A Snapshot of Programs, Services and Partnerships to Address Mental Health and Aging in the Context of Disability and Chronic Disease in Canada

Submitted to the Canadian Working Group on HIV and Rehabilitation (CWGHR)

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Introduction and background to the project

Community-based AIDS service organizations (ASOs) and other health and social service organizations across Canada provide programs and services to meet the needs of people living with HIV. Sometimes organizations work alone but more often they work in partnership. Increasingly, these organizations must address the needs of people living with HIV who are older (50 years or older) and those with mental health conditions. Key informants, surveys and evaluations have suggested to the Canadian Working Group on HIV and Rehabilitation (CWGHR) that service providers are looking for information, skills, resources and program models to better meet these needs. Working from a pan-disease approach, CWGHR commissioned a scan of organizations outside of the HIV sector to identify programs, services and partnership models for consideration and potential adaptation within the HIV sector.

Focus on aging and mental health in HIV

Advances in medical treatments and technologies mean that many diseases are no longer imminently fatal, and disabling symptoms can often be reduced, managed or delayed through the use of effective rehabilitation. HIV infection is one such disease. As a result of widespread access to effective combination HIV antiretroviral medications, the HIV epidemic in Canada is "greying." The number of people growing older with HIV is increasing. In addition, the proportion of new HIV diagnoses in people 50 years old or older is increasing. For many people in the developed world, living with HIV means living with a chronic, at times manageable, infection. However, living with HIV often means dealing with long-term or chronic illness and episodic health problems.

Among those aging with HIV in North America and Europe, the presence of more than one life-threatening chronic health condition (known as multimorbidity) is the norm (Justice & Braithwaite 2012). Older adults living long-term with HIV and on antiretroviral treatment experience a range of comorbid medical conditions: cardiovascular disease, hypertension, kidney disease, liver disease, diseases affecting the central nervous system, bone disease, diabetes, depression, chronic obstructive pulmonary disease, and non-AIDS-associated cancers (Greene et al 2013; Justice & Braithwaite 2012). These comorbidities may be related to HIV infection, pre-existing conditions, the effects of traditional risk factors or the effects of antiretroviral therapy (Greene et al 2013; Justice & Braithwaite 2012). These chronic health conditions have been associated with lower self-reported physical, social and mental health functioning (Greene et al 2013). Polypharmacy, defined as taking five or more medications on an ongoing basis poses a health risk for older people living with HIV and comorbidities. Older people living with HIV may also suffer diminished quality of life related to substance use, poor mental health, social isolation, and stigmatization from health care providers and society at large (High et al 2012). Comorbidity has been identified as a stronger predictor of diminishing physical function and disability than age, regardless of HIV status. The frequency of multimorbidity will grow as people living with HIV age (Justice & Braithwaite 2012).

That said, the biomedical focus of research on HIV and aging may overemphasize disease among older people living with HIV. In recent research involving over 1100 older people living with HIV in Ontario, nearly 80% of participants reported their health as excellent or good (Brennan et al 2013). The same study also suggests that older gay and bisexual men enjoy better mental health-related quality of life, and report lower levels of depression and maladaptive coping than older heterosexual men and women.

Mental health is another important concern for people living with HIV and those who provide services to them. Across diagnostic categories, rates of mental health conditions among people living with HIV are

substantially higher than in the general population (Husbands et al 2012). Elevated rates of mental health problems among people living with HIV may reflect elevated rates of mental disorder in populations most vulnerable to HIV, and are similar to rates observed for other people with chronic or life-threatening illness (Husbands et al 2012). Overall, there is a lack of systematically collected and published data about mental health issues for people living with HIV in Canada (Dingwall 2008; Husbands et al 2012). In the literature from high-income countries, mental health in the context of HIV is not consistently defined. However, a number of mental health conditions have been associated with living with HIV or risk for acquiring HIV infection, including depression, anxiety, post-traumatic stress disorder (PTSD), and substance use. In Canada and internationally, depression has been recognized as a primary health concern among people living with or vulnerable to HIV, with some studies showing rates as high as 50% (Husbands et al 2012; WHO 2008; Williams et al 2005). Depression among people living with HIV has consistently been found to be predictive of worse quality of life, non-adherence to HIV antiretroviral therapy, disease progression, and reduced survival time (Blashill 2011). Social constructs such as stress, interpersonal violence, stigma, shame and poor perception of body image have also been related to poor health outcomes for people living with HIV (Blashill 2011). People living with HIV who are mentally healthy (or have access to mental health support) have a greater capacity to adhere to treatment which lowers their viral load. This, in turn, improves their health and decreases the risk of HIV transmission (Horn 2011).

Data gathered in 2008 found that 80% of British Columbians living with HIV/AIDS and the hepatitis C virus (HCV) accessing services from an ASO experienced a mental health disorder, yet this group of people were much less likely to access mental health services than the general population (Dingwall 2008; Dingwall 2009). Often front-line ASO workers, rehabilitation professionals and other clinical staff who are the most likely to encounter people living with mental health issues are the least likely to have training on mental health interventions (CWGHR 2012).

A pan-disease approach

The number of people living with chronic and episodic medical conditions, the number of organizations serving these communities and the costs associated with chronic illness in Canada are staggering (Mirolla 2004). Chronic disease prevention and management has become an important focus of health policy and health care delivery and is reflected in a growing number of programs and services. Addressing complex chronic illnesses from an integrated pan-disease approach - and using a collaborative rehabilitation strategy across disease groups - can result in increased expertise, reciprocal learning and comprehensive approaches to prevention, care, treatment and support.

Using an integrated pan-disease approach, a search was conducted for programs, services and partnerships delivered by organizations in the non-profit disability and health charities sectors that respond to one of two needs: (1) the needs of people *aging* with disabilities and chronic health conditions; or (2) the needs of people living with physical disabilities and chronic health conditions who also experience *mental health conditions*. Models from outside the HIV sector were the focus. The objective was to document these programs, services and partnerships so that decision-makers within the HIV sector could consider them for possible adaption. The information in this report will also be of interest to those outside the HIV sector who serve populations who are older or who have mental health needs.

The first section of the report describes the methods used. The second section provides a summary and overview of findings. The third and fourth sections describe programs, services and partnerships in the

health charities and chronic disease service sectors which are focused on mental health or aging, respectively. The fifth section provides examples of chronic disease management and self-management programs. The sixth section examines the models of partnership revealed in the programs and services documented. The seventh section briefly examines evidence-based programming and processes for program adaptation. Program details are set out in Appendix A (mental health), B (older adults) and C (health promotion and chronic disease management).

Taking a snapshot

In the spring of 2013, a two-fold approach was used to scan the non-profit disability and health charities sector for programs, services and partnerships that focused on *aging* or *mental health* in the context of disability and chronic disease in Canada. First, key informants in CWGHR's networks of partners established over the past decade and a half working on episodic and cross-disability issues were contacted by email and phone. These key informants were asked to identify programs, services and partnerships involving their organizations (or other organizations, if they were aware of these) and to provide us with program-related information and documentation.

Second, the websites of a wide variety of disability and health charity organizations in Canada at the national, regional and local/chapter levels were searched. Materials searched included organizational newsletters and publications. When a program, service or partnership of interest was identified, the person most responsible for the program or service was contacted by email or phone to request further information and documentation.

Stand-alone publications were not considered to be programs or services; however, links to a selection of publications (e.g., brochures, factsheets, booklets) that focus on aging and mental health in the context of disability and chronic disease are included in this report. Programs and services offered by the formal health care/clinical sector, public health authorities, Local Health Integration Networks (LHINs) and academic institutions were considered to be outside the scope of this scan.

Community-based organizations in the non-profit disability and health charities sectors that address a wide range of disabilities and chronic medical conditions, including arthritis, asthma, breast cancer, diabetes, Crohn's disease and colitis, epilepsy, hemophilia, liver disease and hepatitis, kidney disease, lung disease, mental health and mood disorders, and multiple sclerosis (MS) were contacted. Contact was also made with a small number of disability organizations that focus on specific populations (e.g., women) or provide specific types of programming (e.g., workforce).

Where a program of interest was identified, the following information was documented:

- Program name, organization and most responsible person's contact information
- Program goal
- Information regarding program development
    - Evidence base
    - Theoretical framework
- Program details
    - Start date – end date
    - Funding source
    - Target audience
    - Partners
    - Geographic location/scope of delivery
    - Activities
- Evaluation activities

- Additional information

The scan of programs, services and partnerships was supplemented with a targeted web search and a targeted search of the peer-reviewed and grey literature. The searches focused on: mental health and aging among people living with HIV; chronic disease management and prevention; and program adaptation and fidelity. These searches were not exhaustive but were intended to provide background and context to the programs, services and partnerships revealed by the scan.

Summary and overview of findings

Based on the national scan, a small number of programs and services *specifically designed* to address the needs of people living with mental health conditions *in addition to* chronic physical conditions were identified and documented. These programs are presented below in the section, "Focusing on mental health needs" and in Appendix A.

Numerous more general programs or services that *touched upon* aspects of mental health were also identified. Many organizations within the broader Canadian disability and health charities sector offer peer support programs or support groups, which are presumably intended to promote physical and mental health, but the apparent focus of this peer support (individual or group) is not explicitly mental health. Many organizations also offer general education sessions or workshops that cover mental health issues, including depression, as part of their curriculum or content. These workshops are usually offered at the chapter or local levels to assist people who are newly diagnosed with a chronic medical condition, as primers (i.e., "101"s), or to assist people with changing specific behaviours (e.g., nutrition) or with managing specific aspects of disease (e.g., pain management).

Although it was beyond the scope of the project to scan ASOs and other community organizations serving people living with HIV, it is our general perception that many offer individual and/or group support programs, including peer-based programming, similar to that offered beyond the HIV sector.

As previously mentioned, numerous "one-off" educational sessions or workshops offered or advertised through organizations' local chapters were identified. Some of these addressed emotional health or depression (e.g., a teleconference on fear of recurrence of breast cancer; writing workshop). These "one-off" educational sessions or workshops were not documented as thoroughly since they did not appear to be well-developed programs, services or partnerships. Moreover, this 'workshopping' approach may reflect what is already taking place within the HIV sector. A number of programs and services databases were identified through further research. The interventions listed in these databases might also be adapted to address the mental health needs of people living with HIV in Canada.

A small number of programs and services specifically designed to meet the needs of older people living with disabilities or chronic medical conditions were identified. These programs are presented in the section, "Focusing on the needs of older adults" and in Appendix B. One organization (The Arthritis Society) stated that "[a]rthritis is a life-long disease so many participants in our programs are older." This organization offers a chronic pain self-management program which we categorized as a chronic disease management program and thus we included it in the corresponding section of the report. Two organizations (Epilepsy Toronto; Canadian Mental Health Association - Ontario) are beginning to develop programming for seniors or older adults. There are few well-articulated, evidence-based programs and services for older adults with chronic illnesses outside the HIV sector so there are limited options when it comes to adapting these for people aging with HIV. Organizations in the chronic disease sector may wish to consider working in partnership to address the needs of older adults living with comorbid conditions and/or individuals living with different illnesses which pose similar types of health and social challenges.

Numerous organizations within the disability and health charities sector are relying on health promotion and chronic disease prevention and management (including self-management) programs to address the needs of older adults and others with long-term, chronic health conditions. This is not surprising given that provincial health ministries and other bodies and organizations with a stake in health care delivery are also focusing on chronic disease prevention and management. One of the strengths of this approach is its potential to integrate responses to both physical and mental health concerns. Numerous chronic

disease prevention and (self-) management programs from Canada were identified. Several service providers also referred to programs developed by Stanford University in California. On-line sources of information on evidence-based health promotion and chronic disease management programs were identified, these programs and resources are presented in the section "Health promotion and chronic disease management" and in Appendix C.

Given that HIV is a life-long condition, decision-makers in the HIV sector may want to consider the merits of explicitly adopting a health promotion and chronic disease management approach to programs and services for people living with HIV. Among older people living with HIV and long-term survivors, HIV infection is characterized by multimorbidity, polypharmacy, and often a diminished quality of life related to substance use, poor mental health, social isolation, and stigmatization. The Patient Education Resource Center at Stanford University School of Medicine currently offers an HIV self-management program, in addition to a number of other programs that might be of benefit to older people living with HIV and/or people living with mental health issues.

Within the HIV sector, regional, provincial and national organizations may be able to play an important role in catalyzing the consideration and selection of health promotion and chronic disease self-management programs. Tasks undertaken by these organizations may include proposal-writing and securing funding, facilitating training for front-line service providers, assisting with the logistics of program delivery, supporting evaluation and assisting with reporting requirements. CWGHR might consider an additional scan of health promotion and chronic disease management and self-management programs, with a view to informing those within the HIV sector and beyond. People living with other chronic medical conditions experience some of the same comorbidities and symptoms as do people living with HIV, including diabetes, cardiovascular disease, chronic pain, and frailty. Moreover, elevated rates of depression affect not only those living with HIV, but also people living with other chronic physical disabilities and health conditions. These shared concerns could form the basis of partnerships to develop or adapt and deliver chronic disease (self-) management programs and services across disease groups.

The wide range of partnership models that existed across the programs and services documented is described in detail in the report appendices. There was no predominant model of partnership being used. Some partnerships involved national organizations working with national organizations, others principally brought together provincial organizations, and others combined provincial and local/regional organizations. Most partnerships were tailored to bring together the expertise, skills, and networks necessary to achieve the goals of the program or service. Programs and services that focused on delivering evidence-based interventions or on rigorous evaluation usually included researchers, often from a university or research institution. Two programs led by the Canadian Mental Health Association, Ontario (CMHA Ontario) were documented, both of which brought together partners from various sectors. Insights regarding partnership development and maintenance might be gained from these sample programs.

The principal goal of this scan was to document programs, services and partnerships from beyond the HIV sector which decision-makers might consider adapting for use within the HIV sector. According to most health promotion literature, evidence-based programming is the starting point for program adaptation. This is especially important if fidelity is to be maintained when the original program is adapted. This report sets out some considerations and tools for thinking about program adaptation. While a few of the programs and services documented had a well-articulated evidence base or a recognizable theoretical framework, many did not. Similarly, few programs and services were rigorously evaluated such that they could be described as 'proven' effective or evidence-based (i.e., rigorously-

collected evidence existed to prove that they achieved their goals), with the exception of a number of the chronic disease (self-) management programs documented. Nonetheless, adaptation considerations and tools articulated in the literature might help inform program planning and development within the HIV sector. The accumulated wisdom and experience of front-line service providers, peers, volunteers, and clients are additional sources of "evidence" that often play a central role in program development and delivery. Community-based organizations might rely upon their accumulated wisdom and experience to modify the adaptation process itself to better meet their needs and resources. As such, the distinction between 'acceptable' and 'unacceptable' program adaptations could be considered more of a guide rather than a prescription.

Scan participants expressed a significant amount of interest in the project, especially those people who were in the initial stages of planning programming for older adults. Respondents were interested in the rationale behind the scan as well as its findings and how these might inform their work. CWGHR is pleased to be sharing the information from the scan with those people and organizations that contributed to it. A number of organizations specifically identified a desire to continue discussions and share experiences and best practices (Epilepsy Toronto; MS Society Ontario), or were open to considering partnerships to adapt existing programs (The Arthritis Society's *Chronic Pain Management Workshop*[1]).

This scan has some limitations. As is the case within the HIV sector, programs and services in the broader disability and health charities sector are often delivered, and partnerships formed, at the local level. Staff at the national or regional/provincial level might not be aware of the programs being delivered locally. Although the websites and newsletters of provincial/regional organizations and their chapters were explored, all relevant programs and services may not have been identified. (Of interest however, was the fact that a number of organizations (Ontario Division of the Kidney Foundation of Canada; Ontario Division of Multiple Sclerosis Society of Canada) appear to be making an effort to achieve better alignment of programming, or improve aspects of program delivery and evaluation, across the province or nationally.) An additional limitation was the search strategy used. Many of the programs and services known to CWGHR's key informants were Ontario-based since many contacts, including those who work for national organizations, are based there. As a result, the scan may be somewhat Ontario-centric.

[1] The Arthritis Society programs (Arthritis Self-Management Program; Chronic Pain Management Workshop) are open to people living with HIV who would benefit from them. Personal correspondence with Lynne Moore, Director of Programs and Services.

Focusing on mental health needs

Programs and services

The scan revealed a small number of programs and services focused on the mental health needs of people living with a physical disability or a chronic physical condition, or that addressed both mental and physical disabilities and medical conditions:

- *Managing Diabetes with Mental Health Issues or Addictions Research Partnership* (Canadian Diabetes Association and Centre de santé communautaire de Grand Sudbury). This northern Ontario program was a university-community-health service sector research partnership. The goals were: 1) to create a knowledge base from which to develop programs that promote better management of diabetes for individuals with mental health and addictions issues; and 2) to inform policy.

- *The KIDNEY CONNECT Peer Support Program* (The Kidney Foundation of Canada). This national program provides one-on-one peer support to anyone affected by kidney disease - people living with kidney disease, their families and allies, and people considering kidney donation. In addition, in some locations, monthly or bi-monthly support groups are also offered. This program was modelled after a similar program from the cancer sector.

- *Work With Us* (Mood Disorders Society of Canada and The Arthritis Society).[2] This national, bilingual, three-year program is just getting underway. It is a workplace-based program that will support Canadians living with depression and/or arthritis by giving them tools to actively self-manage, lead healthier lives and fully engage in work. It will also seek to increase workplace awareness while decreasing the stigma associated with mood disorders and arthritis. This bilingual program will be available across Canada and will target employees living with depression and/or arthritis, their colleagues and employers.

- *Connect Counselling Program* (Canadian Hearing Society). Through this program, people who are deaf or hard of hearing and their families can access professional mental health counselling at no charge. Counselling is provided in American Sign Language (ASL), la langue des signes québécoise (LSQ) or with the assistance of captioning or amplification technologies.

These programs are documented in detail in "Appendix A - Programs and services focusing on mental health."

The Kidney Foundation of Canada, Ontario Division is currently reviewing its approach to programs and services, with a focus on mental health and health promotion. They are considering embarking upon greater collaboration with community organizations and agencies (particularly those with a focus on serving ethno-cultural populations and seniors) and other health charities (for example, heart and stroke, diabetes). These partnerships would likely focus on promoting wellness and community engagement, rather than on illness/disease. The Ontario Division has a mental health working group which will provide advice on planning and implementing this new direction.

[2] While this program explicitly uses self-management approaches, we have included it in this section because it focuses on a physical condition plus a mental health condition and will also focus on changing workplace attitudes and environments.

In addition to the programs listed above, a number of publications related to the mental health needs of people living with a disability or chronic medical condition were identified:

- Canadian Breast Cancer Network (2010). *Never Too Young: Psychosocial Information and Support for Young Women with Breast Cancer*.[3]
- The Kidney Foundation of Canada (2010). *Dealing with Depression*.[4]

Considerations for the HIV sector

This scan found a limited number of programs *specifically designed* to respond to the mental health needs of people with physical disabilities or chronic physical conditions. Numerous programs or services that *touched upon* aspects of mental health were identified. The scan revealed that many organizations within the broader Canadian disability and health charities sector offer peer support programs or support groups. These are presumably intended to promote physical and mental health, but such peer support interventions (individual or group) do not seem to focus explicitly on mental health.

Many organizations also offer education sessions or workshops that include information on mental health issues, including depression, as part of their curriculum or content. These predominantly single-session workshops are usually offered at the chapter or local level to assist people who are newly diagnosed with a chronic medical condition, as primers (i.e., "101"s), or to assist people with behaviour change (e.g., nutrition) or coping skills (e.g., pain management). Although it was beyond the scope of the project to scan ASOs and other community organizations serving people living with HIV, it is our general perception that many such organizations offer individual and group support programs, including peer-based programming.

Numerous "one-off" education sessions or workshops were offered or advertised through organizations' local chapters, some of which addressed emotional health or depression (e.g., teleconference on fear of recurrence of breast cancer; writing workshop). These "one-off" education sessions or workshops were not documented since they did not appear to be well-developed programs or services, and may reflect what is already taking place within the HIV sector.

Programs and services to address prevalent mental health needs among people living with HIV have been identified elsewhere. A recent analysis of systematic literature reviews focused on, among other program and services, mental health interventions to support people living with HIV/AIDS by Wilson and colleagues might serve as a starting point for identifying such programs (Wilson et al 2013). This analysis found that, "[t]he highest quality reviews with a focus on mental health evidence suggest that cognitive behavioural interventions (including group therapy) were effective at improving symptoms of depression, anxiety and stress (but not immune functioning)" (Wilson et al 2013, p.1620). One limitation of this research was that it only included programs existing before April 2009. Those within the HIV sector interested in updated information might consider requesting it from the Ontario HIV Treatment Network's Rapid Response Service[5], managed by Michael Wilson, the article's lead author. In the "Health promotion and chronic disease management" section of the report, below, additional sources of examples of evidence-based programs and services, some of which might be adapted to meet the mental health needs of people living with HIV, are identified.

[3] www.cbcn.ca/documents/never_too_young_handbook_en.pdf, accessed 1 July 2013.

[4] www.kidney.ca/document.doc?id=826, accessed 1 July 2013.

[5] www.ohtn.on.ca/pages/knowledge-exchange/rapid-response-service.aspx, accessed 5 July 2013.

Focusing on the needs of older adults

Programs and services

Based on this scan, it appears that organizations are meeting the needs of older adults living with mental and physical health conditions (permanent, episodic or progressive) largely by delivering health promotion and chronic disease prevention and management programs, including self-management programs. For example, two key informants told us that their programs served mostly older adults since the physical conditions they targeted (i.e., chronic obstructive pulmonary disease; arthritis) disproportionately affect older adults. Programs described by these key informants (from The Arthritis Society and The Lung Association) are included in the next section of the report. This scan revealed four programs that focused *explicitly and specifically* on the needs of older adults with disabilities and chronic health conditions:

- *Aging with a Bleeding Disorder* (Hemophilia Ontario, Central West Ontario Region). This was a pilot of a full-day educational workshop developed and delivered by the Central West Ontario Region of Hemophilia Ontario. The goal of the workshop was to equip the aging population and their caregivers with the knowledge and tools to optimize health for older people with inherited bleeding disorders.

- *Chance for Choice* (Ottawa-Carlton Citizen Advocacy). This program pairs volunteer advocates with older adults living with disabilities who are isolated or vulnerable. The goal is to establish long-term supportive relationships which foster social engagement, self-care and autonomous decision-making by older adults with disabilities. Volunteers are also well positioned to identify health and social problems quickly enabling them to be addressed in a timely manner.

- *Hearing Care Counselling for Ages 55+* (Canadian Hearing Society). This program provides information and skills-building supports for older adults (age 55+) who are experiencing hearing loss. The program is designed to help individuals maximize their ability to communicate, engage socially, and remain safe and independent.

- *VON SMART* (Seniors Maintaining Active Roles Together). An evidence-based functional fitness initiative for older adults (age 55+) comprised of volunteer-led group fitness classes and in-home exercise support for individuals who face barriers attending other community-based physical activity programs. The program serves many participants who are living with comorbid chronic illnesses, especially through the in-home program. The program has undergone multiple evaluations (e.g., outcomes, sustainability), and program documentation includes a leading practice start-up and implementation guide.[6] *Note: The MS Society, Ontario Division is entering into an agreement with VON (Victorian Order of Nurses) Canada to adapt the existing VON Canada SMART Program for people living with multiple sclerosis.*

These programs are documented in detail in "Appendix B—Programs and services focusing on older adults."

Two organizations told us that they are starting the process of developing programming for seniors or older adults. As part of its program development process, CMHA Ontario will seek out and review

[6] For more information on the *VON Canada SMART Program*, go to http://www.von.ca/en/special_projects/senior_exercise.aspx.

programs from other jurisdictions to identify best practices. The key informant mentioned, as examples, an older adult adaptation of the CMHA British Columbia division program *Living Life to the Full*[7], and a program developed by an Australian organization to assist older adults with mental health issues like depression.[8] CMHA Ontario has already conducted policy analysis regarding seniors' mental health (CMHA Ontario 2010; CMHA Ontario & Canadian Pensioners Concerned Inc, 2012). The second organization, Epilepsy Toronto, has recently received funding to develop programs for seniors and is currently in the "research and development" stage. This stage will include speaking with seniors about their experiences of living with seizures/epilepsy.

In addition to the program listed above, a number of publications intended to meet the needs of older people living with a disability or chronic medical condition were identified:

- Edmonton Epilepsy Association (2011). *Seniors and Epilepsy*.[9]
- Open Policy Ontario (undated). *Planning for Retirement on a Low Income*.[10]

Considerations for the HIV sector

There are few well-articulated, evidence-based programs and services for older adults with chronic illnesses outside the HIV sector so there are limited options when it comes to adapting these for people aging with HIV. However, there may be opportunities to address the needs of older adults living with chronic and/or episodic illness by building partnerships which include organizations serving people with different illnesses. Program planners within the HIV sector might want to consider for adaptation more broadly focused chronic disease prevention and management (including self-management) programs given that HIV infection tends to present among older adults as a chronic illness characterized by multimorbidity, polypharmacy and frailty. This presentation - especially when it intersects with substance use, poor mental health, social isolation, or stigmatization - can result in diminished quality of life. Chronic disease prevention and management programs, including self-management programs, are addressed in detail in the next section of the report. It is worth considering whether these programs might effectively address the needs of older adults living with HIV.

[7] *Living Life to the Full* is an 8-week interactive course that introduces five topic areas related to cognitive behavioural therapy. Each session of 1.5 hours is expertly moderated and includes a booklet. Participants are taught how to deal with their feelings when fed up, worried, or hopeless, and learn skills that help them tackle life's problems. For more information, go to http://www.llttf.ca

[8] The *beyondblue Older Adults* program works to improve the mental health of older Australians by raising awareness of depression and anxiety and overcoming barriers to care within the context of the needs of an ageing population. For more information, go to www.beyondblue.org.au/about-us/programs/older-adults-program

[9] www.epilepsymatters.com/english/pamphlets/seniorsandepilepsy.pdf, accessed 1 July 2013.

[10] http://openpolicyontario.com/wordpress/wp-content/uploads/2012/09/allinonelowincomeretirement.pdf, accessed 1 July 2013.

Health promotion and chronic disease management

The number of people living with chronic and episodic medical conditions and the number of organizations which serve these communities in Canada is staggering. Chronic disease prevention and (self-) management has become an important focus of health policy and health care delivery, and more and more programs and services are adopting this approach. Numerous provinces have developed chronic disease prevention and management strategies and/or chronic disease self-management programs.[11] This scan of the disability and health charities sector revealed both policy analysis and programming related to health promotion and chronic disease (self-) management.

Managing coexisting mental and physical conditions: policy directions

CMHA Ontario has examined mental health and chronic disease management in a number of policy documents:

- Canadian Mental Health Association, Ontario (2008). *The Relationship between Mental Health, Mental Illness and Chronic Physical Conditions: Backgrounder*
- Canadian Mental Health Association, Ontario (2008). *What is the Fit Between Mental Health, Mental Illness and Ontario's Approach to Chronic Disease Prevention and Management?: Discussion Paper*
- Canadian Mental Health Association, Ontario (2008). *Recommendations for Preventing and Managing Co-Existing Chronic Physical Conditions and Mental Illness: Position Paper*
- Canadian Mental Health Association, Ontario (2009). *Diabetes and Serious Mental Illness: Future Directions for Ontario*

These documents were intended to respond to the Province of Ontario's adoption of a framework for managing and preventing chronic disease.[12] In *Recommendations for Preventing and Managing Co-Existing Chronic Physical Conditions and Mental Illness*, CMHA Ontario supports the integration of physical and mental health programming based on established associations between physical conditions and mental illness (at page 1):

> One of the strengths of the CDPM [chronic disease prevention and management] approach is its potential for integrating physical and mental health care. This is particularly of value in improving the physical health care of people with serious mental illnesses, a population whose physical health is often poor and who are at high risk of developing diabetes and heart disease. In addition, there has been considerable research on addressing depression as a chronic condition. People with chronic physical

[11] See, for example: Alberta Health Services (2012). *Targeted Chronic Disease Prevention and Management Approaches for Diverse and Vulnerable Populations in Alberta—A patient-Centred care Framework and Action plan for Alberta*, http://www.albertahealthservices.ca/hp/if-hp-ed-cdm-gen-div-prov-frame-diverse-vuln-pop.pdf; New Brunswick Department of Health (2010). *A Chronic Disease Prevention and Management Framework for New Brunswick*; Newfoundland and Labrador Department of Health and Community Services (2011). *Improving Health Together: A Policy Framework for Chronic Disease Prevention and Management in Newfoundland and Labrador*, http://www.gnb.ca/0051/pub/pdf/2010/6960e-final.pdf; *Self-Management British Columbia*, www.selfmanagementbc.ca; *Your Way to Wellness* (Nova Scotia) http://yourway2wellness.gov.ns.ca.

[12] Ontario Ministry of Health and Long-Term Care (2007). *Preventing and Managing Chronic Disease: Ontario's Framework*. www.health.gov.on.ca/en/pro/programs/cdpm/pdf/framework_full.pdf, accessed 1 July 2013.

conditions are at risk of depression, and the CDPM model appears to have the potential to improve screening and management of depression in people with chronic physical conditions.

While further discussion is clearly needed, the health system has already begun to move towards improving the management of chronic physical conditions through a CDPM approach. CMHA Ontario believes it is important that action begin immediately to address co-existing chronic physical conditions and mental illnesses, and there is clear evidence to support some health system changes that would begin to do so.

The document outlines 13 recommendations to address co-existing chronic physical and mental health conditions, in two areas: (1) preventing and managing chronic physical conditions in people with serious mental illnesses; and (2) preventing, screening and treating depression in people with chronic physical conditions. The recommendations are directed to the Ontario Ministry of Health and Long-Term Care, the Ministry of Health Promotion, the Local Health Integration Networks (LHINs), public health units, mental health service providers and other health care professionals in Ontario.

Programs and services

CMHA Ontario's policy analysis has informed two recent programs which are focused on diet and physical activity/exercise, important pillars of chronic disease self-management for people with serious mental illness given their elevated risk of diabetes and heart disease. The Arthritis Society, The Lung Association (Ontario and Canada) and several chapters/divisions of the Multiple Sclerosis Society of Canada have also developed chronic disease self-management programs and services:

- *Diabetes and Mental Health Peer Support Project* (Canadian Mental Health Association, Ontario). CMHA Ontario collaborated with a number of established provincial stakeholders on a comprehensive two-year project that provided diabetes competency training to mental health peer support workers. The project had two goals: 1) to increase the capacity of mental health peer support workers to provide support for the prevention and self-management of diabetes in the high-risk population of people living with a serious mental illness; 2) to increase awareness in the diabetes community about the role mental health peer support workers can play in prevention and self-management support.

- *Minding Our Bodies—healthy eating and physical activity for mental health* (Canadian Mental Health Association, Ontario). The goal of this program was to increase capacity within the community mental health system in Ontario to promote physical activity and healthy eating for people with serious mental illness.

- *Chronic Pain Management Workshop* (The Arthritis Society). The main objective of this two-hour workshop is to improve understanding of chronic pain management, introduce different coping methods, and encourage people to take an active role in pain management. The workshop is loosely based on the *Arthritis Self Management Program* developed by the Stanford University School of Medicine, Patient Education Research Center.

- *BreathWorks™* (The Lung Association, National). BreathWorks™ is The Lung Association's national chronic obstructive pulmonary disease (COPD) self-management and support

program. The program offers practical information and support for people with COPD and for their families and caregivers, delivered by professionally certified COPD Educators. It combines a website, a free and confidential helpline staffed by COPD Educators and print resources like factsheets and brochures. In Ontario, the BreathWorks™ program is complemented by volunteer-led support groups.

- *Exercise Maintenance and Support Group Pilot Program* (Ontario Lung Association). This project pilot-tested a community-based supervised exercise maintenance program and monthly support group for people with lung disease, including COPD. The goal was to reduce symptoms and restore quality of life. The Ontario Lung Association partnered with the Abilities Centre, an International Centre of Excellence that serves local, national, and international communities by providing resources and research tools that promote inclusivity and accessibility.

- *Adapted Yoga Program* (Multiple Sclerosis Society of Canada, Hamilton Chapter). Participants in this mental- and physical- health promotion program attend either seated or modified standing yoga classes once per week. The goals are: to reduce stress; and to improve strength, flexibility and balance. The in-person program can be replaced or supplemented by the use of an adapted yoga DVD produced by the MS Society with funding from the Ontario Ministry of Health Promotion.

- *Circle of Wellness* (Multiple Sclerosis Society of Canada, Ottawa Chapter). Originally offered in partnership with the Ottawa Hospital Rehabilitation Centre, this six- to eight-week group wellness series is designed to help participants maximize their quality of life while living with a chronic condition and responding to significant life changes. Participants are empowered to set their own wellness goals for the program. Mental, physical and social well-being are addressed. The program was informed by clinical practice guidelines on fatigue in people living with MS. Participants evaluate their experience after each session, at the end of the series, and at 3 and 6 months post completion.

- *Building Bridges to Better Health* (Multiple Sclerosis Society of Canada, Hamilton Chapter). A no-cost chronic disease self-management program comprised of weekly workshops and a workbook, delivered in partnership with Saint Elizabeth Health Care. The aim is to support participants living with any chronic illness as they develop personal action plans and skills for day-to-day management of their condition. This series was described as being similar to the *Taking Charge* programs offered by the Local Health Integration Networks in Ontario in that it takes a cross-disability approach.

- *MACcess Fitness* (Multiple Sclerosis Society of Canada, Hamilton Chapter). This evidence-based adapted exercise program for people living with multiple sclerosis is delivered in partnership with McMaster University's MacWheelers Exercise Program (for people living with spinal cord injuries). Once per week, skilled trainers and volunteers guide participants through either seated for modified standing aerobic and resistance exercises. The goal is to increase flexibility, balance, endurance, cardiovascular fitness and strength.

- *MAC H^2OPE* (YMCA Hamilton/Burlington/Brantford, McMaster University School of Rehabilitation Science, Hamilton Health Sciences). Through this program, people living with chronic conditions who are in financial need and/or have no health insurance coverage can

access free community-based physiotherapy and occupational therapy services. Services, including home assessments and exercise plans, are provided by students in a supervised environment.

- *MS Active NOW* (Multiple Sclerosis Society of Canada, Alberta and Northwest Territories Division). This research-informed program targets both people living with MS and professionals working in fitness and health care environments. It endeavors to increase access to physical activity for people with MS by: 1) increasing awareness of the value of exercise among those living with the condition; and 2) building the capacity of exercise trainers to develop specialized exercise programs for clients living with MS. As well as helping participants cope with an existing chronic illness, this program aims to decrease the risk of inactivity-related comorbidities among participants. Many resources are available online to support all stakeholders.

These programs are documented in detail in "Appendix C—Health promotion and chronic disease management programs."

In addition to those outlined above, the London-Middlesex chapter of the MS Society has offered *Living a Healthy Life with Chronic Conditions*, a six-week course delivered in partnership with the South West Community Care Access Centre and South West Local Health Integration Network. The Quebec Division of the MS Society offers the *Journey to Wellness* program through multiple chapters. This program consists of nine weekly 2- hour sessions. The program addresses six aspects of health: physical, emotional, intellectual, professional, spiritual and social. Specific topics include: adopting a lifestyle focused on well-being; the role of food and exercise; ways to become an enlightened consumer of healthcare; intellectual stimulation and treatment of cognitive problems; exploration of feelings related to having a chronic illness; employment, volunteer and recreational activities; spiritual health; and healthy relationships. According to the key informant from the Ontario Division of the MS Society who brought these programs to our attention, they are based on programs developed by the Patient Education Resource Center at Stanford University School of Medicine. Stanford's programs will be discussed in the next subsection of the report.

As noted above, The Kidney Foundation of Canada, Ontario Division is currently reviewing its approach to programs and services, with a view to shift programs to focus more on mental health and health promotion. The review and new program approach is being informed by health promotion standards and best practices, theories of behaviour change, and community development strategy.[13] Behaviour change involves supporting the uptake of disease prevention behaviours (eating healthily, exercising regularly), disease management behaviours (eating a renal diet, complying with treatments), and fostering community engagement (volunteer, donate). The essential components of long-term chronic disease self-management have been identified as access to health care, exercise and active living, nutrition and eating well, mental health and coping skills and social inclusion.

This search for aging and mental health programs identified a number of additional publications by Canadian health charities focused on aspects of chronic disease management:

[13] A Chapman, *Programs and Public Policy Department: Shaping Our Future*. Presentation delivered to The Kidney Foundation of Canada, Ontario Branch 2013 AGM & Leadership Conference, May 2013. On file with author.

- The Arthritis Society (undated). *Think Ahead: How to manage pain and fatigue*.[14]
- The Kidney Foundation of Canada, Canadian Diabetes Association, Multiple Sclerosis Society of Canada Manitoba Division, The Arthritis Society (2002). *A Roadmap For Living Well with Chronic Disease in Manitoba*.[15]

Stanford University's evidence-based self-management programs

We were pointed toward the Patient Education Resource Center at Stanford University's School of Medicine by The Arthritis Society, which currently delivers, under license, Stanford's *Arthritis Self-Management Program* using Arthritis Society peer-volunteers trained at the Stanford Center. It also appears that programs delivered by MS chapters, alone or in partnership, are based on Stanford Center programs. The Stanford Center develops, tests and evaluates self-management programs for people with chronic health problems.[16] The Center has designed its evidence-based programs to be delivered as small group workshops in the community or, in the case of selected programs, via the Internet. Each program is tested for effectiveness with randomized, controlled trials funded by research grants that span two to five years. The results of these studies are usually published in peer reviewed journals. The aim of all programs is to improve the physical and emotional health of participants while reducing health care costs. Community workshops are delivered in organizations licensed to deliver the programs, by leaders who have received training at the Center.[17] Workshops are highly interactive and focus on building skills, sharing experiences, and support.

The Stanford Patient Education Resource Center currently offers the following community-delivered programs:

- *The Chronic Disease Self-Management Program*
- *The Positive Self-Management Program for HIV (PSMP)*
- *The Arthritis Self-Management (Self-Help) Program*
- *The Diabetes Self-Management Program*
- *The Chronic Pain Self-Management Program*

The *Chronic Disease*, *Arthritis* and *Diabetes* programs are also offered via the Internet. Some of the programs are available in Spanish. The Center is currently recruiting participants for a mailed version of the *Chronic Disease Self-Management Program*, with funding from the US Centers for Disease Control and Prevention.

The *Positive Self-Management Program for HIV* is a seven-week program (weekly sessions are two and a half hours long), designed for delivery in community settings such as senior centers, churches, libraries and hospitals. Two trained leaders, one or both of whom are non-health professionals living with HIV,

[14] www.arthritis.ca/document.doc?id=424, accessed 1 July 2013.

[15] http://mssociety.ca/manitoba/pdf/Creating%20Balance.pdf, accessed 1 July 2013.

[16] For more information on the Patient Education Resource Center at Stanford University School of Medicine, go to http://patienteducation.stanford.edu.

[17] Licences are valid for three years. Single program licence fees, including leader trainings, start at USD $500. Multiple program licence fees, including four leader trainings, start at USD $1000. Fee reductions are available. Full information about licensing fees is available at http://patienteducation.stanford.edu/licensing/licfees.html.

facilitate the workshop. Topics addressed in the workshop are: (1) how to best integrate medication regimens into daily life to promote adherence; (2) techniques to deal with problems such as frustration, fear, fatigue, pain and isolation; (3) appropriate exercises for maintaining and improving strength, flexibility, and endurance; (4) communicating effectively with family, friends, and health professionals; (5) nutrition; (6) evaluating symptoms; (7) advanced directives; and (8) how to evaluate new or alternative treatments. The program is available in English, Spanish, and Japanese.

Best practice collections

The Public Health Agency of Canada has developed an on-line platform, the Canadian Best Practices Portal.[18] The Portal provides resources and solutions for promoting health and preventing disease, bringing together multiple sources of trusted and credible information. The Best Practices Intervention Section of the Portal is a searchable database of chronic disease prevention and health promotion interventions intended to provide program planners and public health practitioners access to public health programs, interventions and policies that have been evaluated and have the potential to be adapted for use. Community-based organizations and facilities are one of the intended audiences for the Best Practices Interventions.

The Canadian Best Practices Portal defines "best practices" as follows:

> Best practices are interventions, programs/services, strategies, or policies which have demonstrated desired changes through the use of appropriate well documented research or evaluation methodologies. They have demonstrated, through multiple implementations, the ability to be replicated and the potential to be adapted and transferred. A best practice is one that is most suitable given the available evidence and particular situation or context.
>
> In the context of population health/health promotion, such practices are used to demonstrate what works for enhancing the health status and health-related outcomes of individuals and communities, and to accumulate and apply knowledge about how and why they work in different situations and contexts.

All interventions included in the collection use a community-based or population health approach. To date, 336 interventions have been added to the collection. Disease prevention interventions currently in the collection address asthma, cancer, cardiovascular disease, stroke, chronic respiratory disease, diabetes, and integrated chronic disease prevention. The chronic conditions addressed in the interventions include hypertension, obesity prevention and metabolic syndrome. Relevant health promotion programs include harm reduction, healthy eating, mental health and physical safety. Interventions address a range of populations, including adults (age 35-49), older adults (50-69) and seniors (age 70+), men and women, and ethnic and Aboriginal populations.

The Best Practice Intervention collection includes one HIV-specific intervention, *The CHANGES Project: Coping Effectiveness Training for HIV+ Gay Men*.[19] A number of other interventions may be also be relevant to older people living with HIV or people living with HIV and mental health issues. Here is a selection:

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[18] The PHAC Canadian Best Practices Portal can be accessed via http://cbpp-pcpe.phac-aspc.gc.ca.

[19] http://66.240.150.14/intervention/686/view-eng.html, accessed 27 June 2013.

- *Community-based Screening for Depression and Suicide*[20]
- *Mental Health First Aid Canada*[21]
- *Promoting Adult Resilience*[22]
- *Senior Health and Physical Exercise (SHAPE) Project*[23]
- *Behaviour Change Program to Increase Physical Activity*[24]

The US federal government's Substance Abuse and Mental Health Services Administration has also developed a database of evidence-based programs and practices. The National Registry of Evidence-based Programs and Practices (NREPP) is a searchable online database of mental health and substance abuse interventions.[25] All interventions have met minimum requirements for review and have been independently assessed and rated for research quality and readiness for dissemination.

Considerations for the HIV sector

For people in Canada who have access to effective antiretroviral therapy, HIV infection is now a chronic, episodic illness. The health promotion programs and chronic disease prevention and (self-) management programs documented via this scan tend to be theoretically informed, evidence-based and have an established process and material to support program implementation and evaluation. Beyond those programs specifically identified, there appear to be a number of Canadian and international resources related to health promotion programs and chronic disease prevention and (self-) management programs.

Following the lead of CMHA Ontario, The Arthritis Society, The Lung Association, and Multiple Sclerosis Society of Canada, community-based organizations in the HIV sector might want to consider the "fit" between HIV and chronic disease prevention and self-management, both at the policy level and when considering programming to meet client needs. HIV organizations might want to consider whether existing evidence-based chronic disease prevention and (self-) management programs and services can meet the needs of people living with HIV, including older people living with HIV and those living with mental health issues. There appears to be a range of programs that might be appropriate, whether delivered "as is" or with adaptations. Such programs could be adapted and delivered by the HIV sector alone, or potentially in partnership with organizations beyond the HIV sector. Partnerships may increase access to financial and human resources may make new programs available more widely to all those people who could benefit from them. Within the HIV sector, regional, provincial and national organizations may be able to play an important role as catalysts for the consideration and selection of health promotion and chronic disease self-management programs. Roles might include: proposal-writing; securing funding; facilitating program provider training; assisting with the logistics of program delivery; supporting evaluation processes; and assisting with reporting. CWGHR might also consider undertaking an additional environmental scan focused specifically on health promotion and chronic

[20] http://66.240.150.14/intervention/779/view-eng.html, accessed 27 June 2013.

[21] http://66.240.150.14/intervention/824/view-eng.html, accessed 27 June 2013.

[22] http://66.240.150.14/intervention/752/view-eng.html, accessed 27 June 2013.

[23] http://66.240.150.14/intervention/657/view-eng.html, accessed 27 June 2013.

[24] http://66.240.150.14/intervention/741/view-eng.html, accessed 27 June 2013.

[25] The National Registry of Evidence-based Programs and Practices can be accessed at www.nrepp.samhsa.gov.

disease management and self-management programs, with a view to informing those within the HIV sector and beyond.

Focusing on partnerships

A wide range of partnerships existed across the programs and services documented by this scan. There was no predominant model of partnership being used. Some partnerships involved national organizations working with national organizations, others principally brought together provincial organizations, and others combined provincial and local/regional organizations. Programs and services partnerships focused on delivering and evaluating evidence-based programs usually included researchers, often from a university setting. Most partnerships were tailored to bring together the expertise, skills and networks necessary to achieve the goals of the program or service.

Two programs led by CMHA Ontario were documented, both of which brought together partners from various sectors.

- *Diabetes and Mental Health Peer Support Project*: Ontario Peer Development Initiative (OPDI), Christine Grace and Community, Lawson Health Research Institute, and the Provincial Consumer/Survivor LHIN Leads Network (PCSLL). With funding from the Lawson Foundation.

- *Minding Our Bodies—healthy eating and physical activity for mental health*. This project had a steering committee and an advisory committee. The steering committee included: Echo—Improving Women's Health in Ontario, Mood Disorders Association of Ontario, Nutrition Resource Centre, YMCA Ontario, and York University's Faculty of Health. The Advisory Committee included representation from: Parks and Recreation Ontario, Ontario Physical and Health Educators Association, Schizophrenia Association of Ontario, Ontario Public Health Association (Heart Health Resource Centre; Nutrition Resource Centre), Canadian Diabetes Association, and Heart and Stroke Foundation of Ontario. With funding from the Ontario Ministry of Health Promotion and Sport.

The Director of Knowledge Transfer at CMHA Ontario provided insight into the development, functioning and lessons learned from the above project partnerships. He highlighted the following important factors:

> Begin early and build on existing work: Partnerships were often initiated early on in the project, with steering committee partners joining in the funding application process. For example, in planning the *Diabetes and Mental Health Peer Support Project*, OPDI was the recognized provincial voice of consumers/survivors. CMHA Ontario and the OPDI co-wrote the funding application which built on OPDI's successful peer training and support program. When determining who should be invited to join the partnership, focus on the task or role that the individual or organization can best perform (e.g. program knowledge and expertise, leadership and influence, evaluation, student placements).
>
> Leverage networks and personal connections: Being actively involved on an ongoing basis in a "network of networks" is crucial to partnership development. Many CMHA Ontario partnerships were the result of personal or organizational connections, built by taking advantage of opportunities to attend and present at conferences, teach and lecture in academic settings, and participate in networks. CMHA Ontario relied upon the Ontario Chronic Disease Prevention

Alliance[26], of which it is a member, to help identify partners for *Minding Our Bodies*. During the project, relationships with partners can be fostered through ongoing, and wherever possible face-to-face, contact and by incorporating social time. Engagement can break down when partner organizations experience staff turnover.

Alignment of missions and strategic goals: Look for partners who have a similar mission or strategic goals. This is especially important where there is limited funding as partner organizations' participation will help them achieve their mission and strategic goals, even if it does not contribute to their revenue. For example, for *Minding Our Bodies*, the YMCA had as one of its strategic objectives an increased focus on mental health in its recreation programs. This objective aligned with the CMHA's policy and strategic directions and with the physical activity-related goals of the project.

Share resources, responsibility and results: The responsibilities and benefits of partnerships need to be explicitly discussed and clearly articulated so that all partners have a shared understanding of their roles. Partners tend to be more engaged when they have a role in the decision-making process, including decisions about how project resources are spent and how tasks are delegated. When undertaking projects, CMHA Ontario has tried to enhance the evaluation capacity of smaller partner organizations. They rely on external evaluation consultants to both evaluate the project and engage in skills transfer to the project partners. For the *Minding Our Bodies* project, York University Faculty of Health's academics and students fulfilled this role. At the end of the project, sharing can take the form of a gathering to present project results, celebrate successes and recognize partners' contributions.

[26] For more information about the Ontario Chronic Disease Prevention Alliance, go to www.ocdpa.on.ca.

Evidence-based programming and program adaptation

The programs and services identified by this scan varied widely. A small number were explicitly developed based on well-articulated evidence and/or theoretical foundations while many others were not. Even so, each had as its broad goal the promotion of health and wellbeing of people served. The field of evidence-based health promotion is emerging in parallel with an increased focus on the adaptation of health promotion programs from one setting to another. In this section evidence-based health promotion is briefly reviewed and then important considerations for program adaptation and fidelity are summarized.

Evidence-based programming

While there is no firm understanding of how evidence is currently used in health promotion practice, the evidence-based movement has clearly impacted the field of health promotion (Juneau et al 2013). "Evidence" can mean different things in different contexts and settings. It can be difficult to identify with clarity what constitutes 'evidence' of a successful health promotion program in a community setting. Evidence used in the development of health promotion programs can be characterized as internal or external, qualitative or quantitative. Internal evidence is created within the context of program development, using methods such as focus groups, surveys, advisory groups and key informants, among other methods. External evidence is created outside the program development process and includes published and grey literature. Narrow conceptions of "evidence" of effects from biomedicine - the production of which seeks to exclude extraneous factors and control for confounding factors - are seldom met in the field of health promotion (Juneau et al 2013). When 'evidence' is viewed more broadly, there is plenty to show that health promotion interventions change behaviours, attitudes and opinions in populations (Juneau et al 2013).

Based on a recent review of 26 health promotion case studies, Juneau and colleagues identified eight "key levers" for the use of evidence in health promotion programs (Juneau et al 2013):

- Local and cultural relevance of the evidence
- Community capacity-building
- Sustained dialogue from the outset with all stakeholders (including decision-makers)
- Established academic-supported partnerships
- Communication that responds to organizational and political readiness
- Acknowledgement and awareness of gaps between evidence and practice
- Advocacy
- Earmarked resources

Program adaptation and fidelity

The concepts of program "fidelity" and "adaptation," as understood in the literature, take evidence-based programs, services and interventions as a given. Fidelity in the implementation of an evidence-based intervention refers to the degree to which the intervention is implemented 'as designed' and is essential if the intervention is to provide the same results it did when previously studied (Korda 2013). Adaption reflects a departure from fidelity. In practice, and for a variety of reasons, organizations take up and adapt for their own use, programs developed elsewhere. Programs are commonly adapted to

meet the cultural and linguistic characteristics of a different target population (Korda 2013; O'Connor 2007). Attempts to resolve the tension between program fidelity and adaptation have focused on drawing a distinction between adaptations that pose little risk to the effects expected of the program, and adaptations that can compromise the expected effects.

Types of program adaptations	
Acceptable adaptations	**Risky or unacceptable adaptations**
• Changing language – Translating and/or modifying vocabulary • Replacing images to show youth and families that look like the target audience • Replacing cultural references • Modifying some aspects of activities such as physical contact • Adding relevant, evidence-based content to make the program more appealing to participants	• Reducing the number or length of sessions or how long participants are involved • Lowering the level of participant engagement • Eliminating key messages or skills learned • Removing topics • Changing the theoretical approach • Using staff or volunteers who are not adequately trained or qualified • Using fewer staff members than recommended

Source: O'Connor 2007

Chen and colleagues have recently outlined an innovative community engagement method for program adaptation, including eliciting ideas for program modifications and deciding upon program changes. Their approach is called the Method for Program Adaptation through Community Engagement (M-PACE) (Chen et al 2012). The key starting point in program adaptation is identifying differences between the new target population and the community for which the evidence-based intervention (EBI) was originally developed. The M-PACE method draws on principles of community-based participatory research and involves diverse stakeholders as equal-status partners. The M-PACE method solicits comprehensive participant feedback as the basis for program adaptation and establishes a process to analyze, adjudicate and incorporate reactions and suggestions that ultimately culminate in a revised program.

M-PACE consists of five steps, which can be summarized as follow:

1. Convene adaptation steering committee
    - 10 to 12 people
    - responsible for undertaking steps 2 through 5
    - researchers, implementers or practitioners, and community members who would benefit from participating in the EBI (which might include spouses, caregivers, etc)
    - one member of the steering committee must be familiar with the EBI's theory of change as well as research on effectiveness (ideally the person was involved in the creation or validation of the original EBI)

2. Implement un-adapted program to generate recommendations for program change
    - Deliver the un-adapted program under the same conditions (recruitment, setting, timing

and personnel) as planned for the adapted program, maintaining fidelity to the EBI
- participants must give consent to participate in the research into and evaluation of the EBI for adaptation

3. Systematically obtain evaluations of un-adapted program components
    - using standard social science techniques
        - participant survey (after each session)
        - participant focus group (after completion of program)
        - program facilitator feedback (after each session and after program completed)

4. Summarize stakeholder feedback
    - synthesize and present results of step 3
    - distribute results to all members of the steering committee
    - additional analysis may be requested by steering committee

5. Adjudicate program feedback to decide upon program modifications
    - steering committee meets to adjudicate all feedback and make choices about how to adapt the EBI
    - consensus based; every person has a veto
    - adjudicated based on: (a) importance - the degree to which a suggestion could improve program effectiveness or enable the program to reach a new target population; (b) feasibility - taking into account the capacity and resources of participants, the organization responsible for program delivery, and program facilitators; and (c) congruence - verify that is the adapted intervention is working with and not against or outside of the core components of the EBI
    - compile list of program modifications
    - task small group from steering committee with making modifications

The Patient Education Resource Center at the Stanford University School of Medicine has developed a fidelity manual and toolkit to accompany its community-delivered programs (Stanford Patient Education Research Center 2012). The manual distinguishes between “Must Do’s” and “Nice to Do’s” for program implementation. The “Must Do’s” and “Nice to Do’s” framework seeks to promote fidelity (and maintain outcomes) while taking into account the adaptation needs of community-based organizations. The manual addresses fidelity at each stage of program planning and delivery: resource allocation; choosing program personnel; before, during and after personnel training; and during and after workshops.

Considerations for the HIV sector

Gathering evidence about the target population is a crucial step in program development, whether an organization is considering developing a new program or adapting an existing program. When considering a program for adaptation, a key initial question is: ‘Is the group of people for whom the program was designed sufficiently similar to the group of people whose needs we are trying to meet?’ To meaningfully assess whether a program designed for one population can be adapted for another population, it is important to understand the demographic profile and the needs and preferences of both the original and the new target populations. Organizations within the HIV sector that do not have detailed information regarding the characteristics and needs of: 1) older people living with chronic

illness; and/or 2) people living with chronic physical illness who are also experiencing mental health issues, may want to search for this information. Data may already exist in case management and reporting systems and can be compiled and analyzed. Other ways of building an evidence base for programming might include literature reviews and surveys or focus groups conducted with clients, caregivers, partners/spouses, friends and service providers.

While a method of program adaptation based on community engagement may be useful to ASOs and other community-based organizations, the systematic and detailed nature of M-PACE may present barriers for its use in small- or medium-sized, or resource constrained, organizations. Community-based organizations, and especially organizations in rural and remote areas, may not have established relationships with academic institutions or researchers. To maximize the impact of available resources, community-based organizations may want to undertake M-PACE in partnership with other organizations that serve the same target population. Another option would be to scale-back the M-PACE process. Organizations without established relationships with academic institutions or researchers may be able to fill this gap using practicum students from health professional and public health programs, or fellowship training programs such as Universities Without Walls.[27] Regional, provincial and national HIV organizations in Canada may also be able to help local organizations adapt evidence-based interventions by leading or supporting processes such as M-PACE.

Based on the scan of programs and services undertaken here, one of the potential challenges to adapting existing programs from the Canadian disability and health charity sector for the HIV sector is the apparent lack of evidence-based programs from which to choose. This poses a challenge since the literature regarding program adaptation (and program fidelity) presupposes the existence of evidence-based programs. The distinction drawn between 'acceptable' and 'unacceptable' adaptations takes for granted that a program has an evidence-based "core" from which the intended positive effects flow. Changes to that "core" are presumed to dilute or undermine these effects. In day-to-day practice, program development, delivery and adaptation in community-based organizations may depend to a great extent on the accumulated wisdom and experience of front-line service providers, peers, volunteers and clients. These players might also be relied upon to adapt the adaptation process itself to better meet the needs and resources of their community-based organizations. In this light, the distinction between acceptable and unacceptable program adaptations can serve as a guide, rather than a prescription.

[27] Universities Without Walls fellows are required to complete a Field Mentoring Placement. The Field Mentoring Placement (FMP) is a nine-month placement based on the community service learning approach. The FMP is carried out in an AIDS service organization, policy environment, or REACH research project and provides an opportunity for Fellows to develop relationships with people and organizations working in the field, understand contextual factors that will make research projects more relevant, and build research skills in a community environment. www.universitieswithoutwalls.ca

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Appendix A—Programs and services focusing on mental health

Managing Diabetes with Mental Health Issues or Addictions Research Partnership Lead Organizations: Canadian Diabetes Association; Centre de santé communautaire de Grand Sudbury; Health Sciences North/Horizon Santé-Nord Contact: Karen L. Rebeiro Gruhl, Ph.D., M.Sc.O.T., O.T. Reg (ON), Health Sciences North/Horizon Santé-Nord Tel: 1-866-469-0822 / (705) 523-4988 x4383 Email: n/a	
Program Goal	Better understand how client vulnerability impacts their management of diabetes. Create knowledge base to develop programs that promote better management of diabetes for individuals with mental health and addictions issues. Influence policy directions.
Program Development • **Evidence base** • **Theoretical Framework**	Project originated out of diabetes support group (Canadian Diabetes Association and Centre de santé communautaire de Grand Sudbury), where it became apparent that diabetes was not clients' first priority. High prevalence of comorbid psychiatric disorders (DSM) among people served.
Program Details	A research partnership to gather evidence regarding what types of programs and services people with addictions and mental health issues need to manage diabetes.
• **Start Date – End Date**	2012-2013
• **Funding**	Ontario Ministry of Health Promotion (Ministry of Tourism, Culture and Sport)
• **Target Audience**	Adults (>18 years), Type 2 diabetes, Francophone/First Nations/other minorities, precarious housing, economically disadvantaged. Populations with complex needs including those in abusive relationships, those with mental health problems, and those with alcohol and addiction issues.
• **Partners**	Initial partnership among community organizations: Canadian Diabetes Association and Centre de santé communautaire de Grand Sudbury, Iris Addiction Recovery for Women, Rockhaven (residential addiction

	services). Recognizing need for academic support, expanded to include Laurentian University, Health Sciences North, Northern Ontario School of Medicine.
• **Geographic Location / Scope of Delivery**	Greater Sudbury area
• **Activities**	• Identification of researchers • Creation of steering committee • Ethics submission • Literature review • Scan of provincial policies • Scan community agency programs and resources • Focus groups (4) • Research questions: 1. What is it like for you to live with diabetes? 2. What helps you to live well with diabetes? What makes it difficult for you? 3. Does your income impact on your ability to manage your diabetes? If so, how? 4. Can you tell us a bit about any programs you have attended for managing your diabetes? What was helpful? Not so helpful? • Data analysis • Recommendations and future actions • Evaluation
Evaluation	
Additional Information	For a PowerPoint presentation summarizing the program, see http://www.nelhin.on.ca/WorkArea/showcontent.aspx?id=14420. Reflections on the project • Need this kind of research partnership based on the complexity of healthcare • Need to better engage low income Francophones, people from Canada's First Nations (i.e., more vulnerable and marginalized) in project • Important to question: How is the partnership making a difference to the target population? o Policy level: medical versus social issues? o Knowledge of existing resources, how to collaborate? • Expansion of partnership to include academic researchers resulted in "big shift"

	○ Academic rigour versus need for flexibility ○ Time: deadlines, organizing time, meetings ○ Important advantages ▪ Researcher and community knowledge translation and exchange ▪ Usefulness of knowledge generated to inform program development • Collaborative reseach partnerships ○ Need to ensure financial resources of community partners ○ Ensure accountability and transparency amoung community partners beforehand ○ How will decisions related to reseach be made during the project? ▪ Financial matters, need for 3 ethics board approvals, data storage and access ○ Figure out how contributions of community and university partners will be recognized - What knowledge is most valued, valuable? ○ How will knowledge be shared at the end of partnership (academic and community) ▪ How will clients/participants be informed?

Managing diabetes with mental health issues or addictions

Monday, September 24, 2012

Photo: The Corner Clinic cooking class program will also be starting up again, where we teach clients how to cook healthy meals, followed by them getting to eat the meal afterwards.

There are a number of barriers that make it difficult for low-income individuals with addictions and mental health issues to manage their diabetes. The Canadian Diabetes Association, in partnership with service agencies in Sudbury, Ontario, has received a grant from the Ministry of Tourism, Culture and Sport to do research into this unique group of individuals.

People living in a low-income situation with addictions and/or mental health issues are a difficult group to reach. The research being conducted is to learn new ways to reach this population on a regular basis to help them live well with their diabetes.

Focus groups will be held throughout October 2012 to help determine what programs and services are required to better serve this unique population in our community. Once the necessary programs are established, it is hoped that measureable changes can be made in people living with diabetes who also have mental health issues or addictions, including improved health outcomes, improved knowledge of diabetes and changes to lifestyle.

The ability to do the research is due to the wonderful partnerships that have been developed, which include Laurentian University, the Northern Ontario School of Medicine, Rockhaven, Iris Addiction Recovery for Women, the Centre de santé communautaire du Grand Sudbury, Health Sciences North – Positive Steps and the Corner Clinic.

The cost of diabetes to the Canadian healthcare system is crippling. It is projected to balloon from a current $13.2 billion a year to over $19 billion by 2020. Diabetes could well be the disease that brings down the healthcare system. It is the main driver behind one in 10 admissions to acute care hospital settings. Helping individuals with diabetes stay healthy will have a direct impact on the Canadian healthcare system in reducing costs and helping increase the quality of life of people living with diabetes.

The KIDNEY CONNECT Peer Support Program Organization: The Kidney Foundation of Canada Contact: Nadine Valk, National Director, Programs and Public Policy Tel: 1-855-876-0721 (toll free) Email: nadine.valk@kidney.ca	
Program Goal	To provide one-on-one peer support to anyone touched by kidney disease - people living with kidney disease, their families and people who love them, and people considering kidney donation. Monthly or bi-monthly support groups are also offered in some locations.
Program Development • **Evidence base** • **Theoretical Framework**	Modelled on the CancerConnection program, a national telephone-based peer support service delivered by the Canadian Cancer Society that matches cancer patients or caregivers of cancer patients with a trained volunteer who has been through a similar cancer experience.
Program Details	National peer telephone support program delivered by trained volunteers; monthly or bi-monthly support groups are also offered in some locations.
• **Start Date – End Date**	Ongoing
• **Funding**	Internal
• **Target Audience**	Anyone touched by kidney disease. (Note that most participants with kidney disease are aging.)
• **Partners**	Hospital renal units (e.g., social workers within those units)
• **Geographic Location / Scope of Delivery**	National
• **Activities**	• One-on-one telephone support • Support groups (monthly or bi-monthly) • Training for peer volunteers

	The Peer Support program provides the opportunity for a person to speak with a peer who understands what it's like to live with kidney disease and is willing to share their own personal experiences. Peer Support volunteers do not offer medical advice but they can tell a person about their own history of kidney disease and how they balanced their treatment with family life, work and social activities. The Peer will be able to answer many of the person's questions based on lived experience. The Kidney Foundation provides telephone calling cards to peers. At present, there are approximately 200 trained volunteer peers who have different experiences living with kidney disease: patients on different types of dialysis; transplant recipients; living organ donors; or caregivers. Training is 1.5 days in duration and focuses on: • Listening and communication skills • Clarifying roles and responsibilities (personal experience vs medical advice)
Evaluation	The program is evaluated annually. Evaluation criteria include: number of peers matched with clients; issues arising; program challenges. The Kidney Foundation of Canada is developing a more rigorous evaluation framework, with a view to expanding the program to include on-line discussion.
Additional Information	Nationally, The Kidney Foundation of Canada is currently considering: • the development of an on-line patient and peer connection forum to connect peers nationally, combining patient-to-patient communication and input from invited professional content experts; and • expanding and transforming traditional formal peer-support groups to more casual and social events that provide access to peers and peer support (for example: bowling, yoga, social activities, coffee shops). These will be led by volunteers. The Ontario Division of The Kidney Foundation of Canada is developing tools for, and training peers to provide, decision-making support to patients during transition periods in their illness trajectory. In Ontario, the province has set a 40% target for home dialysis for new patients. The Ontario Division is building a team of peers that, upon request by a hospital, will connect with new dialysis patients to provide personal experience and neutral third party information to assist with patient decision-making.

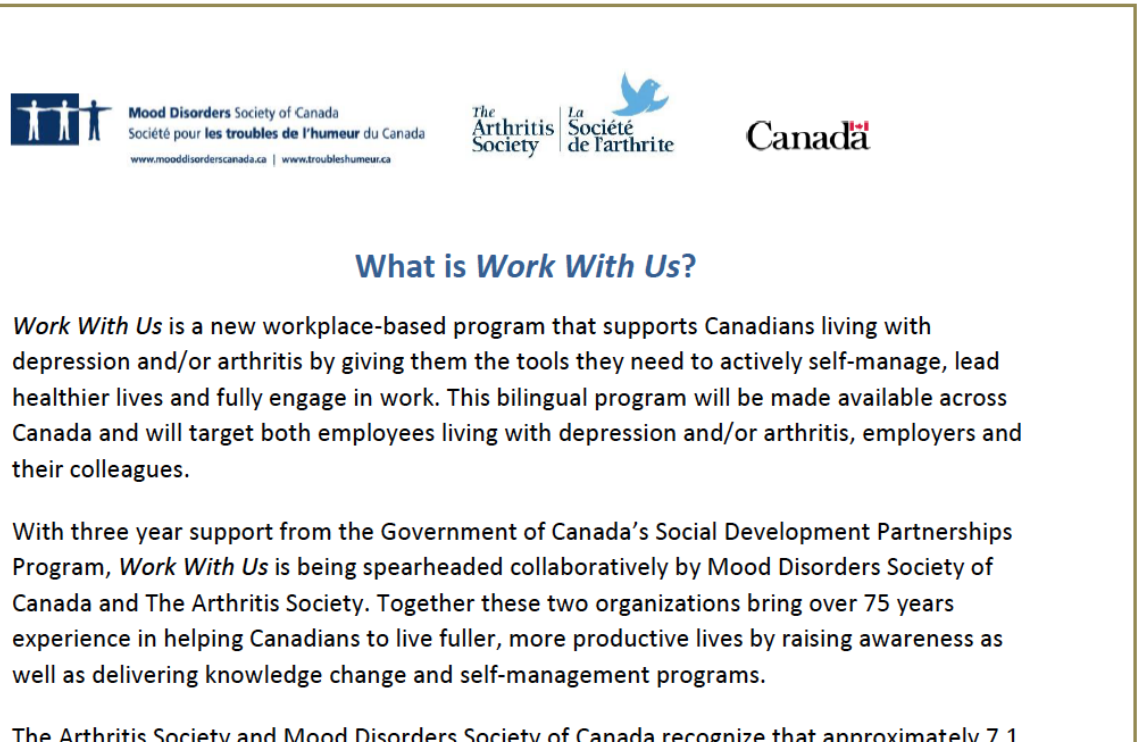
Appendix A—Programs and services focusing on mental health

Work With Us Lead Organizations: Mood Disorders Society Canada; The Arthritis Society Contact: Jennifer Lee, Project Manager, Work With US Tel: 647-629-3720 Email: jennifer@mooddisorderscanada.ca	
Program Goal	To support Canadians living with depression and/or arthritis by giving them the tools they need to actively self-manage, lead healthier lives and fully engage in work. To increase workplace awareness while decreasing the stigma associated with mood disorders and arthritis, both manageable conditions.
Program Development • **Evidence base** • **Theoretical Framework**	The Arthritis Society and Mood Disorders Society of Canada recognize that approximately 7.1 million Canadians now live with arthritis and depression, and both of these conditions frequently strike people during their peak earning years. The Arthritis Society and Mood Disorders Society of Canada acknowledge that the majority of these individuals are of working age, and want to remain productive in the workforce. Mood Disorders Society of Canada reports that 56% of employers consider ongoing increases in employee's mental health claims to be a top concern. In their report, 'Making the Case for Investing in Mental Health,' the Mental Health Commission of Canada found that, in 2011 alone, mental health problems and illnesses accounted for more than $6 billion in direct business losses due to lost productivity from absenteeism, "presenteeism" and turnover. The Arthritis Alliance also estimates that wage-based productivity costs associated with conditions like rheumatoid arthritis could be as high as $45.1 billion by 2020. In a recent Leger Marketing 'Fit for Work Survey,' one third of people living with arthritis reported having to leave work either permanently or temporarily because of their condition. These challenges are not insurmountable and they can be addressed through practical tools. Many Canadians living with depression and/or arthritis lead full and productive lives as a result of effective clinical and self-management of their disease. However, common misconceptions and barriers often get in the way of their ability to fully engage in life and work.

	Evidence base for program models will be examined at outset of the project.
Program Details	Work With Us is a new workplace-based program that supports Canadians living with depression and/or arthritis by giving them the tools they need to actively self-manage, lead healthier lives and fully engage in work. This bilingual program will be made available across Canada and will target both employees living with depression and/or arthritis, their employers and their colleagues. Through proactive workplace engagement, employees, employers and labour organizations can all come together to make it Work for Us.
• **Start Date – End Date**	Three years (2013-2015) • Year 1 – train program delivery volunteers in group setting, pilot delivery • Year 2 and 3 – adapt and roll-out nationally
• **Funding**	Three year support from the Government of Canada's Social Development Partnerships Program (HRSDC)
• **Target Audience**	Employees, managers, team leads, supervisors, senior executives, business owners and human resources professionals
• **Partners**	Work With Us is being spearheaded collaboratively by Mood Disorders Society of Canada and The Arthritis Society. Together, these two organizations bring over 75 years of experience in helping Canadians to live fuller, more productive lives by raising awareness as well as delivering knowledge change and self-management programs.
• **Geographic Location / Scope of Delivery**	National, bilingual
• **Activities**	Examine evidence-based models Advisory Committee • Brings together The Arthritis Society, Mood Disorders Society of Canada, Work with Us project coordinator, human resource professional, University of Toronto Dalla Lana School of Public Health, people with lived experience (possibility of including other consumers with mood disorders and/or arthritis) The Work With Us project is targeting workplaces and providing information to both employers and employees on how they can support an environment of inclusion. The program will provide strong training to community presenters who will deliver this initiative across the country. • One to two hour presentations customized to specific audiences including employees, managers, team leads,

	supervisors, senior executives, business owners and human resources professionals ○ Presentations educate audiences on what depression and/or arthritis are, how they can impact a person's life and how they can be managed • Create open discussion through online and face-to-face sessions, encouraging participants to ask questions, share their lived experiences and test drive self-management tips and tools • Videos and testimonials from individuals who share personal accounts of how self-management techniques have helped them to live well and actively engage in work • Downloadable awareness materials, including posters and hand-outs that dispel myths and stigma as well as provide tips on how to effectively self-manage depression and/or arthritis • An online learning environment where project materials can be accessed by those who want to get involved with hosting a session or engage in self-study • An ongoing discussion on social media about what can be done better to address myths and ensure the needs of Canadians living with depression and/or arthritis are better met in the workplace
Evaluation	Evaluation criteria were developed as part of application for funding, including targets for number of workplaces reached, number of presentations delivered.
Additional Information	Work With Us is being developed by a network of people who understand depression and/or arthritis and have found ways to make it work for them and share their knowledge with others. Webinars will be important in terms of reaching rural and remote areas. A program information sheet is available (see below).

Appendix A—Programs and services focusing on mental health



Mood Disorders Society of Canada
Société pour les troubles de l'humeur du Canada
www.mooddisorderscanada.ca | www.troubleshumeur.ca

The Arthritis Society | La Société de l'arthrite

Canada

What is *Work With Us*?

Work With Us is a new workplace-based program that supports Canadians living with depression and/or arthritis by giving them the tools they need to actively self-manage, lead healthier lives and fully engage in work. This bilingual program will be made available across Canada and will target both employees living with depression and/or arthritis, employers and their colleagues.

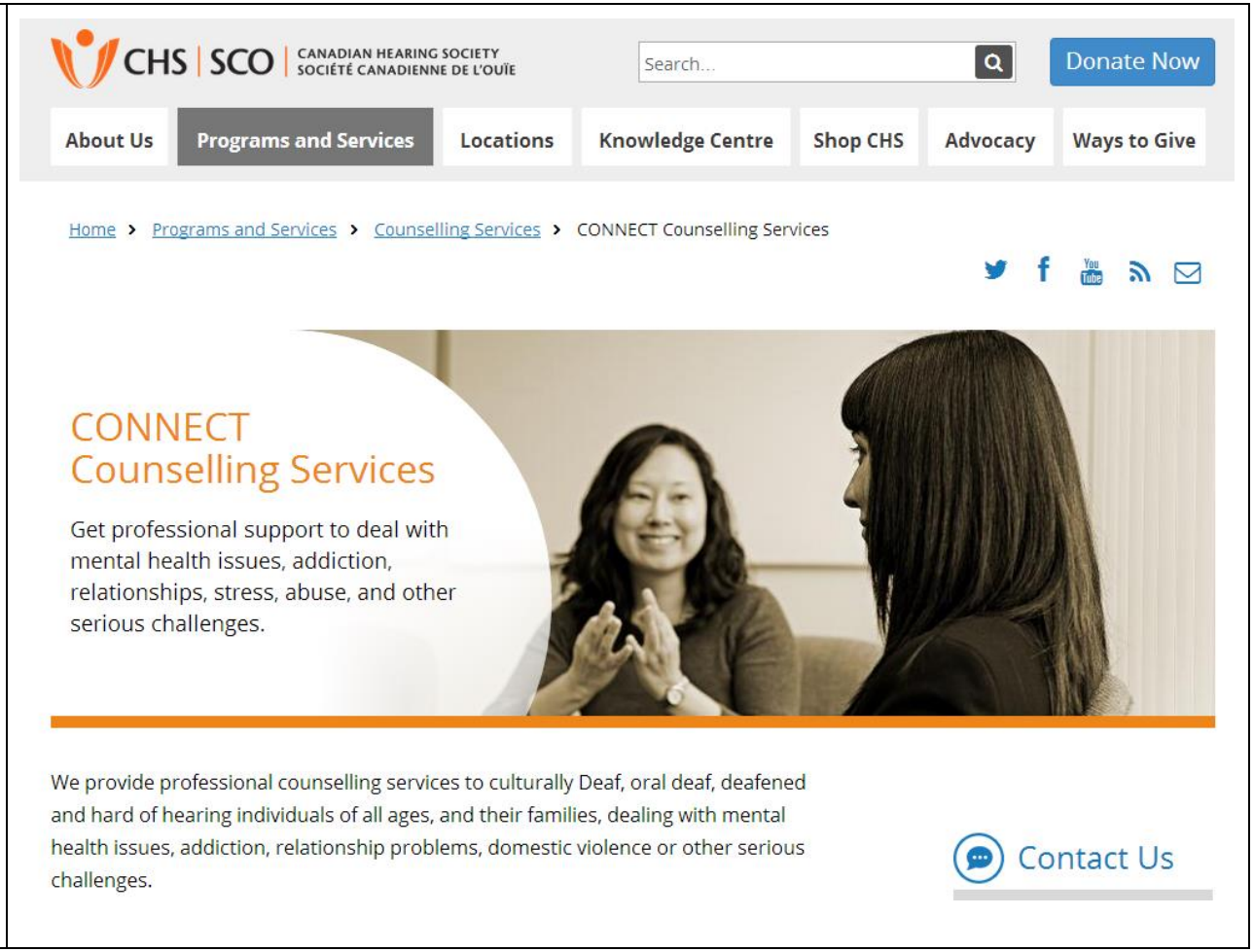
With three year support from the Government of Canada's Social Development Partnerships Program, *Work With Us* is being spearheaded collaboratively by Mood Disorders Society of Canada and The Arthritis Society. Together these two organizations bring over 75 years experience in helping Canadians to live fuller, more productive lives by raising awareness as well as delivering knowledge change and self-management programs.

The Arthritis Society and Mood Disorders Society of Canada recognize that approximately 7.1

CONNECT Counselling Services Lead Organization: Canadian Hearing Society Contact: Rebecca Grundy; Head Office – 271 Spadina Road, Toronto, ON M5R 2V3 Tel: 1-877-347-3427 TTY: 1-877-216-7310	
Program Goal	To provide culturally competent counselling, education and advocacy supports to deaf and hard of hearing individuals who are experiencing mental health issues, trauma, loss, transition, relationship issues, violence and/or substance use and their families
Program Development • **Evidence base** • **Theoretical Framework**	• Social work training/competencies • Solution-focused approaches • Culturally competent approaches to providing support • Professional practice model – clinical supervision
Program Details	Accessible counselling services are offered in American Sign Language (ASL), la langue des signes québécoise (LSQ) or with technical assistance from real-time captioning and amplification.
• **Start Date – End Date**	
• **Funding**	
• **Target Audience**	Culturally deaf, oral deaf, deafened and hard of hearing individuals and their families
• **Partners**	None
• **Geographic Location / Scope of Delivery**	Canadian Hearing Society locations across Ontario
• **Activities**	• Counselling services • Practical assistance supports

	• Referrals
Evaluation	Ongoing statistical monitoring and collection of service use data: (http://www.chs.ca/sites/default/files/uploads/ANNUAL%20REPORT%202012-2013%20FINAL%20READERFORMAT.pdf)
Additional Information	Counselling services are free.

Appendix A—Programs and services focusing on mental health



Appendix B—Programs and services focusing on older adults

Aging with a Bleeding Disorder Organization: Hemophilia Ontario (Central West Ontario Region) Contact: Alex McGillivray - Regional Service Coordinator, Central West Ontario Region Tel: (905) 522-2545 Email: amcgillivray@hemophilia.on.ca	
Program Goal	To pilot the program. To equip the aging population and their caregivers with the knowledge and tools they need to care for themselves or their loved ones with inherited bleeding disorders.
Program Development • **Evidence base** • **Theoretical Framework**	Aging is a subject of much discussion within the Central West Ontario Region of Hemophilia Ontario. In addition, two events were held that featured "aging" content, which provided impetus and formed the basis of some of the content of the "Aging with A Bleeding Disorder" pilot. In 2010, a medical resident of Hamilton Niagara Regional Hemophilia Centre delivered a presentation on aging at the Regional General Meeting. In 2011, a focus group on aging with a bleeding disorder was held at the Canadian Hemophilia bi-annual research conference, Rendez Vous. Central West Ontario Region (CWOR) of Hemophilia Ontario built on the ideas shared in these sessions to develop a pilot project. The pilot focused broadly on issues faced by older people within the bleeding disorder community.
Program Details	This was a pilot educational workshop develop by the Central West Ontario Region of Hemophilia Ontario.
• **Start Date – End Date**	Program development 2012, pilot workshop November 2012, evaluation and reporting to July 2013.
• **Funding**	Internal (Hemophilia Ontario) and pharmaceutical funding.

Appendix B—Programs and services focusing on older adults

• **Target Audience**	People living with bleeding disorders who are 30+ years old. The workshop was open to people did not yet identify as "older adults" but who were thinking about health and aging and who were interested in prevention.
• **Partners**	Hamilton Niagara Regional Hemophilia Centre, McMaster University-affiliated hospital
• **Geographic Location / Scope of Delivery**	Central West Ontario (participants from each of Toronto, Ottawa and London Hemophilia Society regional offices interested in developing and delivering program locally)

• **Activities**	<u>Program Development</u>
	• Led by one staff and one volunteer living with a bleeding disorder
	• Consulted with multi-disciplinary staff at Hamilton Niagara Regional Hemophilia Centre who, in turn, consulted clinic patients and colleagues in other specialities, including gerontology.
	
	<u>Workshop</u>
	• One-day (9:30am to 3:30pm)
	• 27 participants from across the region
	• Presentation and discussion format, with focus on issues faced by older people within the bleeding disorder community.
	• Presentations by staff from Hamilton Niagara Regional Hemophilia Centre
	  ○ Adult hematologist
	  ○ Nurse coordinator
	  ○ Physiotherapist
	• Panel facilitated by Centre's social worker, based on focus group questions used at Rendez Vous 2011 conference
	  ○ bleeding disorders, aging and medical conditions
	  ○ health care professionals and the health system
	  ○ recommendations for future initiatives and strategies
	• Two additional presentations, including Canadian Hemophilia Association report on plans to address aging (intention is to have content framework broad enough so that local needs and concerns can be address)

Evaluation	Workshop questionnaires completed by participants, de-brief meeting, evaluation report of pilot to be

	finalized summer 2013. *The respondent noted that, in future, it may be useful to engage a gerontologist and other local experts working outside the Hamilton Niagara Regional Hemophilia Centre.
Additional Information	http://www.hemophilia.ca/files/Blood_Matters_Summer_2012%20Final.pdf (see page 26) *Blood Matters* (Sumer 2012) http://www.hemophilia.ca/files/HT%20August%202011%20-%20final%20web.pdf (see page 23) *Hemophilia Today* (August 2011)

Chance for Choice/L'Occasion de Choisir Lead Organization: Citizen Advocacy/Parrainage civique Contact: Rachel Levine-Katz, Chance for Choice Program Coordinator – 312 Parkdale Ave., Ottawa, ON Tel: 1-613-761-9522 Email: RLevine-Katz@citizenadvocacy.org	
Program Goal	To connect older people with disabilities to the community and support them in autonomous decision-making thereby reducing their vulnerability and increasing their quality of life.
Program Development • **Evidence base** • **Theoretical Framework**	Experiential evidence - positive participant feedback over time.
Program Details	This program matches older adults with disabilities with volunteers who provide one-on-one social support and advocacy for a few hours 3-4 times per month over the long-term. Volunteers engage their protégés (the term Citizen Advocacy uses to describe the person living with a disability) in recreational activities; provide companionship; support problem-solving and decision-making; look for early warning signs of declining well-being to ensure early intervention; and reduce isolation by providing informal care and friendship.
• **Start Date – End Date**	Ongoing
• **Funding**	
• **Target Audience**	Vulnerable older adults with physical disabilities, mental health issues, developmental disabilities or comorbidities.
• **Partners**	None
• **Geographic Location / Scope of**	Local – Ottawa Area

Delivery	

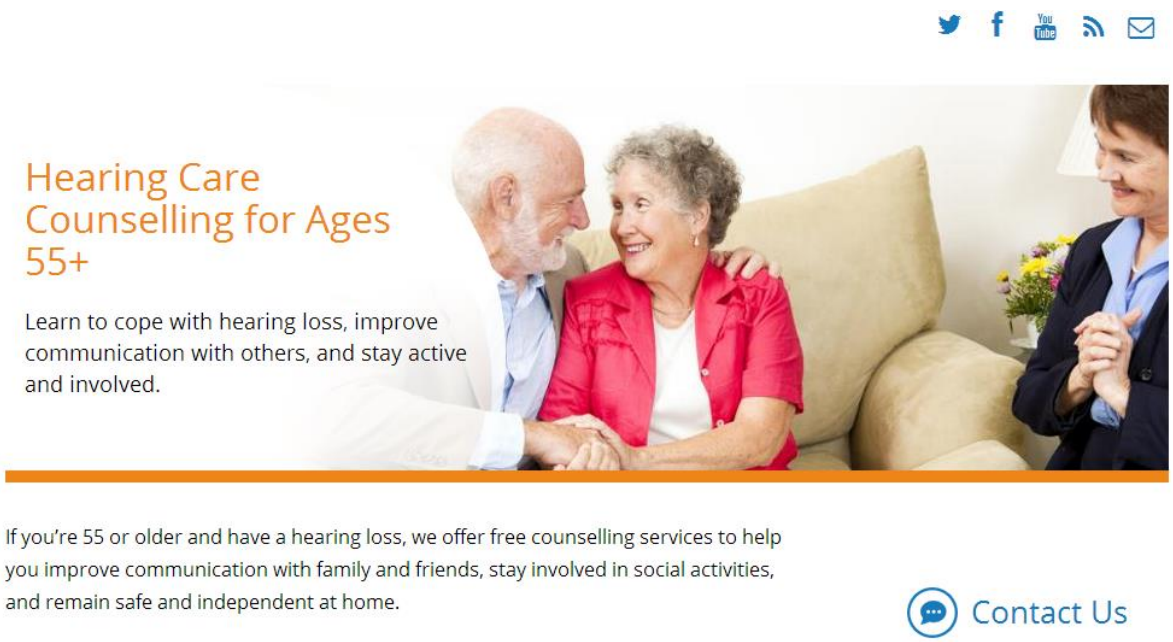
• **Activities**	• Volunteer screening and matching processes
	  • Information sessions for potential volunteers
	  • Interviews with staff social worker to identify potential suitable matches (shared values, interests, etc.)
	  • Volunteer applications
	  • Police records and reference checks
	• Volunteer support
	• Volunteers meet weekly (3-4 times/month) with protégés
	  • Recreational activities
	  • Self care
	  • Problem-solving
	  • Social engagements

Evaluation	• Participant feedback • Metrics/statistical records kept regarding number of new matches/year
Additional Information	

Hearing Care Counselling for Ages 55+ Lead Organization: Canadian Hearing Society Contact: Rebecca Grundy; Head Office – 271 Spadina Road, Toronto, ON M5R 2V3 Tel: 1-877-347-3427 TTY: 1-877-216-7310	
Program Goal	To support older adults who are coping with hearing loss so that they can remain socially engaged and independent and to educate the public regarding how to make programs and services more accessible to older adults with hearing loss.
Program Development • **Evidence base** • **Theoretical Framework**	Unknown
Program Details	Hearing care counsellors (professionally trained in social work, gerontology and related fields) provide one-on-one information, counselling, skills building and referrals to older adults with hearing loss and their caregivers as well as providing demonstrations and help with assistive devices. Hearing Help Classes are also available to individuals with hearing loss to help them foster new/supplementary communication strategies which ensure they can maintain social engagement. Condition-specific support groups provide an opportunity to share peer support and information with others who are experiencing hearing-related issues. These groups are offered by various CHS chapters. Education and training is provided to caregivers (formal and informal) and the general public regarding communication and support strategies that can be used with people experiencing hearing loss as well as tips on making services and spaces accessible to those with hearing loss.
• **Start Date – End Date**	
• **Funding**	

• **Target Audience**	Older adults (age 55+) with hearing loss. Younger adults (age 19-55) with hearing loss and other challenges that require in-home care.
• **Partners**	None.
• **Geographic Location / Scope of Delivery**	26 Canadian Hearing Society locations across Ontario.
• **Activities**	Hearing care counsellors (professionals trained in social work, gerontology, etc.) provide: • Information • Skills building • Referrals • Technical assistance with assistive/communication devices (hearing aids, etc.) • Education/presentations • Hearing clinics
Evaluation	Ongoing statistical monitoring and collection of service use data: (http://www.chs.ca/sites/default/files/uploads/ANNUAL%20REPORT%202012-2013%20FINAL%20READERFORMAT.pdf)

Additional Information	



VON SMART – Seniors Maintaining Active Roles Together Lead Organization: VON (Victorian Order of Nurses) Contact: Sheila Schuehlein, Ontario Trillium Fund (OTF) Project Lead – VON SMART Tel: 519-496-4566 Email: Sheila.Schuehlein@von.ca	
Program Goal	To engage older adults (age 55+) in physical activity.
Program Development • **Evidence base** • **Theoretical Framework**	Informed by a literature review on community-based interventions for older adults.
Program Details	This program aims to provide social and fitness opportunities to older adults through group and in-home fitness instruction provided by volunteers.
• **Start Date – End Date**	VON Canada Functional Fitness Continuum Initiative (2005) to present.
• **Funding**	Trillium Foundation: 2005-2008 Public Health Agency of Canada: 2005-2009
• **Target Audience**	Older adults (age 55+), including older adults who are frail, living with disabilities, or have difficulty accessing other programs
• **Partners**	None
• **Geographic Location / Scope of Delivery**	National; offered in at least 18 communities

• **Activities**	Community-based group fitness program • Led by volunteer instructor • Provides opportunity for social connections and physical activity • Short term goals – increase strength, endurance, flexibility, balance • Long-term goal – for participants to transition into other community-based fitness programs • Many participants living with chronic illness Individual In-Home Fitness Instruction • Reaches individuals with greater functional impairment, chronic illness than group program • On average, participants live with 3.5 comorbidities Congregate In-Home Fitness Program • Offered in facilities housing multiple seniors • Participants exercise in a group, but within their home environment Some communities offer both
Evaluation	Questionnaires completed by volunteer instructors, program participants VON Canada Functional Fitness Continuum Project Evaluation Report: VON SMART In-Home and Group Functional Fitness Programs (Connelly, D., 2008) – available at http://www.von.ca/en/special_projects/docs/SMART_Evaluation.pdf Both outcomes and project sustainability have been evaluated. The vast majority of participants maintained or improved function as a result of participating in this program, based on self report.
Additional Information	

Appendix C—Health promotion and chronic disease management programs

Diabetes and Mental Health Peer Support Project Lead Organization: Canadian Mental Health Association, Ontario Contact: Scott Mitchell, Director Knowledge Transfer, Canadian Mental Health Association, Ontario Tel: 416-977-5580 ext. 4136 Email: smitchell@ontario.chma.ca	
Program Goal	**Goals** Increase the skills of mental health peer support workers in providing support for the prevention and self-management of diabetes in the high-risk population of people living with a serious mental illness. Increase awareness in the diabetes community of the role mental health peer support workers can play in prevention and self-management support. **Anticipated Results** People with serious mental illness will have access to informed, educated peer support workers who will support them around prevention, early identification and self-management strategies. Diabetes policy and health care delivery system across Ontario will have more awareness of the value and role of mental health peer supporters and of Consumer/Survivor Initiatives (CSIs) across Ontario and their potential to contribute to the reduction of the impact of diabetes on high-risk populations. A change in attitude towards, and understanding of, people with lived experience of mental illness among those in the diabetes policy and practice sector. Local diabetes prevention and management resources that have trained diabetes/mental health peer support workers will have the opportunity to increase their capacity to serve people with mental illnesses through developing partnerships with the local CSIs.

	A diabetes training manual will be available for members of both the diabetes and mental health care delivery systems to train mental health peer support workers to support self-management and prevention of diabetes with people living with mental illnesses. The project will strengthen participating Consumer/Survivor Initiatives, giving them more to offer their communities, their participants and their partners.
Program Development • **Evidence base** • **Theoretical Framework**	This project emerged from CMHA Ontario's policy work focusing on the connections between mental health and chronic physical conditions. For an overview of that policy work and links to related information, see: http://ontario.cmha.ca/public-policy/cmha-public-policy/current-issues/chronic-disease-prevention-and-management/. See, in particular, background paper Diabetes and Serious Mental Illness: Future Directions for Ontario (April 30, 2009). **Project Rationale** Among the many health problems facing people with serious mental illness, the high risk of diabetes is well documented. Diabetes is not only more prevalent in the population of people living with serious mental illnesses but also under-diagnosed and under-treated. Rates of diabetes are two to four times greater than in the general population and studies have found a 25 to 33 percent incidence of previously undiagnosed pre-diabetes and diabetes in community-based cohorts, as well as higher rates of complications developing earlier in the course of the illness. Both depression and schizophrenia are risk factors for the development of type 2 diabetes. (For more information, see "Diabetes and Serious Mental Illness: Future Directions for Ontario — A Report from the March 30, 2009 Think Tank on Diabetes and Serious Mental Illness," April 30, 2009, at www.ontario.cmha.ca/diabetes.) Supporting people living with diabetes to manage their own illness and improve their health is one of the key features of chronic disease prevention and management. Self-management support goes beyond education, providing people with the skills, tools and confidence they need to take control of their illness and make positive changes in their lives. **Project Approach** This project applied mental health consumer/survivor expertise in peer support for self-management of mental illness to support for self-management and prevention of diabetes. Mental health peer support is a long-established best practice recognized in Canada. In Ontario, consumer/survivor initiatives (CSIs) have been providing peer support to improve the quality of life for people with lived experience of mental health problems

	since 1991. Mental health peer support workers - who share the experience of living with a mental health problem, though they may not share the experience of living with diabetes - are ideally situated to support their peers to understand their risk of developing diabetes, to learn and practice prevention strategies, and to self-manage diabetes.
Program Details	The Canadian Mental Health Association (CMHA), Ontario, the Ontario Peer Development Initiative (OPDI), and the Provincial Consumer/Survivor LHIN Leads Network (PCSLL) collaborated on a two-year project (2010-2012) to provide diabetes competency training for mental health peer support workers.
• **Start Date – End Date**	2010-2012
• **Funding**	The Lawson Foundation
• **Target Audience**	Peer mental health workers Diabetes community
• **Partners**	The Canadian Mental Health Association (CMHA) Ontario, the Ontario Peer Development Initiative (OPDI), Christine Grace and Community, Lawson Health Research Institute, and the Provincial Consumer/Survivor LHIN Leads Network (PCSLL) A project advisory committee was created to guide the knowledge exchange strategy and included representatives from the Ministry of Health and Long-Term Care, Local Health Integration Networks, Family Health Teams, Community Health Centres, Canadian Diabetes Association, community mental health service providers and other stakeholders.
• **Geographic Location / Scope of Delivery**	Ontario
• **Activities**	• Advisory Committee • Project Website • Project Timeline

	• Diabetes and mental health literature review (narrative; synthesis)
	• Training Module (3 components; see below for link and details)
	  ○ Becoming Diabetes-Informed Self-Guided Review and Knowledge Quiz intended to help participants obtain basic knowledge needed to become diabetes-informed. To be used in conjunction with the Diabetes and You toolkit developed by the Canadian Diabetes Association and the government of Ontario. Participants should complete the review and quiz before taking the two-day training session.
	  ○ A two-day training session intended to teach participants how they can best encourage peers in diabetes prevention and self-care, and to provide Peer Supporters with the opportunity to practice related skills. The module includes a Trainer Guide and a Participant Workbook.
	  ○ A final Participant Application and Knowledge Quiz are intended to help prepare participants to step into a diabetes and mental health Peer Supporter role.
	• A Guide to Facilitating Diabetes and Mental Health Peer Support Groups
	• Pilot Training Sessions (two-day sessions delivered to seven peer trainers; who then delivered to 80 peer supporters)
	• Video (*Standing Together*)
	• Project e-newsletters (4)
	• Regional Roundtables (8)
	  ○ organized to build connections between CSIs and local diabetes and related health professionals
	  ○ held in regions where mental health peer supporters have been trained in diabetes self-management support
	  ○ highlighted local issues related to diabetes and explored opportunities for mental health peer supporters to collaborate with others in the community
	• Roundtable Report
	• Case Studies (3)
	• Evaluation
	
	A Peer Supporter Diabetes and Mental Health Training Module was developed and pilot tested by peer support trainers across Ontario. The module builds on the mental health peer support worker core skills training program previously developed by the Ontario Peer Development Initiative (OPDI), Peer Support Core Essentials. An evaluation of the training and diabetes module and its application in the field were carried out by Cheryl Forchuk, Lawson Health Research Institute. The training module was then revised and distributed provincially as a stand-

	alone resource for training mental health peer support workers delivering peer support in any setting. The project also provided education to the diabetes sector about the existing mental health peer support resources and infrastructure (consumer/survivor initiatives) in Ontario that can be mobilized to address diabetes.
Evaluation	The Diabetes and Mental Health Peer Support Training Module was evaluated by Dr. Cheryl Forchuk, BScN, BA – Psychology, MScN, PhD, of the University of Western Ontario and Lawson Health Research Institute, and Amanda Meier, BA, Research Coordinator, Lawson Health Research Institute. Findings from the evaluation were used to revise the training module before it was published and distributed provincially. Overall, the project increased diabetes knowledge for peer support workers and increased confidence for peer support workers to speak about diabetes and mental illness at their CSIs. Feedback from participants was generally positive and any critiques were valuable in forming recommendations for future training modules. Download the Final Diabetes and Mental Health Evaluation Report 2012 (PDF).
Additional Information	www.diabetesandmentalhealth.ca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Deadline to Register for OPDI Peer Support Training – May 31, 2013
MAY 10, 2013
Ontario Peer Development Initiative (OPDI) is offering a Peer Support Core Essentials Training Program!
New video about peer support
AUGUST 31, 2012
Standing Together is a new video from the Diabetes and Mental Health Peer Support project. Featuring interviews with project team members and peer
About the Project
Diabetes and Mental Health Peer Support was a two-year project (2010-2012) to provide diabetes competency training for mental health peer support workers. [more...]
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News and Events
Deadline to Register for OPDI Peer Support Training – May 31, 2013
New video about peer support
Project Newsletter Number 4
The Lawson Foundation 2012-13 Diabetes Funding Opportunity opens Tuesday, April 10, 2012

Minding Our Bodies—healthy eating and physical activity for mental health Lead Organization: Canadian Mental Health Association, Ontario Contact: Scott Mitchell, Director Knowledge Transfer, Canadian Mental Health Association, Ontario Tel: 416-977-5580 ext. 4136 Email: smitchell@ontario.cmha.ca	
Program Goal	To increase capacity within the community mental health system in Ontario to promote physical activity and healthy eating for people with serious mental illness. CMHA Ontario's mental health promotion program serves as an "incubator" to help mental health service providers in Ontario, together with community partners, to develop and deliver evidence-based physical activity and healthy eating programs, improve access to local resources, and promote social inclusion.
Program Development • **Evidence base** • **Theoretical Framework**	This project emerged from CMHA Ontario's policy work focusing on the connections between mental health and chronic physical conditions. For an overview of that policy work and links to related information, see: http://ontario.cmha.ca/public-policy/cmha-public-policy/current-issues/chronic-disease-prevention-and-management/ People with serious mental illness are at high risk for chronic physical conditions associated with sedentary behaviour and poor nutrition, including diabetes and cardiovascular disease. At the same time, mental illness can influence a person's health behaviours. Studies indicate that depression, for example, negatively impacts a person's nutritional choices, their commitment to exercise, and their adherence to medical therapies. Choices around diet, exercise, smoking and treatment adherence can all have a serious impact on the state of one's physical health. To compound the issue, psychiatric medications can cause significant weight gain and a high percentage of people with serious mental illness are smokers since smoking is often used as a means of combatting the side-effects of medication. Research evidence also shows that increased physical activity and improved diet can have significant positive

	effects when it comes to preventing chronic disease, improving chronic disease outcomes and supporting recovery from mental illness. Exercise can alleviate primary symptoms of depression and anxiety, as well as secondary symptoms such as low self-esteem and social withdrawal. Yet despite the known benefits, physical activity and healthy eating interventions are not commonplace or well integrated with other services delivered by community mental health care providers in Ontario.
Program Details	A health promotion program to promote healthy eating and physical activity for people with serious mental illness.
• **Start Date – End Date**	2008-2013
• **Funding**	Ontario Ministry of Health Promotion
• **Target Audience**	Community mental health system organizations serving people with serious mental illness
• **Partners**	Minding Our Bodies is an initiative of the Canadian Mental Health Association-Ontario, in partnership with Echo: Improving Women's Health in Ontario, Mood Disorders Association of Ontario, Nutrition Resource Centre, YMCA Ontario, and York University's Faculty of Health with support from the Ontario Ministry of Health Promotion and Sport. The project Advisory Committee also includes representatives from: Parks and Recreation Ontario, Ontario Physical and Health Educators Association, Schizophrenia Association of Ontario, Ontario Public Health Association (Heart Health Resource Centre; Nutrition Resource Centre), Canadian Diabetes Association, and the Heart and Stoke Foundation of Ontario.
• **Geographic Location / Scope of Delivery**	Ontario
• **Activities**	• Advisory Committee • Project Website • Training ○ mental health workers, consumer leaders, and volunteers • Toolkit and resource to support program development (on-line)

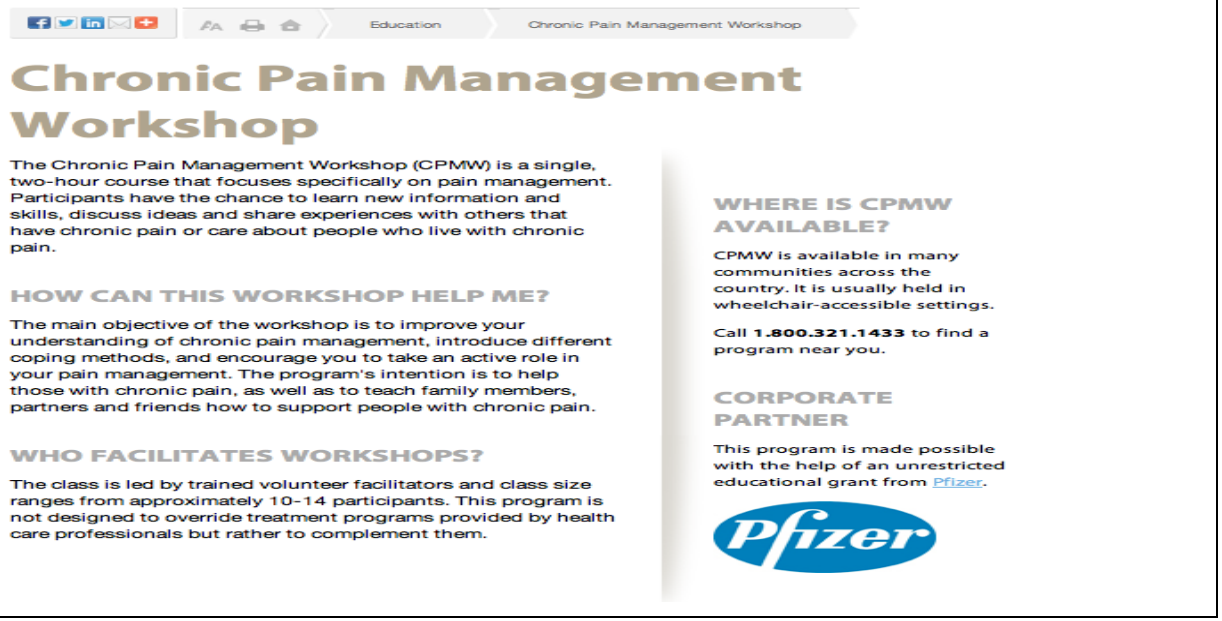
	• Pilot projects in community settings (12) • Strategy to implement the program across the province • Bi-annual project newsletter • Videos • On-line directory of physical activity and healthy eating programs • On-line community of practice • On-line resource library The Project Website (Minding our Bodies) serves as a vehicle for knowledge exchange enabling the sharing of best practices, providing tools to support program planning, and facilitating networking among community mental health providers. The Toolkit is primarily directed toward those who do not have prior experience starting a physical activity or healthy eating program in a mental health care setting. The toolkit was publicly released in March 2010 and significantly revised in March 2011. New resources will continue to be added as they become available. The information is best used in the pre-planning and planning stages of program development, however, the resource directory also includes tools that may be used beyond the planning stage. The toolkit provides a range of easy-to-use resources to help organizations create sustainable physical activity and healthy eating programs for people experiencing or recovering from serious mental illness. Many of the practical examples in the toolkit are drawn from an environmental scan and from the organizations who participated in the project as pilot sites. The toolkit contains the following sections: • Making the Case (including adaptable PowerPoint slides for use with potential partners and funders) • Getting Your Program Started (guide to program planning and preparation) • More Hands on Deck (building and sustaining effective partnerships) • Getting the Word Out (communications strategy) • Measuring Your Success (evaluation) • Sustaining Your Program • Resource Library The training and toolkit can support a variety of implementation scenarios, rather than a single, fixed program. Community mental health providers are expected to work in partnership with local stakeholders and to customize their physical activity and healthy eating programs to make use of local resources. Unlocking the

	Toolkit (promotional flyer) provides an overview of the Minding Our Bodies project and highlights the online resources that are available to help organizations start or sustain physical activity and healthy eating programs for people with mental illness. The training and toolkit were piloted in 12 communities during the first two phases of the Minding Our Bodies project (2008-2011). The purpose of the pilot phase was to assess the strengths of the Minding Our Bodies toolkit and training sessions and to identify gaps and areas for improvement. Staff and volunteers from the pilot sites attended a one-day training session in Toronto (April 2009 in phase 1, and September 2010 in phase 2). The pilot organizations were then responsible for planning, implementing and evaluating new physical activity and healthy eating programs in their local communities. A communications strategy was developed to raise awareness of the project and engage the broader community. Communications activities included the creation of program branding and production of a bi-annual project newsletter. The on-line Community of Practice (Community Forum) allows staff and volunteers across Ontario with a common interest in physical activity and healthy eating programs for people with mental illness to connect, start discussions, ask questions of experts, share and view success stories, and learn from peers. The Resource Library, part of the toolkit, is a database of ready-to-use resources to help plan, implement, evaluate and sustain a program. The purpose of the library is to share ready-to-use templates, forms, questionnaires and guides to help leaders develop and maintain their own physical activity programs and/or healthy eating programs in community mental health organizations. The library includes links to external resources created by government and non-profit organizations, new resources developed by the Minding Our Bodies team, and resources created by mental health agencies with physical activity programs and/or healthy eating programs that have joined the online community of practice.
Evaluation	An evaluation consultant was engaged to develop a detailed evaluation plan, create the necessary evaluation tools, train pilot coordinators and staff, assess the development and implementation of the project and look at project outcomes to identify whether the project has made a difference. Learnings from the evaluation process will be applied to improve the provincial mental health promotion program and inform the strategy for future implementation. The program pilot evaluation reports are available online.
Additional Information	In phase three, 20 new programs will be funded, training for peer facilitators will be developed and delivered in

	three locations around the province, and a series of knowledge exchange forums will organized to share lessons learned. 

Chronic Pain Management Workshop (CPMW) Organization: The Arthritis Society Contact: Lynne Moore, Director of Programs and Services Tel: (416) 979-3353 ext 3347 Email: lmoore@arthritis.ca	
Program Goal	The main objective is to improve understanding of chronic pain management, introduce different coping methods, and encourage people to take an active role in pain management. Help those with chronic pain; teach family members, partners and friends how to support people with chronic pain.
Program Development • **Evidence base** • **Theoretical Framework**	Based on a theory of behaviour change. In this regard, the Chronic Pain Management Workshop is loosely based on the Arthritis Self-Management Program developed by the Stanford University School of Medicine, Patient Education Research Center.
Program Details	A single, two-hour workshop intended to promote self-management of chronic pain.
• **Start Date – End Date**	
• **Funding**	Pfizer
• **Target Audience**	People living with arthritis, family members, partners and friends
• **Partners**	None
• **Geographic Location / Scope of Delivery**	National

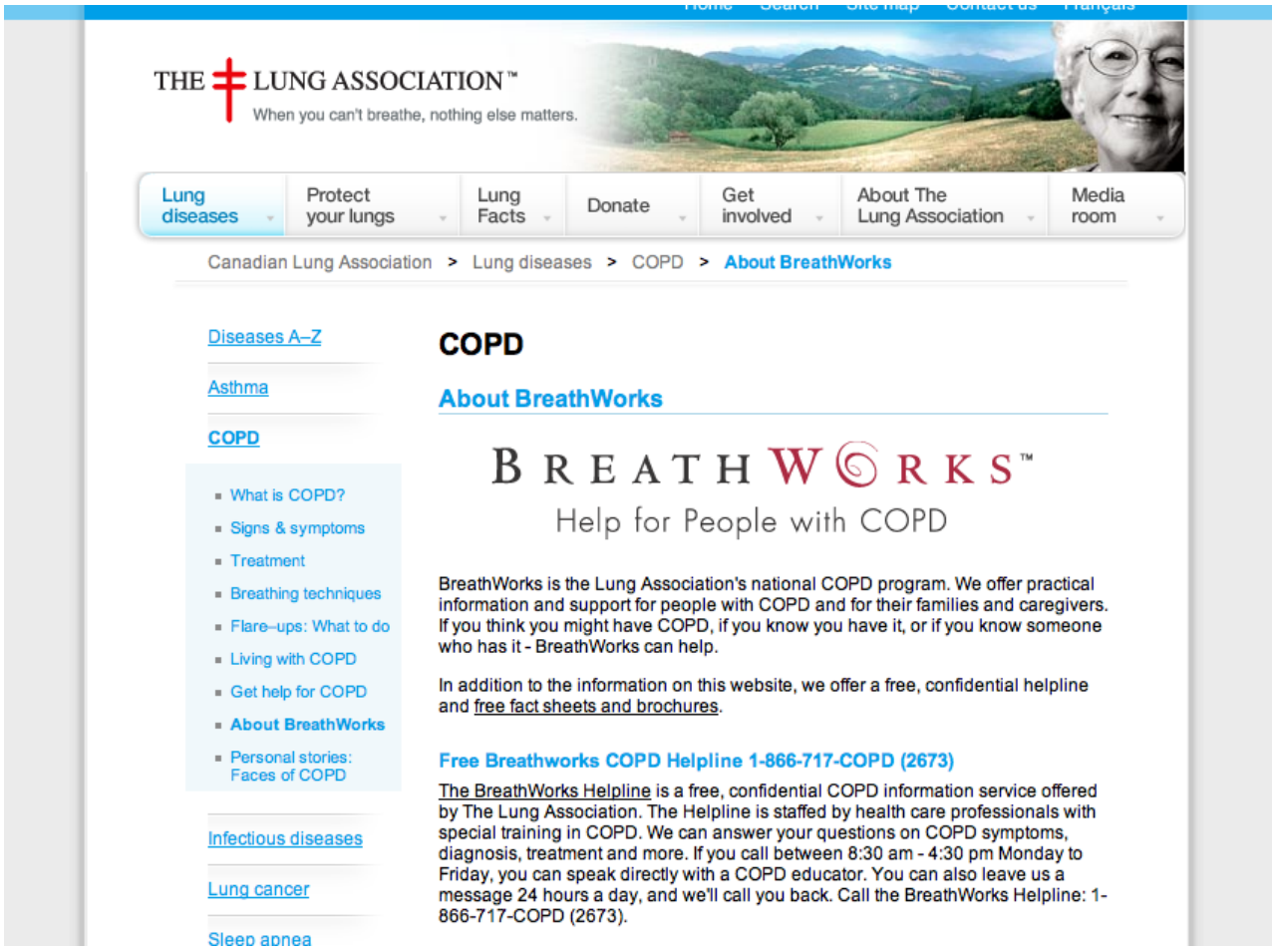
• **Activities**	Single two-hour workshop: • Learn new information and skills, discuss ideas, share experiences • 10-14 participants per workshop • Led by trained volunteers (peers, trained in delivery of Stanford's Arthritis Self-Management Program or people with experience of arthritis who have attended Arthritis Self-Management Program and taken the Chronic Pain Management Workshop) The content was developed by two experts: a rheumatologist (MD) and a PhD physiotherapist, both of whom specialize in pain and adult learning. The Stanford Arthritis Self-Management Program provided the background.
Evaluation	The Arthritis Society regional divisions that delivered the CPMW were asked to use a standardized evaluation template for participants, but there was no central collection or analysis of that data. In June 2013, The Arthritis Society soft-launched a new standardized evaluation process that is intended to give the national office the ability to provide consistent input and to analyze evaluation data across divisions.

Additional Information	

BreathWorks™ Organization: The Lung Association Contact: Andrea Stevens Lavigne, Ontario Lung Association, VP Provincial Programs Tel: (416) 864-991 x229 Email: astevens@on.lung.ca	
Program Goal	To offer practical information and support for people with chronic obstructive pulmonary disease (COPD) and for their families and caregivers (health professionals).
Program Development • **Evidence base** • **Theoretical Framework**	The program is theory- and evidence-based. Certified COPD Educators provide the intervention and the Canadian Thoracic Society Guidelines for COPD inform its content. The program is based in a chronic disease self-management model.
Program Details	BreathWorks is The Lung Association's national COPD self-management and support program. The program offers practical information and support for people with COPD and for their families and caregivers. It combines a website, a free and confidential helpline staffed by professional educators, and factsheets and brochures.
• **Start Date – End Date**	Ongoing since the late 1990s
• **Funding**	Majority internal to The Lung Association; small amount of pharmaceutical funding.
• **Target Audience**	People with COPD and their families and caregivers (health professionals). **Note that most people with COPD are over 65 years old.
• **Partners**	None
• **Geographic Location / Scope of Delivery**	National (Ontario Provincial Association takes lead on website maintenance and staffing the phone line)

• **Activities**	• BreathWorks Helpline • Website • Publications (factsheets, brochures guides and poster) • Support Groups (Ontario only) The BreathWorks Helpline is a free, confidential COPD information service offered by The Lung Association. The Helpline is staffed by health care professionals (Certified COPD Educators) with special training in COPD. Educators answer questions on COPD symptoms, diagnosis, treatment and more. The Helpline is open 8:30am - 4:30pm Monday to Friday; messages are accepted 24 hours a day and calls are returned. 1-866-717-COPD (2673). The Canadian Network for Respiratory Care certifies healthcare professionals as Certified COPD, Asthma and Respiratory Educators. This multidisciplinary group of educators represents a range of healthcare professionals, including: respiratory therapists, nurses, pharmacists and physiotherapists. COPD Educators rely on the Canadian Thoracic Society Guidelines for COPD. The website provides information on how to call the phone line and access to the specialized publications. • BreathWorks Plan Guide (PDF) - 40 pages. Explains what COPD is and lists the symptoms. Explains how to slow down COPD, how to treat it, and how to manage symptoms. • Medicines for COPD (PDF) - 8 pages. Describes the main medicines used to treat COPD symptoms and explains how to use them. • Oxygen therapy for COPD (PDF) - 8 pages. Explains the use of oxygen therapy for certain COPD patients. Talks about oxygen tanks, nasal prongs, and other oxygen equipment. Answers common questions about oxygen. Includes tips on using oxygen safely. • Pulmonary rehabilitation (PDF) – 4 pages. Explains how this specialized exercise and disease management program helps people with COPD. Talks about different kinds of pulmonary rehabilitation programs. • Managing COPD – includes a COPD action plan (PDF) – 6 pages. Explains how to manage COPD and treat symptoms. Talks about how to avoid flare-ups and what to do if flare-ups occur. Includes a COPD action plan, a form the physician can fill out to provide personalized instructions for each individual. This action plan explains how to change treatment depending on symptoms and when to get help. • How to avoid feeling tired: managing your energy with COPD (PDF) - 4 pages. Gives practical advice on how to pace and plan activities to avoid running out of energy. Explains simpler ways of doing everyday chores. • What to do if you are out of breath: breathlessness and COPD (PDF) - 4 pages. Provides strategies for catching

	the breath for those who feel breathless. Explains how to do pursed lip and diaphragmatic breathing. Shows pictures of body positions that make it easier to breathe. • Exercise and COPD (PDF) - 16 pages. Explains why exercise is important for people with COPD. Tells people how to introduce an exercise program gently. Introduces stretches and exercises that help people with COPD and includes pictures of people demonstrating each exercise. • BreathWorks poster, 11 x 17 • COPD brochure(PDF) - A trifold brochure • BreathWorks Package: This package includes fact sheets, a brochure, the 40-page BreathWorks Plan guide, a poster, and an order form. The Ontario Lung Association has supported the establishment of volunteer-led support groups. There are 18 support groups, with between 5 and 50 people attending meetings. Most participants are older people with COPD. The provincial office plays a central coordinating function, supports learning for group leaders, and engages group participants in provincial level advocacy (e.g., lobby days with MPPs, advocacy training). In 2013, The Ontario Lung Association published the How to Start a Lung Health Support Group booklet to provide practical step-wise advice to anyone who would like to develop a lung health support group in their community. The content was developed by volunteers, and encourages a health promotion focus for support activities. The booklet discusses several key areas for consideration when starting a support group such as: choosing a location, logistics, group structure, promotion of the support group and topics that might be of interest to group members. The Government of Ontario contributed funding to the production of this resource.
Evaluation	Periodic national evaluation (feedback from service users); most recent was 2 years ago.
Additional Information	http://www.lung.ca/diseases-maladies/copd-mpoc/breathworks-actionair/index_e.php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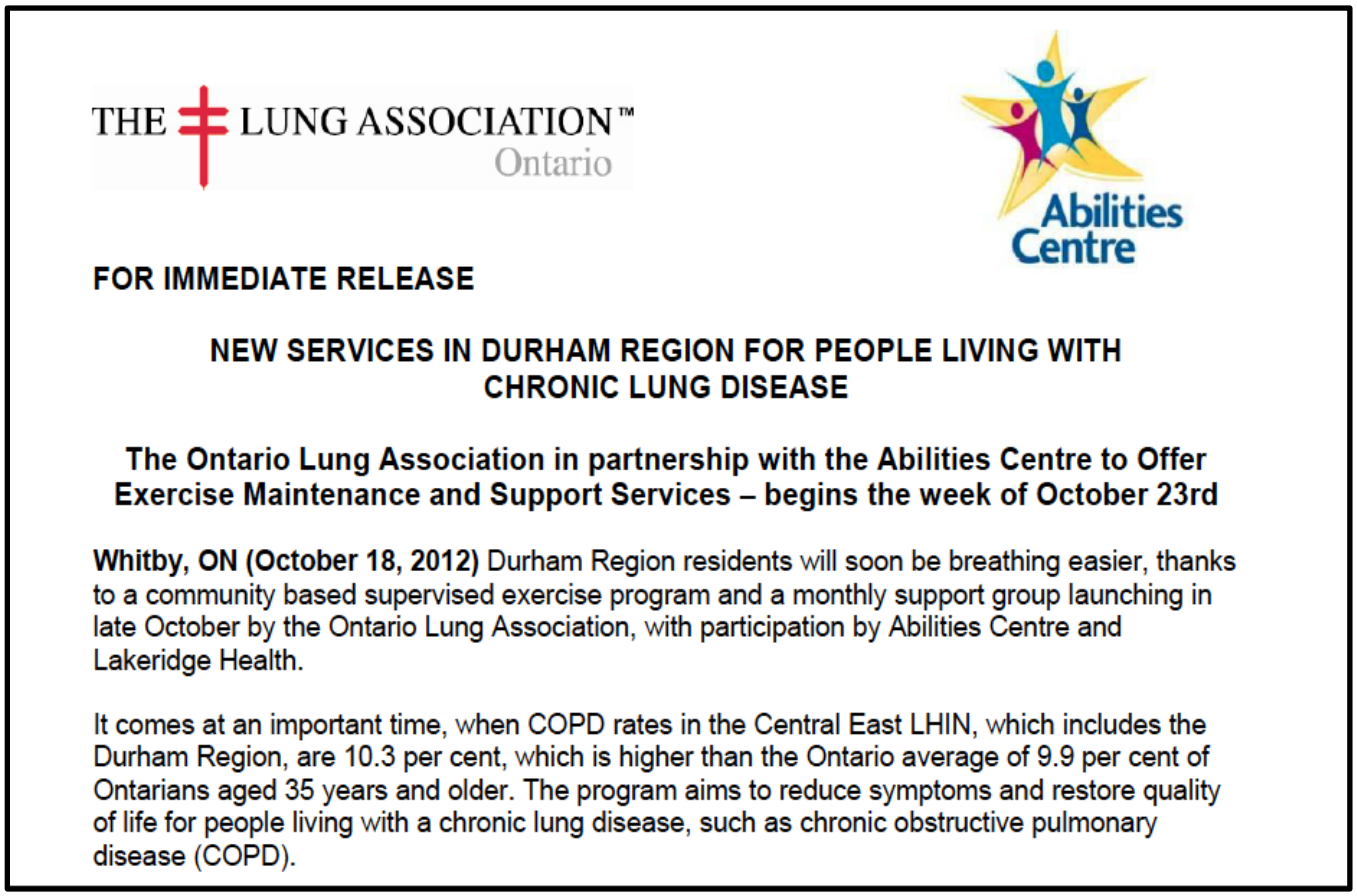
BreathWorks is the Lung Association's national COPD program. We offer practical information and support for people with COPD and for their families and caregivers. If you think you might have COPD, if you know you have it, or if you know someone who has it - BreathWorks can help.
In addition to the information on this website, we offer a free, confidential helpline and free fact sheets and brochures.
Free Breathworks COPD Helpline 1-866-717-COPD (2673)
The BreathWorks Helpline is a free, confidential COPD information service offered by The Lung Association. The Helpline is staffed by health care professionals with special training in COPD. We can answer your questions on COPD symptoms, diagnosis, treatment and more. If you call between 8:30 am - 4:30 pm Monday to Friday, you can speak directly with a COPD educator. You can also leave us a message 24 hours a day, and we'll call you back. Call the BreathWorks Helpline: 1-866-717-COPD (2673).

Exercise Maintenance and Support Group Pilot Program Lead Organization: Ontario Lung Association Contact: Andrea Stevens Lavigne, Ontario Lung Association, VP Provincial Programs Tel: (416) 864-991 x229 Email: astevens@on.lung.ca	
Program Goal	To reduce symptoms and restore quality of life for people with lung disease including chronic obstructive pulmonary disease (COPD).
Program Development • **Evidence base** • **Theoretical Framework**	This program was based on a long-term intervention offered by a local chapter (Ottawa) of the Ontario Lung Association.
Program Details	Community-based supervised exercise maintenance program and monthly support group for people with lung disease, including COPD.
• **Start Date – End Date**	The pilot ran from October 2012 to March 3013. The program is ongoing.
• **Funding**	Ontario Ministry of Tourism and Recreation
• **Target Audience**	People with lung disease, including COPD. **Note that most people with COPD are over 65 years old.
• **Partners**	Abilities Centre (Whitby Ontario), Lakeridge Health Corporation Respiratory Rehabilitation Program. The Abilities Centre is a charitable organization that delivers enriching sports, arts, music, and life skills opportunities for all ages and abilities. Opened in June 2012, the Abilities Centre is an International Centre of Excellence that serves local, national and international communities by providing resources and research tools that promote inclusivity and accessibility. The Abilities Centre helps people lose weight, increase mobility, follow their passions, and connect with their community.

	Lakeridge Health's Ambulatory Rehabilitation Centres (ARC) are a group of multidisciplinary outpatient clinics geared toward helping people continue their recovery following a hospital admission. One of the goals of these Centres is to prevent re-admissions to hospital by helping people better manage their conditions. The ARC's Respiratory Rehabilitation Clinic offers a supervised 8-week program of assessment, education and exercise designed to help persons with chronic lung disease live independently in the community, improve their quality of life and overcome the limitations resulting from their disease.
• **Geographic Location / Scope of Delivery**	Durham Region, Ontario
• **Activities**	Twenty people participated in the pilot program. The program was offered twice weekly in one-hour sessions. The exercise program combined endurance and resistance training (treadmills, cycles, weights) and walking on an indoor track. The cost was $5 per session. A physician referral may be required. Prior to starting, participants were assessed by an Abilities Centre qualified fitness trainer who had received lung disease and COPD training from the Ontario Lung Association. The support group is a BreathWorks support group, held monthly (See separate program documentation sheet for BreathWorks.) The program provides a much-needed social opportunity, providing patients with the chance to meet on a regular basis and share coping strategies with each other as well as build their physical endurance. The exercise maintenance program differs from hospital-based pulmonary rehabilitation programs in that the patients are not discharged after a few weeks or months.
Evaluation	A final evaluation report is being prepared.
Additional Information	The Ontario Lung Association has put in a proposal to the Ontario Ministry of Tourism and Recreation to expand the program to other sites. See the complete media release for the pilot at http://www.on.lung.ca/document.doc?id=1365.



THE LUNG ASSOCIATION™ Ontario

Abilities Centre

FOR IMMEDIATE RELEASE

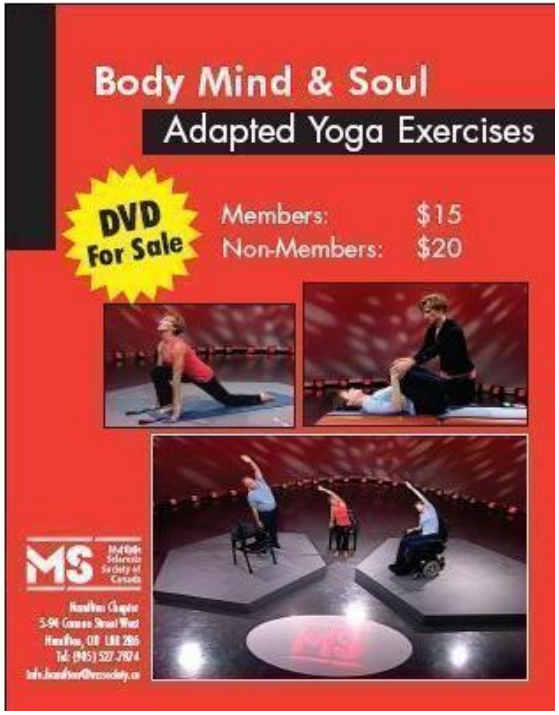
NEW SERVICES IN DURHAM REGION FOR PEOPLE LIVING WITH CHRONIC LUNG DISEASE

The Ontario Lung Association in partnership with the Abilities Centre to Offer Exercise Maintenance and Support Services – begins the week of October 23rd

Whitby, ON (October 18, 2012) Durham Region residents will soon be breathing easier, thanks to a community based supervised exercise program and a monthly support group launching in late October by the Ontario Lung Association, with participation by Abilities Centre and Lakeridge Health.

It comes at an important time, when COPD rates in the Central East LHIN, which includes the Durham Region, are 10.3 per cent, which is higher than the Ontario average of 9.9 per cent of Ontarians aged 35 years and older. The program aims to reduce symptoms and restore quality of life for people living with a chronic lung disease, such as chronic obstructive pulmonary disease (COPD).

Adapted Yoga Program Lead Organization: Multiple Sclerosis Society of Canada, Hamilton Chapter Contact: Catharine Everets, Senior Client Services Coordinator, Hamilton Chapter Tel: 905-527-7874 ext. 17 Email: catharine.everets@mssociety.ca	
Program Goal	To reduce stress and improve strength, flexibility and balance among people living with multiple sclerosis.
Program Development • **Evidence base** • **Theoretical Framework**	Evidence-informed – beneficial effects of hatha yoga are well known and this type of exercise is well-suited for people who require adapted fitness programs.
Program Details	Program consists of two different in-person yoga classes offered weekly and an adapted yoga DVD.
• **Start Date – End Date**	1993 to present.
• **Funding**	Ministry of Health Promotion (DVD production) In-person class participants pay $65 for 10 weeks of instruction DVDs are available for purchase - $15 for members, $20 for non-members
• **Target Audience**	People living with multiple sclerosis
• **Partners**	Certified yoga instructors
• **Geographic Location / Scope of Delivery**	In-person classes – Hamilton DVD – Available for purchase by telephoning Hamilton Chapter

• **Activities**	In-person yoga classes • One seated class per week, one modified standing class per week Adapted yoga DVD
Evaluation	
Additional Information	

Circle of Wellness Lead Organization: Multiple Sclerosis Society of Canada, Ottawa Chapter Contact: Laurie Cucheran-Morris, Director of Client Services, Ottawa Chapter Tel: 613-728-1583 ext. 3325 Email: laurie.cucheran-morris@mssociety.ca	
Program Goal	To build the capacity of people living with multiple sclerosis to achieve their wellness goals and live healthy lives with chronic illness.
Program Development • **Evidence base** • **Theoretical Framework**	Informed by clinical practice guidelines regarding the use of self-management strategies to combat fatigue among people living with multiple sclerosis. Positive outcomes observed when similar programs were offered in other communities (Calgary, Hamilton) – Ottawa chapter decided to adapt the program for their use. Peers provide input into the program – inform the choice of topics to be covered, speak about their experiences to the group during the wellness series.
Program Details	Circle of Wellness is a chronic disease self-management workshop series for people living with MS.
• **Start Date – End Date**	Series offered on on-going basis.
• **Funding**	Original grant from Ottawa Community Foundation. Participants pay $20 to participate. This fee covers the cost of speaker honourariums and a portion of program coordinator's time.
• **Target Audience**	People living with multiple sclerosis who have experienced significant change and have the cognitive capacity to set goals for themselves.

• **Partners**	Originally offered in partnership with the Ottawa Rehabilitation Centre who provided in-kind support from a staff social worker. Due to funding changes, this partnership is no longer in place.
• **Geographic Location / Scope of Delivery**	Ottawa Region

• **Activities**	• Wellness workshop series
	  • Workshops offered once/week (2 to 2.5 hours) for 6-8 weeks (offered in two four-week blocks)
	  • Goal setting – each participant sets 2-3 wellness goals at the beginning of the series which they would like to work towards meeting
	  • Topics include: symptom management, emotional healing, anger management, healthy relationships, building self-confidence and self-esteem, exercise, nutrition, naturopathy, yoga, stress management.

Evaluation	Program participants provide feedback on their experience at several time points: • Feedback on guest speakers/topic-specific content at end of each workshop session • Verbal and written feedback at the end of the series, participants rate their own participation in each session • Follow up feedback collected at 3 months and 6 months post-workshop • Participants are asked to comment on outcomes – did they meet their wellness goals? (Scale of 1-10)
Additional Information	There are approximately 8 participants/group. Lunch is provided at each session.

Building Bridges to Better Health Lead Organization: Multiple Sclerosis Society of Canada, Hamilton Chapter Contact: Catharine Everets, Senior Client Services Coordinator, Hamilton Chapter Tel: 905-527-7874 ext. 17 Email: catharine.everets@mssociety.ca	
Program Goal	To improve the ability of people living with chronic illnesses to cope with their disease and its treatment and live fulfilling lives.
Program Development • **Evidence base** • **Theoretical Framework**	Based on programs developed by the Patient Education Resource Center at Stanford University School of Medicine.
Program Details	This chronic disease self-management program consists of a series of workshop designed to introduce and refine skills that are useful for the daily management of chronic illness. Participants also develop personal action plans to ensure they can translate their learnings into practice.
• **Start Date – End Date**	
• **Funding**	
• **Target Audience**	People living with chronic illnesses
• **Partners**	Saint Elizabeth Health Care
• **Geographic Location / Scope of Delivery**	Hamilton

• **Activities**	Workshop series: • Different topics covered each week • Skills-building related to daily management of chronic illness • Development of personal action plans Supplementary Workbook Education sessions are offered by the MS Society based on member interests (2-4/year). Though these are usually advertised within the MS community, all people living with chronic disease are welcome to attend. Topics include: symptom management, MS and exercise, stress management, communication with health care professionals, etc.
Evaluation	
Additional Information	All workshop participants receive a workbook. Participation in this program is free. *Note: Building Bridges to Better Health* was described as being similar to the *Taking Charge* programs offered by the local LHIN. In an effort not to duplicate services, the MS Society, Hamilton Chapter have stepped aside, allowing the LHIN to deliver cross-disability chronic disease self-management programs moving forward.

MACcess Fitness Program: Adapted Exercise Program for Individuals with MS

Lead Organization: Multiple Sclerosis Society of Canada, Hamilton Chapter

Contact: Suzie Ward, Kinesiologist & Program Coordinator, McMaster University
Catharine Everets, Senior Client Services Coordinator, Hamilton Chapter

Tel: Suzie – 905-525-9140 ext 22576, Catharine - 905-527-7874 ext. 17

Email: catharine.everets@mssociety.ca

Program Goal	To increase access to adapted exercise for persons living with multiple sclerosis so that they may experience the benefits of physical activity (flexibility, balance, endurance, aerobic fitness, strength, etc.)
Program Development • **Evidence base** • **Theoretical Framework**	Program is evidence-based. Research shows that people living with multiple sclerosis benefit from exercise.
Program Details	This adapted group fitness program is delivered by skilled trainers and trained volunteers for people living with multiple sclerosis once per week. Participants have the option of a seated class or a modified standing class, both including both aerobic and resistance exercises.
• **Start Date – End Date**	
• **Funding**	Pharmaceutical company provided initial funding to get program up and running. This covered equipment costs, instructor training, etc. Participants pay $50 per 16 week semester to participate.
• **Target Audience**	People living with multiple sclerosis.
• **Partners**	McMaster University – MacWheelers Exercise Program (accessible physical education for people with spinal cord injuries)

• **Geographic Location / Scope of Delivery**	Hamilton, ON
• **Activities**	Group fitness classes • Led by trainers with specialized education in adapted fitness programming • One-on-one support from volunteers (university students in Kinesiology and Physiotherapy programs) • Aerobic and resistance exercise • Seated or modified standing classes • One hour/week
Evaluation	Though the MS Society offers support and referrals for this project, it is technically a MacWheeler program. The MS Society usually uses participant surveys to collect feedback on this type of intervention, but they are not aware of the evaluation plan for this activity. To their knowledge, no evaluation has been completed as yet.
Additional Information	Participants may attend on an on-going basis, but must re-register every 4 months.

New Fitness Program

The MS Society of Canada, Hamilton Chapter is pleased to inform you of a new **Adapted Exercise Program** offered to individuals living with Multiple Sclerosis. This program is called **Mac***cess Fitness* offered through the MacWheelers Exercise Program.

It is well documented that individuals living with MS experience vast benefits from regular exercise. However, finding an adapted exercise program that can accommodate the varied needs of the MS community is challenging to say the least. Meeting that challenge is **Mac***cess Fitness*. A weekly group fitness class geared specifically towards the adaptive needs of the MS population to increase flexibility, balance, endurance, as well as cardiovascular and muscle strength. Classes will be held in the athletic center at McMaster University, and will include a combination of aerobic and resistance training, and will be taught by trainers who have experience working with special populations to ensure appropriateness of exercises in this group. Participants will also benefit from one-on-one assistance from trained volunteers. This program will run two classes once a week however based on demand it may increase.

MAC H^{2}OPE Lead Organization: YMCA Hamilton/Burlington/Brantford Contact: Hamilton Downtown Family YMCA Tel: 905-529-7102 ext 5024 Email: machopeclinic@mcmaster.ca	
Program Goal	To increase access to physiotherapy and occupational therapy services for people with limited financial resources and limited health insurance benefits.
Program Development • **Evidence base** • **Theoretical Framework**	Plenty of evidence exists to show the benefits of physiotherapy and occupational therapy for people living with chronic conditions.
Program Details	No-cost community-based occupational therapy and physiotherapy services provided by rehabilitation students (with clinical supervision). Services include home assessments, exercise plans, chronic disease management, etc.
• **Start Date – End Date**	July 2013 to present
• **Funding**	Forward with Integrity Initiative
• **Target Audience**	Individuals who require physiotherapy or occupational therapy but who do not have the financial resources or insurance coverage to pay for these services.
• **Partners**	Live Well Partnership – McMaster University School of Rehabilitation Science, YMCA Hamilton/Burlington/Brantford, Hamilton Health Sciences
• **Geographic Location / Scope of Delivery**	Hamilton Downtown Family YMCA

• **Activities**	One-on-one physiotherapy and occupational therapy services by appointment or on drop-in basis
Evaluation	
Additional Information	This program provides services to the community while also providing practical learning opportunities for rehabilitation students.

MS ActiveNOW: Activating Your Life Organization: Multiple Sclerosis Society of Canada Contact: Alberta & Northwest Territories Division Tel: 1-800-268-7582 Email: active@mssociety.ca	
Program Goal	• Increase awareness of the value of exercise for persons with MS among those living with MS and service providers in the health and physical activity sectors. • Support trainers in developing exercise programs that are safe and appropriate for individuals with MS. • Increase access to community-based fitness and exercise opportunities for individuals with MS. • Encourage individuals with MS to integrate physical activity into their daily lives.
Program Development • **Evidence base** • **Theoretical Framework**	Literature on the benefits of exercise for people living with multiple sclerosis (symptom management, increased strength and mobility, decreased fatigue, decreased risk of comorbidity, etc.) is cited throughout program documents (website, tools & resources, etc.). Also, books and articles which provide evidentiary support for this intervention are listed on the program website at: http://mssociety.ca/alberta/active-literature.htm
Program Details	For people living with MS, local chapters provide in-person fitness and recreational programming and the MS ActiveNOW website offers fact sheets, tools and resources (such as training logs) for download. For professionals, MS ActiveNOW provides capacity building opportunities such as education sessions. Several evidence-based online resource guides written for fitness and lifestyle providers and health professionals on how to support engagement in physical activity by people living with MS are also available. More information on the program is available at: http://mssociety.ca/alberta/active.htm
• **Start Date – End Date**	2008? to present
• **Funding**	Alberta Lottery Fund

• **Target Audience**	This program targets people living with MS, professionals in the exercise sector and health care providers.
• **Partners**	Many resources developed in partnership with The Steadward Centre for Personal & Physical Achievement.
• **Geographic Location / Scope of Delivery**	Province of Alberta
• **Activities**	• In-person exercise and recreation programs offered by MS Chapters in cities across Alberta. Clients also linked to other community-based exercise programs available in their jurisdiction. • Physical activity resources developed and made accessible to people living with MS, fitness professionals, health care providers. • Education sessions on physical activity and MS. • Advocacy to improve access to physical activity programming for people living with MS.
Evaluation	None publicly available

Additional Information