic forecast for many people living with lifelong episodic illness is bleak. The phrase ‘income security’ implies a reliable and predictable source of income. While income support and security is a concern among all people with disabilities, the unpredictable nature of episodic illness poses unique challenges in terms maintaining a steady income. If your main source of income is a disability pension (tied directly to your health status) and your health status is changing frequently due to the nature of your condition, then income security is tenuous, at best. Disability benefits may be “cut off” during periods of improved health status, and then be difficult to reinstate later, when your health status takes a turn for the worse. There is an acknowledged need for integrated health and social policy and service provision relating to income support.

A number of issues pertaining to long-term disability insurance arise as people with chronic and unpredictable conditions seek financial support from insurance plans, in both the public and private sectors. There is a complex ethical dilemma regarding disclosure of health information, and an agreement that the system itself often provides disincentives to return to work (ie. danger of loss of benefits if you return to work, with no means to re-access benefits if the return to work is not permanent). A common fear was expressed as, “I’m feeling fine now, but I am afraid of what might happen if I go back to work and then I get sick again.”

The claims process is very complicated and laborious and there is consensus that it needs simplification. If a claimant’s health status is changing frequently (unwell/very unwell/now feeling better) ‘new’ forms must be constantly filed to reflect changes in health status. There is a requirement to continually prove (or re-prove) your illness. This becomes unwieldy not only for the individual, but also his/her health care provider(s), especially the family physician, who often functions as ‘gatekeeper’ for both the public and private sector insurance providers.

“My patient is feeling better right now, and would like to return to work... If he does return, however, he will be cut off from his long-term disability benefits. [Consequently] he has decided not to return to work because the fear is too great... I think return to work would help his self-esteem – he has suffered from depression – if going back to work doesn’t work out, there’s a real sense of failure.”

*Dr. David W. Grossman
College of Family Physicians of Canada*

There is also a perceived lack of understanding on the part of many government assistance assessors and private insurance claim adjudicators in regards to the unique circumstances of claimants living with episodic illness.

II e) **Legislation and Policy**

There was acknowledgement of the need for barrier free legislation and an enabling environment for people living with the unique challenges of an episodic illness. Human rights legislation was also seen as an important vehicle for affecting and enforcing change.

II f) **Education**

The theme of education came up repeatedly throughout the day, including the need for greater awareness at many levels: the person living with the illness; the caregiver(s) and family of the person; healthcare providers; employers; insurance companies and funders; and, policy makers at various levels of government, etc. regarding the unique needs of people living with episodic, unpredictable illness and disability.

Suggested Actions

The closing session of the forum was used by participants to brainstorm the following possible next steps:

1. Articulate why lifelong episodic illness is unique or different from other chronic illness/disability.
2. Undertake shared work on developing useful common definitions.
3. Define similarities pertaining to long-term episodic illness among disability groups and define common goals re: policy, research and programming.
4. Create flexible alliances to address public education, public action, and support.
5. Explore organizational support for ongoing collaboration.
6. Investigate funding sources to support collaborative work in regards to episodic disability issues.
7. Encourage an environmental scan re: programs and strategies (Canada and abroad) that address long term, episodic illness in an integrated manner.
8. Encourage research re: early intervention and relapse prevention.

9. Encourage research on the economic benefit of best practices (i.e. cost savings of effective management of episodic illness).
10. Encourage a comprehensive review of existing studies pertaining to labour force involvement of people living with episodic illness/disability.
11. Advance the agenda on workplace accommodation/workforce involvement
12. Advocate for change with insurance providers (public and private) regarding current claim management and criteria. Re-establish a formal means of communication with the “Disability Insurance Committee” of the Canadian Life and Health Insurance Association (CLHIA).
13. Consider forming a national consumer-provider task force to address insurance policy issues.

Evaluation of the One-Day Forum by Participants

The general response of participants was very favorable, with a sense that the project was effective as a first step in exploring issues common to people living with lifelong and episodic illness. There was unanimous agreement that future cross disability work of this nature should continue.

*“We got further into complex issues than I thought possible...
a good start...”*

*Rick Kennedy
Canadian Mental Health Association*

Those organizations that were unable to participate requested copies of the final project report, and have asked to be included in future cross disability initiatives.

EMERGING THEMES

Through Phase One and Phase Two of the project, participants identified many common issues:

- a) Definitions
- b) Care, Treatment, and Support
- c) Workplace Issues
- d) Income Security and Support
- e) Legislation and Policy
- f) Stigma and Prejudice
- g) Education

These emerging themes present a complex array of issues for analysis. When asked to define ‘disability’ and ‘rehabilitation’ in the context of their experience, participants consistently identified both broad, general disability issues as well as specific issues unique to episodic illness.

The broad, general disability issues seemed too general and overarching in scope to consider within the confines of this project, and yet participants continued to identify these “big” issues as important to the well being of people living with episodic illness.

On the other hand, “specific issues unique to episodic illness” were difficult to explore in great depth, perhaps due to the wide range and diversity of participants, but also in part because the big general issues consistently emerged in discussion.

As the Cross Disability Project Advisory Committee analyzed and discussed the project outcomes, an Advisory committee member living with episodic illness offered the following perspective:

“... for most people living with episodic illness, the big general issues are their day to day struggles, [and] these are the people that the service providers (ie. participants at the forum) are dealing with – so it follows that these big issues are, in a sense, the “episodic” issues that they know and have experience to talk about.

Until the big general issues are dealt with it will always be a struggle to [neatly define those issues “specific” to episodic illness]. To use an HIV analogy: in Africa, it is difficult to think about prescription meds when clean drinking water, food and decent shelter are daily struggles – or closer to home, for the HIV+ drug addict in Vancouver’s downtown eastside, HIV is far down on their list of health concerns coming after such things as food, shelter, drugs, drug rehab, dental destruction, social alienation, ongoing abuse since childhood, fear for their lives including thefts, and so on and on.

I think we are doing a disservice if we take the attitude that because these “big general issues” are either too big to deal with or too common to everyone that they don’t have a place in the discussion on what is unique about the episodic lifelong condition(s).

I’d like to turn this around and look at it another way – that is, how does someone with an episodic illness cope with or manage the day to day big general issues that is [different or] unique from other people living with illness facing these same struggles? Is it that one day you can walk up your 2 flights of stairs to your apartment and the next day you can’t, but there is no one there to carry you up because you didn’t see this coming around the corner and have the help you require arranged? Is it that for the last 16 months your welfare benefits cover

your monthly living expenses (just barely I might add) but this month an unforeseen illness forced you to go buy over the counter medications and completely wiped out your food budget 9 days into the month? And so on...”

*Tom McAulay
person living with HIV
CWGHR member
Cross Disability Project Advisory Committee member*

PROJECT ANALYSIS

In analysis of the Cross Disability Project data, a conceptual model was developed to illustrate the wide array of issues identified throughout the project. See Figure 1.0.

The first circle (lower left) represents those issues pertaining to people living with disabilities that are “permanent” in nature. That is, they are lifelong and relatively consistent, such as cerebral palsy, spinal cord injury, etc., and include invisible disabilities such as cognitive impairment, learning disabilities, etc. Examples of important issues in this circle include: barrier free legislation; employment and education equity; income security; assistive devices; long term care and support; independent living; barrier free access, etc.

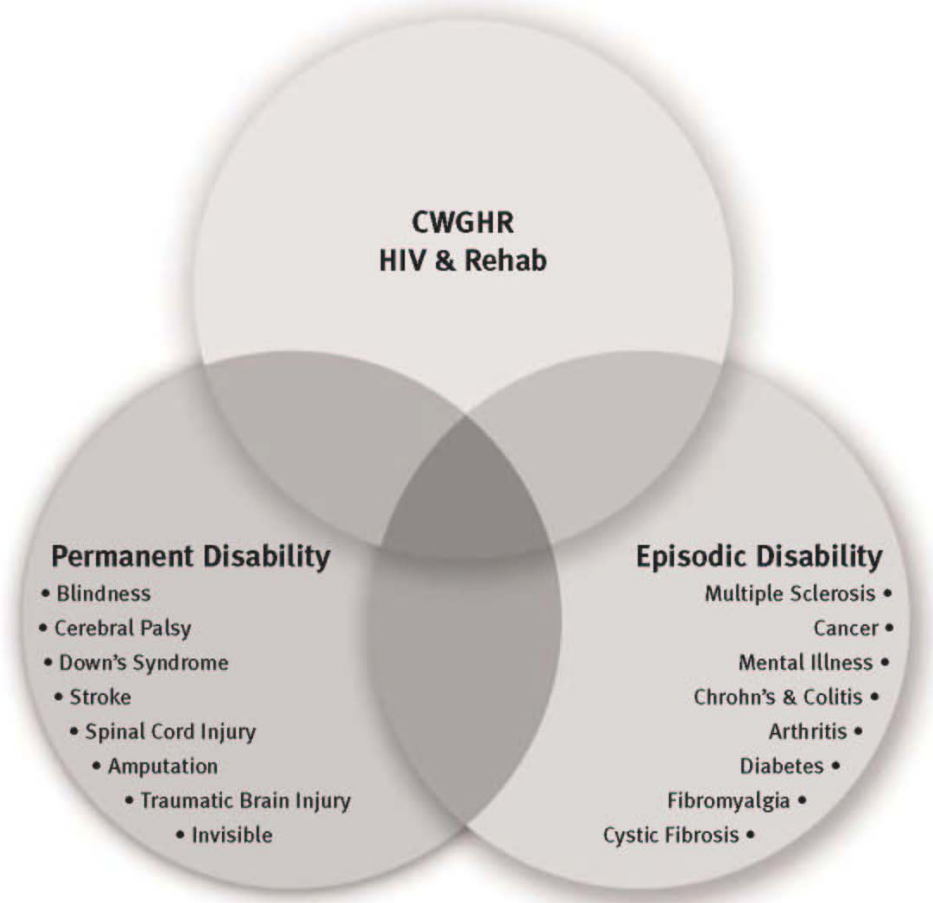
The second circle (lower right) represents those issues pertaining to people living with “episodic” illness or disabilities such as multiple sclerosis, cancer, mental illness, arthritis, fibromyalgia, etc. Examples of important issues in this circle include: being well/unwell; able to work/not work/part-time work; unpredictable nature of the condition; specific insurance issues; changing vocational rehabilitation needs; exorbitant drug costs due to new research, etc.

The area of overlap between the “permanent” and “episodic” circles (a) represents common issues relevant to both groups – as well as demonstrating the concept that many people live in the overlapping zone of both circles – for example, the person with diabetes (“episodic”) who has had a foot amputated (“permanent”), or the person with bipolar disorder (“episodic”) who has limited mobility due to osteoarthritis (“permanent”).

The third circle represents the Canadian Working Group on HIV and Rehabilitation and represents all issues pertaining to HIV and rehabilitation. This circle overlaps with both the other circles, indicating that people living with HIV share many common concerns with both the “permanent” (b) and “episodic” (c) disability groups.

The dark shaded area of overlap between the three circles (all) represents those issues affecting the lives of people in all three circles. These are often overarching general issues such as: care and treatment, effects of health care

Figure 1.0 Conceptual Model of Cross Disability Issues



reform, availability of health care providers, social determinants of health, national standards of care, social justice, human rights, palliative care, “disability” definitions, etc.

This conceptual model can be used to guide future cross disability work by providing a framework for conceptualizing the issues faced by people living with disabilities, including people living with HIV. As such, this model may be used as a tool to help identify potential partners for collaboration on certain issues.

PHASE III: MEETING WITH DR. CAROLYN BENNETT

The initial work plan of the project included meeting with politicians/policy makers to discuss cross disability issues defined in Phases I and II of the project. As the project unfolded, it became clear that the most effective option available was to meet with Dr. Carolyn Bennett, Member of Parliament, and Chair of the Sub-Committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities, Government of Canada.

A meeting was held between the CWGHR Project Advisory Group and Dr. Carolyn Bennett on Tuesday, February 12, 2002, in Toronto.

Those in attendance included:

- Dr. Carolyn Bennett, M.P., Government of Canada
- Stephanie Nixon, Co-Chair, CWGHR
- Tom McAulay, CWGHR member
- Elisse Zack, Executive Director, CWGHR
- Peggy Proctor, CWGHR Cross Disability Project Coordinator
- Peter Crighton, CWGHR staff

The purpose of the meeting was to discuss common themes pertaining to lifelong episodic illness arising from the CWGHR Cross Disability Project. It was also hoped that Dr. Bennett might suggest strategies in regards to affecting systemic change on pertinent issues.

Dr. Bennett was very receptive to discussion of the Cross Disability Project and encouraged future collaboration between disability groups on common issues. She appeared well aware of several of our concerns in regards to disability pensions and insurance company policies. She emphatically stated that certain insurance policies and practices must be addressed, and that she is a firm proponent of “citizen engagement” in terms of stakeholder consultation in important policy discussions.

She suggested ways CWGHR might collaborate with other groups to identify problems and propose changes. She encouraged disability groups to support the proposed “Social Union Framework” currently being discussed in government circles. She also suggested that disability groups be prepared to speak before parliamentary committees using compelling real life stories that illustrate significant problems with existing policy on various issues.

The CPP tribunal will soon be seeking input under the direction of Commissioner Peter Smith, and this would also be an appropriate place to present a collective case.

An interactive website will soon be up and running to facilitate electronic consultation on behalf of the Sub-Committee on the Status of Persons with Disabilities. Dr. Bennett encouraged feedback via the website from CWGHR and other cross disability project partners.

Dr. Bennett congratulated CWGHR on their initiative in undertaking this collaborative project, and encouraged future cross disability work.

LOOKING BEYOND THE SILO

This project provides an important foundation for exploring cross disability issues pertaining to lifelong episodic illness. There has been expressed commitment from a number of organizations to participate in future collaborative work, and this bodes well for future endeavors.

A line of communication has been opened with Dr. Carolyn Bennett, Chair of the Sub-Committee on Persons with Disabilities, which could develop into a very productive and effective relationship in terms of policy discussion on cross disability issues. Further meetings and communications with policy makers from various levels of and departments in government will also enhance the ability to affect change on policy issues.

The key to successful future collaborative work will be the ability to identify and attract the right people from the right organizations at the right time to tackle various issues. This process will take time, and a concerted effort at building relationships among key groups. CWGHR is well positioned to assume a leadership role in future work, given the multi-sectoral and multi-disciplinary nature of the organization.

Community based organizations, governments and people dealing with specific illnesses tend to work within their silos, often unaware of similar work going on in many other silos. The challenge is to know when to pause, step outside your own silo, and join with other silo folk to form some new work crews.

CWGHR CROSS DISABILITY PROJECT KEY INFORMANT INTERVIEWS

I N T E R V I E W S C H E D U L E

Note: All interview were conducted by Peggy Proctor, Project Coordinator

NAME	ORGANIZATION	DATE OF INTERVIEW
Gerard Yetman	Canadian AIDS Society	January 23, 2002
Kris McDonald	Multiple Sclerosis Society of Canada	January 30, 2002
Beth Easton	Canadian Breast Cancer Foundation	February 7, 2002
Francine Knoops	Canadian Psychiatric Association	February 4, 2002
Rick Kennedy	Canadian Mental Health Association	February 2, 2002
Donna Klaiman	Canadian Association of Occupational Therapists	January 31, 2002
Dr. David Grossman	College of Family Physicians of Canada	February 4, 2002
Sean B. Rourke	Canadian Psychological Association	January 31, 2002
Dr. Carole Miles	Centre on Disability Studies	February 7, 2002
Tova Sherman	Reach Nova Scotia Association	January 25, 2002

**CWGHR CROSS DISABILITY PROJECT
February 2002**

CWGHR CROSS DISABILITY PROJECT

Key Questions / Discussion Template for Interviews

I. Desired Outcomes of the Project:

1. To initiate dialogue among Canadian disability groups – particularly groups representing individuals living with conditions that are **chronic, episodic** and **cyclical** in nature.
2. To define some common “disability and rehabilitation” issues among people living with conditions which are chronic, episodic and cyclical in nature.
3. To explore the concept of cross-disability partnerships and/or future collaboration.

II. Objectives:

1. To host a **successful one-day forum** which facilitates dialogue:
 - Amongst groups representing individuals living with conditions that are chronic, episodic and cyclical in nature (including a cross-section of consumer-based and provider-based groups)
 - Between the aforementioned groups and funders / policy makers
2. To share information regarding program and policy issues affecting people living with conditions that are chronic, episodic and cyclical in nature.
3. To develop an awareness of the potential for influencing cross-disability policy and programming decisions in both the public and private spheres.
4. To facilitate potential partnerships and/or potential collaborative work.

THE INTERVIEW QUESTIONS:

1. What do the terms “Disability” and “Rehabilitation” mean in the context of people living with
2. What are the key issues / concerns / gaps / barriers in terms of “disability” and “rehabilitation” from the perspective of the people you work with?
3. Are there examples of programs &/or initiatives that are “working well” (or have worked well) for your organization / stakeholders?
4. Are there examples of projects you can think of demonstrating effective collaborative work (past or present) intended to influence program or policy change?
5. We are interested in exploring how various groups go about building community capacity at the grassroots level... How have

you engaged or encouraged community response to important issues in your organization? What do you see as key to getting people actively involved?

6. Would you like to suggest anyone else (individual or group) that could / would make a significant contribution to this type of gathering?
7. Thank you for accepting our invitation to attend the one-day forum:
 - What do you hope to get out of the gathering?
 - What do you hope to share with others during the gathering?
8. We are in the process of planning the day... Do you have any suggestions regarding any particular format for the day (for example: free-flowing discussion, lecture, small groups, etc.)
9. Do you have any other comments or suggestions?

Thank you for your kind time and attention!

Peggy Proctor
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“Success Story” Examples from Key Informant Interviews

NAME	EXAMPLES
Gerard Yetman Canadian AIDS Society	<ul style="list-style-type: none">▪ Collaborative work between CAS and the Hemophilia Society of Canada in the blood transmission era▪ Response of CAS and HSC to “hot issues” in the blood handling and tracking system▪ Legal and justice agenda was promoted with the Keever commission due to collaborative efforts of so many people▪ End result was a new blood handling system in Canada▪ Another examples is CAS work with curriculum development for Schools of Social Work across Canada and the Canadian Social Work Association
Kris McDonald Multiple Sclerosis Society of Canada	<ul style="list-style-type: none">▪ Ontarians with Disabilities Act – legislation passed in 2001 with the MS society working on that campaign▪ The MS Society Committee for Social Action do advocacy and lobby work
Francine Knoops Canadian Psychiatric Association	<ul style="list-style-type: none">▪ Canadian Alliance on Mental Health and Mental Illness→ serves as a consensus body for advocacy and has issued a joint policy paper “Call for Action”▪ Is intended to be inclusive of all mental health stakeholders
Rick Kennedy Canadian Mental Health Association	<ul style="list-style-type: none">▪ Support for students with psychiatric disabilities in post-secondary education – raising awareness that not all disabilities are physical – students need special accommodation(s) in order to be successful at university▪ ‘Roots for Real Work’ project that involves return to meaningful employment for people living with mental illness▪ ‘Inclusion in Community’ project that encourages people living with mental illness to go out and serve on various Boards of Directors (ie. YMCA, etc.) in their communities▪ Canadian Alliance on Mental Illness and Mental Health (CAMIMH) which encompasses professional, consumer, family and community perspectives▪ Collaboration with Dietitians of Canada on S.A.D.

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Donna Klaiman
Canadian Association
of Occupational
Therapists

- Quebec CLSC Model – multidisciplinary team approach
- LCOA Active Living Coalition – the Diabetes Project (Health Canada) re: risks of Diabetes
- CAOT soon to conduct a national forum with Canada Mortgage and Housing to look at issues of barrier free design in housing
- HRDC sector study on home care – CAOT and Home Care Association lobbying that respite care be recognized as part of the continuum of home care

Dr. David W.
Grossman
College of Family
Physicians of Canada

- Community Advisory Panels at St. Michael's Hospital provide a "community forum" to advise the hospital
- The clinic he works in operates as a large multidisciplinary team, with an effective team approach to care

Sean B. Rourke
Canadian
Psychological
Association

- Current research he is involved in → a controlled trial doing "rehab" with people suffering cognitive impairment and seeing positive results

Dr. Carole Miles
Centre on Disability
Studies

- The concept of "self-managed care" in the context of home care services within the public health care system in the province of Manitoba

Tova Sherman
Reach Nova Scotia
Association
(Access to Justice for
Nova Scotians with
Disabilities)

- The 9 / 4 Program, which promotes employment opportunities for people living with disabilities

**CWGHR CROSS DISABILITY PROJECT
February 2002**

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Canadian Working Group on HIV and Rehabilitation

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