

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

**POLICY ISSUES ON REHABILITATION IN THE
CONTEXT OF HIV DISEASE: A BACKGROUND
AND POSITION PAPER**

June, 2000

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SUMMARY

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sector and multi-discipline 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 term “rehabilitation” is a broad term used to describe a range of techniques or interventions that can be applied to maintain, restore, or enhance aspects of health and quality of life. Rehabilitation services often involve a multidisciplinary team approach that can include specialities such as physical and occupational therapy, nursing, social work, pharmacy, counselling and medicine. Given that HIV disease is a relatively new illness and that life-extending treatments are also quite recent, rehabilitation services have not, in the past, been important considerations in the continuum of HIV care.

This research paper was undertaken to: i) provide background on policy issues concerning rehabilitation in the context of HIV disease, ii) identify key players and guide CWGHR’s planning in addressing these issues, and iii) inform potential research and project areas. The paper is the product of a literature review and a key informant interview process. Part I gives an overview of the role of CWGHR and explains the salience of rehabilitation to the care of persons living with HIV disease. The topic areas include professional development and education, vocational rehabilitation, income support, community research, and cross-disability issues. Part I also contains 28 recommendations for action. Each recommendation is presented with a statement of context and potential parties to act on the recommendations are identified.

Part II of the paper elaborates on many of the issues identified in Part I and presents a more detailed account of the current body of literature on rehabilitation and HIV disease. Additionally, Part II focuses on topic areas raised by key informants and summarises several research projects, service delivery models/programs, and rehabilitation related activities by organisations such as the Multiple Sclerosis Society and the Arthritis Society.

The emergence of CWGHR, recent shifts toward models of multidisciplinary and client-centred care, and a number of unique research initiatives all speak to a convergence of interests dedicated to enhancing the quality of life for persons with HIV disease. In Canada, rehabilitation in the context of HIV disease is at a critical and formative period. Cooperation across sectors of government and private industry, HIV/AIDS organisations, persons with HIV disease, health care professionals, academe and other disability groups is needed because rehabilitation issues are inter-related and require a coordinated approach.

PART I Overview of the CWGHR Project & Key Issues

A) Rationale & Context for the Position Paper

Background of the Canadian Working Group on HIV and Rehabilitation

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sector and multi-discipline working group. Formed in 1998, its vision is to have in place rehabilitation interventions that enhance the lives of Canadians living with HIV disease.¹

CWGHR's mission is to “facilitate development in rehabilitation programs and resources, promote innovation and excellence in the field, and generate awareness of and access to rehabilitation services” so that Canadians living with HIV disease can have improved quality of life. The mandate of CWGHR includes two roles: a development and advisory role, and a project and research funding role.

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

The Changing Nature of HIV Disease

Perceptions have changed about HIV disease being a progressive, deteriorative and terminal illness with no effective treatment. It is increasingly viewed as a chronic-terminal condition that can be managed through antiretroviral medications. Nevertheless, there can be serious limitations to antiretroviral medications, including sometimes debilitating side effects from toxicity and resistance to therapy. It is often reported that many persons living with HIV disease feel worse after initiating antiretroviral treatment. Still, it is undeniable that antiretroviral treatment and better understanding about HIV have contributed significantly to improved health and an extended trajectory of life² for many persons with HIV disease.

For the many persons with HIV disease who have benefited from antiretroviral therapies, there remain a number of impairments, disabilities and handicaps that

¹ This report refers to “HIV disease” and avoids acronyms such as PWA (persons with AIDS). The intent is to minimise labelling effects and to recognise HIV as integral to the disease process that it creates.

² The *trajectory of life* is defined as our anticipated life span and the plan we make for living out our lives. There is a disruption to our life trajectory when we realise that we may die much sooner than anticipated. The time between when we discover that we will die sooner than we thought and the time that we actually die is called the *living-dying interval* and is characterised by three phases of development: acute, chronic, terminal. The goal of those who treat people in the living-dying interval is to help them cope with all three phases of development (Pattison, 1977).

are barriers to active participation in society. Indeed, the cyclic nature of HIV disease is a constant reminder that leading a relatively normal life often means reliance on a range of techniques of rehabilitation that can involve specialists from a variety of health care and social fields.

Given the relative infancy of HIV disease and the very recent development of life-extending treatments, rehabilitation has not, in the past, played an important role in the continuum of HIV care. Management of a chronic illness requires much more than just disease management. HIV care is shifting from a supportive/palliative mode to a restorative mode. A challenge for care providers will be the development, promotion, integration and coordination of rehabilitation techniques into the mainstream of HIV care and service. The roles of rehabilitation in the HIV care continuum and the determination of the most appropriate model for addressing such needs have been central challenges for CWGHR since its inception (Nixon, 1998a).

Priority Setting for CWGHR

At its national meeting in September 1999, CWGHR decided to prepare a paper that would provide background on the scope of policy issues concerning rehabilitation in the context of HIV disease; guide CWGHR's planning in addressing these issues; identify other key players for planning; and help inform research project areas and priorities through a request for proposals. An advisory committee was formed to guide the development of a paper that would address four broad objectives:

1. To provide an overview of rehabilitation services in the context of HIV disease in Canada.
2. To provide background and scope regarding current policy issues in Canada in relation to HIV disease and rehabilitation.
3. To identify what people living with HIV disease need from rehabilitation services. To explore whether such policy work has been done before and what has been learned.
4. To identify important challenges, solutions and actions.

At the May 1998 meeting of CWGHR, several groups presented overviews of their rehabilitation-related projects. At that time CWGHR identified a number of areas for "work still to be done" for these projects. Although it is not the scope of this paper to evaluate the outcomes of those areas of work, CWGHR should ensure that its respective parties report their progress regularly.

Also at the May 1998 meeting, five key areas of HIV rehabilitation were identified—professional education, community development and quality of life, income support and insurance benefits, vocational rehabilitation, and HIV in the workplace. It was determined that all of these initiatives should have a research component. This document suggests a number of research initiatives for

consideration by CWGHR as it engages in the creative and multidisciplinary process of promoting rehabilitation in the context of HIV disease.

Method

One of the challenges for CWGHR in evaluating, developing and promoting services and policies regarding rehabilitation is the sheer complexity of the subject. People with HIV disease come from all walks of life and are diverse in their needs, interests and capabilities. Similarly, there is variance in the kinds of barriers that they face and the types of interventions that would enhance and extend their quality of life.

Many policy and program areas, although they often seem separate and distinct, are actually interrelated. In the context of rehabilitation, initiatives in one area can have implications in another. For example, active participation in society for a person with HIV disease is affected not just by the availability of medical care, but also the availability of personal support, adequate housing, nutrition, income programs/employment, and the attitudes of other significant people or agencies. Therefore, researching the broad and interdisciplinary aspects of rehabilitation in the context of HIV disease requires a broad and general approach. This project is exploratory and the narrow time frame in which it was completed has consequences for the depth and scope, as well as content, of the rehabilitation themes identified.

It is recognised that a number of issues may not receive mention in this report but it is hoped that they will ultimately receive attention through the coordinated approach that CWGHR is seeking to promote. The project is not designed as a survey, but as a research project to inform priority policy areas for further work in HIV and rehabilitation, including priorities for CWGHR project funding allocations for the fiscal year 2000-2001.

The research process for this paper was initiated in mid-November 1999 and completed by mid-February 2000. A literature review was undertaken to explore the body of research, programming and activism concerning HIV disease and rehabilitation issues. The literature search included a number of indices and databases, such as MEDLINE, AIDSLINE, and EBSCOhost. The project was also informed by more than 50 key-informant interviews with CWGHR members, their referred contacts, persons living with HIV disease, professional agencies, members of AIDS service groups, and academic and government institutions. The CWGHR Position Paper Advisory Committee provided the framework for the paper as well as guidance and feedback throughout its development.

B) What is Meant by “Rehabilitation”?

Rehabilitation is derived from the Latin *habile* (Kamanetz, 1983). It is a broad term used to describe a range of techniques or interventions that can be applied to maintain, restore, or enhance aspects of health and quality of life. Unfortunately, ‘rehab’ is often associated with behavioural reform for criminals and substance abusers, and also historical medical paternalism imposed on people with mental and physical disabilities. This association with social control presents some difficulties for understanding rehabilitation in wider, non-coercive contexts.

To provide a framework for rehabilitation in the context of HIV disease, CWGHR has adopted the World Health Organization’s *International Classification of Impairments, Disabilities and Handicaps* (World Health Organization, 1980)³. The concepts of impairments, disabilities and handicaps include health-related experiences that are not covered by the concept of disease.

Impairments are defined as any loss or abnormality of anatomical, physiological or psychological structure or function, such as weakness, impaired cognition, or fatigue. *Disabilities* are defined as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being, such as difficulty walking, bathing or getting dressed. *Handicaps* are defined as disadvantages for a given individual resulting from an impairment or a disability impacting on environmental barriers. These disadvantages may relate to work or to other societal roles and relationships.

The Process and Benefits of Rehabilitation

In the context of HIV disease, Philips et al. (1998) describe rehabilitation as being about a range of services that individuals can choose “to rehabilitate themselves when they experience an impairment or disability caused by their illness.”

Rehabilitation in the context of HIV disease addresses the impairments, disabilities and handicaps that result from HIV-related conditions and the side effects of anti-retroviral medication (Nixon & Cott, in press). The goal of rehabilitation is to slow the deterioration in an individual’s condition by improving, restoring or maintaining activities and participation in daily life. Ultimately, rehabilitation aids an individual to optimise independence and quality of life, while minimising health and income support costs.

Therefore, the goals of rehabilitation are centred on the person living with HIV disease. Many different people and organisations can be involved in the rehabilitation process. First and foremost, the individual is often involved

³ The World Health Organization first published the *International Classification of Impairment, Disability and Handicap* (ICIDH) in 1980. In 2000, the ICIDH-2 is being published (see World Health Organization, 1997). In this version, the term ‘disability’ is being replaced by ‘activity’ and ‘handicap’ is being replaced by ‘participation’ in order to avoid the negative connotations associated with the original terms.

personally in self-care activities that minimise impairments, disabilities and handicaps. The individual's circle of friends and family may also play a role in this process.

Rehabilitation services may also be delivered by health care and social service professionals, including physiotherapists, occupational therapists, physicians, nurses, speech-language pathologists, social workers, psychologists, pharmacists, dieticians, and others. These services are often delivered by an interdisciplinary team of professionals and may be provided in a variety of environments, including inpatient and outpatient hospital settings, community clinics or in an individual's home.

Finally, rehabilitation activities may also be delivered through AIDS service organisations or other people working in the HIV community. Examples of such rehabilitation activities include recreation and support services such as dance or yoga classes, food banks, or mobility equipment exchanges.

C) Overview of the Literature on Rehabilitation in the Context of HIV Disease

The emerging body of literature pertaining to rehabilitation in the context of HIV disease can be described as limited, exploratory, and topically discursive. Subject areas include professional education issues, vocational rehabilitation, physical rehabilitation, and psycho-social matters.

The introduction of antiretroviral therapies has broad implications for HIV care and issues pertaining to rehabilitation. This section offers an overview of the growing body of literature on the topic. A more detailed literature review is contained in Part II of this report.

Professional Development and Education

Rehabilitation professionals are only just beginning to assume a leadership role in the area of HIV care. Indeed, there are few examples of research from the disciplines of psychiatry (O'Dell, 1996, 1998) and physiotherapy (Nixon & Cott, in press). This category of literature emphasises the functional deficits associated with HIV disease, the need for early interventions, and the roles of rehabilitation professionals (e.g. Phillips et al., 1998).

Several authors have identified gaps in training for rehabilitation professionals (Glenn & Garcia, 1998; Souheaver & Benshoff; Werth, 1993) and there have been calls for curriculum development in graduate and undergraduate programs.

A recent initiative by the Association of Canadian Medical Colleges (ACMC) took the form of a workshop attended by a number of university educators and professional groups to examine ways to implement interdisciplinary instruction in

HIV disease care and education (Rowe & Hanvey, 1998). However, the workshop report also documented that financial, curriculum and scheduling barriers make interdisciplinary models of education difficult to establish.

Notwithstanding the above-mentioned initiative, rehabilitation health services have, through the 1990's, already established interdisciplinary team structures and processes. The Canadian Council on Health Services Accreditation (CCHSA) has fostered this development through the Client-Centred Accreditation Process (CCAP). Through CCHSA standards, this team concept has been applied to all sectors of health care outside of rehabilitation and has achieved a high level of definition in the most recent draft standards of the Council's Achieving Improved Measurement Project (AIM) (CCHSA, 1999).

The fundamentals of interdisciplinary care are client-centred and emphasise mutual interdisciplinary goals rather than discipline specific goals. They involve the setting of goals that include those of the client. Additionally, the client is included in the review of treatment and the evaluation of the treatment, in the context of realistic and measurable outcomes. Most importantly, the CCHSA standards require that the interdisciplinary team adopt a population health approach, meaning that they must understand the needs of their own defined population, know its health status and capacities, appreciate related determinants of care and be able to link or complement relevant community services.

These fundamentals are essential to rehabilitation in the context of HIV disease and professional schools and faculties need to teach the essentials of HIV disease. Students must be provided with direct experience in interdisciplinary settings. This has the potential to stimulate students, enhance interdisciplinary teams and transcend some of the difficulties of dependency on purely academic settings. In summary, the interdisciplinary process in Canada, currently accredited through the CCHSA, is already in place and the education system should use it in order to strengthen the process and ultimately enhance the provision of rehabilitation services.

Vocational Issues

Vocational issues have been raised even before the advent of antiretroviral therapies (Caulfield & Carey, 1994). The Canadian AIDS Society report, *Force for Change* (CAS, 1998) canvassed a range of concerns—including loss of health and disability benefits—that persons with HIV disease have about entering or re-entering the workforce (see Appendix 2). Some authors have identified areas where occupational therapy and psychotherapy can play a role in workplace accommodations (Hooten, 1998; Vitry-Henry et al., 1999).

Income Support

Concerns about income support are increasingly apparent as more persons with HIV disease look to insurance plans for income support during periods of uncertain health status. To meet the need for information in this area, the

Canadian AIDS Society and the AIDS Committee of Toronto (1998) published the *HIV/AIDS Guide to Insurance Benefits*. The need for counselling about disability benefits has been identified as important, particularly as people consider entry or re-entry to the labour force (Grubb & McClure, 1997; Zack, 1998). Training in this area is currently being developed by the Canadian AIDS Society. Additionally, Elliott (1999) recently identified a number of areas of advocacy required for Canadian group insurance plans. Another organisation representing the interests of people with cyclical illness, the Multiple Sclerosis Society of Canada, has also identified insurance and income support issues for disabled people (see, MS Society, 1999; Sadovnik, 1992).

Community Research

At the community level, there is a growing body of literature on a number of rehabilitation topics. At the 1998 World Conference on AIDS, the majority of papers under the key-word “rehabilitation” came from Canadian researchers, many at the community level. This suggests that community-based HIV organisations and community researchers in Canada are using community-based, participatory research to identify needs and to advance the quality of care and programming in rehabilitation services.

D) Issues Identified by Key Informants

Key informant interviews were conducted in person and by telephone with members of CWGHR, their referred contacts, persons with HIV disease, persons belonging to AIDS service organisations, and other private and government bodies (see Appendix 1). Informants demonstrated a high degree of confusion about the meaning of rehabilitation and its relationship to HIV care. Many viewed rehabilitation from the narrow perspectives of return-to-work or harm reduction. For persons with HIV disease, there was a deficit of knowledge about what to expect from rehabilitation. This is problematic because consumers who lack expectations from rehabilitation services are poorly positioned to advocate for services. This gap, with the exception of a small number of informants who were rehabilitation professionals, was quite generalised across the group of informants assisting with this project.

Additionally, many of the informants currently working in HIV-related rehabilitation fields expressed feelings of isolation in their work because they often do not know where their colleagues are. This suggests that the interdisciplinary team approach to rehabilitation is inadequately developed and there is a need for professional development and training. Rehabilitation professionals in HIV care need to be able to locate and interact with their colleagues in order to fulfil team roles and to deliver integrated and comprehensive services to persons with HIV disease.

Informants identified a number of interesting current research projects and service programs/models that have recently been initiated in a number of provinces. These are detailed in Part II.

E) Cross-Disability Issues

i) Disability Policy and Programming

The Human Resources Development Canada Report: Disability Policies and Programs

Disability is a citizenship and human rights issue. Section 15 of the Canadian Charter of Rights and Freedoms affords people with mental or physical disabilities a constitutional right to equality. Nevertheless, removing barriers that prevent people with disabilities from exercising their rights and participating fully in society is often limited by fiscal and social environment factors.

Probably one of the most persuasive and authoritative documents concerning the policy area of disability is the Human Resources Development Canada (HRDC) evaluation paper *Disability Policies and Programs: Lessons Learned* (HRDC, 1997). The following section is a précis of the report, which summarises what appears to work or not work in various areas related to disability policy and programming.

General findings of the HRDC report are:

“1. Disability issues and topics are inter-related and require a co-ordinated approach.

Without some form of coordination amongst various government departments, the resulting disability policy is frequently a fragmented effort, with inconsistencies, overlaps, and gaps within and across jurisdictions. For example, the all-or-nothing approach inherent in eligibility requirements of some income programs, which label people as fully employable or unemployable, acts as a major disincentive to employment and reinforces the welfare trap for people with disabilities.

2. Environmental barriers are a greater impediment to participation in society and to employment than are functional limitations.

For people with disabilities, their ability to function in society is limited, as much by the openness of the society in which they live, as it is by the specific functional limitations that identify them as having a disability.

3. People with disabilities vary in their characteristics and needs.

The barriers faced by persons with disabilities are as varied as the disabilities themselves. As such, personalised approaches which feature

services adapted to the particular needs of each individual are most likely to be successful.

4. Many approaches to permit participation of people with disabilities can be low-cost but require involvement of different sectors in society, frequently on a partnership basis.

This report identifies a number of approaches that have facilitated participation of people with disabilities in employment and in independent living which have proven to be cost-effective in reducing the direct and indirect costs of disability. Costs are minimal when accessibility is built into the design of facilities and generic programs, as opposed to retrofitting.

5. Direct involvement of individuals with disabilities with programs, services, and policies that affect them increases their satisfaction and support, produces higher levels of functioning, and greater success at community integration.

The more that persons with disabilities are brought on board as members in the decision-making process for issues that affect them directly, the more effective are the decisions made.”

Specific findings of the *Report* address, i) employment of disabled persons, ii) barrier removal legislation, iii) income programs, and iv) independent living:

i. Employment

A substantial proportion of people with disabilities who are not currently in the labour force are capable of employment in some form, given proper supports and removal of barriers. Unfortunately, many programs and policies hold an all-or-nothing view of employability and this leads to disincentives to work (see section on CPP disability benefits). The HRDC suggests a more supportive approach that would view employability on a continuum rather than an either/or situation.

Workplace barriers are classified as either physical or attitudinal. It is pointed out that physical barriers are usually of nominal cost and can enable full employment for many people with disabilities. The HRDC says that employers who have provided physical accommodations report an average savings 27 times the cost of providing physical accommodations.

Attitudinal barriers amount to misperceptions and lack of information on the part of employers. Wage subsidies are designed to encourage the private sector to increase training and employment opportunities for persons with disabilities but their effectiveness has been mixed. There is no certainty that subsidies lead to long-term employment once the subsidy ends, especially if attitudes remain unchanged.

The most effective return-to-work programs emphasise early intervention and active case management. Vocational rehabilitation programs for people with disabilities that follow such a model are effective, but the biggest limitation has been the lack of access to vocational rehabilitation.

ii. Barrier Removal Legislation

When it comes to enabling people with disabilities to participate more fully in society, barrier removal legislation has proven to be more effective than awareness campaigns and public relations. Legislation that has clear and precise standards is more effective in removing barriers than legislation with generalised criteria. In Canada, human rights commissions and employment equity legislation have had limitations in their effectiveness to address the barriers faced by people with disabilities. Because their standards have been unclear, they have had to resort to costly litigation for enforcement. In contrast, the Americans with Disabilities Act (ADA) has seen greater successes in enabling access for people with disabilities in a number of different areas. Moreover, there is proof that changes in attitudes can follow changes in behaviour. In the case of the ADA support from the business community came after its implementation, and not before.

iii. Disability Income Programs

Different definitions of disability for the purpose of eligibility to income assistance programs is controversial and sometimes viewed as leading to inconsistencies (see MS Society, 1999). However, the HRDC notes that relationships between programs need to be taken into account and that prospective changes should be examined from systemic rather than program perspectives.

iv. Independent Living & Community Support Services

Most people with disabilities can live independently and participate in the community if appropriate supports are provided. People with disabilities are no different than the general population in that independent living gives them control over their lives. From the perspective of the service provider, services based upon independent living principles are more effective than traditional, professionally driven services.

ii) The Canada Pension Plan Disability Benefits Program

The CPP disability benefits program has been the subject of debate for many years. During the most recent round of CPP consultations there was controversy over whether what is essentially a pension plan should be providing benefits to disabled workers and their families (Canada Pension Plan, 1996). Many groups representing the interests of disabled people said that they did not oppose the removal of disability benefits from the CPP. However, they sought assurance that such a change would coincide with a new comprehensive disability program. Presumably, such a vision would include the equivalent of universal health coverage for seniors.

There are two primary areas of concern about CPP disability. For those who have benefits, it is the issue of losing them on return to work. For those who don't have CPP disability benefits, it is about the definition of disability for eligibility.

It is frequently argued that the CPP provides no incentive for people to return to their jobs, yet it has been estimated that at least 10 % of CPP disability recipients have the potential for successful vocational rehabilitation (HRDC, 1997). Individuals who return to work risk losing their CPP benefits if a return to employment is unsuccessful.

At the 1996 CPP consultations, the Canadian Mental Health Association called for a revised definition of disability that would take into account the cyclical nature of mental illness, to encourage people with mental illness to work when they are able without risking their CPP disability benefits. More recently, the MS Society (1999) has argued that the fluctuating nature of MS makes it "very difficult for people with MS to continue working while, at the same time, prevents them from qualifying for disability benefits." A similar case could be made for HIV disease.

For the purposes of benefits, the definition used by the *Canada Pension Plan Act* to define disability is:

42 (2) "a person shall be considered to be disabled only if he is determined in prescribed manner to have a severe and prolonged mental or physical disability, and for the purposes of this paragraph,
(i) a disability is severe only if by reason thereof the person in respect of whom the determination is made is incapable regularly of pursuing any substantially gainful occupation, and
(ii) a disability is prolonged only if it is determined in prescribed manner that the disability is likely to be long continued and of indefinite duration or is likely to result in death; and
(b) a person shall be deemed to have become or to have ceased to be disabled at such time as is determined in the prescribed manner to be the time when the person became or ceased to be, as the case may be, disabled, but in no case shall a person be deemed to have become disabled earlier than fifteen months before the time of the making of any application in respect of which the determination is made."

Recently, the CPP has become moderately more flexible about vocational rehabilitation. People who return to work continue to receive benefits for three months while they are working and if their reintegration to work is unsuccessful, there is a "fast track" system to restore benefits. These changes are relatively new and it is not yet known if they are proving effective or fair to recipients. However, there have been anecdotal reports from the MS Society that some CPP

disability recipients are attending school as a component of vocational training. On completion of the schooling, recipients are having their benefits terminated, even though they may not be able to find employment as a result of the schooling.

F) Conclusion

Given the relative infancy of HIV disease and the recent clinical advances in its treatment, rehabilitation services are far from being included in the mainstream of HIV care. Indeed, it is only recently that a small but growing body of literature pertaining to rehabilitation in the context of HIV disease has emerged. It cries out for professional development, community development, and policy reform to improve the quality and scope of rehabilitation services for persons with HIV disease.

A number of programs and initiatives have begun to focus on the needs of persons with HIV disease with respect to disability and quality of life issues, disease prevention, and health promotion. Often, there is theoretical recognition that the complex physical and psychosocial impacts of HIV disease require a coordinated, integrated, and multidisciplinary approach. Although there are recent examples where such theory is being applied to practice—for example the CHAP Program at Casey House in Toronto (see Part II)—the programming is still too new to be evaluated.

The role of rehabilitation in the context of HIV care is in the midst of a critical and formative period in Canada. The emergence of CWGHR, initiatives by the ACMC for interdisciplinary HIV disease education, new research initiatives and seminal programming in community based AIDS service organisations all represent a convergence of interests and agendas dedicated to the enhancement of quality of life for persons with HIV disease.

HIV, both as disease and disability, is of immense importance because of its economic, medical, social, ethical, and political impact. The challenge for CWGHR and the rehabilitation community is to foster coordination and cooperation across public and private sectors to promote solutions in education, research and service so that rehabilitation techniques can be established as integral to the care for persons with HIV disease. Fundamental to this process is that there be a client-centred focus. This means that goals must be multidisciplinary rather than discipline specific, and that the wishes and values of the client must be incorporated and evaluated with clients' input. The following section lists a series of recommendations intended to foster a multidisciplinary, client-centred, and research based approach to promote rehabilitation in the context of HIV disease.

G) Recommendations for Action^{4,5}

Research

1. Given that a variety of comprehensive, interdisciplinary models of integrated service for people living with HIV disease exist, **it is recommended that these models be identified and evaluated for best practice standards of rehabilitation service delivery in the context of HIV disease.**

Sphere of influence: Researchers; practitioners; educators.

Potential partners: Provincial and national professional organisations.

2. Given the complexity of impairments, disabilities and handicaps that people living with HIV/AIDS may experience, **it is recommended that accurate and appropriate assessment tools be developed.**

Sphere of influence: Researchers; practitioners; educators.

Potential partners: Provincial and national professional organisations.

3. Given that the field of rehabilitation in the context of HIV/AIDS is so young, **it is recommended that strategies be explored for encouraging interdisciplinary research in this area.**

Sphere of influence: Researchers; HIV/AIDS research funders; practitioners.

Potential partners: Provincial and national professional organisations.

⁴ These recommendations should be considered with regard to the context of all people with HIV disease, with reference to gender, age, culture and other relevant background. The “potential partners” named in this section are suggestions only; there may be additional appropriate partners. CWGHR recognises and acknowledges the different functions of both HIV consumer and/or disability groups, and AIDS service organisations (ASO’s). The identification of various community-based HIV organisations and their respective roles in effecting change should proceed according to such roles and mandates. CWGHR’s involvement as a partner will vary with different issues and various organisations will be appropriate to give leadership in relation to specific recommendations. The recommendations are not listed in accordance with any specific priorities for action.

⁵ In the sphere of influence and potential partners categories, “practitioners” include relevant health care and social service professionals. “Educators” include people working in relevant undergraduate and graduate programs, and “researchers” refers to researchers associated with these professions. “Professional organisations” refers to local, provincial, and national bodies, including general associations and HIV/AIDS organisations (i.e. College of Family Physicians of Canada, Canadian Physiotherapy Association, Canadian Association of Physical Medicine and Rehabilitation, Canadian Association of Occupational Therapists, Canadian Association of Social Workers, Canadian Nurses Association, Canadian Association of Nurses in AIDS Care, Canadian Psychological Association and Dietitians of Canada, Canadian Association of Speech Language Pathologists and Audiologists).

4. Given that there is a lack of reliable empirical research into the existing arrangements and requirements for active living for persons with HIV disease, **it is recommended that a comprehensive survey into the socio-demographic characteristics and health status of Canadians with HIV disease be conducted. The survey should investigate arrangements for active living, use of and satisfaction with existing services and caring professionals. It should explore differences in service provision and availability in rural and urban locations, and it should measure the degree of satisfaction with quality of life as experienced by persons with HIV disease so that rehabilitation professionals and organisations can better determine ways to enhance quality of life.**

Sphere of influence: CWGHR (through a request for proposals).

Potential partners: Community-based HIV organisations.

5. Given that return to meaningful activity is a goal of rehabilitation for people living with HIV/AIDS, **it is recommended that research be undertaken to understand the impact on individuals when this goal is achieved.**

Sphere of influence: Researchers.

Potential partners: Researchers; community-based HIV organisations; practitioners in primary care.

6. Given that the simple, local, and multi-discipline approach of the Vancouver MAT/DOT (Maximally Assisted Therapy/Directly Observed Therapy) program has the capacity to establish important care and support relationships with marginalised persons with HIV disease, **it is recommended that the outcomes of the program be evaluated to determine if there are lessons that could be of benefit to similar populations, nationally. Additionally, the capacity of such a model to be integrated with services such as stable housing, psychosocial support, methadone programming and heroin substitution should be explored.**

Sphere of influence: BC Centre for Excellence in HIV/AIDS; researchers.

Potential partners: CWGHR (through a request for proposals); Vancouver AIDS service organisations.

7. Given that issues of “engagement” and “therapeutic alliance” are currently being researched as important variables in the delivery of rehabilitation services to “difficult” multi-challenged populations⁶, **it is recommended that similar research involving gay men with HIV disease should also be conducted.**

Sphere of influence: Researchers and research funders.

Potential partners: CWGHR (through a request for proposals); Health Canada.

⁶ This research is taking place at the Dr. Peter Centre in Vancouver.

8. Given that access to and effectiveness of rehabilitation is often difficult for people living with HIV disease who are chemically dependent, **it is recommended that research be undertaken into harm reduction models of health care, or where research exists, appropriate action be taken.**

Sphere of influence: Researchers and research funders.

Potential partners: CWGHR (through a request for proposals); Health Canada; HIV/AIDS Legal Network.

Professional Practice and Education

9. Given that health care and social service professional students may not receive adequate comprehensive education in the area of rehabilitation in the context of HIV/AIDS, **it is recommended that gaps in undergraduate and graduate education be identified and addressed.**

Sphere of influence: Educators and practitioners in academic and clinical settings.

Potential partners: Provincial and national professional organisations.

10. Given that many health care and social service professionals currently working in the area of rehabilitation in the context of HIV/AIDS have never received formal education about HIV disease, **it is recommended that continuing education needs are identified and addressed.**

Sphere of influence: Educators and practitioners in academic and clinical settings.

Potential partners: Community-based HIV organisations; Provincial and national professional organisations.

11. Given the advantages of early rehabilitation intervention, **it is recommended that primary health care providers be educated about these advantages and be given guidance in how to make appropriate referrals.**

Sphere of influence: Educators and practitioners in academic and clinical settings.

Potential partners: Community-based HIV organisations; Provincial and national professional organisations.

12. Given that the role of rehabilitation for infants and children living with HIV/AIDS is a relatively new and growing field, **it is recommended that relevant issues in rehabilitation education, practice and research are explored.**

Sphere of influence: Educators, researchers and practitioners in paediatrics.

Potential partners: Provincial and national professional organisations.

13. Given the advantages of early rehabilitation intervention, **it is recommended that AIDS service organisations and the broader HIV community be educated about these advantages and be given guidance in how to make appropriate referrals.**

Sphere of influence: Community-based HIV organisations; practitioners; educators.

Potential partners: Canadian AIDS Society; community-based HIV and professional organisations.

14. Given the increase in older people with HIV disease and that specific treatments prescribed for normal ageing processes will have implications for medical interventions for HIV disease, **it is recommended that AIDS service organisations prepare their education and programming to include the needs of older people. Partnerships with organisations that serve older people need to be developed in order to ensure that older people with HIV disease and their care providers are able to benefit from community HIV services.**

Sphere of influence: Health Canada; Community-based HIV organisations; Canadian AIDS Society.

Potential partners: CWGHR; AgeWise.

15. Given that HIV/AIDS affects diverse populations, such as people from First Nations, **it is recommended that implications for rehabilitation education, practice and research be explored with regard to the unique needs of such populations.**

Sphere of influence: Practitioners, educators and researchers.

Potential partners: Community-based HIV organisations; First Nations communities; provincial and national professional organisations.

16. Given that some professional organisations working in the area of rehabilitation in the context of HIV/AIDS do not have current position papers recognising the significance of their roles in the field, **it is recommended that these organisations be identified and encouraged to do so.**

Sphere of influence: Professional organisations.

Potential partners: Canadian AIDS Society; CWGHR.

17. Given that rehabilitation in the context of HIV disease is part of a social movement to enhance care for persons living with HIV disease, **it is recommended that researchers, community-based organisations, other partners/stakeholders, and persons living with HIV disease collaborate to ensure that their mutual projects are published and widely disseminated.**

Sphere of influence: CWGHR.

Potential partners: The Canadian AIDS Society; Community-based HIV organisations; professional organisations of health and social service workers; academic institutions; internet publishers.

Vocational Issues & Income Support Issues⁷

18. Given that some aspects of group insurance policies have been identified as barriers to successful rehabilitation efforts (see Elliott, 1999), **it is recommended that such aspects be identified and that research be undertaken to develop solutions that could include further engagement of partners to overcome or minimise such barriers, with advocacy being undertaken as necessary.**

Sphere of influence: Federal Department of Finance; provincial regulatory bodies; private health insurance companies.

Potential partners: AIDS Committee of Toronto, Canadian Life and Health Insurance Association; Canada Pension Plan.

19. Given that medical advances are changing the nature of HIV disease, **it is recommended that advocacy be undertaken for innovative rating structures to make all forms of insurance more accessible to people living with HIV disease.**

Sphere of influence: Disability insurers.

Potential partners: HIV/AIDS Legal Network; MS Society.

20. **Given that the CPP disability program has been criticised by disability groups for inadequacies in its definition of disability, contribution rules, and processing of applications and appeals as well as for its lack of an effective transitional vocational rehabilitation program which recognises chronic and cyclical disability,** it is recommended that a review of the implications of the CPP disability program be undertaken and that areas for reform be identified and addressed.

Sphere of influence: Human Resources Development Canada/Canada Pension Plan Disability Benefits Program.

Potential partners: HIV/AIDS Legal Network; Canadian AIDS Society; Council of Canadians with Disabilities.

21. Given that the *Guide to Insurance Benefits* is intended to be updated periodically, **it is recommended that amendments include the following: i) information about risk-benefit issues concerning long term disability and return to work; ii) contact lists about current programs offering detailed benefits counselling (e.g. Employment Action at ACT); iii) working pages and checklists to assist readers in determining the kind of coverage they may require, if any; and iv) information about sub-standard insurance (rated life insurance) and partial disability insurance.**

Sphere of influence: The Canadian AIDS Society.

Potential partners: Community-based HIV organisations; MS Society; Canada Pension Plan.

⁷ Income support issues and vocational issues are a shared category because it is common for persons with HIV disease to fluctuate between employment and unemployment. More specifically, “vocational issues” relates to recommendations related to helping people become or stay employed. “Income support” relates to all people, whether employed, employable or not.

22. Given that the recent bankruptcy of Eaton's revealed a legal loophole in self-insured long term disability plans, **it is recommended that there be legislated reform to ensure that all long-term disability benefits provided by employers have protection similar to that of regular pension plans** (see p. 36).

Sphere of influence: Relevant government departments.

Potential partners: Provincial governments; unions; professional organisations; Canadian Labour Congress; Canadian AIDS Society; HIV/AIDS Legal Network; Community-based HIV organisations.

23. Given that many persons with HIV disease are already employed, **it is recommended that information and assistance be provided to employees and employers about disclosure of HIV status, workplace accommodations, health and life insurance benefits, access to provincial drug programs and access to legal counsel.**

Sphere of influence: Canadian AIDS Society.

Potential partners: HIV/AIDS Legal Network; community based HIV organisations; CWGHR; provincial disability support programs; provincial health and social service ministries/departments; HRDC; Canadian Human Rights Commission; employers; unions; Provincial disability support programs.

24. Given that analysis is needed to determine what makes it possible for a person with HIV disease to stay in the workplace and what systemic barriers make it difficult to sustain work, **it is recommended that employer associations, insurance industry, governments, unions and AIDS service organisations come together to find common ground in accommodating the medical needs of persons with HIV who work.**

Sphere of influence: (none, per the group)

Potential partners: HIV/AIDS Legal Network; Canadian AIDS Society; provincial AIDS service organisations; Canadian Labour Congress; HRDC; professional organisations; insurers.

25. Given that progressive employment practices set examples for improved industry standards, **it is recommended that a national AIDS in the workplace manual be developed to promote standards for workplace policies and accommodations for persons with HIV disease. It is also recommended that a program be established for employers to be recognised for their best practices with respect to HIV/AIDS in the workplace.**

Sphere of influence: Canadian AIDS Society; HIV/AIDS Legal Network.

Potential partners: Community-based HIV organisations; Conference Board of Canada; Fraser Institute; Canadian Labour Congress; European AIDS and Enterprise Network.⁸

⁸ The European AIDS and Enterprise Network recently initiated a program for employers to nominate themselves in three categories: HIV and AIDS policy regarding employment and work place; supporting people living with HIV disease in remaining or returning to work; and HIV education for the work force.

26. Given anecdotal reports across disabilities regarding terminations of CPP disability benefits, **it is recommended that research be undertaken to explore the scope and nature of such terminations and that any necessary advocacy be undertaken.**

Sphere of influence: Canada Pension Plan/Human Resources Development Canada.

Potential partners: HIV/AIDS Legal Network; Canadian AIDS Society; Community-based HIV organisations; MS Society; CWGHR.

Other

27. Given that the HIV/AIDS Legal Network has recently begun a major project to identify legal and policy issues in HIV care, treatment and support, **it is recommended that CWGHR collaborate with the Network to determine common interests and potential partnerships on issues relating to disability and rehabilitation.**

Potential partners: Health law institutes; Canadian AIDS Society; centres for bioethics.

28. Given that the wellness approach is widely recognised within the AIDS/disability movement, is client centred and empowering, and provides a framework for professionals and support groups to focus discussion and set priorities, **it is recommended that a resource and/or education program for health promotion be developed for persons with HIV disease to manage issues that could include: pain management, fatigue, adherence, access to care, support and treatment programs.**

Sphere of influence: Canadian AIDS Society; Community-based HIV organisations.

Potential partners: Multiple Sclerosis Society; Council of Canadians with Disabilities; Canadian Association of Occupational Therapists.

PART II Literature Review, Key Informant Issues & Appendices

A) Literature on Rehabilitation in the Context of HIV

A literature search was conducted through a number of indexes and databases, including MEDLINE, AIDSLINE, and EBSCOhost. The body of literature pertaining to rehabilitation in the context of HIV can be described as limited, exploratory, discursive, and growing. Topic areas include modification of sexual behaviours and drug use, professional education issues, vocational rehabilitation, physical rehabilitation, and psycho-social matters. The following literature review is an overview of the existing body of knowledge in North America. Emphasis is given to publications dated from 1996 since this is when rehabilitation issues began to emerge as a priority for HIV care.

Physiatry

Physiatry is commonly known as the medical field of physical medicine and rehabilitation. Despite the profession's suitability to assume a leadership role with respect to HIV care, physiatry has only recently begun to give attention to the subject in its professional journals.

For example, it has been noted by O'Dell et al. (1996) that there is a lack of empirical literature about rehabilitation interventions for HIV as well as a paucity of knowledge about physical disability progression in HIV infection. In a seminal article, O'Dell et al. (1996) argued that physiatry could play an important role in HIV care given the growing numbers of symptomatic persons with HIV and decreased mortality (see also Herbert et al., 1998). In a comprehensive psychiatric review of the management of HIV-related disability, O'Dell et al. (1996) outlined a clinical framework to assess the physical pathologies and systemic manifestations of HIV disease and discussed a range of medical rehabilitation interventions (see Table 1). The authors concluded that most HIV disability could be managed by a general psychiatrist because "rehabilitation interventions in persons with HIV infection are based on functional deficits, rather than disease processes."

In a subsequent article, O'Dell et al. (1998) evaluated physical disability in a large cohort ($n = 876$) of men with HIV disease. The researchers compared their perceived disability with that of a national probability sample and found that both symptomatic and asymptomatic participants reported higher levels of disability than a non-HIV cohort. Also, a relative parity in physical function and other health status measures between symptomatic and asymptomatic men was an unexpected finding. The researchers theorised that mood disturbances such as depression and anxiety as well as medication side effects could have an effect of perceived disability. Because data for the study was collected from 1989 to 1994, possible benefits of new drug therapies could not be measured. O'Dell et al.

(1998) concluded that disability in persons with HIV disease tends to be associated with disease and psychosocial variables rather than demographic variables. They recommended that future studies “should address specific physical and psychological impairments leading to disability in persons with HIV infection, the relationship between functional status, and the clinical and cost efficacy of rehabilitation interventions.”

Table 1:

Physiatric Management of HIV-Related Disability

Adapted from O’Dell et al. (1996)

Medical Treatment and Complications in HIV Infection: Impact on Rehabilitation

Objective 1. Discuss the impact of current medical treatments on the rehabilitation of patients with HIV infection.

Objective 2. Design a rehabilitation program for a patient with pulmonary, cardiac, or rheumatological complications from advanced HIV infection.

Neuromuscular Complications: Management of HIV-Related Pain and Weakness

Objective 3. Describe the most common disorders of peripheral nerve and muscle associated with HIV infection, the electrophysiological abnormalities that may be associated with each, and the rehabilitation approaches to the management of resulting pain and disability.

Objective 4. List the relative indications and contraindications of an aerobic exercise program for persons at each clinical stage of HIV infection.

Central Neurological Complications: Models for Neurorehabilitation

Objective 5. Develop a comprehensive rehabilitation program for impairments associated with central nervous system dysfunction in HIV infection, including cognitive impairment, focal neurological deficits, and myelopathy.

Psychosocial Consideration in the Rehabilitation of Persons with HIV Infection

Objective 6. Outline the psychosocial stressors seen in persons with HIV-related disability due to both the characteristics of and the societal response to the disease.

Paediatric HIV Infection

Objective 7. Develop a rehabilitation plan to manage the impairments unique to the paediatric population with HIV infection.

Physiotherapy

Similar to physiatry’s recent attention to HIV care, physiotherapy is also emerging on the scene. However, rehabilitation in the context of HIV disease has

not yet been identified as a priority issue for the Canadian Physiotherapy Association. Toronto's St Michael's Hospital, Wellesley Central Site, is one of the few facilities in Canada that has developed physiotherapy expertise for HIV disease. There, Nixon (1998b) has reported a case example of how the role of an HIV-specialised physiotherapist on the HIV multidisciplinary team has expanded to include inpatient, outpatient and community care as well as research and teaching of undergraduates.

It has been suggested recently by Nixon and Cott (in press) that the medical model of rehabilitation and HIV disease lacks a conceptual framework to guide education, research and practice. Extending O'Dell's (1996) argument that HIV rehabilitation interventions are based on functional deficits, Nixon and Cott propose the use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) as a "framework to place HIV disease within a rehabilitation model" for physiotherapy. In this capacity, the physiotherapist needs to be concerned with health experiences that extend beyond the concept of disease. Early literature has been focused on establishing the existence of HIV disease and disability. Future research needs to evaluate the "relationship of impairment to disability and handicap to identify the levels at which rehabilitation interventions will have the greatest impact as well as identify how services can best be delivered" to persons with HIV disease. In this regard, Nixon and Cott suggest that physiotherapists develop practice, education and research partnerships with AIDS service organisations in order to build upon existing service strategies.

In a report on best practices for rehabilitation services to persons with HIV disease, Fitts et al. (1998) reviewed client use of 25 health services in the Seattle area. Of the 125 clients, more than half (51%) had received psychological counselling and 46% had used massage and acupuncture. Interestingly, fewer than 15% had received physical therapy, occupational therapy, recreational therapy, or vocational counselling. Focus groups determined that the best practices for maximising quality of life for persons with HIV disease include "case management, independent living assistance, flexibility in funding eligibility, massage, acupuncture, integrated services for mental health and substance abuse problems, and support groups." The authors further noted that these best practices resembled those provided by the National Multiple Sclerosis Society for its consumers who suffer from fatigue and episodic disability.

Resource Guides for Professionals and Persons with HIV Disease

Among the many manuals and guidebooks about HIV management, two stand out in the context of rehabilitation. One is directed at persons with HIV disease, and the other is oriented to professionals.

The first book, *The Guide to Living with HIV Infection* (Bartlett & Finkbeiner, 1998) is one of the most comprehensive books in its field. This American book

can be regarded as a rehabilitation text for persons with HIV disease, although it is not specifically presented as such. Its 12 chapters cover issues ranging from physical health, emotional well being and social difficulties, to financial, legal and other practical matters. Much of the material could help a person to avoid problems and to prepare for situations before they become serious. The information includes medical facts as well as more theoretical and subjective areas. For example, Chapters 3 and 7 discuss the effects of HIV on the body and brain. Chapter 4 explores HIV and its effects on the emotions and Chapter 10 addresses the matters of legal, financial and medical decisions.

The second book, *Module 7: A Comprehensive guide for the care of persons with HIV disease* (Phillips et al., 1998) was developed primarily to meet the needs of the increasing number of rehabilitation professionals working with persons with HIV disease. It provides an overview of HIV disease and describes the social dimensions and diversity of people living with HIV disease. The *Module 7 Guide* is a useful educational tool for rehabilitation professionals to reflect on how they may apply their existing techniques to the special context of HIV disease. A consistent message in the *Module* is that “general rehabilitation philosophy and management principles can be readily applied to rehabilitation services for persons living with HIV.”

The introduction of *Module 7* is timely for continuing education because most rehabilitation professionals do not receive training in the area of HIV disease. For example, Nixon and Cott (in press) have identified that undergraduate curricula for Canadian physiotherapists do not address HIV disease. Moreover, the professional attitudes and skills necessary for competency in treating clients with HIV disease are not addressed in most post secondary education programs for rehabilitation professionals (Glenn et al., 1998; Hunt, 1996a; Souheaver et al., 1996; Werth, 1993). Indeed, as mentioned previously, the Canadian Physiotherapy Association (CPA) has not formally identified HIV/AIDS and rehabilitation as an area of need and does not have a current position paper on HIV disease (D. Parker-Taillon, personal fax communication, December 24, 1999). Similarly, the Canadian Association of Occupational Therapists’ (CAOT) position paper on HIV was originally adopted in 1990 and is no longer in effect.

HIV/AIDS Curriculum and Training

Health professionals should be able to address a number of areas when working with persons with HIV disease. First of all, they should have knowledge about HIV and its diverse effects on a person. Second, they need to be able to explore their own feelings and attitudes toward persons with HIV disease and have self-awareness about how these affect the quality of a therapeutic relationship. Providing rehabilitation services to persons with HIV disease is often different from providing similar services to other populations because of the social stigmatisation of HIV infection. Therefore, rehabilitation workers need to have awareness of issues around human sexuality, drug use, privacy and confidentiality. Additionally, the constantly evolving nature of HIV research and

treatment means that rehabilitation workers need to have access to regularly updated information.

In the early 1990's, Werth (1993) argued for progressive education programs and direct contact with persons with HIV disease should be included in graduate education programming. Since then, a number of articles have questioned the ability and preparation of rehabilitation workers to serve people with HIV disease (All & Fried, 1996 & 1997; Glenn et al., 1998; Hunt 1996b). They argue that since the goals of rehabilitation are to help individuals with disabilities adapt to the changes associated with disability and to teach ways of coping, persons with HIV disease similarly require counselling about their disease, risk behaviours, work potential, and independent living choices.

Several authors have noted the tendency for many healthcare providers to carry negative attitudes about the subgroups of the population that are most affected by HIV disease. It is suggested that people with HIV disease may not be referred for rehabilitation because of negative attitudes and incorrect beliefs about the capacity for people with HIV disease to benefit from rehabilitation services.

Education has been found to reduce anxiety and fear and increase knowledge about HIV/AIDS (Souheaver et al., 1996), but studies have shown that HIV educational programs need to provide contact with persons with HIV disease (All & Fried, 1996; McCann & Sharkey, 1998). This is because knowledge about HIV disease can be acquired within a few hours of instruction, but overcoming personal biases and making behavioural changes require different teaching strategies. Additionally, given the evolving nature of HIV treatments, rehabilitation workers require on-going training programs that provide current information, rather than one-time educational opportunities.

Despite the fundamental importance of education about HIV disease for future and existing rehabilitation professionals, it is unlikely that existing training programs are meeting the need in this area. The body of literature describing levels of training in academic programs is small and somewhat dated. Campos et al. (1989) surveyed the American Psychological Association's approved clinical and counselling psychology programs to determine the level of HIV disease instruction for students. They found that three-quarters of graduate programs did not offer even basic information about HIV disease, six percent offered relevant colloquia and 19 percent had a full course. Less than one percent of master's theses and slightly more than one percent of PhD dissertations related to HIV disease. Only two percent of faculty were involved in HIV-related research.

In a near-replication of the Campos et al. (1989) study, Diaz and Kelly (1991) surveyed 70 social work master's programs and found that 23 percent offered no HIV instruction, 63 percent offered at least a colloquium and 14 percent had HIV-specific courses. About three percent of master's theses were related to HIV

disease and less than two percent of faculty were involved in HIV-related clinical services or research.

Campos et al (1989) and Diaz and Kelly (1991) shared the conclusion that further education was required for counselling psychologists and social workers. Both studies suggested that HIV instruction draw from existing courses in other disciplines, rather than attempt to develop completely new curricula. Diaz and Kelly (1991) also suggested that practicum and internship placements should be encouraged in agencies that provide services to persons living with HIV disease. This would help to promote “hands-on” experience and expertise for the next generation of rehabilitation workers as well as enhance services in the community.

Hunt (1996b) extended the research of Campos et al. (1989) and Diaz and Kelly (1991) to counsellor education programs in the USA. He surveyed the 62 counsellor education programs accredited by the Council for Accreditation of Counseling and Related Programs (CACREP). Hunt (1996b) found that less than two percent of the 6,852 graduate students “were involved in research or direct clinical counselling service to people with HIV/AIDS in their jobs or training.” Only two of 262 completed PhD dissertations related to HIV and less than three percent of faculty were involved in HIV research.

Among 115 American Psychological Association accredited psychology programs, Sayette and Mayne (1990) found only eight schools with faculty members doing research on HIV/AIDS and only two provided programs that included practicum training on HIV disease.

There does not appear to be any quantitative literature about the state of HIV disease education in Canada, but it is probably safe to assume that there are comparable gaps in Canadian academic programs. Hanvey (1994) conducted a survey of 11 out of 16 faculties of medicine in Canada to explore the extent to which undergraduate and postgraduate medical programs address HIV disease education. It was found that medical programs seem to be more successful at addressing the pathophysiological and transmission aspects of HIV disease but not its psychosocial aspects. Additionally, the two main barriers to effective teaching of HIV care and treatment were a) lack of trained faculty, and b) overcrowded curriculum.

The Association of Canadian Medical Colleges (ACMC) has been working in collaboration with a number of professional organisations (dentistry, nursing, psychology, social work) in a venture to implement interdisciplinary education in HIV/AIDS education. The initial experiences of four pilot projects at Memorial University of Newfoundland, McGill University, Université de Montréal/Université Laval, and University of BC are reported at the ACMC web page [<http://www.acmc.ca/docs/survey2.html>]. The reports suggest that the students and instructors had positive feelings about the programs and that they

were worth continuing. However, in some instances it appears that there were differences in attendance and motivation, depending on the academic disciplines of students and whether course credit was offered.

Although there appears to be general consensus on the importance of interdisciplinary education, there are a number of difficulties in establishing interdisciplinary programs. Rowe and Hanvey (1997) have documented a range of barriers:

- “the disparity in norms and traditions between different faculties and disciplines
- the university structure, with its rigid departments
- the culture of competition that typifies academe
- the specialised research agendas of health care educators
- the lack of faculty training
- wide disparities in the knowledge, perceptions and attitudes of participating students
- the difficulty of constructing a common curriculum, and
- competing demands on teachers' time, students' schedules and curricular content.”

In addition to the significant barriers facing interdisciplinary education, there is a lack of research about its effects. Moreover, according to Hanvey (1995), the literature concludes that interdisciplinary education is “difficult to establish and maintain” and that “no quantitative evidence exists to demonstrate that interdisciplinary education results in long-term payoffs of more effective, less expensive health care provision.” That noted, a primary reason for the lack of evidence is a paucity of evaluation research on both the content of interdisciplinary education programs and the effectiveness of interdisciplinary student teams (Hanvey, 1995).

The 12th World Conference on AIDS (Geneva, 1998)

Given the relatively recent shift in thinking to include rehabilitation as part of the continuum of HIV care, the body of Canadian literature is quite small. Indeed, prior to the 1998 World Conference on AIDS in Geneva, most literature relating to rehabilitation was aimed either at palliative issues or prevention efforts, such as needle exchange programs.

The emerging literature tends to come from grass-roots organisations and much of it has been presented in conference abstract and poster forms. Canadians presented several abstracts on themes of rehabilitation at the 1998 World

Conference, indeed, more than any other country.⁹ Topics addressed can be classified as follows:

Return to work issues (4) (Bally & McAulay, 1998; Jalbert, 1998; Kort & Zamprelli, 1998; Thomas, 1998)

Physical fitness (2) (Bally & Murphy, 1998; Swan & Hiebert, 1998)

Interdisciplinary service models (2) (Bally et al., 1998; Seidelman & Grondin, 1998)

Intravenous drugs (3) (Gagnon et al., 1998; Ivan et al., 1998; Hogg et al., 1998)

Adherence/Engagement (2) (Hogg et al., 1998; Schilder et al., 1998a & 1999)

Nutrition provision for IDU (1) (Ivan et al., 1998)

Abstract and poster presentations are often pilot initiatives for researchers and it is common for them to never reappear in peer-review or mainstream literature. Indeed, many abstracts are never even developed to the point where they are circulated as papers or essays. Although this may be the fate of most of the above-mentioned papers, the themes they address give glimpses of some of the emerging areas for policy and practice in HIV rehabilitation.

The Geneva conference papers confirm that rehabilitation in the context of HIV involves a continuum of services, depending on the particular needs of individuals. Schilder et al. (1998a & 1999) observed that access to health care is a challenge for sexual minority groups and that they have improved participation in health care when providers are sensitive to issues of sexual identity. Moreover, Schilder et al., (1998a & 1999) found that adherence to antiretroviral therapy appeared to be more effective when addiction treatment (methadone) was combined with HIV care. In a subsequent peer-review article Schilder et al., (1998b) argued that interventions for marginalised transgendered persons “should occur at the point of primary care—the entry point—and should address issues of HIV, addiction, and gender care.”

In summary, the Geneva papers sketch a rough and emergent outline of the scope of rehabilitation in HIV care, starting with determinants of health such as fitness, nutrition and access to health care services. The optimism of antiretroviral therapy has given many persons with HIV disease and their care providers the opportunity to think about the future as a period of productivity and active living. To realise the potential behind such hope, interventions such as goal setting, life-planning and vocational rehabilitation were identified as important. One paper suggested that primary care facilities can develop non-traditional, interdisciplinary models of care that are responsive to community and training needs (Seidelman & Grondin, 1998). The implication here is that existing rehabilitation services can be adapted to provide integrated HIV care.

⁹ Five of 12 conference abstracts were captured under the subject heading of rehabilitation. India had three abstracts, but these focussed on rehabilitation of sexual behaviours.

There are other general lessons that can be drawn from the materials presented at Geneva. The most obvious theme is that rehabilitation has emerged on the scene as a relevant issue for persons with HIV disease and community based service organisations. Another theme is that rehabilitation services are multidisciplinary and that they include everything from prevention and engagement techniques to personal fitness and vocational rehabilitation. More broadly, implicit in several of the abstracts is the notion that determinants of health are an important foundation for quality of life. Finally, the papers demonstrate that local organisations and persons with HIV disease understand the value of participatory research in community development.

AIDS Impact: 4th International Conference (Ottawa, 1999)

Given the number of Canadian papers about rehabilitation topics presented at Geneva, it is surprising that the subject received less profile by researchers a year later at the Ottawa AIDS Impact Conference. A few papers touched upon broad rehabilitation issues, such as workplace discrimination and adherence to therapy, but there were none that addressed rehabilitation.

There was, however, a “hot topics” forum led by CWGHR to discuss the meaning of rehabilitation (Nixon, 1998a). Three members from CWGHR led the forum, representing the AIDS service community, government, and health care. Two main topics of discussion at the forum were: the meaning of rehabilitation and the best model for addressing diverse rehabilitation needs for persons with HIV disease.

Access to Resources (rural areas, mentally ill, and older persons)

Access to health care resources in rural areas has been identified as a challenge and there have been calls for stronger advocacy in this area (Taylor, 1999). Similarly, access problems exist in urban settings, where geography and service availability are not necessarily barriers. Davis (1998) has documented that injection drug users who also suffer from serious mental illness experience difficulty in accessing needle exchange sites and other health care services. It was proposed that an “assertive case management model” may help improve continuity of care for this population (Davis, 1998).

In a recent survey, MacLean (1999) found that older people (50+) constitute an increasing clientele to Canadian AIDS service organisations. It was reported that ASO staff and volunteers find that older persons with HIV disease have limited social support networks, lack awareness about HIV disease, and experience financial challenges. Normal symptoms associating with ageing processes were also seen as complicating the ability to recognise symptoms and deficits associated with HIV disease. Additionally, older persons were found to experience increased burdens in providing care to persons with HIV disease because of other caregiving roles that often arise with age. The main suggestion

in MacLean's (1999) report was for further work to "improve care, treatment and support for older people with HIV/AIDS and older caregivers of people with the illness." Indeed, given the increased life expectancy of persons with HIV disease, it should be anticipated that a new demographic "risk group" will be older people. Consequently, emphasis should be given to education and programming that focuses on the needs of older people with HIV disease.

Vocational Rehabilitation Issues

Even prior to antiretroviral therapies, vocational rehabilitation was seen to have an important role to play in helping a person with HIV disease to maintain a healthy and productive lifestyle (O'Dell, 1993). Caulfield (1994) reported that it is not uncommon, on learning of their diagnosis, for persons with HIV disease to consider inappropriate employment changes because they are unaware of their rights. Workers with HIV disease, just as with other chronic diseases, can work effectively provided that job accommodations are made. Nevertheless, many leave their jobs without negotiating important accommodations with their employers. Some rule out employment because of the potential impact on disability benefits.

In Canada, the *Force for Change* report (CAS, 1998) was commissioned to establish the range of labour force attachment issues for persons with HIV disease and to raise awareness about their needs with respect to integration in the workplace. The report shared findings similar to those articulated previously by the BC Persons with AIDS Society (1998). It found that persons with HIV disease have a number of concerns about entering or re-entering the workforce, including loss of disability and other health benefits, workplace discrimination, and the need for training and education. Similar concerns have been measured empirically by Jalbert (1998).

A main finding in *Force for Change* was that many persons with HIV disease are able and desirous of employment, but disincentives within disability benefits programs serve as barriers to work. The all or none approach of disability insurance was seen as perpetuating the welfare cycle; it was suggested that more flexible alternatives are required to allow persons with HIV disease to attempt to return to work without risking punishment by loss of important health insurance and other benefits.

A number of recommendations were made in *Force for Change* and nearly all of them require various forms of integration and cooperation between local, provincial and national organisations (see Appendix 1 for the recommendations). Currently, many of the *Force for Change* recommendations are at various stages of work in progress at a number of levels. However, the challenge of providing support for the labour force is complex, and the need for a coordinated approach with respect to the evaluation and reform of policy on disability and employment is well understood, but extremely difficult to implement (HRDC, 1997).

A less noticeable but important finding in the *Force for Change* report was that about 30% of the 1,400 persons with HIV disease who responded to the survey were employed. From a maintenance point of view, rehabilitation is important for this group and attention should be given to services that will help employed persons with HIV disease to *remain* in the workforce. Recent studies suggest that early rehabilitation intervention should be a priority in this regard, to maximise both physical and mental capacities. For example, Hooten et al. (1998) assessed physical capacity and perceptions of employability in 179 persons with HIV disease and found that those with CD4 counts of less than 200 were significantly weaker in tests of strength than the general population. In addition to measurable evidence of decreased physical capacity, other subjective barriers to employment “such as impairments in upper extremity function, motor speed, mobility, endurance, concern about losing disability benefits if employed, and job availability” were reported. Workplace cessation can be due to psychological reasons (Vitry-Henry et al., 1999) as well as physical symptoms, raising a role for occupational therapy, social work and psychology.

Income Support Issues

A number of issues around long term disability insurance have become apparent as more persons with HIV disease seek financial support from insurance plans. In 1998 the Canadian AIDS Society and the AIDS Committee of Toronto co-published the *HIV/AIDS Guide to Insurance Benefits*. The *Guide* offers a good description of the range of insurance benefits that are available and it notes that the life insurance industry is constantly updating its standards as knowledge about HIV disease and mortality evolves. For example, the insurance industry no longer accepts a diagnosis of HIV as sufficient to establish disability. If HIV does indeed become a chronic but manageable illness, insurance companies may eventually view HIV disease as carrying less insurance risk. Consequently, there may be opportunities for revising “pre-existing condition” clauses that often limit coverage for persons with disabling illness.

At about the same time that the *Guide* was published, a gap in knowledge and expertise about benefits counselling, particularly risk-benefit counselling for persons with HIV disease on long term disability who are considering a return to work, was identified (CAS, 1998; Grubb & McClure, 1997; Zack, 1998). Often it is not understood that insurance companies are inflexible about this and that a person could see an elimination of benefits if it is known that return to work is being explored. Additionally, some insurance plans have prescribed time limits to apply for benefits. For example, under CPP rules, a person may have made the necessary contributions to qualify under the plan but can be deemed ineligible if an application is not filed in time (MS Society, 1999).

In a recent article that discusses group insurance benefits in the context of HIV, Elliott (1999) argues that this field of insurance is “awkwardly regulated” and that

policies are often inaccessible and incomprehensible to the members of such plans. Elliott (1999) identified five areas of advocacy for legislative change:

1. Group insurance benefits should be portable so that “pre-existing condition” clauses would not apply to persons who change plans as a result of changes in employment (in Québec this is not an issue).
2. A direct right of access to the group policy should be permitted for members of group plans.
3. Employers should be required to maintain group coverage for employees on long term disability.
4. Time limits should be required for insurers to assess long term disability benefits and claimants who establish prima facie disability entitlement should be allowed to receive their benefits pending any legal trial.
5. Individuals leaving long term disability to return to work should be allowed a 12 month grace period so that they can return to long term disability benefits if illness forces them out of employment.

Most group disability benefit plans are insured and this guarantees that payments will continue as long as an individual meets the criteria for disability under the plan, to the maximum benefit period. However, sometimes large companies will opt to self-insure their long term disability plans. At present, Canadian laws protect pensions but not self-insured disability plans. A company could choose to create a trust account to assure workers of continued long-term disability payments, but this would involve setting aside approximately \$100,000 per disability recipient.

When a large company with a self-insured long term disability plan goes bankrupt, employees lose their benefits. This scenario happened in Canada last year when Eaton’s went out of business, leaving approximately 200 employees on disability benefits—some with AIDS—without any income from Eaton’s (“Eaton’s disabled,” 1999; Wong, 1999).

Traditionally, the life insurance industry has marketed its products to the majority of people who can be insured at standard premium rates. Typically, companies target young people who are early in their careers and are looking to insure the financial obligations that accompany decisions to purchase homes and begin families.

The industry has begun to develop more diversified rating structures and specialised insurance for common health problems such as diabetes. However, it is unwilling to insure people with health problems that are considered to be a high mortality risk. Given advances in HIV disease management, service organisations should be looking ahead to a time of improved life expectancy. In this regard, the Multiple Sclerosis Society of Canada is working to change the view that the insurance industry has toward MS since “the overall life expectancy for MS is

only about 6 to 7 years less than that for the “insured” population without MS” (Sadovnik et al., 1992). The MS Society has a guide to life insurance, *Insuring Your Future*, (MS Society, 1999).

Haemophilia & HIV

In British Columbia, the Haemophilia Programme Enhancement Project (HPEP) recently did an evaluation because of growing awareness of changing needs among people who are dually diagnosed with HIV and haemophilia, as a result of advances in medical treatment. Although the qualitative study by Taylor (1999) involves a small sample of people (n = 15), it raises a number of issues concerning “availability and structure of community resources; outreach to geographically distant patients; empowerment; advocacy; education and information access; and services to families.”

One of Taylor’s (1999) first observations was that many of the persons with AIDS and Haemophilia had lived with their infection for more than a decade and this had led to a shift in thinking. In earlier years they believed that they had only a few years to live, and they were now experiencing difficulty in recovering momentum on the realisation that it is no longer necessary to set aside life goals. Consequently, it was suggested that vocational counselling and other counselling to support short term and long term goal setting be made available.

A high level of satisfaction around tertiary HIV centres and resources was reported and this was seen as a positive development in light of distrust and avoidance of such services several years ago. Moreover, the Haemophilia Programme’s capacity to triage medical and psychological concerns and to refer clients to the appropriate facility was viewed as something that encouraged clients to access resources. Due to the sex-linked¹⁰ aspects of haemophilia, HPEP have the advantage of knowing generations of their clients and this familiarity has helped with knowing their clients well and therefore being able to make prompt referrals to HIV resources.

Access issues were identified for persons living outside Greater Vancouver. Geographical distance from HIV/AIDS services was overcome by self-reliance on travelling to Vancouver regularly for blood monitoring services. This often is a financial burden and use of community mental health services was limited because of a lack of knowledgeable therapists in rural areas. It was suggested that health care services needed to make greater efforts to coordinate their services to coincide with visits from rural areas. Another suggestion was that multidisciplinary teams travel to outlying areas in order to provide services directly to clients in their own communities.

¹⁰ Haemophilia is an incurable, sex-linked, congenital, hereditary disorder of blood clotting. It is transmitted on the X chromosome, therefore females are the carriers but usually it is males who are affected.

Taylor noted that most of the haemophilia clients living with HIV had been infected for more than a decade and had developed their own strategies for coping with their dual diagnoses. This is a source of expertise that would benefit health care providers. Unpublished research by the HFPEP suggests that persons with haemophilia who are living well with HIV tend to: “develop strategies for controlling negative thoughts; continue the process of normalisation learned from the haemophilia experience; and identify personal life purpose.”

Quality of Life for Persons with HIV Disease

People living with HIV disease have a variety of needs depending on the particular trajectory of their illness and symptoms. Health care and utilisation of services are important factors that influence whether an individual’s needs are being met. Depending on the individual, various requirements for assistance with active living may arise. A serious gap in the literature is a lack of reliable and empirically valid documentation around the existing arrangements and requirements for active living for persons with HIV disease. Empirical investigation into the following research questions is badly needed: are existing services meeting the needs of persons with HIV disease and are they satisfied with these services? Are there services that are needed in rural centres? Are the services that exist in urban locations adequately accessible to persons with HIV disease? Additionally, it is often assumed that the quality of life for persons with HIV disease is poorer than that of the general population. The socio-economic and psychosocial characteristics of persons with HIV disease in general are deserving of empirical attention.

B) Issues Identified by Key Informants

Key informant interviews were conducted by telephone with members of CWGHR, their referred contacts, persons with HIV disease, and persons belonging to AIDS service organisations, advocacy organisations and academic and government bodies (see Appendix 1). Interestingly, there was a high degree of confusion regarding what is meant by rehabilitation and its implications for HIV care. Many informants viewed rehabilitation from the narrow perspectives of return-to-work or harm reduction. From the perspective of consumers, there was deficit of knowledge about what persons with HIV disease should expect from rehabilitation. This is problematic because if consumers are not educated about what to expect from rehabilitation services, they are in a disadvantaged position to advocate for services. This gap, with the exception of a small number of informants who were rehabilitation professionals, was quite generalised across the group of informants assisting with this project.

Similarly, many of the informants who were working in HIV rehabilitation fields expressed feelings of isolation in their work. This suggests that the interdisciplinary role of rehabilitation is inadequately developed and confirms the

need to promote professional development and training in this area. Rehabilitation professionals in HIV care need to know whom and where their colleagues are in order to fulfil team roles and to deliver integrated and comprehensive services to persons with HIV disease.

Informants identified a number of interesting current research projects and service programs/models that have recently been initiated in Canada. The next sections highlight three current research projects (Legal Network; MAT/DOT; Issues of Engagement) and four models/programs of AIDS service delivery (Dr Peter Centre; Casey House CHAP Program; Nine Circles Community Health Centre; Employment Action). Finally, an overview of rehabilitation activities at the Multiple Sclerosis Society, Arthritis Society and Canadian National Institute for the Blind is presented:

Research Projects:

1. The HIV/AIDS Legal Network

The Canadian HIV/AIDS Legal Network is in the initial stages of a two-year project that will analyse legal, ethical and policy issues in the areas of care, treatment and support. This project is a response to a recommendation in a recent planning report commissioned by Health Canada – *Legal, Ethical and Human Rights Issues Raised by HIV/AIDS: Where Do We Go from Here?* (Bell, 1999).

Through a process of consultation, in-depth research and analysis, the Network intends to produce a series of reports that can be used as tools for legal advocacy, law reform and formulation of policy and practice relating to the care and treatment of persons with HIV disease. In March 2000 a 12 member Advisory Committee will hold its first meeting to determine a limited number of priority areas for in-depth analysis.

Broadly, the process of analysis and consultation will be about “the issue of care and treatment because of its high priority to people with HIV/AIDS and to health-service providers, and of its growing legal, ethical, and human rights implications in the face of changing testing and treatment technologies” (Canadian HIV/AIDS Legal Network, 1999, p. 2).

Part of the Network’s plan for 2000 is to undertake an assessment of legal, ethical and human rights issues that are raised when providing care, treatment and support. These will be detailed in a short paper and discussed at a small national workshop (March 3-4, 2000) for the purposes of identifying “top priority issues” for further analysis.

2. The MAT/DOT Program, Vancouver

This is a new BC Centre for Excellence in HIV/AIDS program designed to reach out to persons with HIV disease in Vancouver’s Downtown Eastside district

(DTES). The DTES is known for high rates of injection drug use, poverty, homelessness and HIV infection.

The Maximally Assisted Therapy (MAT)/Directly Observed Therapy (DOT) program is designed to assist “hard to reach” people who need support taking antiretroviral medication. The program provides simplified, user-friendly and once-a-day therapies. The service is provided in partnership with the Vancouver Richmond Health Board and Vancouver Native Health Society. The MAT/DOT is both a service and a research program (MAT/DOT Program, 1999).

MAT/DOT was introduced in November 1999. Following directly observed therapy principles, clients attend the central facility to receive and take their medications. DOT is a daily single dose regimen for persons with HIV disease who have never taken antiretrovirals. MAT is for persons with HIV disease who require added support. A daily lunch is also available at the neighbouring Native Health Positive Outlook Program. MAT/DOT staff include physicians, registered nurses, support workers and a pharmacist.

Although the MAT/DOT program was not designed specifically with rehabilitation in mind, it does promote rehabilitation techniques, beginning with two determinates of health—nutrition and health care. End-points of measurement for the program include adherence to therapy, patient satisfaction and clinical progression/survival.

3. Issues of Engagement in Rehabilitation Services, Dr. Peter Centre, Vancouver

This rehabilitation research project is in its early stages at the Dr. Peter Centre in Vancouver. The Centre provides a wide range of rehabilitation services to people who are considered at high risk for declining health. The research project intends to explore issues of engagement that contribute to (or detract from) successful provision of HIV rehabilitation services.

A large proportion of the clients at the Dr. Peter Centre have drug dependencies (70%) and many (26%) have been diagnosed with mental illness. Moreover, over 90% receive income assistance and nearly 40% have a prison history. Clearly the social and economic profile of most of these clients can be described as “multi-challenged.” The Centre’s research recognises that there is frequently a gulf between consumer and provider in such contexts and that this contributes to inequities in service.

The Issues of Engagement project seeks to identify barriers to engagement in care so rehabilitation specialists can develop better therapeutic alliances with their clients. Three phases of the project are planned: 1) evaluation of the rehabilitation services offered at the Centre; 2) participant-action research, and; 3) dissemination of the findings to AIDS care providers and service organisations.

Specific objectives of the project include:

1. To identify the barriers among the multi-challenged HIV population that inhibit therapeutic engagement in rehabilitation.
2. To identify the impact of therapeutic alliance on therapeutic engagement (in rehabilitation) among the multi-challenged HIV population.
3. To identify the impact of various contextual factors on therapeutic engagement in rehabilitation.
4. To identify the impact of involvement in rehabilitation on quality of life of the multi-challenged HIV population.
5. To engage the multi-challenged HIV population in research activity designed to improve the quality of rehabilitation service offered at the Centre.
6. To share and disseminate information on issues of therapeutic engagement in rehabilitation to the HIV community and service organisations.
7. To share and disseminate information on approaches to improving rehabilitation services offered to the multi-challenged HIV population.

Models/Programs of Service Delivery:

1. The Dr. Peter Centre, Vancouver

The Dr. Peter Centre offers a range of rehabilitative services to persons living with HIV disease. These are delivered through residential and day program services provided by a multidisciplinary clinical team. The Centre's model is client-focussed and participant-based, to promote optimal health for persons with HIV disease while they are living in the community. Clients are encouraged to take part in weekly meetings at the Centre, participate in committees, and discuss issues about the operations of the Centre.

The goals of the Dr. Peter Centre are:

- Provide day-program facilities to support persons with HIV disease to live independently in the community
- Improve health status and quality of life for persons with HIV disease
- Promote efficient use of health care services and to reduce unnecessary hospitalisation
- Provide respite care for participants' care providers

Specific rehabilitating services offered include:

- Supportive housing (10 bed residence & respite service)
- Recreational therapy (fitness, arts, outings)

- Nutritional counselling and direct provision of nutrition
- Music therapy (including relaxation and imagery, instruction, song writing)
- Complementary therapy (including acupuncture, Reiki, therapeutic touch, massage)
- Nursing Service (including self care education, pain management, stop smoking)
- Counselling (including psychotherapy and substance abuse counselling)

The Centre is intended to complement but not duplicate other AIDS organisation services. The Centre serves over 120 HIV-positive clients, the majority of whom are multi-challenged with combinations of substance abuse, mental illness, and poverty difficulties. The Centre cannot meet demand for its services. For example, there is a wait list of approximately 100 people for its programs.

2. Casey House Hospice CHAP Program, Toronto

Opened in 1988, Casey House Hospice was Canada's first free standing hospice for persons with HIV disease. It operates a 13-bed palliative/respite residential program and a community program. The community program offers in-home care, consultation, and education services.

Casey House has recently taken steps to prepare the foundation for a comprehensive HIV community care service that would provide a single referral source for in home care. To achieve this initiative, Casey House has developed partnerships with several community care providers—Community Occupational Therapists & Associates¹¹ (COTA), Central Neighbourhood House¹² (CNH), and Spectrum Health Care¹³ (SHC)—to develop a Community HIV/AIDS Partnership, the “CHAP Program.”

The CHAP program is unique for service delivery to persons with HIV disease. A full range of services (nursing, nutrition, occupational therapy, physiotherapy, social work, speech therapy, homemaking, and personal support) are integrated with primary care HIV physicians, HIV clinics, acute and chronic care hospitals, ASO's and hospice services. This comprehensive and integrated approach is a useful model for rehabilitation services. The vision of the CHAP Program is to deliver in-home services to metro-Toronto persons with HIV disease through a single point of access, Casey House. The program components and care delivery are as follows:

¹¹ COTA is a non-profit community health agency that provides rehabilitation and mental health services in Toronto. It has provided services to persons with HIV disease since the outset of the epidemic. COTA services also include physiotherapy, speech therapy and nutrition services.

¹² CNH is a non-profit agency. Its staff are educated about HIV and provide homemaking services to many persons with HIV disease.

¹³ SHC is a for-profit nursing, homemaking and allied health agency. SHC is noted for provision of services to person with HIV disease and its recruitment of staff from communities affected by HIV disease.

1. *Referral:* When a person with HIV disease is admitted to the metro-Toronto community home care program, a referral is made to the Casey House CHAP Program. A primary care coordinator (who is a trained HIV specialist) is assigned to be the main link between the community home care program and the interdisciplinary team. The objective is to improve communication between services and to involve the community home care coordinator. All staff providing service through the CHAP Program are trained in HIV/AIDS.
2. *Assessment:* The community home care referral serves as the baseline assessment for care. The primary care coordinator conducts an in-depth clinical assessment with the client, significant others and the interdisciplinary team. This assessment forms the foundation for the development of a personal care plan.
3. *Planning:* The clinical assessment, client needs and team input lead to the development of a care plan. The care plan, which is subject to ongoing revision, forms the framework for interdisciplinary team services.
4. *Evaluation:* The delivery of care services are evaluated and revised on an ongoing basis depending on the needs of the client. Alterations to the plan are made in collaboration with the client and the home care coordinator.

CHAP's comprehensive and integrated community service strategy was developed with community input and is a response to consumer need. Given that the program is in its first year of operation, some components are under development and project outcomes are undetermined.

3. Nine Circles Community Health Centre, Winnipeg

The philosophy of co-location and integrated service delivery is the foundation of the Nine Circles Community Health Centre. Opened in 1999, the provincial government contributed a million dollars to create a facility that houses the following five HIV/AIDS agencies:

- **AIDS Shelter Coalition of Manitoba (ASCM)**
Provides advocacy and support to persons with HIV disease to access public and private housing. ASCM also provides support and education with housing rights, nutrition, education and employment.
- **Kali Shiva AIDS Services**
Kali Shiva is a volunteer centred organisation that provides non-medical supports to persons with HIV disease. Its services are based on harm reduction, health promotion and community development.

- **Manitoba Aboriginal Task Force (MAATF)**
The MAATF provides information, resources and service to Aboriginal persons with HIV disease. It also conducts social research on HIV/AIDS and provides training and program development.
- **Village Clinic**
The Village Clinic is a community health centre that provides client services and public health education regarding HIV disease. It works in partnership with community health, social, allied health and AIDS service organisations.
- **Winnipeg Regional Health Authority**
The Winnipeg Sexually Transmitted Diseases Team of Public Health Nurses is dedicated to prevention and control of sexually transmitted disease. It provides education, case management, contact tracing, and information services.

The integrated model of HIV/AIDS services at Nine Circles Community Health Centre places the client at the centre of the primary health care system. Rather than a one-to-one medical approach, the Centre's objective is to provide multi-disciplinary, holistic care through a team approach. Therefore, each of the agencies at the Centre is linked through a central management system and their activities are inter-linked in terms of programming and service approach. The services are subject to ongoing evaluation and are seen to belong to a continuum of care. Additional services such as pharmacy and dentistry may be included in the model at a later date.

The Nine Circles model is detailed and complex. For a comprehensive explanation of various components of the model and its underlying rationale for the Winnipeg context, it is suggested that readers refer to the planning committee report by Kutcher et al. (1998). At present, the Nine Circles is in the midst of its second phase of implementation (co-location of agencies). The third and final phase of formulating a "centralised coordination body" is to be complete by 2001. Consequently, the outcomes of this service model have yet to be measured and evaluated.

4. Employment Action, Toronto

This program is offered through the AIDS Committee of Toronto (ACT) and the Toronto People with AIDS Foundation (TWPAF). Launched in September 1999, the program is an outcome of *Back to the future: A feasibility study on return to work programming for people living with HIV/AIDS* (Grubb & McClure, 1997).

The Employment Action program is described as an innovative and client-focussed employment program. It offers a free and confidential service that includes information and support for persons with HIV disease who are considering and seeking work. Confidentiality for persons with HIV disease who

are seeking work is particularly important for those who are on long term disability insurance benefits since insurers can be inflexible about beneficiaries who seek work (CAS, 1998). This is because insurers are concerned about the ability of a client to work, and not the actual availability of a job.

Employment Action targets gay friendly and HIV friendly employers and attempts to match them with prospective qualified employees. A brochure for the program offers the following services:

- Benefits consulting
- Employment planning
- Career exploration
- Skill, interest and abilities assessments
- Job trials
- Employment skills development
- Self employment development
- Job placement
- Employment support resources

Since the program is in its early stages, outcomes are unknown. However, there is a project evaluation component for Employment Action and information is being tracked internally for annual reporting.

Rehabilitation Activities of Other Organisations:

1. The Multiple Sclerosis (MS) Society

MS is a disease of the spinal cord and the brain. A disorder of the central nervous system, it interferes with the ability of the brain to control vision, speech and physical movements. Fatigue is common and so is depression, although neither are unique to the disease. MS is chronic and like HIV disease, often cyclic and progressively deteriorative (Schapiro, 1991). It is estimated that approximately 50,000 Canadians have MS.

Little empirical attention has been given to quality of life perceptions and service use by people with MS. Consequently, the MS Society has undertaken a recent survey of quality of life, assistance arrangements, and use of services by people with MS and their caregivers (Aronson et al, 1996; Aronson, 1997). The survey was part of an evaluation effort and when it was originally developed, “it was thought that a new model of services would be developed from the research” (Aronson, circa 1995). On completion of the project, the Society concluded that there was greater level of satisfaction with existing services than believed, both by persons with MS and their care providers. However, the study did reveal that attention needed to be given to questions regarding how and when assistance could be delivered in areas of less satisfaction. In particular, it was found that lack of financial resources was a major concern for care givers. For people with MS, unemployment, increased disease activity and disruption of social activities all contributed to lower quality of life ratings.

The survey informed the MS Society that home care for people with MS could be supported and prolonged, thereby preventing premature institutionalisation. The study gave insight into the daily reality of MS for its sufferers and care providers. It also gave the “impetus for the MS Society to focus more on care giver support and related concerns” (Aronson, circa 1995).

In another initiative the MS Society collaborated with the Educating Future Physicians of Ontario project (EFPO) to produce a physician education workbook, *Taking Charge: The Team Approach to Managing Multiple Sclerosis* (MSS/EFPO, 1995). The EFPO project is a collaborative venture between all of Ontario’s medical schools and it is designed to train doctors to be responsive to community expectations. Its starting point is the “analysis of public expectations, health needs and societal trends for determining the roles and competencies of future physicians.” The rationale is that this kind of “demand-side” approach can be an effective alternative to the traditional “supply” approach where information is provided through limited curriculum time.

The workbook is intended to be of use to current medical students, to provide an opportunity for collaboration across Ontario’s medical schools, and to facilitate consultation with community-based agencies and groups.

A third example of advocacy is the *Employer’s Guide to Multiple Sclerosis in the Workplace* (MS Society, 1996). This document is intended to give “employers and co-workers an understanding of the effects of MS and provide an overview of the many approaches that can be taken to assist and support an employee with MS to remain an active and productive member of the workforce.” Although the manual is geared to MS, it is highly applicable to HIV disease and other disabilities. The manual is fairly prescriptive, identifying workplace modifications ranging from workstation adjustments and job redesign, to review of benefits packages and part-time or staggered work schedules. Additionally, there is a question and answer section to help employers and co-workers to understand MS and its implications for both work performance and working relationships.

The MS *Employer’s Guide* is in many ways a more practical model than the *AIDS in the Workplace/Sida en milieu du travail* program in Quebec (Ministry of Health & Social Services, 1999). *AIDS in the Workplace* tends to emphasise legal issues and matters about transmission and prevention. Values, attitudes and behaviour are framed quite legalistically and defensively, rather than ethically and proactively.

Finally, the MS Society promotes the concept of wellness. *Beyond MS: A Journey to Wellness* (MS Society, undated) is a program to help people with MS and their families live a healthy lifestyle while adapting to the illness. The project was developed by the Society in consultation with people with MS, their families and health professionals.

The rationale of *Beyond MS* is that a healthy lifestyle promotes wellness and helps people to look beyond their illness for quality of life. Wellness is defined as the “best physical, emotional, and spiritual health that a person is capable of achieving.” As a model of health promotion, there are six dimensions of wellness:

1. Occupational
2. Social
3. Spiritual
4. Emotional
5. Intellectual
6. Physical

The *Beyond MS* workbook is approximately 100 pages in length, written in simple language. It is a planning and decision making tool for individuals that encourages a dynamic process of self-assessment of the six dimensions of wellness, leading to goal planning, implementation and evaluation of goals. The workbook employs the user-friendly metaphor of taking an automobile journey to link its eight chapters from the initial decision to strive for wellness to the end-point of being “out in traffic,” that is, interacting and living well in the community.

The BC Coalition for People with Disabilities introduced in 1999 a new program called the Wellness and Disability Initiative (WDI). A core component of the WDI is the AIDS and Disability Action Program (ADAP) collection of resources. However, within the WDI/ADAP materials, there does not appear to be a personal tool comparable to the MS Society’s *Journey to Wellness* workbook.

2. The Canadian National Institute for the Blind (CNIB)

The CNIB is a rehabilitation service organisation for persons with loss of vision. In general, clients are referred on the basis of a vision assessment by a physician, although it is believed that a great many people do not take advantage of CNIB services. One reason given is the use of the word “blind” when it is not necessary to have complete vision loss to use CNIB services. The services offered by the CNIB for persons with HIV disease are the same as those for other individuals. They include:

- Counselling (individual, family and peer support counselling)
- Rehabilitation teaching (instruction in practical skills for daily living)
- Orientation & mobility training (travel skills and cane techniques)
- Sight enhancement (training with visual aids)
- Career development (vocational services and job search techniques)
- Library services (lending services of Braille and audio books)

Persons with HIV disease may experience vision loss as a result of cytomegalovirus infection (CMV). A case worker at the British Columbia branch

reported that the number of HIV client referrals had decreased substantially in recent years (see table 2). It is not known if this is a function of new therapies for HIV disease.

Table 2

Number of HIV-related referrals to CNIB (BC)	
1995	12
1996	17
1997	5
1998	5
1999	3
Total	42

3. The Arthritis Society of Canada

According to the Arthritis Society, arthritis is responsible for more long term disability than any other illness. Under sponsorship with Searle and Pfizer, the Society has developed, a health promotion program called the Arthritis Self Management Program (ASMP). The ASMP is designed to help persons to better understand their arthritis, cope with chronic pain, and take an active role in managing arthritis.

ASMP is a six-week program taught in weekly two-hour sessions. There is cost for the program, which is taught by trained leaders who have successfully completed a 15-18 hour ASMP Leader Training Workshop. The standardised content for the ASMP covers the following topics:

- exercising with arthritis
- managing pain
- eating healthy
- preventing fatigue
- protecting joints
- taking arthritis medications
- dealing with stress and depression
- working with one's doctor and healthcare team
- evaluating alternative treatments
- outsmarting arthritis: problem solving

Benefits reported by ASMP participants, which has existed for 10 years, are:

- less pain
- improved ability to move around
- increased understanding of arthritis
- learning of new ways to cope with arthritis
- more active in managing arthritis

C) Summary (Part II)

There is a growing body of literature, much of it at the grass-roots level, concerning HIV disease and rehabilitation. Over time, and the AIDS social movement is witness to this phenomenon, grass roots issues often evolve into mainstream issues. Indeed, the array of research projects and emerging models and programs of service delivery are evidence of increasing interest in client-centred, multidisciplinary care for persons with HIV disease.

There are many indicators that rehabilitation in the context of HIV disease is part of a social movement and CWGHR, along with other seminal community initiatives, is leading the way. To give momentum to this movement and to enhance care for persons with HIV disease, researchers, community-based organisations, government, the private sector and persons living with HIV disease need to collaborate and ensure that their mutual projects are published and widely disseminated. Moreover, programs need to be multidisciplinary, integrated, and evaluated from a client-centred perspective to ensure that consumers are the primary beneficiaries.

Appendix 1: Key Informants & CWGHR Members

Key Informants

Brenda Barr
St Paul's Hospital, Vancouver

Louis Binder
Canadian Treatment Activists Council, Toronto

Jesse Bodyan
Interministerial Project, Vancouver

Sheila Braidek
Village Clinic, Winnipeg

Donna Braybrook
AIDS Committee of Toronto, Toronto

Michael Compeau
Toronto

Sarah Cross
University of Toronto (physiotherapy student)
Toronto

Maxine Davis
Dr. Peter Centre, Vancouver

Shelley Dean
MAT/DOT programme, Vancouver

Jeanette Edwards
Primary Care, Winnipeg Health Authority,
Winnipeg

Howard Engel
Vancouver

Angela Favretto
ACAP, HIV/AIDS Policy Programs, Ottawa

John Flannery
Casey House Hospice, Toronto

Marcia Gillespie
Ontario Public Service Employees Union,
Toronto

George Harris
AIDS Shelter Coalition of Manitoba, Winnipeg

Mike Holtby
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Appendix 2: Force for Change: Labour Force Participation for People Living with HIV/AIDS

The following is a verbatim list of the recommendations contained in *Force for Change* (CAS, 1998), reprinted with the permission of the Canadian AIDS Society.

I Free choice and quality of life

Given that the BCPWA Society has provided an excellent framework on free-choice and a non-coercive approach to labour force (re)integration, it is recommended:

1. That the Canadian AIDS Society review these guidelines and principles for official endorsement and promotion as the policy position of the Society in its advocacy and education activities regarding return to work and the related quality of life guarantees for PLWHIV/AIDS.
2. That provincial and local CBAOs use these guidelines and principles in education and advocating with provincial and community-based service providers and disability organisations to ensure these sectors have a better understanding of the complex issues related to HIV and how these issues affect the return to work decision.
3. That primary care physicians treating an HIV clientele be better sensitised and educated on the free-choice and quality of life principles related to return to work, and more specifically that:
 - a) CAS undertake to organise and promote this education through national associations of physicians and health care professionals;
 - b) Provincial CBAOs do the same with provincial associations;
 - c) Local CBAOs do outreach and education to community primary care physicians and health care workers on these guiding principles.
4. That the private insurance industry be better educated and sensitised to the issues related to labour force decisions for PLWHIV/AIDS especially around free-choice and the primacy of enhancing quality of life, and more specifically that:
 - a) CAS continue to work in partnership with industry organisations such as the Canadian Life and Health Insurance Association in this regard;
 - b) Provincial and local CBAOs develop strategies of outreach, advocacy and education to providers of private insurance coverage in their jurisdictions.

II Benefits counselling and decision-making assistance

Given the complexity of issues around benefits coverage and financial security for PLWHIV/AIDS who are still in the labour force, and given that PLWHIV/AIDS who are

considering a return could benefit from access to appropriate expertise or benefits counselling prior to making any decisions, it is recommended:

5. That the model of benefits counselling as outlined in the recent study by Elisse Zack (Zack 1998) be better integrated and anchored in the package of support services offered to PLWHIV/AIDS at CBAOs.
6. That CAS continue to refine an appropriate benefits counselling model and develop capacity building/training approaches for CBAOs to ensure that their clients have accurate, current and reliable benefits information to make the best possible decisions, and further that CAS assist CBAOs in developing links and networks with other community providers of this service.
7. That CBAOs have access to on-going training and technical support to offer benefits counselling as a standard support service.
8. That CBAOs develop links and co-ventures with existing providers of disability programs and services related to benefits counselling to ensure appropriate referrals of PLWHIV/AIDS can be made to these centres of expertise in benefits counselling.
9. That the Wellness Team model be further developed and considered for application in individual cases of PLWHIV/AIDS who desire such technical, psychosocial and benefits counselling support in mapping a possible return to work and further that CBAOs develop a capacity to assist the PLWHIV/AIDS to plan and sustain such personal Wellness Teams.¹

III Vocational rehabilitation and disability services for PLWHIV/AIDS

Given that HIV/AIDS is a disabling disease and that PLWHIV/AIDS should have access to vocational rehabilitation and other appropriate programs which assist persons with disabilities to return to work, it is recommended:

10. That public or community-based providers of vocational rehabilitation be better educated and sensitised to the particular needs of PLWHIV/AIDS who see vocational rehabilitation as an appropriate intervention and more specifically that:
 - a) CAS continue or initiate productive links with national organisations or programs which offer rehabilitation services or other labour force integration services for persons with disabilities.
 - b) Provincial and local CBAOs should develop outreach plans to provincial and local providers of vocational rehabilitation and service to persons with

¹ A “Wellness Team” is a circle of support formed by the PLWHIV/AIDS to provide coaching, advice and multi-disciplinary support to the individual who is investigating or negotiating a return to work with potential employers and existing benefit payers. The Team could consist of a personal physician, friends/peers, social workers, and individuals who have expertise in benefits counselling.

disabilities on how to better serve and integrate PLWHIV/AIDS needs into the existing streams.

IV Psychosocial issues

Given that HIV is an extremely complex illness, the need for psychosocial care and support is paramount. Participants at the consultations were clear in their message that this support is basic to their return to work challenges. It is therefore recommended:

11. That the BCPWA return to work issues and guiding principles be integrated into the existing psychosocial counselling and support provided by CBAOs.
12. That education and advocacy be done with professional care giving associations on the psychosocial needs of PLWHIV/AIDS who are considering a return to work and more specifically that:
 - a) CAS continue to advocate and work with the national associations such as the Canadian Psychological Association and the Canadian Association of Social Workers on continual improvement and updating of psychosocial care especially as it concerns return to work.
 - b) Provincial and local CBAOs work to educate and co-venture with provincial or local chapters of these associations in updating the professional practice of their members.
 - c) That CAS and the local CBAOs educate and advocate with primary care physicians and other health care providers on the importance of the psychosocial aspects of return to work.
13. That providers of return to work services, e.g., labour market training providers, vocational rehabilitation providers, occupational therapists be encouraged to include psychosocial perspectives in their program planning and service delivery.

V Treatment coverage

Given that medications and new therapies are critical to PLWHIV/AIDS in their potential return to work and that the costs of these treatments are prohibitive, particularly for those who are without adequate financial support, it is recommended:

- 15.² That treatment issues related to new therapies be taken into account when decisions on return to work are considered.
16. That CBAOs advocate with provincial ministries of health to ensure that policies and practices on treatment coverage can facilitate return to work and not act as a disincentive.

² Note that numerical ordering skips “14”, per original.

17. That insurers and employers be educated on issues of confidentiality and protection from mandatory disclosure.
18. That employers be educated and sensitised on treatment issues, and how workplaces can be more supportive in accommodating PLWHIV/AIDS.

VI HIV/AIDS in the workplace

Given that return to work strategies can only be successful if the workplace is responsive to the needs of PLWHIV/AIDS, and has appropriate policies to support the employee, it is recommended:

19. That education and advocacy be done with employers, labour unions and employer associations on HIV/AIDS in the workplace to ensure that the workplace environment is not a disincentive to returning to or maintaining employment, and more specifically that:
 - a) CAS work with national organisations and associations of employers and unions to improve workplace policies and implement best practice models in workplace accommodation for PLWHIV/AIDS;
 - b) Provincial and local CBAOs develop strategies and outreach to employers, associations and unions in their jurisdiction to implement update HIV workplace policies.
20. That CAS provide technical support and be a leader in developing and adapting existing workplace policies in light of emerging return to work realities and further that CAS promote best practices in workplace policies and accommodation.
21. That the Quebec program, *Sida en milieu de travail* (AIDS in the Workplace program) be promoted as a model for provincial and local CBAOs to structure and offer workplace assistance to employers and unions.
22. That CAS produce an inventory of current member groups' AIDS in the Workplace programs and interventions.
23. That CAS in co-venture with provincial and local CBAOs advocate with employers and labour unions on the economic benefits of employing and maintaining PLWHIV/AIDS in the labour force.

VII Public and private disability benefit programs

Given that the current public and private disability benefit programs require improvements in order to facilitate a return to work by program claimants, it is recommended:

24. That CAS, provincial and local CBAOs advocate and provide opportunities for increased collaboration and sharing of best practices between private and public (federal and provincial) disability benefit and insurance programs.
25. That CAS develop tools and models to support member groups and other CBAOs in their outreach and collaborative work with disability insurers.
26. That provincial and local CBAOs communicate with disability insurers in their jurisdictions on how to improve benefit programs so that they are responsive and flexible, non-punitive, and financially adequate for those individuals who wish to return to work on a trial basis.

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