Vocational Rehabilitation
and Rehabilitation Services

in the context of HIV Infection

Issues and Guiding Principles

Prepared by the
British Columbia Persons With AIDS Society
in consultation with
Health Canada

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This is a living document.

In collaboration with Health Canada and
The British Columbia Persons With AIDS Society

ISSUES AND GUIDING PRINCIPLES FOR RETURN TO WORK, VOCATIONAL REHABILITATION AND REHABILITATION SERVICES IN THE CONTEXT OF HIV INFECTION

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EXECUTIVE SUMMARY

RATIONALE

- The opportunity to go to or return to work may prove to be one of the most rewarding developments in the lives of persons living with HIV disease. However, without supportive policies and the availability of innovative programs, it could as easily be transformed into a terrible burden which further exacerbates the hardships related to living with HIV disease.

- With the introduction of a new class of drugs, the Protease Inhibitors, and the development of multiple combination therapies for treatment of HIV, there is an indication of improved health and increased life expectancy for up to 80% of people living with HIV disease. It is important to remember that the durability of this clinical stabilization is unknown over the long term. With less than three years experience with these new combination therapies, latest data now indicates that only 50% of people on these treatments continue to have a sustained remission.

- It is the British Columbia Persons With AIDS Society's (BCPWA) observation that now some of our members are considering making decisions about work force re-training, returning to previously held jobs, or entering the workforce for the first time.

- BCPWA needs to know how to best support our members in making these decisions. This document is our first initiative and response to the complex issue of returning to work or returning to productive daily activity. Vocational rehabilitation, rehabilitation services, related issues of quality of life, income maintenance, safety, and transition issues all need to be addressed in an humane way if we expect to see a significant proportion of our population successfully return to work and productive participation in society.

PRINCIPLES

1. Medical Science and Research

- Virological and immunological markers should not be used as indicators of functional capacity or employment capability.

- In order to adhere to their life saving drug regimes people living with HIV disease and AIDS require sufficient accommodation to take their medications.

- Research must be undertaken to define and validate best practice models of care.

2. Self-determination

- The person living with HIV disease must be at the center of the decision-making process.

- People living with HIV disease are their own experts in determining:
  - their physical, emotional, spiritual health and well being
  - their life plans
  - the means for achieving their goals

- People living with HIV disease should have representation on all groups defining programs, policies and initiatives regarding vocational rehabilitation and return to work.

3. Flexibility

- Going to work should be considered an option in the continuum of care.

- Government and private agencies need to recognize and accommodate the special needs of persons with episodic disabilities.

- Return to work programs and services must be flexible and responsive to the individual's lived experience.

4. Safety

- In accordance with the Human Rights Act, every person with HIV disease has the right to live free of discrimination, prejudice and harassment.

- Every person with HIV disease has the right to a minimum adequate standard of living, regardless of their employment status.

- Every person with HIV disease has the right to privacy and to keep their health status confidential. Medical confidentiality must be controlled by the individual.

5. Responsibility

- All employers, work force unions, professional associations, government personnel, service providers, and private insurance payers need to be educated and knowledgeable in all aspects of HIV disease.

- Existing policies and procedures which may hinder work force entry/re-entry and training need for people living with HIV disease and need to amended to eliminate systemic barriers.

- Failed trials of work, early re-application, and "second chance" policies must be incorporated into workplace and private insurance policies to recognize the unpredictable nature of episodic and cyclical disabilities.

6. Income Security

- People living with HIV disease should be able to pursue their educational and vocational goals without losing financial safety and security.

- Eligibility for long term disability insurance, medical insurance, drug coverage, CPP, housing subsidies, etc., should be flexible and encompass the needs of persons with episodic and cyclical disabilities.

- People administering government and private agency programs need to recognize, accommodate, and ensure the income maintenance needs of persons with episodic and cyclical disabilities.

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- With the introduction of a new class of drugs, the Protease Inhibitors, and the development of multiple combination therapies for treatment of HIV, there is an indication of improved health and increased life expectancy for up to 80% of people living with HIV disease. It is important to remember that the durability of this clinical stabilization is not known over the long term. With less than three years experience with theses new combination therapies, latest data now indicates that only 50% of people on these treatments continue to have sustained improvement in their health status.

- It is the British Columbia Persons With AIDS Society's (BCPWA) observation that now some of our members are considering making decisions about workforce retraining, returning to previously held jobs, or entering the work force for the first time.

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PROCESS OF DEVELOPMENT AND HOW TO USE THIS DOCUMENT

Collaborative Process

- This document is based upon the collective work of all the major departments in the British Columbia Persons With AIDS Society. This document was created after several sessions of issue identification and brain-storming."

- Widespread recognition that there are critical issues for our community led to this collaborative effort between BCPWA and Health Canada.

Organization and Use of this Document

- The document is organized into the following sections:
  An Executive Summary
  Background
  Issues
  Definitions and Context
  Principles

- This paper outlines the issues and guiding principles developed by people living with HIV disease and by people working in the HIV/AIDS community.

BACKGROUND

The B C P W A Society

The British Columbia Persons With AIDS Society is Western Canada's largest consumer directed AIDS organization with a membership of over 3,500 individuals. Our goal is to empower persons living with HIV disease through mutual support and collective action.

The History of HIV-affected Communities

- ***Engagement in the work force:*** Throughout the HIV epidemic, many persons with HIV disease left their employment and educational pursuits due to declining health and expectations of reduced life expectancy. Further, many younger persons did not act on their educational and career goals, and many, due to a feeling of hopelessness, combined with the debilitating effects of the disease, did not enter the work force at all.

- ***Recent Therapeutic Advances and Implications for People Living With HIV Disease:*** In 1996, the introduction of a new class of drug to treat HIV disease, the Protease Inhibitors, and the further development of combination therapies resulted in a stabilization and improvement in immune status and quality of life for up to 80% of HIV+ Canadians receiving this new therapy. The durability of this improvement over years is not known. As recently as August 1997, early information from experienced HIV caregivers in the United States indicates that up to 50% of HIV+ persons on combination therapy may ultimately decline in their health status due to the emergence of drug resistant strains of HIV. This creates tremendous uncertainty for people living with HIV disease who must once again consider an unclear future, while most of society still holds the inappropriate view that these combination therapies are the definitive answer to HIV infection.

Safety of People With HIV Disease

- People living with HIV disease have only recently resumed considering their lives with a greater sense of optimism. Many of us have endured continuous, multiple and chronic grief; anticipatory loss; and a host of life changes intrinsic to living with a progressively degenerative and life threatening illness. To change a life-perspective and introduce new activities, such as returning to work or school, requires a supportive environment and pragmatic programs.

- This early work is intended to help prevent damage to our lives and benefit programs and to prevent systemic policies from being put in place that will be detrimental to our health and rights. We need to provide safe environments for people living with HIV disease based upon pragmatic transition, education and training, income maintenance, drug plan support, and workplace strategies which do not expand our vulnerability.

- Medical advancements must not affect government and private insurance policies for income maintenance supporting persons with HIV disease. Those of us who have benefited from new treatment advances will need to re-evaluate our health and future financial security. The result for some will be to re-enter the work force, however, this may not be an easy process, or indeed, the right decision.

- It must be recognized that returning to the work force will only be applicable for a relatively small portion of our population. The process of returning to the work force must not damage the safety of people living with HIV disease who cannot work, or those who do return to work and find that they cannot continue to work.

ISSUES

Bio-Medical Issue

- HIV disease and AIDS are complex disease syndromes with significant variations between individuals, and affecting multiple systems in the body.

- Debilitating effects of HIV disease are episodic in occurrence, unpredictable, and result in cyclical disability.

- Drug therapies currently available may be effective only for a limited period of time, are ineffective for up to 20% of people with HIV disease over the short to mid terms, and may be ineffective for 50% or more of our population over the long term. Further, drug therapies remain inaccessible or unavailable to many in Canada due to their cost, complexity, or multiple adverse effects.

- People with HIV disease who are benefiting from new drug therapies must adhere to intense and strictly regimented dosage schedules, complicated by food and drug interactions, and often suffer from drug side-effects; all of which create impediments to returning to productive work.

- Recent information on the immune reconstitution for people with HIV disease demonstrates that HIV causes irreversible, significant impairments to the immune system as early as the first year of HIV infection. The longer one is infected with HIV damages to the immune system increases and the ability for the immune system to restore is lessened. This means that even people on anti-retroviral therapies will continue to have impaired immune functionality. This immune impairment is irreversible with current treatments and will cause a decrease in quality of life and has the potential for long term consequences and disability.

- Innovative approaches must be developed and adopted to safeguard the health, security, and overall well-being of people living with HIV disease who wish to enter or re-enter the work force.

Social and Work Environment

- Work opportunities for Canadians have decreased over the last decade. Barriers to enter or re-enter the work force have increased due to the competitive nature of the work place, the change in employer-employee relationships, and the increased emphasis on high technology skills.

- Persons with disabilities have always had difficulty engaging in the traditional job market. A person who has been out of the work force, or has never been engaged in the work force will consistently have barriers in the transition to productive and remunerative work. Statistics relevant to the back injured population and other disabled populations reveal the major impediments to work force participation. Resource allocations are required for work force re-entry.

- Access to training and education programs has been consistently limited for persons with cyclical disabilities. Investment of limited retraining funds for persons with chronic disabilities has always led to difficult choices in the allocation of those finite programmatic resources.

- HIV/AIDS in the Workplace policies are outdated. Existing HIV/AIDS in the Workplace Policies focus on persons who are in and expected to leave the work force. There is need for new workplace policies to focus on people with HIV disease remaining in and returning to the work environment. These policies need to incorporate suitable accommodation for people with HIV disease: such as drug coverage, hours of work, duties and responsibilities, and consideration for episodic disabilities and ongoing care.

- For the person living with HIV disease, returning to work is a personal choice based on how they feel about their own situation. For some, they may be returning to the work force, or a job previously held. For many, "back to work" means entering a periods of education/training or joining the work force for the first time. For others, because their health continues to decline or does not improve substantially, going back to work is not an option.

- From the insurance industry perspective, there is an ongoing market-based incentive to get as many people as possible off their disability benefit programs.

- From a government standpoint, work force entry/re-entry is an attractive goal for the purpose of getting people off social assistance.

- From the HIV/AIDS communities' position, work force entry/re-entry can only be addressed effectively within the broader context of the determinants of health.

Definitions and Context

Health

- On November 21, 1986 the first International Conference on Health Promotion presented and ratified 'The Ottawa Charter' which outlines the pre-requisites of health. This charter was accepted and utilized by the HIV/AIDS community in setting our own health standards, programs and advocacy strategies.

- These pre-requisites of health include:
  - stable housing
  - health care
  - nutrition
  - income security
  - psychosocial support
  - physical environment
  - safety
  - employment

- Health is further defined as an individual's own sense of physical, emotional and spiritual well-being, including feeling productive, feeling whole, having a positive sense of self, and feeling connected to the world.

Rehabilitation

- Rehabilitation services for people living with HIV disease have not been incorporated in the continuum of HIV care, because until recently HIV disease was a progressive degenerative disease with no obvious form in arresting therapy.

- Medical science has now developed to the point where effective combination therapies have resulted in the slowing, and even halting of disease progression, while increasing or regaining functional capacity over the short duration of experience with these drugs. Consequently, there will be far greater need for rehabilitative services in the HIV/AIDS community.

- The three major goals of rehabilitation are:
  - to increase or maintain functional capacity,
  - to improve or maintain the quality of life, and
  - to decrease hospitalizations and increase self care.

- Within the larger context of rehabilitating one's health is the subject of vocational rehabilitation. Traditionally, vocational rehabilitation is associated with job-related issues, educational pursuits and volunteerism. From the point of view of the HIV/AIDS community, vocational rehabilitation, considered in the context of the pre-requisites of health, is a return to productive daily activity at whatever level is appropriate for the individual.

Principles

The following section presents and describes the guiding principles from the community of people living with HIV disease for considering vocational rehabilitation and a return to productive activity. The six major principles outlined below define issues which affect the individual living with HIV disease, HIV/AIDS community organizations, governments and private agencies which support people living with HIV disease.

1. Medical Science and Research

- ***Virological and immunological markers should not be used as indicators of functional capacity or employment capability.*** Surrogate markers do not define the functional capacity or quality of life of a person with HIV disease. CD4 cell count and HIV RNA viral load do not tell us how sick, or healthy, or functional a person is.

- ***In order to adhere to their life saving drug regimes people living with HIV disease and AIDS require sufficient accommodation to take their medications.*** Current combination therapies are complex and require specific and exacting drug administration to prevent the development of drug resistance and consequent treatment failure. These combination therapies often have significant adverse affects.

- ***Research must be undertaken to define and validate best practice models of care.*** Rehabilitation and returning to productive daily activity are new to HIV disease. Best practices and models of care have not been developed or tested in the population of people with HIV disease. Resources must be committed to defining best practices and outcomes for people with HIV disease. Research on best practices, models of care, and returning to productive daily activity will take the commitment of professionals, the HIV-affected communities, researchers and people living with HIV disease.

2. Self-determination

- ***The person living with HIV disease must be at the centre of the decision-making process.***

- ***People living with HIV disease are their own best experts in determining:***
  - their physical, emotional and spiritual health and well-being;
  - their life plans; and,
  - the means for achieving their goals.

2. Self-determination - Continued

- ***People living with HIV disease should be able to set and pursue individual goals.***

- ***Under no circumstances should a person be pressured or coerced to enter or re-enter the work force.*** Those who do not choose to return to the work place should not be penalized or harassed by their financial support agencies or government. The focus on job re-entry and return to work should be on *creating opportunities, innovative supportive programs, and safe environments* for people living with HIV disease.

- ***Timely, accurate and comprehensive information regarding income maintenance, drug benefits, education and employment should be easily accessible to enable people living with HIV disease to make informed choices.***

- ***People living with HIV disease should have representation on all groups defining programs, policies and initiatives regarding vocational rehabilitation and return to work.***

3. Flexibility

- ***People living with HIV disease require a continuum of supportive systems.*** These systems must recognize that every individual is different and they must be able to respond accordingly.

- ***Entry/re-entry to the work force is an option in the continuum of care.***

- ***Programmatic responses must protect the individual's right to negotiate his or her own plan.*** Programmatic responses must be based on the individual's self-identified needs, plans, goals, and must be structured for sustainability.

- ***Returning to work and returning to productive daily activity programs and services must be flexible and responsive to the individual's lived experience.*** Through a process of constant evaluation, programmatic responses must remain accountable to people living with HIV disease. An individual's plans or priorities may change and the program must be able to adapt accordingly.

- ***Government, insurance companies and employers must recognize each person's right to self-determination, and respect the paths and means by which they may choose to exercise it.***

- ***Government, private insurance companies, and employers must recognize that people living with HIV disease require flexibility in terms of working hours, rest***

3. Flexibility - Continued

breaks, scheduled meals, treatment regimes, time for appointments, and sick or extended leave. HIV disease is progressively degenerative, episodic and cyclical, and it will manifest with great individual variation, affecting different people in different ways.

- ***Support and guidance must be available for self employment creation and enterprise development.***

- ***Employers must practice and adhere to Human Rights and Harassment policies.***

4. Safety

- ***In accordance with the Human Rights Act, each individual has the right to live free from discrimination, prejudice and harassment.***

- ***Every individual has the right to privacy and to keep their health status confidential.*** Medical confidentiality must be controlled by the individual.

- ***People living with HIV disease have the right to a minimum adequate standard of living, regardless of employment status.*** Persons with episodic and cyclical disabilities should have on-going access to the full range of supports and the right to return to benefits for which they previously were entitled.

- ***Continuous coverage of benefits provided by governments, other than financial benefits - access to drug programs, extended health coverage, etc. - should be available over the period of transition into the work force.*** Part time employees should maintain all government pro-rated benefits.

- ***No individual should be required to leave a supportive program for any reason other than their own personal choices.*** No individual receiving long term disability benefits should be removed from financial assistance or have their benefits canceled solely based upon virological or immunological markers, or the opinion of any caregiver. Only an individual's own physician in conjunction with the person living with AIDS and their family is in the position to advise that individual on his or her ability to productively participate in a work environment; however, even then, only the individual living with HIV disease can make that decision.

5. Responsibility

- ***All employers, work force unions, professional associations, government workers, service providers, and private insurance payers need to be educated and knowledgeable in all aspects of HIV disease.***

- ***Service providers and employers should not make assumptions about the capacity of "hard-to-reach" populations, or any group's ability to participate in, or benefit from, entry/re-entry to the work force or training services.***

- ***Existing policies and procedures regarding work force entry/re-entry and training need to be amended and augmented to eliminate systemic barriers and facilitate work force entry/re-entry and training of persons with episodic and cyclical disabilities.***

- ***Public and private insurers are responsible to communicate, clarify, and explain existing policies and procedures regarding work force entry/re-entry and training to the HIV/AIDS community, employment and rehabilitation counselors.***

- ***Government, insurance companies, and employers have a "duty to accommodate" people living with HIV disease and other kinds of disabilities.*** The debilitating effects of both the disease and the medical management of it require that these agencies take responsibility for accommodating people living with HIV disease in order that they can be productive and fulfill their own responsibilities.

- ***It is the responsibility of government agencies, insurance companies and other related stakeholders to fully and completely inform an individual of the potential consequences and implications of any work force decisions that an individual may make.***

- ***Failed trials of work, early re-application, and "second chance" policies must be incorporated into workplace and insurance policies.*** It is the responsibility of government, insurance companies and employers to recognize that people may decide to return to the work force too early to sustain their improved health, therefore, they may have to change their decisions.

6. Income Security

- ***Individuals should be able to pursue their educational and employment goals without losing financial safety and security.***

- ***Income maintenance programs need to establish clear guidelines, policies and procedures which will guarantee financial safety and security.***

6. Income Security - Continued

- ***Government and private agencies need to recognize and accommodate the income maintenance needs of persons with episodic and cyclical disabilities.***

- ***Eligibility for LTD, medical insurance, drug coverage, CPP, housing subsidies, etc., should be flexible and encompass the needs of persons with episodic and cyclical disabilities.***

- ***Processes for the fair negotiation of existing government and private debts with individuals should be developed, (e.g. government welfare program overpayments, CPP, tax, life insurance settlements, credit and debts, etc.)***

Conclusion

The opportunity to go to or return to work may prove to be one of the most rewarding developments in the lives of persons living with HIV/AIDS. However, without supportive policies and the availability of innovative programs, it could as easily be transformed into a terrible burden which further exacerbates the hardships related to HIV disease.

A positive experience in the area of vocational rehabilitation and return to work will be determined in large measure in consequence of the adoption of employment and systemic policies and practice. These policies and practices must be based on the humane treatment of people by responsible agents of governments, disability insurers, community, health and rehabilitation professionals. Adoption of the principles outlined herein will go far to expedite the emergence of pragmatic and effective policies and programs for the vocational rehabilitation and return to work of those people living with HIV disease who choose to do so.