

HIV and Rehabilitation: Bridging Policy and Practice.
A Scan of Policies Related to Access to Rehabilitation
in Canada and the United Kingdom

FINAL REPORT

June 2012

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EXECUTIVE SUMMARY

Research Purpose and Objectives:

This research aimed to explore the current HIV and rehabilitation policy literature in order to inform the development of recommendations to enhance access to rehabilitation for people living with HIV (PHA). Specifically, the objectives of this research were to:

1. conduct a scoping review of existing HIV-related rehabilitation policies in Canada,
2. conduct the same scoping review of the UK literature, and
3. synthesize this information to inform novel approaches to addressing the policy-to-practice implications for access to rehabilitation across the lifespan for adults living with HIV in Canada and the UK¹.

Definitions:

For this research, we broadly defined ‘rehabilitation’ as any provider or service that addresses or prevents impairments, activity limitations, or social participation restrictions experienced by an individual (Worthington et al., 2005). Examples of rehabilitation may include traditional forms of rehabilitation including physical therapy (PT), occupational therapy (OT) as well as more non-traditional forms of rehabilitation such as complementary and alternative therapies, social supports and counselling services delivered through AIDS service organizations. While we approached this review in a manner to broadly include literature that addressed this range of rehabilitation services, we recognize the differences in policies, funding structure and mechanisms for accessing traditional versus non-traditional forms of rehabilitation.

Alignment with CWGHR and CUHRRC Research Priorities:

This research builds on the work of the Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) research team and specifically focuses on one of the six Canadian Working Group on HIV and Rehabilitation (CWGHR) identified research priorities: access to and role of HIV rehabilitation (O’Brien, Wilkins, Zack & Solomon, 2010).

Methodology:

For the purpose of our scoping study, we employed the literature scoping search flow described by David, Drey and Gould (2009). Further, we adopted Arksey and O’Malley’s (2005) scoping review framework for our research. We conducted a scoping study of literature documenting policies related to access to rehabilitation services in Canada and the UK. We drew from both Canadian and UK sources in relation to the intersections of: 1) HIV as a manageable chronic illness; 2) health policy and access to rehabilitation; and 3) a variety of key determinants of health, such as gender and age.

¹ As discussed by Arksey and O’Malley (2005), we initially included search terms (see Appendix A) for non-HIV related chronic and episodic illnesses in order to capture potential novel approaches involved with these illnesses.

A comprehensive scan of the literature was completed in alignment with the following key research questions:

1. What are the strengths and gaps of HIV health rehabilitation policy evidenced in Canada and the UK with particular reference to access issues?
2. Do these policies take into consideration determinants of health, such as gender and socioeconomic status?
3. If so, how?

The Canadian portion of our literature scoping efforts included searches of CINAHL, PubMed, MEDLINE, ERIC, PsycInfo, the Canadian Public Policy Collection (Canadian Electronic Library) and Cochrane Library for published policy documents related to rehabilitation service delivery, as well as grey literature focused on AIDS service organizations, non-governmental organizations, and discipline-specific professional organization websites including: Canadian AIDS Society, Canadian AIDS Treatment Information Exchange (CATIE), Ontario AIDS Bureau, Canadian HIV/AIDS Legal Network, Episodic Disability Network, British Columbia Coalition of People with Disabilities, Episodic Disability Employment Network (EDEN), Canadian Council on Rehabilitation and Work, AIDS Committee of Toronto, Positive Living British Columbia, Canadian Working Group on HIV and Rehabilitation (CWGHR), AIDS New Brunswick, and the AIDS Coalition of Nova Scotia.

Our United Kingdom (UK) literature scoping efforts accessed the following sources and online resources: UKPubMed Central, British Medical Journal, National AIDS Trust (NAT), Terrence Higgins Trust, National Health Service Information Centre, UK Department of Health, Care Quality Commission, Chartered Society of Physiotherapy, British Association for Sexual Health & HIV (BASHH), British Association of Occupational Therapists and College of Occupational Therapists, Sexual Health Organizations Group (SHOG), National Institute for Health Research, Medical Research Council, Health Protection Agency, National Institute for Health and Clinical Excellence, Kings College London, NAM AIDSmap, Rehabilitation in HIV Association (RHIVA), British HIV Association (BHIVA), UK Consortium on AIDS and International Development, www.parliament.uk, and www.namlife.org. The following medical facility websites were also searched for relevant documents: Chelsea and Westminster Hospital, Barts and the London Hospital, and Mildmay Hospital. Noting the similarities between HIV/AIDS and other chronic and episodic diseases, our initial search included terms related to several of these diseases, as we were searching for novel policies and practices that could potentially be applied to HIV/AIDS.

For the purposes of the Canadian scoping portion, we initially included search terms for several chronic diseases and episodic illnesses (see Appendix A) in an effort to capture novel and potential wise or novel practices from related illness and disease organizations. This process was not repeated for the UK scoping portion.

Review and Coding of Documents:

The study selection process reduced the number of included documents to 58 Canadian and 21 UK documents that discussed HIV/AIDS and/or rehabilitation issues relevant to HIV/AIDS. Included documents were added to a spreadsheet and initially categorized as to whether they were specific to

HIV/AIDS and whether they pertained to access generally, employment and work factors, or traditional rehabilitation services (occupational therapy and physical therapy). The documents were read by pairs of research team members and categorized according to the following criteria, largely based on frameworks developed work by Canadian Working Group on HIV and Rehabilitation (CWGHR):

Type of document

- Policy Review
- Research
- Framework
- Other

Rehabilitation Category

- Access to Rehab
- Employment-related Rehab
- Traditional Rehabilitation

HIV Specificity

- Specific to HIV
- Not Specific to HIV

In order to more specifically identify novel approaches (or lack thereof) and themes related to access, six “Themes of Access to Rehab” were constructed, based upon major themes extracted from the background literature and reassessed following the final selection of documents, in order to help direct the final REACH report (Raphael, 2010). Readers rated each article on the basis of whether the following were included as factors that influence access to rehabilitation.

Age & Access

- Age Cut Off
- Time since Diagnosis
- Novel Ideas

Socio-economic Status (SES) & Access

- Income Cut Off
- Eligibility for Benefit
- Novel Ideas

Gender & Access

- Role Expectations
- Caregiving
- Novel Ideas

Social Inclusion/Exclusion

- Stigma
- Discrimination
- Social Supports
- Novel Ideas

Provider as Gatekeeper

Lack of Awareness of HIV
Clinical Judgment
Novel Ideas

Unpredictable Nature of HIV

Acute Episodic Health Status
Continuity of Benefits
Novel Ideas

Key Findings:

A forward-thinking, realistic model of HIV, rehabilitation and health of PHAs over the life course will do well to take into account the novel and promising ideas presented in the documents included in this scoping review. Specifically, policies and programs that have already been suggested and/or implemented include:

- Rehabilitation and care
 - *Education for health and human resource professionals*
 - *Integrated care/coordinated service provision models*
 - *Using rehabilitation models from other diseases with HIV/AIDS patients*
 - *Integration and utilization of complementary and alternative care modalities*
- Building multidisciplinary and well-informed provider communities
 - *Education for health and human resource professionals*
 - *Integrated care/coordinated services*
- Models of rehabilitation/Broadening HIV health care practice
 - *Using rehabilitation models from other diseases with HIV/AIDS patients*
 - *Integration and utilization of complementary and alternative care modalities*
- Addressing the mental health needs of persons with HIV across the lifespan
 - *Education for health and human resource professionals*
 - *Integrated care/coordinated service provision models*
 - *Promotion of mental health and psychological well-being*
- The maintenance of employment and income/Addressing disability in the workplace
 - *Coordinated disability benefits frameworks*
 - *Flexible work/disability arrangements to allow for the episodic nature of HIV/AIDS*
- Social inclusion and the importance of HIV supportive environments
 - *Emphasis on reducing stigma and discrimination*
 - *Education for health and human resource professionals*

Discussion:

For the purpose of this research, we conducted an extensive scoping review of articles and reports from Canada and the UK related to HIV, disability, aging, and the concept of 'chronic illness.' We discovered that researchers, providers, and policy makers are generally aware of how the trajectory of HIV/AIDS has shifted from a life threatening condition towards an illness with features of manageable chronic illness. However, little is known about how this new illness trajectory fits into and/or merges with established

models of treatment and supports for persons with other chronic illnesses characterized by episodic disability. This lack of experience and knowledge highlights possible areas of potential inequities related to the reclassification of HIV as an illness being on par with such illnesses as diabetes, hypertension, cancer, and arthritis. Specifically, we remain concerned with how historical issues such as HIV/AIDS stigma, discrimination, and the need for cultural competence in treatment settings will continue to be recognized and accounted for within new models of treatment and care for persons living with HIV/AIDS across the life span. This concern is the foundation for the development of appropriate policy and rehabilitation models of care that will necessitate evolving dimensions of training and awareness by a full range of stakeholders. No single continuum of care or set of policies that addressed each of our core ‘themes of access’ was discovered, however this study indicated that the UK draws on a more cohesive and integrated approach to providing care to PHAs than that which is currently utilized in Canada.

There is good news however, as Canada takes steps to develop new approaches towards the integration of HIV into established models of care. In addition to identifying a lack of knowledge and expertise, this study also identified a plethora of novel ideas based on the insight and experience of researchers, health providers and policy makers. This category, which emerged from our research, provides both theoretical and conceptual frameworks of embrative and integrated models of care, as well as strategies and new paradigms related to the ongoing training and education of providers. These frameworks, ideas, and strategies are the basis upon which we have made our recommendations towards the urgent next steps related to policy and service delivery in the context of HIV as a ‘manageable chronic illness’ across the lifespan.

Recommendations:

Based on the findings of our research, a number of recommendations for future research were identified, including:

- Research on further developing and evaluating policy interventions, particularly in relation to access to rehabilitation services, in consultation with policy and programming stakeholders;
- Research on examining the impact of the categorization of HIV as a chronic illness on access to care, policymaking, and clinical practice as it related to PHAs;
- Research on developing ‘healthy aging’ health promotion strategies aimed at health care providers working with PHAs across the lifespan and through an integrated continuum of care; and
- Case studies that explore the context of access issues identified from the perspective of PHAs.

Our findings suggest there is much to be gained by establishing a greater research presence within emerging, multi-disciplinary settings organized to educate providers about the distinct economic, social and political factors that impact the lives of PHAs. Determining integrated treatment policies related to the inclusion of PHAs within established models of care for persons with chronic, episodic illness through consensus building should be further examined and evaluated. As part of this process, diverse stakeholders can provide input into how their own clinical and service backgrounds impact—and are impacted by—the process of building new policy and provider frameworks to better meet this needs of PHAs. Specific research into ‘healthy aging’ strategies for PHAs may help to mitigate some of the issues

related to living and aging with a chronic, episodic illness, and would be a welcome acknowledgement of the unique needs of PHAs and their care providers.

Finally, a case study approach can provide additional contextual data that speaks to the actual lived experiences of PHAs as they attempt to navigate new landscapes of service delivery informed by policies used to determine eligibility and access. To this end, qualitative, ethnographic research approaches that aim to capture the day-to-day lived experiences of PHAs—in their own words—can be of great importance in understanding the ways in which rehabilitation policies and practices help or hinder the health outcomes of PHAs across the lifespan. It may be of great interest, for example, to evaluate the effectiveness of policies and programs stemming from integrated, single-point-of-entry service delivery arrangements and other emerging models of care that are responsive to the needs of PHAs within the broader chronic disease framework.

SECTION ONE

1.0 Introduction

Although there are differing opinions on whether or not to regard HIV as a chronic illness, among those living with HIV who have access to HIV medications, programs and services, HIV is increasingly experienced as a chronic, rather than acute illness. Health policies, including those related to *eligibility* for access to HIV rehabilitation programs and services, may differentially impact the *health outcomes* of men and women living with HIV (PHA). Health policy is particularly important to the health outcomes of both men and women living with HIV in that such policies can play a role in shaping and influencing access to and uptake of rehabilitation programs and services. Thus, rehabilitation, broadly defined as any provider or service that addresses or prevents impairments, activity limitations, or social participation restrictions experienced by an individual, remains relevant for the health and wellness of all people living with HIV (Worthington et al., 2005). In addition, PHA-specific health determinants act to vary the context, related policies, and types of rehabilitation that influence patterns of access. Little is known about how the health-seeking experiences of adults living with HIV may differ in relation to existing rehabilitation policies and further, how determinants of health, such as gender, age, socio-economic status, among others, may influence access to and utilization of HIV rehabilitation programs and services.

Canada and the United Kingdom (UK) share many common features in terms of health care systems and the provision of health services and this serves as the impetus for our research. Further, this research is meant to help inform ‘novel’ approaches to overcoming rehabilitation policy-to-programming gaps for PHAs based on similarities and differences between these two contexts. This is particularly salient given that the UK has a well-developed and accessible rehabilitation system for those living with HIV and therefore serves as an important comparator for the Canadian HIV and rehabilitation context.

1.1 Objectives

This research builds on the work of the *Canada-UK HIV and Rehabilitation Research Collaborative* (CUHRRRC) research team and specifically focuses on one of the six Canadian Working Group on HIV and Rehabilitation (CWGHR) identified research priorities: access to and role of HIV rehabilitation (O’Brien, Wilkins, Zack & Solomon, 2010). Our research aimed to explore the current HIV and rehabilitation policy literature review in order to inform the development of recommendations of ways to enhance access to rehabilitation for people living with HIV.

Specifically, the objectives of this research were to:

- 1) *conduct a policy scoping review of existing HIV-relevant rehabilitation policies in Canada,*
- 2) *conduct the same policy scoping review of the UK literature, and*
- 3) *use this information to inform novel approaches to addressing the policy-to-practice implications for the health outcomes of adults living with HIV in Canada and the UK.*

1.2 Research Questions

1. What are the strengths and gaps of HIV health rehabilitation policy evidenced in Canada and the UK with particular reference to access issues?
2. Do these policies take into consideration determinants of health, such as gender and socio-economic status (SES)?
3. If so, how?

SECTION TWO

2.0 Background

As antiretroviral therapy (ART) shifts HIV/AIDS treatment away from a more palliative care focused model and toward a more chronic illness model, a challenge for caregivers is to provide necessary rehabilitation and to incorporate this into the mainstream of HIV care (CWGHR, 2000). Policies can act as a guide for health providers, and can either facilitate or detract from the accessibility and uptake of health programs and services. In order to enhance our understanding of PHAs access to rehabilitation programs and services, it is necessary to first establish a better understanding of varying kinds of policy.

For the purposes of this research we examined both formal and informal policies. For formal policies, we utilized the definition from the National Collaborating Centre for Healthy Public Policy (2010):

An action or group of strategic actions carried out by a public authority with the aim of attenuating or promoting particular phenomena occurring in the population (p. 13).

Informal policy is more difficult to define, as its definition must recognize both the ability and practicality of local communities and organizations in responding to issues with, or barriers to, rehabilitation that may or may not be unique to their group, but which are not being adequately addressed by formal policy. Informal or community-based policies and programs frequently seek to bridge the gaps which appear following the establishment of formal policy, or where formal policy has not yet been created to address such gaps (Beeker, Guenther-Grey, & Raj, 1998; Guenter et al., 2005). Particularly in the field of HIV/AIDS policy, informal policies can be critical in achieving access to programs and services and may inform further development of formal policy.

In examining current policies and practices that may impact access to rehabilitation for PHAs, two important trends must be considered. The first trend is the perspective of many policy decision makers in classifying and including HIV/AIDS within the chronic illness category, thus ignoring many of the unique features of HIV/AIDS that may make qualifying for access to rehabilitation more challenging. While this does bolster the link between HIV and rehabilitation, as rehabilitation services are often already strongly linked to chronic illness, these previously established links may fall short of meeting the needs of this specific population across the lifespan. Second, PHA populations are aging and living into their senior years in both Canada and the UK, primarily as a result of access to and utilization of antiretroviral therapy (ART). However, PHAs are also experiencing earlier onset of conditions generally seen among older non-PHA populations in addition to the unique complications of ART. Earlier onset of such conditions suggest the need for access to rehabilitation, broadly defined, as well as other programs or services meant to enhance and promote the health and wellbeing of PHAs as they age. Policies that encourage and promote both healthy aging and access to rehabilitation among PHAs are likely to enhance and improve health outcomes across the lifespan.

2.1 Comparison of the Canadian and UK Health Care Systems

There are many similarities in the Canadian and UK health care systems, as indicated in Table 1. While universal health coverage is provided to some extent by both countries, non-hospital care, such as mental health and rehabilitation services, whether covered by private insurance or provided for certain groups by government, generally are subject to “gatekeeper decisions”, often a family practitioner in Canada, or in England, the Primary Care Trusts.

However, documents that outline or provide strategic direction for health policy are not always up to date, nor do they necessarily account for the unique struggles of PHAs. For example, two foundational, but now dated Government of Canada documents, *The Federal Initiative to Address HIV/AIDS in Canada: Strengthening Federal action in the Canadian response to HIV/AIDS* (Public Health Agency of Canada [PHAC], 2004) and *Leading Together: Canada takes action on HIV/AIDS: 2005-2010* (Canadian Public Health Association [CPHA], 2006), provide a framework for responding to HIV/AIDS and set broad goals and policy directions for Provincial Departments of Health. While these documents speak to the need for PHAs to have access to non-HIV-specific health services, including rehabilitation programs, neither document provides specific guidance for provision of services to and access by this population (CPHA, 2006). By comparing the respective policies related to PHAs and access to rehabilitation, this research sought to identify gaps in policy and uncover wise or novel approaches to policymaking which may be shared and incorporated into future policies and practices.

Table 1. Comparison of Canadian and UK Health Systems (Thomson, Osborn, Squires, & Reed, 2011)

Parameter	Canada	UK
Coverage	<ul style="list-style-type: none"> • Universal coverage for physicians and hospitals, based on legal residency in a province; • Coverage for other services provided through a mix of public programs, supplementary private insurance, or out-of-pocket payments 	<ul style="list-style-type: none"> • Universal coverage for those “ordinarily resident” by the National Health Service • In practice includes screening, immunization and vaccination; inpatient and outpatient hospital care; physician services; inpatient and outpatient drugs; dental care; some eye care; mental health care; palliative care; some long term care, and rehabilitation
Supplementary Coverage	<ul style="list-style-type: none"> • Provincial and territorial governments provide some supplementary benefits for groups such as children, seniors, and social assistance recipients • Roughly two-thirds of Canadians have private health care insurance, which covers services such as vision, dental care, prescription drugs, rehabilitation services, home care, and private rooms in hospitals 	<ul style="list-style-type: none"> • Out-of-pocket spending made up about 10% of health expenditures in 2009

Prescription Drugs	<ul style="list-style-type: none"> • Covered within hospital setting • All provinces and territories provide coverage for over 65 • All have drug coverage plans for low-income recipients of social assistance 	<ul style="list-style-type: none"> • Some groups exempt from prescription co-payments • About 89% of prescriptions are free of charge
Preventive Services	<ul style="list-style-type: none"> • Health promotion education activities and screening programs 	<ul style="list-style-type: none"> • Screening, immunization and vaccination are covered
Mental Health Care	<ul style="list-style-type: none"> • Delivered by physicians in ambulatory and hospital settings; no coverage mandated outside these settings 	<ul style="list-style-type: none"> • Commissioned by local Primary Care Trusts (PCTs) and local authorities, with provision split between NHS (63%); social services (7%); private and voluntary sector (29%); general medical services (1%)
Long-term Care	<ul style="list-style-type: none"> • Funded by provinces 	<ul style="list-style-type: none"> • Some care provided by NHS based on a means test; in 2009, private sector provided 70% of residential care
Dental and Optometry	<ul style="list-style-type: none"> • Not publicly covered except for certain age groups in certain provinces 	<ul style="list-style-type: none"> • Eyeglasses and dental care for young people and students and people with low income on financial assistance
Coverage Decisions	<ul style="list-style-type: none"> • Majority made at provincial/territorial level as to what constitutes “medically necessary” 	<ul style="list-style-type: none"> • PCTs make decisions regarding mental health care, dental care

Note: Canada ranks amongst the lowest in Organization for Economic Co-operation and Development (OECD) countries in terms of benefit provision to people with disabilities and ranks 18th out of 23 OECD nations in “incapacity spending”, which includes all the funds provided to people with disabilities or to assist them in gaining employment (Raphael, 2010).

2.2 Importance of Rehabilitation Services for People Living with HIV/AIDS (PHAs)

As antiretroviral therapies (ART) extend the lifespan of PHAs, a number of co-morbidities and disabilities occur in this population, both as a result of the disease as well as from side effects of ART. Several studies have shown an increased prevalence of disability among those living with HIV/AIDS (Worthington, Myers, O'Brien, Nixon, & Cockerill, 2005). It is important that health policies take into consideration that both the disease and the antiretroviral treatment may cause a number of disabilities, including body impairments, activity limitations, and participation limitations (Myers et al., 2003). Related to the diverse needs of PHAs, we used a broader focus on ‘rehabilitation’, rather than concentrating solely on physical therapy and occupational therapy, which are termed here as “traditional rehabilitation”. The Canadian Working Group on HIV and Rehabilitation (CWGHR) defines

rehabilitation “as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual” (CWGHR, 2010b, p. 5).

For example, PHAs can experience ‘wasting disease’, an involuntary loss of more than 10% of body weight accompanied by chronic diarrhea and/or fever (Dudgeon, Phillips, Bopp, & Hand, 2004; Wasserman, Segal-Maurer, Webbeh, & Rubin, 2011). While it is often assumed this does not occur in people on ART, studies have shown that weight loss and wasting continue to be common problems, even for those treated with ART (Wanke et al., 2000). Individuals with HIV also have a high prevalence of anemia as well as diseases of the peripheral nervous system (McReynolds & Garske, 2001). Impairments related to HIV central nervous system involvement may lead to cognitive impairments or to symptoms similar to stroke (McReynolds & Garske, 2001).

Individuals with HIV also have higher incidences of psychiatric disorders than those without HIV, the most frequent being anxiety and depression, and often show typical immune disorders associated with chronic stress (Dudgeon et al., 2004). The unpredictability of the course of the disease, including periods of ‘episodic’ disability, and therefore uncertainty about one’s health status, future plans, family and social activities, relationships, and work all impact one’s psychological and mental health (Chiou et al., 2006; McReynolds & Garske, 2001; O'Brien, Bayoumi, Strike, Young, & Davis, 2008). Increased levels of stress are associated with an increase in depression, distress, and HIV symptoms (Myers et al., 2003; Worthington et al., 2005), and these issues have been associated with more rapid progression to AIDS (Dudgeon et al., 2004). These complications indicate that health care providers and policy makers should be sensitive to PHAs need for rehabilitation in addressing these potential issues before they become permanently disabling.

Goal of Rehabilitation

The symptoms and physiology of HIV/AIDS, and the side effects of ART may overlap in any one individual, once again suggesting the need for holistic, integrated policy and rehabilitation approaches. The goal of rehabilitation for PHAs is to slow deterioration by “improving, restoring or maintaining activities and participation in daily life” (CWGHR, 2000, p.12). Due to the cyclic nature of HIV disease and the complex side effects of antiretroviral therapy, PHAs may require a range of rehabilitation approaches aimed at promoting health and wellness across the lifespan. These may include physicians, nurses, pharmacists, physical therapists, occupational therapists, speech-language pathologist, and psychiatrists, and dieticians, as well as complementary and alternative medicine, such as massage and osteopathy. For vocational rehabilitation, there are vocational counsellors, rehabilitation counsellors, and occupational therapists. Psychosocial rehabilitation may include social workers, psychiatrists, psychologists, recreation and exercise therapists, and non-traditional health care providers, such as spiritual advisers, and traditional healers (CWGHR, 2000; Worthington et al., 2005). AIDS service organizations and other community-based organizations often deliver recreation services such as dance, yoga, and exercise (CWGHR, 2000; McReynolds & Garske, 2001).

2.3 HIV as a Chronic Illness

Since the advent of ART in the mid-1990's the special status previously granted to HIV has been called into question in Canada given that HIV is no longer equated with a death sentence. Instead, in patients with regular access to ART, HIV is being viewed as a 'chronic illness' and is beginning to be grouped with other chronic conditions and illnesses such as diabetes, hypertension, cancer, and arthritis (Colvin, 2011). As with a number of other illnesses, HIV is experienced as a chronic episodic illness (O'Brien et al., 2008). That is, the level of disability associated with the experience of HIV varies over time, and as a result, a great deal of uncertainty is associated with the maintenance of health status among PHAs.

HIV Exceptionalism

Historically, HIV has been considered an 'exceptional disease' (Colvin, 2011) in that unlike other conditions, it has been associated with extreme social stigma, discrimination, violence, and rejection (Canadian AIDS Society, 2011; Canadian HIV/AIDS Legal Network, 2006). The concept of HIV/AIDS 'exceptionalism' stems from the belief that HIV was a unique health issue requiring a response beyond what other public health issues required and this in turn was seen as valid reasoning for drawing needed resources away from other significant health issues (Smith & Whiteside, 2010). In the early years of HIV such public health responses were, to an extent, accepted and expected (Lazzarini, 2001). As a result, health policies and approaches were developed that were—and still are—atypical of other illnesses. Further, specialized policies were developed with regard to informed consent in order to conduct testing, anonymous testing, and pre- and post-test counselling (Casarett & Lantos, 1998; Lazzarini, 2001). Recently criminalization of HIV for non-disclosure of one's HIV status has become an issue on the legal landscape (Canadian HIV/AIDS Legal Network, 2010). This exceptionalism has continued through to the present day and can be seen in the variety of HIV/AIDS-specific organizations, advocacy and awareness efforts, as well as targeted services within specific communities. However, a reframing of HIV as a chronic illness threatens the foundation of HIV-specific funding and the well-established network of HIV/AIDS community-based organizations, particularly as competition for limited resources increases. Further, this shift detracts from the historical rationale that previously secured 'exceptional' funding for an 'exceptional' disease. It is essential that funding for a continuum of care for PHAs, including rehabilitation services, is maintained in order to meet the complex needs of this population across the lifespan.

Decreasing Stigma: A Case for 'Normalization'

Among the perceived benefits of the shift toward HIV chronicity is the belief that the removal of the special status granted to HIV would lead to the positive consequence of 'normalization'. The suggestion being that through the reclassification of HIV as a chronic illness, a process of normalization will result and thereby help remove the lingering social stigma associated with HIV/AIDS (Lazzarini, 2001). Despite efforts to address current negative conceptualizations of HIV, social stigma and discrimination remain core issues in the shift to 'normalize' HIV as a chronic illness (Colvin, 2011).

2.4 HIV, Aging & Rehabilitation

As stated earlier, due to significant advances in the development and delivery of ART, individuals living with HIV are surviving longer, and these individuals are facing unique challenges to their health status as they age (Kirk & Goetz, 2009). For example, compared to non-HIV infected individuals 50 and older, older PHAs have a higher prevalence of hypertension, high levels of triglycerides, and lipodystrophy, suggesting that HIV treatment-related needs exceed ‘normal’ aging in the development of health problems (Onen et al., 2010).

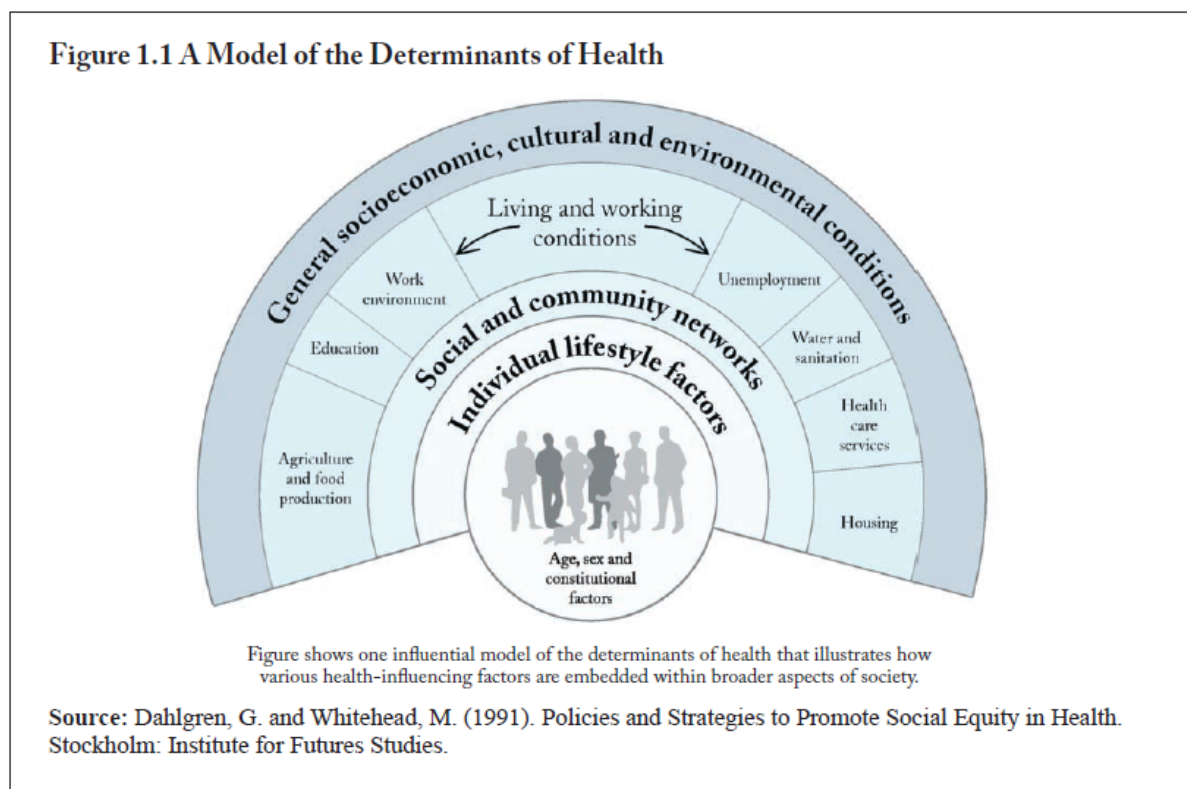
According to the Canadian Working Group on HIV and Rehabilitation (2010a), HIV and aging can be approached from two key conceptual frameworks: 1) the biological and physiological factors, and 2) to social-structural and gender factors associated with HIV and aging (CWGHR, 2010a). The majority of seniors in Canada have at least one chronic disease or condition, which may act as an impediment to individuals striving to achieve a certain quality of life, and which puts great cost on the health system (Public Health Agency of Canada, 2006).

Health Canada has defined healthy aging as “a lifelong process of optimizing opportunities for improving and preserving health and physical, social and mental wellness, independence, quality of life and enhancing successful life-course transitions” (Public Health Agency of Canada [PHAC], 2006, p. 12). This is in clear alignment with the 2005 definition of rehabilitation put forth by CWGHR, mentioned earlier, and rehabilitation services are well suited to address issues of ‘healthy aging’ both within the general population, and among PHAs. ‘Healthy aging’ can minimize or delay the severity of chronic diseases and disabilities in later life and is as a means of controlling costs, increasing health, and maintaining the autonomy of our ‘older’ citizens (PHAC, 2006). The complex relationship between ‘healthy aging’ and HIV infection is not always clear, and few studies have thoroughly addressed both (Kahana & Kahana, 2001; Vance & Robinson, 2004).

2.5 Determinants of Health

As suggested by Raphael (2010), the determinants of health recognize the importance of social, economic, and political factors—not simply individual level biological or genetic factors—in contributing to the health of individuals and of populations. While there are a variety of definitions of the determinants of health in existence, for the purposes of this research, we draw largely from the work of Dennis Raphael in framing the following sections. In alignment with the research questions that guided this research, the research team used the lens of determinants of health to assess variability in access to rehabilitation services by PHAs as evinced by the literature included in our scoping review. To that end, a number of care determinants were selected and are described in greater depth later in this section. It is important to note that determinants of health can include what are generally termed non-modifiable biological factors related to sex, age, and other genetic factors, as well as broader determinants of health, which constitute the socioeconomic, political, cultural and environmental context within which individuals live (Raphael, 2010).

Figure 1. A Model of the Determinants of Health (Dahlgren & Whitehead, 1991)



Although the above models are used extensively in policy development, they do not specifically address how determinants of health affect access to services for people living with HIV. For example, disability as a determinant of health is described as clearly related to physical and mental functions (Mikkonen & Raphael, 2010) and the primary issue is whether society is willing to support people with disabilities. For the purposes of this research, we have followed the recommendation of McGinn, Gahagan and Gibson (2005) to use a functional definition of disability, which according to the United Nations (UN), describes *disability as the result of the interaction between a person and his or her environment:*

'Disability' results from the interaction between persons with impairments, conditions or illnesses and the environmental and attitudinal barriers they face. Such impairments, conditions or illnesses may be permanent, temporary, intermittent or imputed, and include those that are physical, sensory, psychosocial, neurological, medical or intellectual (United Nations, 2006).

The use of 'attitudinal barriers' and reference to 'temporary, intermittent, or imputed' impairments make this definition particularly pertinent among PHAs who may experience HIV as a chronic episodic illness. As such, this research sought to identify factors that limit or encourage access to rehabilitation among PHAs and to determine the intersection of key determinants of health: age, gender, socio-economic status, social inclusion/exclusion, and health service providers as gatekeepers. These factors are well-known issues that can individually and collectively impact on the health outcomes of PHAs.

Age & Aging

Age plays an important role in the relationship between HIV and 'healthy aging', particularly as the demographics of HIV-infected individuals continues to shift. Being 'young-old', that is, being one of the younger participants grouped into the category of 'older' individuals, was the most common predictor of successful aging, according to Depp and Jeste (2006).

As a result of the increased effectiveness of ART, PHAs are no longer simply surviving with HIV, but are now living into their senior years (Casarett & Lantos, 1998). Along with the greater availability of ART in developed countries has come a reframing of HIV as 'living with HIV across the lifespan' (Colvin, 2011). The implications of aging with HIV and the issues related to healthy aging policies are discussed later in this report.

Gender

Gender, unlike the concept of biological sex, takes into consideration the ways in which social factors such as societal roles and expectations are differentially attributed to women and men (PHAC, 2010; Status of Women Canada, 1998). In terms of biological differences among Canadian women and men, women are more likely to experience arthritis and rheumatism, cataracts and glaucoma, and back problems (PHAC, 2006). However, Canadian men experience higher rates of heart disease, diabetes, cancer, the effects of stroke, and Alzheimer's and dementia (PHAC, 2006). Further, women and men living with HIV may experience differences in ease of access to rehabilitation services due in part to gender roles and expectations such as childcare responsibilities or the burden of earning a household income.

Socio-economic Status (SES)

Socio-economic status (SES) is well known as a determinant of health, but takes on special meaning when one considers the impact of SES on the health of PHAs. As the findings from this research suggest, HIV can create a financial roller coaster for PHAs due to the episodic nature of the disease and the difficulty this poses in, for example, working full-time and being able to access rehabilitation. In fact, the episodic nature of the disease may itself be considered a health determinant for many PHAs.

Social Inclusion/Exclusion

Again, this determinant of health takes on special meaning for PHAs due to the stigma and discrimination experienced. Many issues explored in this research relate to the impact of stigma and discrimination on access to rehabilitation, including as Kabeer suggests "...the multiple and overlapping nature of the disadvantages experienced by certain groups and categories of the population" (Kabeer, 2006, p. 65). According to Labonte (2002), "social exclusion describes the structures and dynamic processes of inequality among groups in society. Social exclusion refers to the inability of certain groups

or individuals to participate fully in Canadian life due to structural inequalities in access to social, economic, political and cultural resources” (p. 87).

Providers as Gatekeepers

While health services are considered an important determinant of health, this research specifically explored the role of health care providers as possible gatekeepers in access to rehabilitation among PHAs. This scoping review sought to establish whether lack of knowledge of the physical and psychological effects of an HIV diagnosis and lack of experience in exercising relevant clinical judgement were identified in the literature as a factor that impacts access to appropriate rehabilitation services for PHAs.

SECTION THREE

3.0 Methodology

Scoping studies are increasingly used across a range of disciplines (Anderson, Allen, Peckham, & Goodwin, 2008) and for myriad purposes. For example, Arksey and O'Malley (2005) identified four purposes for scoping studies, namely to examine depth, breadth, and nature of research activity; to determine the value of completing a more complete review; to synthesize and disseminate research findings; and to identify existing gaps in the body of literature. In their discussion of scoping methodology, Levac, Colquhoun and O'Brien (2010) revealed that no consistent or universal definition of a scoping study exists.

For the purpose of our scoping study, we employed the scoping literature search flow described by David, Drey and Gould (2009). Figure 2 shows Arksey and O'Malley's (2005) scoping review framework that was adopted for our research. Drawing on the work of Arksey and O'Malley (2005), David, Drey, and Gould (2009) provided a flow of literature search and selection that was relevant to our scoping study. Figure 3 reveals the flow of the scoping process as implemented in our research.

Figure 2. Arksey and O'Malley's (2005) Literature Scoping Framework

Stage 1	<i>Identifying the research questions:</i> Attention to which aspects of research questions are particularly important. Focus on maintaining breadth of approach to allow for maximum coverage of search area.
Stage 2	<i>Identifying relevant studies:</i> comprehensive search for primary studies and documents which answer research questions.
Stage 3	<i>Study selection:</i> Post hoc evaluation of found documents for relevance to research questions. Familiarity with found documents allows determination of relevance of documents.
Stage 4	<i>Charting the data:</i> Sorting, interpreting, shifting data according to key issues and themes and relevance to research questions.
Stage 5	<i>Collating, summarizing, and reporting results:</i> Use of consistent approach in reporting findings. Allows for comparison and identification of gaps in literature.
Stage 6	<i>Consultative exercise (Optional stage):</i> Stakeholders and practitioners participate in review of found documents to identify potential documents to include or sources of additional documents.

The following sections describe the methodology used to search for documents related to access to rehabilitation for PHAs in Canada and the UK.

3.1 Scan of the Literature and Initial Inclusion of Documents

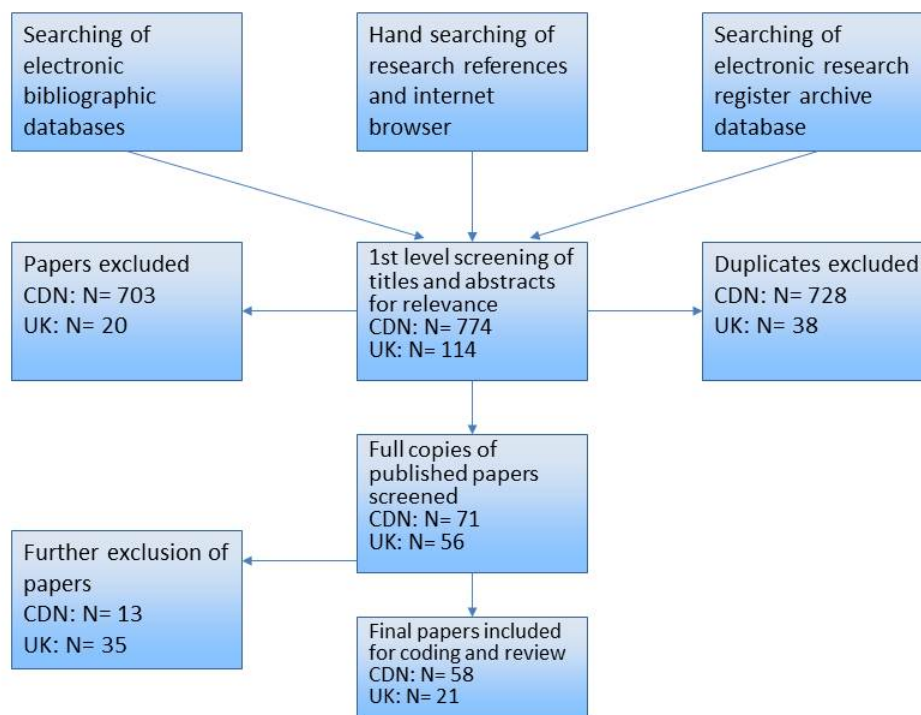
A comprehensive scoping scan of the literature was completed in alignment with the established research questions:

1. What are the strengths and gaps of HIV health rehabilitation policy evidenced in Canada and the UK with particular reference to access issues?
2. Do these policies take into consideration determinants of health, such as gender and SES?
3. If so, how?

The Canadian portion of our scoping efforts included searches of CINAHL, PubMed, MEDLINE, ERIC, PsycInfo, the Canadian Public Policy Collection (Canadian Electronic Library) and Cochrane Library for published policy documents related to rehabilitation service delivery, as well as grey literature on AIDS service organizations, non-governmental organizations, and discipline-specific professional organization websites including: Canadian AIDS Society, Canadian AIDS Treatment Information Exchange (CATIE), Ontario AIDS Bureau, Canadian HIV/AIDS Legal Network, Episodic Disability Network, British Columbia Coalition of People with Disabilities, Episodic Disability Employment Network (EDEN), Canadian Council on Rehabilitation and Work, AIDS Committee of Toronto, Positive Living BC, Canadian Working Group on HIV and Rehabilitation (CWGHR), AIDS New Brunswick, and the AIDS Coalition of Nova Scotia. Although useful for framing this study, professional association and government documents often lacked relevance to HIV and rehabilitation and were therefore excluded from the final analysis.

Our UK scoping efforts accessed the following sources and online resources: UKPubMed Central, British Medical Journal, National AIDS Trust (NAT), Terrence Higgins Trust, National Health Service Information Centre, UK Department of Health, Care Quality Commission, Chartered Society of Physiotherapy, British Association for Sexual Health & HIV (BASHH), British Association of Occupational Therapists and College of Occupational Therapists, Sexual Health Organizations Group (SHOG), National Institute for Health Research, Medical Research Council, Health Protection Agency, National Institute for Health and Clinical Excellence, Kings College London, NAM AIDSmap, Rehabilitation in HIV Association (RHIVA), British HIV Association (BHIVA), UK Consortium on AIDS and International Development, www.parliament.uk, and www.namlife.org. The following medical facility websites were also searched for relevant documents: Chelsea and Westminster Hospital, Barts and the London Hospital, and Mildmay Hospital. Noting the similarities between AIDS and other chronic and episodic diseases, our initial search included terms related to several of these diseases, as we were searching for novel policies and practices that could potentially be applied to HIV/AIDS. Figure 3, below, describes the flow of the scoping literature search.

Figure 3. Flow of Scoping Literature Search and Selection (Davis, Drey, & Gould, 2009)



Adapted from: Davis, K., Drey, N., and Gould, D. (2009). What are scoping studies? A review of nursing literature. *Intl. Journal of Nursing Studies*, 46, 1386-1400.

3.2 Study Selection

Using the stated search terms (see Appendix A), the Canadian portion of the scoping review yielded 774 documents, after excluding duplicates. Upon reviewing these documents, it was determined that, despite having used MeSH terms and discrete search terms, many documents were not germane to our research, did not contain our search terms, or did not meet our other search criteria. After consulting with research librarians at Dalhousie University, we determined that searches completed using website search engines, rather than the more robust search engines associated with research databases, are susceptible to the uniqueness of each particular website's search engine. These website-specific search engines are inherently less able to select materials related to the search terms entered. For this reason, a preliminary review of all found documents was completed by two research team members. In this cursory review, documents were excluded that held no relationship to the purpose of our research. This was determined by excluding documents that did not contain at least one of the search terms (see Appendix A).

A second and more robust review for relevance of the resultant 71 documents was completed by 2 research team members to further determine document inclusion and was subsequently confirmed by 5 team members. For the purposes of the Canadian scoping portion, we initially included search terms for several chronic diseases and episodic illnesses (see Appendix A) in an effort to capture novel and potential wise or novel practices from related illness and disease organizations. This process was not repeated for the UK scoping portion.

The process described above for the Canadian scoping portion was repeated for the UK portion of the scoping review. The initial search yielded 56 documents. The inclusion and exclusion criteria in this portion of the scoping review were modified toward more HIV-specific terms, and these terms were adopted as a means of streamlining the review for relevance following the initial UK search. After applying these modified inclusion/exclusion criteria, the number of documents was reduced to 21. For example, for the UK scoping portion, the following search terms were added to delimit sources and materials limited to the United Kingdom: 'British', 'UK', and 'United Kingdom'. Documents produced by UK organizations but which dealt exclusively with HIV in the context of the African continent were excluded. Further, a closer examination of documents uncovered using the terms "rehabilitation" and "rehab" revealed that in the UK these terms are most frequently used to refer to substance abuse and reintegration into society following a prison sentence.

3.3 Review and Coding of Documents

The study selection process reduced the number of included documents to 58 Canadian and 21 UK documents that discussed HIV/AIDS and/or rehabilitation issues relevant to HIV/AIDS. Included documents were added to a spreadsheet and initially categorized as to whether they were specific to HIV/AIDS and whether they pertained to access generally; employment and work factors; or traditional rehabilitation services (occupational therapy and physical therapy). The documents were read by pairs of researchers and categorized according to the following criteria, largely based on frameworks developed work by CWGHR:

Type of document

- Policy Review
- Research
- Framework
- Other

Rehabilitation Category

- Access to Rehab
- Employment-related Rehab
- Traditional Rehabilitation

HIV Specificity

- Specific to HIV
- Not Specific to HIV

In order to more specifically identify novel approaches (or lack thereof) and themes related to access, six “Themes of Access to Rehab” were constructed, based upon major themes extracted from the background literature and reassessed following the final selection of documents, in order to help direct the final REACH report (Raphael, 2010). Readers rated each article on the basis of whether the following were included as factors that influence access to rehabilitation.

Age & Access

Age Cut Off
Time since Diagnosis
Novel Ideas

Socio-economic Status (SES) & Access

Income Cut Off
Eligibility for Benefit
Novel Ideas

Gender & Access

Role Expectations
Caregiving
Novel Ideas

Social Inclusion/Exclusion

Stigma
Discrimination
Social Supports
Novel Ideas

Provider as Gatekeeper

Lack of Awareness of HIV
Clinical Judgment
Novel Ideas

Unpredictable Nature of HIV

Acute Episodic Health Status
Continuity of Benefits
Novel Ideas

Each of the “Themes of Access to Rehab” categories was ranked on a scale from 1 to 3 as outlined below:

1. Highly or somewhat featured: the topic was one of the main points of the article, and the impact of this factor on access was specifically discussed OR the topic was a factor, but not the main factor;
2. Peripherally featured or mentioned: the topic’s impact on access was mentioned but not explored in depth; or
3. Not mentioned at all.

In addition, the readers noted 'novelty of approach' in the notes section of the spreadsheet. Novel approaches were defined as potentially important frameworks and/or applications of policy related to HIV and rehabilitation.

Each article was read by two members of the core research team, after which the coding was compared. If there was a discrepancy among the coding, a third member read the article to achieve a consensus rating. In this way, inter-rater reliability was established. In a very few cases, discrepancies between readers who rated the documents a #1 and those who rated them a #2 were not resolved, and in these cases, a #2 coding was used, which is a conservative approach. This occurred for a very small percentage of the #2 codes. In addition, each reader became the point person in one of the following factors: Gender, SES, Age, and Provider, so that when questions arose in these areas, the point person resolved them.

3.4 Limitations & Scope

The scope of this paper was limited to documents focusing primarily on HIV or which were directly relevant to policies affecting PHAs who require access to rehabilitation. This approach was also used for literature addressing disability and chronic illness. This served to streamline the process as well as allowed the research team to clarify the purpose of the study.

No date range was specified in the scan for policy documents. The oldest document used for the scoping review was published in 1998, which is in alignment with the goal of this research to provide a current snapshot of the post-ART state of access to rehab for PHAs in Canada and the UK through a scoping review.

The search was restricted to English language documents dealing with Canada or the UK. Documents published in Canada or the UK by Canadian or British NGOs or policy organizations but which dealt with HIV/AIDS outside of Canada and the UK (i.e., Africa) fell outside of the scope of our research and were therefore excluded.

SECTION FOUR

4.0 Findings

The following section provides a summary of the finding of the scoping review and subsequent coding.

4.1 Numbers of Documents and General Areas Addressed

Table 2 presents a summary of the number of documents found for the UK and for Canada. Because broader search terms were used for Canada, more documents were found, and the average length of the documents tended to be longer because of a number of large government documents presenting overviews of policies. Related to the greater specificity of search terms used for the UK portion, 80.9% of the documents were specific to HIV, whereas in Canada the percentage was 45.9. However, fewer UK documents were specific to rehabilitation (14% for UK; 44% for Canada), which is likely due to the different definition of rehabilitation in the UK.

Table 2. Number of Documents per Country and General Characteristics

Country	Total Documents	Average # of pages	HIV Specific	Rehab Specific
Canada	58	54.4	25	24
UK	21	24.2	17	3

4.2 Types of Documents

Documents were categorized as to whether they addressed access, employment, or traditional rehabilitation. For access and employment, the two countries were similar: 48% of Canadian documents and 47.6% of the UK primarily addressed access. 25% of Canadian documents and 23.8% of UK documents primarily addressed employment. As might be expected from the difference in definition of rehabilitation, none of the UK documents primarily addressed traditional rehabilitation, although three documents did mention it.

In Canada, 44.8% of documents were primarily research documents, whereas 28.6% of the UK documents focused on research. Fifty percent of Canadian documents contained policy frameworks, compared to 4.7% of UK documents.

Table 3. Topics & Document Types

Country	Relevance	Classification Topic			Type of Article			
		Access	Employment	Traditional Rehabilitation	Policy Review	Research	Framework	Other
Canada	Primary	28	15	14	26	29	5	18
	Secondary	10	6	8	4	7	8	10
UK	Primary	10	5	0	6	8	1	8
	Secondary	5	5	3	3	3	5	5

4.3 Social Determinants of Health

Tables 4 through 9 present findings related to social determinants of health and access to rehabilitation. These tables present the number of documents in which these health determinants were a main feature (coding #1), were peripherally mentioned (coding #2), or not mentioned at all (coding #3).

Age

Table 4 presents the findings related to age and access to rehabilitation. Generally age and access was a main topic in only 8.6% of Canadian documents and 9.5% of UK documents. A cut-off age for access was a main topic in 2 Canadian documents and 1 UK document. Taking into consideration the #2 codes, age is addressed in more Canadian documents. Time since diagnosis as a factor for access was not a prevalent topic, as it was addressed or mentioned in only 15.5% of Canadian documents when including #1 and #2 coding. One novel idea related to this topic was found in the UK, and one was identified in a document from Canada.

Table 4. Number of Documents Addressing Age & Access

Country	Coding Score	Themes of Access to Rehab			
		Age & Access	Age Cut-Off for Access	Time since Diagnosis	Novel Ideas
Canada	1	5	2	0	0
	2	26	10	9	1
	3	27	46	49	57
UK	1	2	1	1	1
	2	2	0	3	0
	3	17	20	17	20

Socio-economic Status (SES)

Table 5 shows the coding for documents related to SES and access. We note that there is a contrast between Canada and the UK. More Canadian documents addressed SES and income cut-offs: 34.5% of Canadian documents addressed SES and access as a main feature, compared to 9.5% of UK documents. Income cut-offs were featured by 27.5% of Canadian documents and 9.5% of UK documents. Similarly, eligibility was addressed by 27.5% of Canadian documents and only 9.5% of UK documents. This may indicate that SES is more of an issue for PHAs in Canada, compared to those living in the UK. If one considers the #2 codes, the difference between Canada and the UK is even more marked. Five Canadian documents provided novel ideas for dealing with this issue, whereas none of the UK documents featured novel ideas.

Table 5. Number of Documents Addressing Socio-economic Status (SES) & Access

Country	Coding Score	Themes of Access to Rehab			
		SES & Access	Income Cut Off for Benefits	Eligibility for Benefits	Novel Ideas
Canada	1	20	11	16	5
	2	27	13	17	5
	3	11	34	25	48
UK	1	2	2	2	0
	2	8	0	3	1
	3	11	19	16	20

Gender and Access

Findings for gender and access are shown in Table 6. Gender and access were featured in 12% of Canadian documents and 9.5% of UK documents. Role expectations and caregiving were each featured in 3.4% of Canadian documents. UK documents showed 9.54% featuring role expectations and 4.7% featuring caregiving roles. Combining the #1 and #2 codes, 46.6% of Canadian documents and 28.5% of UK documents addressed gender. Because this topic was discussed in a minority of documents in both countries, this suggests that this topic has not been given sufficient consideration. This is especially

relevant in Canada where, in 2009, the Auditor General mandated the inclusion of gender-based analysis in all research projects (Auditor General of Canada, 2009). These numbers suggest the directive may not have been followed.

Table 6. Number of Documents Addressing Gender & Access

Country	Coding Score	Themes of Access to Rehab			
		Gender & Access	Role Expectations	Caregiving	Novel Ideas
Canada	1	7	2	2	0
	2	20	3	3	0
	3	31	53	53	58
UK	1	2	2	1	0
	2	4	2	1	1
	3	15	17	19	20

Social Inclusion/Exclusion

Social inclusion/exclusion appears to be more pertinent to UK documents than to Canadian documents, as shown in Table 7. In the UK, 47.6% of documents featured social inclusion/exclusion; 38% featured stigma, and 42.8% featured discrimination. In Canada, the comparable percentages are 15.5%, 8.6%, and 12%, respectively. When the #2 codes are included, 60% of Canadian, and 71% of UK documents addressed social inclusion/exclusion. The #2 codes bring the percentage of documents addressing stigma to 38% for Canadian and 62% for UK documents. Similarly, including #2 codes brings the percentage of documents addressing discrimination to 43% for Canada and 76% for the UK. This suggests these topics are being given attention and more specifically, this speaks to the importance of social inclusion/exclusion as factors affecting access to rehabilitation. Both countries are similar in terms of documents that featured social support: 5.2% in Canada and 4.8% in the UK. Five novel ideas related to this determinant were found in UK documents, and only one Canadian document featured novel ideas.

Table 7. Number of Documents Addressing Social Inclusion/Exclusion

Country	Coding Score	Themes of Access to Rehab				
		Social Inclusion/Exclusion				
		Social Inclusion/Exclusion	Stigma	Discrimination	Social Support	Novel Ideas
Canada	1	9	5	7	3	1
	2	26	17	18	17	6
	3	23	36	33	38	51
UK	1	10	8	9	1	5
	2	5	5	7	8	1
	3	6	8	5	12	15

Provider as Gatekeeper

Provider as gatekeeper (Table 8) may be a factor that has not been adequately considered. In Canada, 2 documents featured this factor, whereas none were found in the UK. Considering the #2 rated documents, provider as gatekeeper emerges as more of an issue in Canada, with 31% of documents featuring or mentioning it as a factor. Six documents were found that addressed lack of awareness of HIV/AIDS rehabilitation and inappropriate clinical judgment of practitioners as barriers to access to rehabilitation. Novel ideas included providing education on HIV/AIDS rehabilitation to practitioners.

Table 8. Number of Documents Addressing Provider as Gatekeeper

Country	Coding Score	Themes of Access to Rehab			
		Provider as Gatekeeper	Lack of Awareness	Clinical Judgement	Novel Ideas
Canada	1	2	0	0	3
	2	16	6	6	1
	3	40	52	52	54
UK	1	0	0	0	0
	2	6	7	5	4
	3	15	14	16	17

Unpredictable Nature of HIV/AIDS

Documents were also categorised as to whether they featured the unpredictable, episodic nature of HIV/AIDS as a factor in access to rehabilitation. Table 9 shows that this factor was featured in 13.8% of Canadian documents and 4.7% of UK documents. If the #2 codes are considered, 48% of Canadian and 43 % of UK documents are rated as featuring or mentioning this factor. Including the #2 codes, 45% of Canadian, and 38% of UK, documents feature or mention the acute episodic nature of HIV/AIDS as a factor in accessing rehabilitation. Thirty-four percent of Canadian documents feature or mention continuity of benefits as a factor. It appears that in Canada, the acute episodic nature of the disease and the continuity of benefits are fairly important factors in obtaining access to rehabilitation.

Table 9. Number of Documents Addressing Unpredictable Nature of HIV/AIDS

Country	Coding Score	Themes of Access to Rehab			
		Unpredictable Nature of HIV/AIDS			Novel Ideas
		Lack of Awareness	Acute Episodic Nature	Continuity of Benefits	
Canada	1	8	7	6	1
	2	20	19	14	3
	3	30	32	38	54
UK	1	1	2	0	1
	2	8	6	5	2
	3	12	13	16	18

4.4 Novel Policies and Approaches

Novel Ideas from the Canadian Scan

Fifty-eight documents were reviewed and coded for the Canada section of this scoping study. Thirty (51.7%) of these documents were coded as containing some degree of a novel idea(s), defined here as *potentially important frameworks and/or applications of policy related to, or which could be applied to HIV and rehabilitation*. Fifteen (25.9%) were documents that specifically addressed the topic of HIV and fifteen (25.9%) addressed themes related to the topics of investigation (i.e. rehabilitation, health policy, persons with disabilities, etc.).

This summary report highlights areas identified as novel in the HIV-relevant category and concludes with recommendations towards incorporating relevant novel ideas into our developing framework of healthy aging across the lifespan for persons with HIV.

Novel Ideas from HIV-Specific Documents

Models of rehabilitation and care relevant to HIV

Eight documents specifically identified frameworks and/or models of integrated care related to HIV, rehabilitation, and aging across the lifespan:

1. "HIV and Aging Final Report" (CWGHR, 2010a). Construction of models of integrated care related to HIV, aging and rehabilitation is identified as a priority activity.
2. "Saskatchewan's HIV Strategy" (2010-2014) (Saskatchewan Ministry of Health, 2010). A clinical management aim is articulated as the adoption of cross-disciplinary teams to provide a continuum of support to HIV-positive individuals, and to incorporate best practice plans and standardized protocols for enhanced case and clinical management of HIV.
3. "Force for Change: Labour Force Participation for People Living with HIV/AIDS" (Canadian AIDS Society, 1998). This report identifies HIV as amenable to the therapeutic principles and interventions of rehabilitation medicine, stating further that HIV symptoms can be treated with existing rehabilitation strategies already employed in the rehabilitation of people living with other disabilities such as cardiac disease, etc.
4. "Rehabilitation in HIV/AIDS: Development of an Expanded Conceptual Framework" (Worthington et al., 2005). Key informants were used to create a framework for rehabilitation and HIV that is goal oriented and client centered (the perspective of the person with HIV should be the foundation). The framework includes a) roles of rehabilitation professionals; b) barriers to access; and c) delivery.
5. "Exploring Disability from the Perspective of Adults Living with HIV/AIDS: Development of a Conceptual Framework" (O'Brien et al., 2008). This report provides the "episodic disability framework" which takes into consideration the variable aspect of disability, including uncertainty and life events that may trigger a major episode.
6. "Scoping the Field: Identifying Key Research Priorities in HIV and Rehabilitation" (O'Brien, Wilkins, & Zack, 2008). This report contains a framework for research priorities for HIV and

rehabilitation with core themes centered on living with HIV across the lifespan, disability, and access to services.

7. "Final Report: Rehabilitation Services for People with HIV/AIDS" (Myers et al., 2003). This report provides two novel research findings:
 - a. An HIV conceptual research framework resulted in domains describing physical, social, and vocational features of life with HIV (chronicity = increased disability)
 - b. Persons with HIV/AIDs are wide users of complementary and alternative therapies – sometimes to remediate effects of HAART. This feature can be of use in developing a model of HIV, rehab and healthy aging across the lifespan.
8. "HIV as an Episodic Illness: Revising the CPP(D) Program" (The Canadian AIDS Society & CWGHR, 2003). This report recommends expanding the criteria for HIV-related disability towards the encouragement of persons with HIV to remain in the workforce, albeit in a different capacity.

Building Provider Communities

Three documents contained novel ideas related to the education and training of multidisciplinary health professionals who could take part in new treatment/care frameworks that holistically address the range of health and rehabilitation needs of persons with HIV.

1. "An Interprofessional, Problem-Based Learning Course on Rehabilitation Issues for Persons with HIV" (Solomon, Salvatori, & Guenter, 2003). This report details study results of a problem-based learning course on rehabilitation issues in HIV taught within the context of the reclassification of HIV as a manageable chronic illness. The course resulted in improvement in collaborative practice, which could be key part of any framework addressing HIV, rehab and healthy aging.
2. "Policy issues on rehabilitation in the context of HIV disease: A background and position paper" (CWGHR, 2000). This report recommends the education of primary health providers about the advantages of early rehabilitation intervention and to provide guidance towards making appropriate referrals.
3. "Barriers and facilitators to participation in work among Canadian women living with HIV/AIDS." (Barkey, Watanabe, Solomon, & Wilkins, 2009). This report presents the idea that rehabilitation professionals (particularly occupational therapists) play a role in enabling women with HIV to enhance their work performance.

Vocational/Income Issues

Four documents contained novel ideas related to employment and income retention for persons with HIV.

1. "Back to Work: Vocational Issues and Strategies for Canadians living with HIV AIDS" (McGinn, Gahagan, & Gibson, 2005). This report references the US Trial Work Program as a model to ensure income supports.
2. "Volunteering by People Living with HIV/AIDS or a Major Chronic Disease: Issues and Challenges: A Research Report" (Samson, 2006). This study was conducted within the known importance of work (connection to the outside world, structure) for persons with HIV. It suggests non-HIV service organizations become educated around HIV issues and recruit volunteer workers that are HIV-positive.

3. "Navigating the Maze: Improving Coordination and Integration of Disability Income...HIV/AIDS: A Discussion Paper" (Stapleton & Tweddle, 2008). This report offers a breakdown of coverage for disability and employment policies for persons with HIV by province and suggests coordination of benefits at different levels of government
4. "Final Report for the Labour Force Participation and Social Inclusion for People Living with HIV and other Episodic Disabilities" (CWGHR, 2007). This report contains an extensive framework entitled "A strategy for policy change: Addressing return to/stay at work incentives."

Novel ideas from selected non HIV-Specific documents

1. "Sickness, Disability and Work: Breaking the Barriers: A Synthesis of Findings across OECD Countries" (Organisation for Economic Co-operation and Development, 2010). This report suggests a "one-stop shop" for disbursing both federal and provincial benefits.
2. "Chronic Conditions and co-morbidity among residents of British Columbia" (Broemeling, Watson, & Black, 2005). The article references the "chronic care model" which emphasizes the combination of measures in an integrated approach to chronic disease management and calls for recognition of co-morbidity within the planning and organizing of health services.
3. "Removing Barriers to Work: Flexible Employment for People with Disabilities in BC" (Cohen et al., 2008). Multiple policy recommendations are set forth, including: 1) increasing the amount of money people can earn while still receiving crucial benefits; 2) increasing funding for supportive employment programs; 3) improving communications on policies that are already in place but not widely known about.

Novel Ideas from the UK Document Review

Twenty-one documents were reviewed and coded for the UK part of the scoping study. Seventeen (81%) were directly related to HIV and four (19%) were not. Of the HIV-related documents thirteen were coded as having novel ideas. The categories for the novel ideas are somewhat different from the categories for the Canada documents above. This is because the bulk of the UK documents were more directly related to HIV and rehabilitation than the Canada documents.

Novel Ideas in HIV-related documents

Social Inclusion/The Importance of HIV Supportive Environments

1. "Positive Nation: The UK's HIV and Sexual Health Magazine" (Positive Nation, 2011). This magazine was coded as novel for two reasons:
 - a) A series of first-person essays speak to the importance of HIV service organizations as places for persons with HIV to go when they are despondent and/or suicidal. This is important to understand as the potential defunding of HIV service organizations will eliminate these safe spaces; and
 - b) "Talking Points" an online tool for people with HIV to help individuals with HIV prepare for appointment and help them make informed decisions about treatment.
2. "Social Exclusion and HIV: A Report" (Policy Campaigns and Research Division, 2001). This report recommends (p. 17) the establishment of a cross-departmental coordinating mechanism to

oversee legislative and other changes to combat HIV-related social exclusion at the government level.

Vocational/Income issues

1. "HIV in the Workplace" (University and College Union, 2009). Page 2 references the "social model of disability" that shifts the focus away from people's impairments towards removing the barriers that disabled people face in everyday life."
2. "NAT Parliamentary Briefing: The Welfare Reform Bill" (National AIDS Trust, 2012). This report details the impact of novel approaches to disability.
3. "HIV – Taking the Plunge" (NAM, 2011). This paper describes a series of steps to follow to minimize issues associated with returning to work and living with HIV.

Managing HIV through the lens of the experience of other chronic illness

1. "Young People Living with HIV and the Transition from Children to Adult Services" (Howell & Hamblin, 2011). An entire section, beginning on page 11, details parallels of the experience of transitions by young people with other chronic illness and/or disabilities with recommendations for holistic approaches. This can be a framework for constructing a model for healthy aging for adult persons with HIV.

Broadening HIV healthcare practice/frameworks for episodic disability

1. "Blueprint for the Future: Modernising HIV & Sexual Health Services" (Policy and Public Affairs Division, 2004). Recommendations include a) the establishment of HIV outpatient departments attached to GP services; b) an increased range of self-management approaches (p. 14-15).
2. "Government Response to the House of Lords Report..."(Secretary of State for Health by Command of Her Majesty, 2011). This report references the development of the new Sexual Health Policy Framework and lists on p. 21 innovative ways to deliver HIV services.
3. "Five Steps to Better Sexual Health ..." (Association of Directors of Public Health & Terrence Higgins Trust, 2008). This report lists HIV policy frameworks throughout the countries of the UK. Additionally, it recommends outpatient HIV care through specialist nurse services and integration of health and social services for those with the greatest need.
4. "Principles of Physical and Cognitive Rehabilitation in HIV Disease" (Chegwidden et al., 2010). There is a reference to development of the "Episodic Disability Framework" on page 4, shown in the appendices on p. 28-29.
5. "Fluctuating Symptoms of HIV" (National AIDS Trust, 2011). Recommendations are made on page 21 related to benefit programs and changes to assessment criteria for accessing social care.

Addressing the mental health needs of persons with HIV

1. "Standards for Psychological Support for Adults Living with HIV" (British Psychological Society, British HIV Association, & Medical Foundation for AIDS & Sexual Health, 2011). This paper recommends relevant issues related to rehab and HIV including HIV sensitive care, required

competencies and pathways of care, among others. Additionally, a model of “stepped care” (p. 23) can be adapted to HIV rehabilitation services from psychological services.

2. “Help when You’re Troubled: Getting the Right Psychological Support” (Cairns, 2011). This report advocates for a “stepped care” model as a new means of approaching psychological support for persons with HIV. Essentially the model is built from the foundation of having all healthcare professionals complete basic training in the psychological aspects of HIV.

Potentially relevant novel findings from non HIV-specific documents:

1. “Then and Now: Disability Legislation and Employers Practices in the UK” (Woodhams & Corby, 2007). Study results here indicate that employers within large organizations and the public sector are more likely to hire disabled persons.
2. “Disability Rights and Mental Health in the UK” (Sayce & Boardman, 2008). This report references the 2005 amendments to the Disability Discrimination Act extended to cover persons with HIV (p. 267). This provides examples of what steps an employer may have to take in this context.
3. “What do Mental Health Rehabilitation Services Do and What are They For? A National Survey in England” (Killaspy, Harden, Holloway, & King, 2005). An expansive definition of rehabilitation is given (p. 163): “A whole system approach to recovery from mental ill health which maximizes an individual’s quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the future which leads to successful community living through appropriate support.”

4.5 Summary of Findings

A realistic model of HIV, rehabilitation and healthy aging will do well to take into account the novel and promising ideas presented in the documents summarized above. Specifically, policies and programs that have already been suggested and/or implemented include:

- Rehabilitation and care
 - *Education for health and human resource professionals*
 - *Integrated care/coordinated service provision models*
 - *Using rehabilitation models from other diseases with HIV/AIDS patients*
 - *Integration and utilization of complementary and alternative care modalities*
- Building multidisciplinary and well-informed provider communities
 - *Education for health and human resource professionals*
 - *Integrated care/coordinated services*
- Models of rehabilitation/Broadening HIV health care practice
 - *Using rehabilitation models from other diseases with HIV/AIDS patients*
 - *Integration and utilization of complementary and alternative care modalities*
- Addressing the mental health needs of persons with HIV across the lifespan
 - *Education for health and human resource professionals*

- *Integrated care/coordinated service provision models*
 - *Promotion of mental health and psychological well-being*
- The maintenance of employment and income/Addressing disability in the workplace
 - *Coordinated disability benefits frameworks*
 - *Flexible work/disability arrangements to allow for the episodic nature of HIV/AIDS*
- Social inclusion and the importance of HIV supportive environments
 - *Emphasis on reducing stigma and discrimination*
 - *Education for health and human resource professionals*

SECTION FIVE

5.0 Conclusions

For the purpose of this research, we conducted an extensive scoping review of articles and reports from Canada and the UK related to HIV, disability, aging, and the concept of ‘chronic illness.’ We discovered that researchers, providers, and policy makers are generally aware of how the trajectory of HIV/AIDS has shifted from a life threatening condition towards an illness with features of manageable chronic illness. However, little is known about how this new illness trajectory fits into and/or merges with established models of treatment and supports for persons with other chronic illnesses characterized by episodic disability. This lack of experience and knowledge highlights possible areas of potential inequities related to the reclassification of HIV as an illness being on par with such illnesses as diabetes, hypertension, cancer, and arthritis. Specifically, we remain concerned with how historical issues such as stigma, discrimination, and the need for cultural competence in treatment settings will continue to be recognized and accounted for within new models of treatment and care for persons with HIV across the lifespan. This concern is the foundation for the development of appropriate policy and rehabilitation models of care that will necessitate evolving dimensions of training and awareness by a full range of stakeholders. No single continuum of care or set of policies that addressed each of our core ‘themes of access’ was discovered, though this study indicated that the UK uses a more cohesive and integrated approach to providing care to PHAs than that which is utilized in Canada.

There is good news as we take steps to develop new approaches towards the integration of HIV into established models of care. In addition to identifying a lack of knowledge and expertise, this scoping study also identified a plethora of novel ideas based on the insight and experience of researchers, health providers and policy makers. This category, which emerged from our research, provides both theoretical and conceptual frameworks of embrative and integrated models of care, as well as strategies and new paradigms related to the ongoing training and education of providers. These frameworks, ideas, and strategies are the basis upon which we have made our recommendations towards the urgent next steps related to policy and service delivery in the context of HIV as a ‘manageable chronic illness’ across the lifespan.

5.1 Further Research Needed

Based on the findings of our research, a number of recommendations for future research were identified, including:

- Research on further developing and evaluating specific policy interventions, particularly in relation to access to rehabilitation services, in consultation with policy and programming stakeholders;
- Research on examining the impact of the categorization of HIV as a chronic illness on access to care, policymaking, and clinical practice as it related to PHAs;

- Research on developing ‘healthy aging’ health promotion strategies aimed at health care providers working with PHAs across the lifespan and through integrated continua of care; and
- Case studies that explore the context of access issues identified from the perspective of PHAs.

Our findings suggest there is much to be gained by establishing a greater research presence within emerging, multi-disciplinary settings organized to educate providers about the distinct economic, social and political factors that impact the lives of PHAs across the lifespan. Determining integrated treatment policies related to the inclusion of PHAs within established models of care for persons with chronic, episodic illness through consensus building should be further examined and evaluated. As part of this process, diverse stakeholders can provide input into how their own clinical and service backgrounds impact—and are impacted by—the process of building new policy and provider frameworks to better meet this needs of PHAs. Specific research into ‘healthy aging’ strategies for PHAs may help to mitigate some of the issues related to living and aging with a chronic, episodic illness, and would be a welcome acknowledgement of the unique needs of PHAs and their care providers.

Finally, a case study approach can provide additional contextual data that speak to actual experiences of PHAs as they attempt to navigate new landscapes of service delivery informed by the policies used to determine eligibility and access. To this end, qualitative, ethnographic research approaches that aim to capture the day-to-day lived experiences of PHAs—in their own words—can be of great importance in understanding the ways in which rehabilitation policies and practices help or hinder the health outcomes of PHAs. It may be of great interest, for example, to evaluate the effectiveness of policies and programs stemming from integrated, single-point-of-entry service delivery arrangements and other emerging models of care that are responsive to the needs of PHAs within the broader chronic disease framework.

APPENDICES

Appendix A. Search Terms and Results

Search Terms	Subsort	Documents
"HIV" and "rehabilitation"		341
	"HIV-positive persons"	10
	"HIV Infections	26
	AIDS (Disease)	25
"Chronic" and "illness"		1502
	Chronic disease	15
"Chronic" and "illness" and "policy"		1444
	Health Policy	56
"HIV" and "rehabilitation" and "policy"		333
	HIV infections	24
	Law and legislation	15
"Return to work" and "HIV"		39
	Services for	6
	HIV Infections	5
"Episodic" and "disability" and "policy"		163
	Government policy	19
	Health policy	10
"Episodic" and "disability"		165
	People with disabilities	11
	Government policy	19
	AIDS (Disease)	4
	HIV infections	8
"Multiple Sclerosis" and "Rehabilitation" and "Policy"		76
	Employment	4
	Government Policy	10
	Services for	9
	People with Disabilities	11
"Diabetes" and "Rehabilitation" and "Policy"		430
	Government Policy	50
	Services for	37
	Health Policy	26
"Crohn's" and "Rehabilitation" and "Policy"		4

"Arthritis" and Rehabilitation"		199
	Health Services	13
	Accessibility	
"Arthritis" and "Rehabilitation" and "Policy"		185
	Health Policy	10
	Government Policy	17
	Health Services	18

Appendix B. List of Documents Reviewed and Coded

Canada:

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