Guide to Multi-Sector Workshops on Rehabilitation in the Context of HIV

Canadian Working Group on HIV and Rehabilitation

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Acknowledgements

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2. Definition of Rehabilitation Slides
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3. Prevalence Study Slides and Presentation Notes
   Developed by Melanie Rusch, BC Centre for Excellence in HIV/AIDS
4. Rehabilitation in the Hospital Setting Slides
   Developed by Kelly O'Brien, University of Toronto
5. Complementary Therapy Slides
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6. Aboriginal Holistic Health Presentation Notes
   Develop by Brian Mairs, Okanagan Aboriginal AIDS Network
7. Canada Pension Plan Slides
   Developed by Barbara Farber, Canada Pension Plan
8. Benefits Presentation Notes
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A. Introduction

The purpose of this Guide is to help co-ordinate and hold workshops on rehabilitation in the context of HIV. In this Guide, you will find:

- information about CWGHR and our work
- an overview of a multi-sector workshop
- outlines of presentations for different stakeholders involved in rehabilitation in the context of HIV
- background reference material

B. What is CWGHR? What is rehabilitation in the context of HIV?

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, multi-sector organization that was started in 1998 in response to the growing need for rehabilitation for people living with HIV. CWGHR's mandate is to:

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

CWGHR understands **rehabilitation in the context of HIV** in its broadest sense: it is about giving people with HIV the tools to help them do what is meaningful to them. The French translation of rehabilitation, *réinsertion sociale* or, literally translated, social re-insertion, captures a fundamental aspect of the rehabilitation process: return to active living and participation in society. The rehabilitation process, then, can include a range of services, programs and policies that seek to address a variety of issues for people living with HIV, including addressing impairments and disabilities related to HIV or the side effects of medications, developing or reconnecting with a support network, accessing available insurance benefits, or deciding whether to return to work.

CWGHR members come from a number of sectors and disciplines who are involved in this broadly defined rehabilitation process. They include:

- 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

For a list of CWGHR members, see Appendix I. Check out CWGHR's website for more information about the organization and our work, www.backtolife.ca.

C. What is a multi-sector CWGHR workshop?

One of CWGHR's goals is to promote awareness of rehabilitation services and programs among the various stakeholders in rehabilitation in the context of HIV. One of the ways that CWGHR does this is through multi-sector workshops: bringing stakeholders in the rehabilitation process together to discuss the issues and develop strategies to address these issues. Workshop participants can include the following groups:

- people living with HIV and their caregivers
- volunteers and staff from community-based organizations
- health and social service professionals, including rehabilitation professionals and those involved in HIV care, treatment and support
- students
- policymakers
- vocational counselors
- employers and union representatives
- representatives from the private sector, including pharmaceutical and insurance companies
- researchers

CWGHR's multi-sector workshops can be effective at promoting awareness of rehabilitation programs and services in your community bringing the various people involved in the rehabilitation process together for what may be the first time. It is intended that creating and strengthening connections between people in different sectors and disciplines is one way to foster an interdisciplinary approach to care and facilitate access to rehabilitation services for people living with HIV.

Participants of CWGHR workshops have found the workshops very beneficial. Below are several responses from participants to the question "What was the most useful aspect of the workshop?" For more comments from participants, see Appendix V.

> "I didn't know much about this and I walked away with a ton of information"
>
> *- From a person living with HIV*

> "Very good definition of rehabilitation for HIV+ people. It will improve my services… Before I only thought rehabilitation was to do with physical disability."
>
> *- From a counsellor at women's AIDS organization*

> "Sharing between all providers. Gives an idea of how we all fit together."
>
> *- From a chiropractic intern*

> "The opportunity to network with agencies my clients might use in the future. Obtaining information on services available."
>
> *- From a social worker*

D. What exactly happens in a CWGHR workshop?

CWGHR works with local partner organizations, such as professional associations or AIDS Service Organizations (ASOs) to plan, promote and carry out workshops. Local partners help to determine the priorities of the workshop and to identify participants and presenters for the workshop.

Objectives of Workshop
Workshops can take a number of different formats, and as a result, specific learning objectives will vary depending on the group. The general objectives of each workshop are:

- To identify a common definition of rehabilitation
- To explore various perspectives on rehabilitation
- To identify barriers to rehabilitation services
- To introduce tools and resources, such as *Module 7: Rehabilitation Services*
- To develop strategies to improve access to services
- To foster an interdisciplinary, client-centered approach to care
- To build and strengthen connections between disciplines and sectors
- To link experiences working with other disability groups to work with people living with HIV
- To increase awareness about CWGHR

Workshop Agenda
Below is an example of an agenda from a full-day multi-sector workshop.

Sample agenda

1. Welcome and Introduction (20 minutes) 10:00-10:20

2. Profile of the Canadian Working Group on HIV and Rehabilitation (20 minutes) 10:20-10:40
   CWGHR Education Co-ordinator

3. Definitions of Rehabilitation & ICF model (20 minutes) 10:40-11:00
   CWGHR Education Co-ordinator

4. Break (15 minutes) 11:00-11:15

5. Perspectives on Rehabilitation: Sector/Discipline Presentations
   1. Rehabilitation in the Hospital Setting (15 minutes) 11:15-11:30
      Physiotherapist
   2. Complementary Therapy (15 minutes) 11:30-11:45
      Massage therapist
   3. Aboriginal Holistic Health (15 minutes) 11:45-12:00
      Aboriginal community worker
   4. Benefits Issues (15 minutes) 12:00-12:15
      Community-based benefits counsellor for people living with HIV
   5. Experiences of a person living with HIV (15 minutes) 12:15-12:30
      Person living with HIV

This is just a small sample of possible presentations. Other presenters can include vocational counsellors, other health providers, other government representatives or representatives from the private sector (a pharmaceutical company, or an employer). Slides and notes from other presentations have been included in the Appendix.

6. Lunch (60 minutes) 12:30-1:30

7. Small Group Work (90 minutes) 1:30-3:00
   a. Challenges and barriers to rehabilitation services
   b. Strategies for improving access to rehabilitation services

8. Break (15 minutes) 3:00-3:15

9. Small Groups Report Back (75 minutes) 3:15-4:30

10. Wrap-up and Conclusion (15 minutes) 4:30-4:45

11. Evaluation (15 minutes) 4:45-5:00

E. What happens in each section of the workshop?

As local partners help to determine the priorities, focus and format of workshops, the following outline is offered only a guide.

1. Welcome and Introduction (20 minutes)
This part of the workshop serves to introduce participants to CWGHR and its work, the local partner organization, the purpose of the workshop and the other participants. Participants introduce themselves to the group, explain their interest in rehabilitation in the context of HIV, and state what they hope to learn from the workshop. Participants should also agree to a few ground rules for the day to ensure that all participants feel safe disclosing personal information. See Appendix II for an example of ground rules.

2. Profile of the Canadian Working Group on HIV and Rehabilitation (20 minutes)
This section serves to further develop participants' understanding of CWGHR, and to elaborate on the history and goals of CWGHR. Participants learn about the development of Module 7: Rehabilitation Services. This book was developed in 1998 to respond to the increase in demand for rehabilitation services seen after the introduction of more effective treatments for HIV in the mid-1990s. During the development of Module 7, it became clear that there was a need for a national strategy on rehabilitation. Many of the authors of Module 7 went on to form the Canadian Working Group on HIV and Rehabilitation. Module 7 is available on CWGHR's website, www.hivandrehab.ca.

See Appendix III for slides for this section of the presentation.

3. Definitions of Rehabilitation & ICF model (20 minutes)
In this section, participants are introduced to CWGHR's definition of rehabilitation in the context of HIV. There are three parts to this presentation:

a. Brainstorm definitions of rehabilitation
In this section, participants identify definitions and words that relate to rehabilitation. This is to show that rehabilitation is very broad and can involve a number of services, programs and policies.

b. Overview of definitions
Participants are introduced to definitions of rehabilitation that CWGHR uses in our work, including a definition from Module 7 and a model developed by a person living with HIV.

c. Introduction to conceptual frameworks
Participants are introduced to a variety of conceptual models that help to define disability and the roles that various stakeholders can play. One of these conceptual frameworks, called the International Classification for Functioning, Disability and Health (ICF) created by the World Health Organization, explores health-related experiences beyond those covered by the concept of disease. The model lays out

three categories, from micro level (body part, individual) to macro level (community or society):

- **Impairments:** Impairments are problems in body function or structure; they are at the level of the body part.
  E.g.: pain or tingling in feet (peripheral neuropathy).

- **Activity Limitations:** These are difficulties an individual may have executing activities; they are at the level of the person.
  E.g.: difficulties walking because of pain and sensitivity in feet.

- **Participation Restrictions:** These are problems an individual may experience in life situations or the social and environmental consequences of impairments and activity limitations; they are at the level of community or society.
  E.g.: the person has trouble working or taking care of their children because these activities may require walking

This model is useful as it helps participants to understand their roles, where their interventions fit within these three levels, and how interventions geared at each level fit together.

See Appendix III for slides from this presentation. Also see the slides and presentation notes on the BC Centre for Excellence in HIV/AIDS prevalence study for more information about the prevalence of impairments, limitations and restrictions experienced by people living with HIV.

4. Break

5. Perspectives on Rehabilitation: Sector/Discipline Presentations

The sector presentations in a multi-sector workshop offer participants the opportunity to learn about a range of roles and perspectives on rehabilitation. Any of the stakeholder groups involved in the rehabilitation could be invited to share their experiences and perspective. From these presentations, participants begin to understand the roles of the various sectors, how the sectors can fit together and where their own work and/or experiences fit in. The following are examples of sector presentations to help guide presenters, and should not be prevent presenters from developing their own content or format for a presentation.

a. Rehabilitation in the hospital setting, by a physiotherapist

The purpose of this presentation is to introduce participants to rehabilitation professionals based in hospital settings, to explore their roles and activities, and to identify ways to access services from these providers.

See Appendix III for slides from this presentation.

b. Complementary therapy, by a massage therapist

This presentation outlines the role that a complementary therapist, in this case a massage therapist, might play in rehabilitation for a person living with HIV. The presentation uses a case study to outline the role of the massage therapist, and to show how community agencies and service providers can work together to provide co-ordinated care in the rehabilitation process.

See Appendix III for an example of slides used in this presentation.

c. Aboriginal Holistic Health, by an Aboriginal community worker

This presentation provides an Aboriginal perspective on CWGHR's broad definition of *rehabilitation*: tools, services, programs or policies that facilitate a return to active living and improve a person's quality of life. Similarities and differences between the two models can be discussed.

See Appendix III for notes used in this presentation.

d. Benefits issues, by a community-based benefits counsellor for people living with HIV

This presentation helps participants to understand the complex issues faced by people living with HIV related to income support and other benefits and programs.

See Appendix III for notes used in this presentation. Also see the slides for the presentation on the Canada Pension Plan-Disability Program.

e. Experiences of a person living with HIV

This presentation is a critical part of a multi-sector workshop on rehabilitation. A person living with HIV may not identify their experiences as part of the rehabilitation process, particularly if they are unfamiliar with the broad definition of rehabilitation that CWGHR uses. However, it is likely that they have had experience with some aspect of the rehabilitation process, be it setting up financial support, contemplating going back to work, accessing treatment and addressing side effects of medications, or seeking out social or emotional support. Hearing from a person living with HIV helps participants to understand the range of complex issues faced by people living with HIV, the importance of having a client-centred approach and the need to work with other disciplines and sectors to address the rehabilitation needs of people living with HIV.

6. Lunch

7. Small Group Work (90 minutes)

The purpose of this section of the workshop is to encourage networking among participants, to identify challenges and barriers to rehabilitation, and finally, to develop strategies to improve access to rehabilitation.

Participants break into small groups with representation from a number of disciplines and sectors. Then participants identify barriers to accessing and delivering rehabilitation services. They select three or four and develop strategies to address these barriers.

See Appendix IV for an example of a worksheet to use for small group work.

8. Break

9. Small Groups Report Back (75 minutes)
The small groups report back to the larger group on the process, the identified barriers and the proposed strategies. They place their strategies into three categories: micro-level, meso-level, and macro-level. These categories mirror the categories developed in the ICF model of disability: impairments, activity limitations and participation restrictions. Interventions that can be carried out by individuals are placed in the micro-level column; interventions at an institutional level are placed in the meso-level column; interventions that involve policy change are placed in the macro-level column. This exercise clarifies for participants what change they can effect on their own or within their institution or agency, and what change CWGHR and other advocacy groups might try to effect relating to policy.

10. Wrap-up and Conclusion (15 minutes)
This provides participants with the opportunity to see how the components of rehabilitation that they have learned about over the course of the day fit together. Participants can determine any next steps to address barriers to access and to promote awareness of rehabilitation in their agency or community. The facilitator can also outline how CWGHR's work is currently seeking to address the barriers that participants have identified and how the participants' proposed strategies might be incorporated into CWGHR's future work.

11. Evaluation
The evaluation process is critical to increasing the effectiveness of workshops and helping participants to assess their learning. Further, priority areas for future activities are identified by participants at workshops during discussions, as well as through the evaluation process.

Feedback from participants of CWGHR's multi-sector workshops has been very positive. See a list of comments from participants in Appendix V. Also see an example of an evaluation form in Appendix VI.

F. What else do presenters need to know?

Who are the workshop's participants?
Participants at a workshop will depend on the format and objectives of the workshop, the needs of the partner organization and the make-up of the community where the workshop is taking place. Participants may be from a variety of different stakeholder groups. Presentations should be accessible to a diverse audience with different levels of knowledge about HIV and rehabilitation. Below are tips to consider when preparing a presentation.

Workshop Learning Principles
Learning something new takes energy, commitment and risk.
In order to support people in this process, it is helpful to incorporate what we know about the Principles of Adult Education and the Learning Process.

> *People are active and creative beings...They learn... when they are personally involved. Learning is NOT poured INTO people. Learning emerges from people.*
>
> (Pine & Horne, 1969.110)

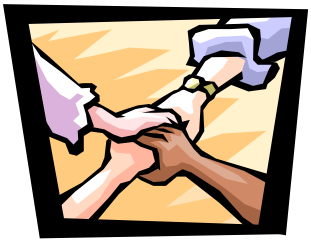
1. **People learn in different ways and usually have one dominant style they prefer.**

The more senses (hear, see, touch, taste (talk), smell) we involve in our teaching methods and the more ways we stimulate those senses increases the number of people we reach and the extent to which they may retain/integrate the learning.

- Be aware of your own learning style. This often dictates our preferred teaching style. Know that everyone else may not respond effectively to that style.
- Use a variety of styles or methods, delivering the same message in more than one style. For example a verbal or image presentation accompanied by a hand out for reading.

2. **Participants and Presenters/Facilitators becoming partners in the process is very effective.**

This relieves some of the pressure from the "teacher as expert" and encourages the participants to "buy-in" and take ownership for their own learning. Also where this interaction is well facilitated the process of exchange is itself, a learning experience.



- Please build opportunities for participants to share their knowledge and experiences with others into your session.
- In introducing your session you might acknowledge the various kinds of experience and

knowledge in the room and identify how you hope to draw on it.
- Establish the ground rules, expectations and role of facilitator and participant for the session.

3. **People learn best when they have opportunities to talk together.**

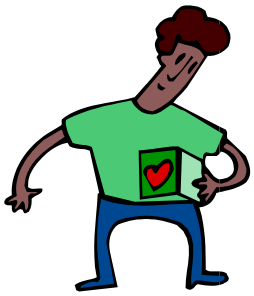
Talking allows people to reframe information they are trying to absorb and to hear others share ideas, experiences, and interpretations that assist the learner to relate to, and integrate new information or concepts. Integrating new information requires process time, talking is only part of this. Silent reflection is another. Be prepared for, and allow, "dead air" to happen as people think about what they have heard and formulate responses. A synergistic effect may result where the group generates ideas that are more than the sum of the individual input.

- Where possible, design opportunities for small group activities as well as large group interaction.
- Allow frequent opportunities for questions.
- Ask people to relate experiences that support/have relevance to the topic

4. **People learn best when their sense of self worth and dignity is nurtured, when people are encouraged to trust themselves, instead of relying only on experts.**

Validating peoples experiences and perceptions allows them to seek learning from their experiences, to share experiences with others and support others' learning.

- Use activities that allow participants to demonstrate their expertise.
- Make connections where the ideas/experiences of the group match the experts.
- When asked for directing advice, ask a question back that encourages the participant to connect to their own feelings about the issue.



5. **Learning is a holistic process.**

Learning is more likely to happen when the whole person is involved - mind, body, senses, intuition, and emotion.

- Relate new information to existing/current contexts.
- Make information relevant to real life situations today.

Adapted from the Ontario AIDS Network's Facilitators' Guidelines

G. Appendices

Appendix I: List of CWGHR Members
Appendix II: Ground rules
Appendix III: Presentation Slides and Notes
1. Profile of CWGHR Slides
2. Definition of Rehabilitation Slides
3. Prevalence Study Slides and Presentation Notes
4. Rehabilitation in the Hospital Setting Slides
5. Complementary Therapy Slides
6. Aboriginal Holistic Health Presentation Notes
7. Canada Pension Plan – Disability Insurance Slides
8. Benefits Presentation Notes

Appendix X: Worksheet for Small Group Work
Appendix XI: Comments from participants of CWGHR workshops
Appendix XII: Sample Evaluation Form
Appendix XIII: Other Resources

Appendix I: List of CWGHR Members (April 2003)

Below is a list of CWGHR members as of April 2003. CWGHR members meet twice a year to discuss issues related to rehabilitation and to determine future priorities for CWGHR's work. Check CWGHR's website for more information about our members.

Organizational members

AIDS Committee of Toronto
- Don Phaneuf

BC PWA Society
- Glen Bradford

Bristol-Myers Squibb
- Ruth Pritchard

Canadian AIDS Society
- Ainsley Chapman

Canadian Association of Nurses in AIDS Care
- Stephen G. Tattle

Canadian Association of Occupational Therapists
- Carolyn Gruchy

Canadian Association of Physical Medicine and Rehabilitation
- Ron Bowie

Canadian Physiotherapy Association
- Stephanie Nixon

Canadian Union of Public Employees
- Jeremy Buchner

COCQ-Sida, CWGHR Co-chair
- Marie-Josée Charbonneau

College of Family Physicians of Canada
- Dick Smith

Hoffman LaRoche Canada
- Samantha Ouimet

Individual members

Francisco Ibanez-Carrasco, CWGHR Co-Chair
Ken King
Tom McAulay
Duane Morrisseau-Beck
Louis-Marie Gagnon

Associate (non voting) Members

Health Canada: HIV/AIDS Division
- Nena Nera

Federal, Provincial, Territorial Advisory Committee on HIV/AIDS
HRDC: Canada Pension Plan-Disability
- Marcel Larivière

HRDC: Office for Disability Issues
- Linda Brown

Appendix II: Ground rules

1. Have generosity of spirit
2. Listen to each other
3. Do not interrupt
4. Ask for clarification
5. Participate
6. Challenge respectfully
7. Honour confidentiality
8. Speak from your own perspective
9. Take care of yourself

Adapted from Self Reflection: A Move Towards Culturally Competent Practice: Participant Workbook by Len Lopez, Gloria Murrant and Doug Stewart.

Appendix III: Presentation Slides and Notes

1. Profile of CWGHR Slides
2. Definition of Rehabilitation Slides
3. Prevalence Study Slides and Presentation Notes
4. Rehabilitation in the Hospital Setting Slides
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3. Prevalence of Impairments, Activity Limitations and Participation Restrictions among Persons living with HIV in British Columbia

Introduction
[Slide 1]

This presentation outlines the problems faced by HIV positive individuals in regards to Impairment, Activity Limitation and Participation restriction, and emphasized the need for rehabilitation programs in this community.

Background
[Slide 2]

WHO redefined their classifications of disabilities in order to more comprehensively assess the experiences faced by individuals. Levels of daily functioning and the ability to continue to participate in an individual's normal daily roles have become an important issue among HIV positive populations.

[Slide 3]

At the impairment level, HIV positive individuals can experience symptoms not only from the disease itself, but also as a result of the antiretroviral medications they may be taking. These impairments may then result in limited ability to carry out daily tasks, although the former is not necessarily required for the latter. A combination of impairments, limitations and other factors may then lead to a restricted ability to function in normal life roles. Given the continuing stigmatization of HIV and the mental burden of the illness, participatory restrictions become extremely important among this population.

The Survey
[Slide 4]

Every few years the BCPWA and the BC Centre for Excellence in HIV/AIDS mail out a survey to HIV positive participants living in B.C. The survey contains a wide range of questions covering sociodemographics, social history, disease status, antiretroviral use, functioning levels, and resource use. The survey is anonymous and all information is self-reported. In 2002, 1508 questionnaires were mailed out and 761 (50.5%) were returned with complete data.

The population responding to the survey were mainly white (87%), homosexual (77%) males (90%) with a median age of 44 (IQR: 33-49). Approximately 73% had completed a high school education and over 75% were earning at least 10,000 dollars a year.

Overview of Prevalence
[Slide 5]

Although the survey is self-report, the question about diagnosed conditions specifically asked " Has a doctor ever told you that you had…..". Depression in this population is extremely high, regardless of CD4 cell count. Although there appears to be a non-significant increase (p=0.238) in levels of depression as CD4 counts increase, what is not shown is that there is an overall increase in *any* diagnosed condition as CD4 levels increase. The levels of depression among individuals with a diagnosed condition are similar across all CD4 levels.
These three CD4 levels are compared because they represent different stages of the disease. At CD4 counts above 500 cells/mm3, the immune system should still be functioning relatively well. Below 500, the immune system may start to become impaired, and below 200 an individual is classified as having AIDS. [Note that this is not the only criteria for an AIDS diagnosis – an individual may have a CD4 count higher than 200, but have other AIDS-defining illnesses.]

The median number of symptoms is slightly higher among those with low CD4 counts, although it is high across the board. The prevalence of symptoms indicates that very few individuals, even with high CD4 counts, do not experience any symptoms. The p-values listed do indicate that there is a significant difference in the experience of those with CD4 counts under 200 and those over 200 cells/mm3.

Moderate or severe pain is also experienced by a large portion of the participants, representing over a third among those with CD4 counts over 200 cells/mm3 and over half among those with lower CD4 counts.
Median numbers of activity limitations range from 2 to 3, while the median number of participation restrictions is seven across all levels of CD4 counts.
The overall number of individuals experiencing any limitation is high, even among those with CD4 counts above 500 cells/mm3; indicating that immune function is not the only thing driving these experiences. Likewise, participation restrictions are as high as 84% among those with high CD4 counts and are nearly 100% among those under 200 cells/mm3.

Impairments
[Slide 6]

This slide illustrates the prevalence of specific symptoms or impairments experienced by this population. The list incorporated in the survey was much longer, with a total of 28 possible symptoms as well as a space to indicate any symptoms not listed. In this bar graph, symptoms experienced by at least 20% of the population are shown. For certain symptoms, there is a significant relationship between the prevalence and the CD4 cell counts, as indicated by the stars above the bars.

The prevalence indicated for the total population is not simply the composite of the three CD4 categories, since only 602 individuals included information about their counts. This last bar includes individuals who are therefore missing from the previous three.

In general, there is a large number of symptoms related to mental impairments (general weakness / fatigue, difficulty with thought processes, headache, endurance problems). Diarrhea and reduced libido are, however, the most prevalent, at greater than 50% regardless of CD4 cell count.

Activity Limitations
[Slide 7]

Out of the fifteen activity limitations contained in the survey, vigorous (running, moving large objects, sports) and moderate (moving a table, carrying groceries) activities, sexual activities and household activities were the most prevalent, with close to 80% experiencing limitations with vigorous activities down to 40% experiencing limitations with household chores.
There appears to be a hierarchy in the types of limitations experienced, with these four more general limitations being experienced first, followed by progressively more limitations such as transportation and personal care.

Participation Restrictions
[Slide 8]

Participation restrictions have a much higher prevalence than would be expected if there was simply a linear relationship between impairments, limitations and restrictions.
All ten participation categories have prevalence of restriction above 40%, regardless of CD4 counts. In relation to the ability to function in society, feelings of discrimination were also measured and were experienced by over 60% of this population.

Overall, these past three slides indicate high levels of disability among this population and underline the need to address impairments, limitations and restrictions with rehabilitation programs to help them improve their ability to function on a day to day basis.

Comparison to the General Population
[Slide 9]

Standardized prevalence ratios (SPR) were calculated using the B.C. portion of the National Population Health Survey conducted in 1999. This survey was sent out to a sample of the Canadian population and contained a large number of health related questions, including a subset of questions asking about limitations in activities of daily living. The comparable questions contained in the BCPWA survey were singled out in order to compare the limitations experienced by this population to the general population.

There were four relevant questions taken from the two survey's, including 1)help required in eating/preparing meals, 2) help required in household chores, 3) help required in shopping and) help required in personal care (dressing, showering, toileting).

The standardized ratio takes the age specific rates of limitation experienced among the general population and applies them to the corresponding age groups of the BCPWA participants. This gives and ' expected' level of limitations. The actual levels of limitations experienced in the BCPWA, or the observed levels, are then divided by the expected levels to give the SPR. An SPR of 1.0 would indicate that the amount of limitations is equivalent between the two groups. An SPR greater than 1.0 indicates that the observed levels are that many times higher than would be expected given the rates seen in the general population.

The first column shows the SPRs calculated for men and women when comparing to the general population of B.C. In both cases, the levels of limitations are approximately nine times that seen in the general population. The second column shows a similar comparison, only the standard used here includes only those from the general population who indicated they had a chronic condition. While the SPRs go down, the HIV positive population still has 6 to 7 times the limitations. The third column uses the entire general population, but this time only compares this to the observed rates among HIV positive individuals with CD4 counts above 500 (thus should have relatively normal immune function). Even among this group, limitations are still 7 to 8 times higher. Finally in the last column, those with CD4 counts above 500 are compared to the general population experiencing chronic conditions. Again, the SPR drops but remains approximately 5 times higher among the HIV positive population.

Conclusions
[Slide 10]

In conclusion, among this population of HIV positive individuals, there are high rates of depression, impairment, limitation and restriction. It is important to note that the population sampled is biased towards a more stable group with generally better access to care and contact with the health system. It is likely that more marginalized groups of HIV positive individuals would have experiences compounded by other external factors.

Regardless of CD4 cell count, there is a much higher rate of activity limitation among persons living with HIV than among the general population, even when restricting the comparison to those with chronic conditions.

It is clear that this population is in need of rehabilitation services and targeted intervention programs in order to help them regain some functional capacity and remain active in their own lives. While antiretrovirals may help to fight the virus, social and rehabilitative support is needed to help fight the disease.

5. **Aboriginal Holistic Health Presentation Notes**
   Developed by Brian Mairs at Okanagan Aboriginal AIDS Society

HOLISTIC as an adjective…

Are you confused about the meaning of holistic? Have you ever been discussing holistic health and discovered that the other person was defining holistic in a totally different way than you? This is not surprising, since there are no accepted standard definitions for holistic, holistic health, or holistic medicine. Most usage falls within two common definitions:

1. Holistic as a whole made up of interdependent parts

You are most likely to hear these parts referred to as

- The mind / body connection,
- Mind / body / spirit, or
- Physical / mental / emotional / spiritual aspects.

When this meaning is applied to illness, it is called holistic medicine and includes a number of factors, such as

- Dealing with the root cause of an illness,
- Increasing patient involvement, and
- Considering both conventional (allopathic) and complementary (alternative) therapies.

2. Holistic as a synonym for alternative therapies

By this definition, "going holistic" means turning away from any conventional medical options and using alternative treatment exclusively. This meaning mainly relates to illness situations, and sometimes is used for controversial therapies.

The expanded perspective of holistic as considering the whole person and the whole situation allows us to apply holistic as an adjective to anything. For example, we can develop a new project at work or re-organize our life holistically. When illness is involved, the broad definition of holistic allows us to integrate both conventional and complementary therapies. Consider adopting this holistic approach to your life.

My holistic approach…

I see holistic health as an approach to creating wellness, which encourages you to:

- Balance and integrate your physical, mental, emotional and spiritual aspects
- Establish respectful, cooperative relationships with others and the environment
- Make wellness-oriented lifestyle choices
- Actively participate in your health decisions and healing process.

6. **Benefits Presentation Notes**
   Developed by Pamela Bowes at the Ontario AIDS Network

"We are all one banana peel slip away from disability."

- Take a moment and think about what would happen to you, where would you turn, and how would you get by if you slipped on that banana peel tomorrow. Where would your money come from?
    - Who here knows exactly where and how much they would receive?
    - How many people have a Will and Medical Power of Attorney?
    - How many people have planned for that rainy day?

- What are the sources of potential income for a PHA who has to leave work

    - Brainstorm and categorize

- Points to remember for accessing this process:
    - You are sick at the point you are having to work through this process, sometimes very sick or too sick to do it alone or do it at all
    - Every program has a different definition of disability
        - Give some examples for EI, OW, ODSP, CPP, Disability tax credit
    - Every program has different forms, different process, different timelines, different amount they pay
    - This is all very stressful
    - It is like creating a personal map, fitting together all the pieces of entitlement and how they will work together
    - Finally, it works out and some stability in life is created

- You probably now have some major worries worked out: a drug coverage, maybe rent-geared-to-income housing, a schedule that accommodates your interests, medical needs, social life, limitations and periods of wellness
- NOW THINK ABOUT RETURNING TO WORK:

- In my opinion and experience in working with well over 1000 PHAs in Toronto, and speaking to groups of PHAs from around the province, the BIGGEST issue to returning to work is Benefits

    - How does your present income plan work if you earn money
    - What happens to all the extras you have established like your drug coverage and affordable housing
    - What happens if you get sick again
    - Will you ever get long term disability again with a pre-existing condition
    - Will you have to go through that whole maze of programs all over again if you get sick
    - Could you end up actually getting less than you do now

    - Is it worth the stress of shaking up my stability for the benefits of returning to work

For professionals who are working with PHAs who are thinking of returning to work, my advice is:

- Carefully, extremely carefully review all the benefits information, know the implications, assess costs and benefits, play out all potential scenarios
- Let the client assess their level of risk
- Have the client complete a budget of how much money they will need to earn in order to maintain a comparable lifestyle (ie market value rent, clothing, transportation)
- Understand if the client sees the risks as too high at this point, and may return to the process later

Appendix IV: Worksheet for Small Group Work

Workshop on Rehabilitation in the Context of HIV

- Please ensure that there is a **mix of perspectives in each small group**. Feel free to move around to achieve this mix.
- We recognize that there is a limit to what may be achieved in the time allowed during the workshop and hope that you take advantage of this as a **networking opportunity** so that results may be pursued beyond the workshop.

Before you begin, each group should select a recorder, a time keeper and a reporter.

PART ONE – Create a Personal List - 5 minutes

1. On your own, consider and list the **challenges in delivering rehabilitation services** for people living with HIV. If you do not have direct experience, imagine what you believe to be challenges. **(2 minutes)**

    -
    -
    -
    -
    -
    -

2. On your own, consider and list the **challenges accessing rehabilitation services** for people living with HIV. If you do not have direct experience, imagine what you believe to be challenges. **(2 minutes)**

    -
    -
    -
    -
    -
    -

PART TWO – Create a Master List – 30 minutes

1. As a group, share and compile the personal lists of challenges and create a master list of challenges to access and delivery of rehabilitation services. Discuss and document any themes or patterns you notice. **(20 minutes)**

    - When discussing challenges, try to be specific. For example, if access is named as a challenge, try to identify the specific access issue: physical barriers, language differences, geography, etc.

2. Prioritize the master list of challenges. Select the top four or five challenges. **(10 minutes)**

PART THREE – Strategize – 45 minutes

1. On your own, spend a few minutes thinking about how some of these challenges might be overcome or what changes would need to happen to overcome these challenges. **(5 minutes)**

2. As a small group, create a list of ways to address challenges to access and delivery of rehabilitation services. Identify the tools, skills, new knowledge or attitude shifts that would support the changes or solutions you list. **(30 minutes)**

3. In the last few minutes, prepare to report back to the whole group. Each group will have a chance to present one change or solution. Be sure to identify whether it is primarily a tool, a skill, new knowledge, or an attitude shift. **(10 minutes)**

PART FOUR – Report Back – 5 minutes for each group

1. Present to the larger group the list of top four or five access and delivery challenges.

2. Present a change or solution that addresses one of these barriers. Remember to identify whether it is primarily a tool, a skill, new knowledge or an attitude shift.

NOTES:

Appendix V: Comments from participants of CWGHR workshops

"I am pleased workshops continue to take place. This gives me hope."
- *From an AIDS organization volunteer*

"Thank you for the workshop. I found it very beneficial and informative. It gave me some insight into the field that I am hoping to work in."
- *From a student in Massage Therapy*

"Very well planned; diverse topics; great speakers."
- *From a social worker*

"Presentations were very informative and easy to follow. Very stimulating and thought provoking."
- *From a clinical researcher and AIDS organization volunteer*

"Presentations and individuals like her [the presenter from a local AIDS organization] keep me involved, active and encouraging others to do the same."
- *From an AIDS organization volunteer*

"On arrival, my want was for information. Upon departure, it was for a way to make change."
- *From a peer educator*

What was the most useful part of the workshop?

"Discussing returning to work, spiritual care instead of discussing how poor your health is. Hope for the future."
- *From a person living with HIV*

"Hearing the experience of people living with HIV/AIDS, being exposed to real life stories."
- *From an intern at an AIDS organization*

"Learning about this new [World Health Organization] model. Exciting to see all the energy around this field and the desire to expand and progress - thanks!"
- *From a staff person at an AIDS organization*

How will you use what you learned in your work or your life?

"Advocate for intergovernmental tools to support education on income support for people with disabilities."
- *From a federal government (HRDC) employee*

"Will be able to utilize strategies for employment"
- *From an occupational therapist*

"Be more proactive in my education of resources and available services."
- *From a chiropractic intern*

"Advocate for more education for staff at my facility."
- *From a social worker*

"Educate colleagues re: resources; educate clients in community; be proactive in consulting with other professionals."
- *From an occupational therapist*

"I learned things that I can realistically do in my setting right away – [they are] not time sensitive."
- *From a social worker*

These quotes are taken from evaluations from the following workshops:

- **London, ON, Opening Doors Conference, September 21, 2001**
- **Winnipeg, MB, Nine Circles Community Health Centre, October 16, 2002**
- **Toronto, ON, Casey House in-service session, November 25, 2002**
- **Toronto, ON, Toronto Community Care Access Centre, January 24-25, 2003**

Appendix VI: Sample Evaluation Form

EVALUATION

Workshop on Rehabilitation in the Context of HIV
Canadian Working Group on HIV and Rehabilitation

Date: _____

Please check all that apply. I am a:

____ Rehabilitation service provider – Please specify : _____
____ Staff person – Please specify : _____
____ Volunteer – Please specify : _____
____ Care giver
____ Person living with HIV
____ Other – Please specify: _____

1. The workshop was well planned and flowed effectively.

1 2 3 4 5
(Not true) (Very true)

Comments:

_____

_____

2. The facilitators were: (check all that apply)

___ Effective ___ Knowledgeable ___ Presented useful information
___ Used vocabulary and concepts I could understand ___ Facilitated group participation
___ Presented useful materials and handouts ___ Provided a stimulating learning experience

3. I found the content of the workshop relevant to my: (please check all that apply)

___ Current Work ___ Future Work ___ Personal Health ___ Future Quality of Life

4. My expectations were for the workshop met. (Please check one)

___ YES ___ PARTIALLY ___ NO

Please explain:

_____

5. The most useful or satisfying aspect of the workshop was:

_____

_____

6. Was there anything about the workshop that was not helpful? If so, what?

_____

_____

7. I made connections with participants and/or facilitators that will assist me or be useful in the future:

1 2 3 4 5
(Not true) (Very true)

8. How will you use what you learned today in your work or your life?

_____

_____

9. Overall, I have a better understanding of the range of issues relating to HIV and rehabilitation:

1 2 3 4 5
(Not true) (Very true)

Comments:

_____

_____

9. How much did your knowledge about issues relating to rehabilitation in the context of HIV increase as a result of participating in this workshop? By…

<10% 10% 25% 50% 65% 80% >90%

10. In future, I would like to see the following topic(s) covered relating to rehabilitation in the context of HIV:

_____

_____

11. Other recommendations or comments.

_____

_____

Name (optional): _____

Contact Information (optional): _____

Thank you for taking the time to complete this workshop evaluation.

Appendix VII: Other Resources

For additional resources, please see the following documents available on CWGHR's website, www.hivandrehab.ca, and/or through the HIV/AIDS Clearinghouse.

A Comprehensive Guide for the Care of Persons with HIV Disease: Module 7: Rehabilitation Services by the Wellesley Central Hospital and Health Canada

backtolife.ca, CWGHR's newsletter

HIV/AIDS: A Guide to Insurance Benefits by the Canadian AIDS Society (only available at the Clearinghouse)

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

Policy Issues on Rehabilitation in the Context of HIV Disease: a Background and Position Paper by Russel Ogden

Also available on CWGHR's website are the following research projects funded by CWGHR.

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)

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 February, 2002)

6. AIDS Committee of Toronto - Employment ACTion Program: Needs Assessment Study (completed April, 2003)

7. University of Toronto - Development of a National Survey of Rehabilitation Professionals on Services for People living with HIV Disease (completed March, 2003)

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 (completed December, 2002)