



HOLISTIC APPROACHES FOR APHA'S IN RELATION TO CAREER DEVELOPMENT

Fact Sheet



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Overview

Established in 1997, CAAN:

- is a National and not-for-profit organization.
- represents over 160 member organizations and individuals.
- provides a National forum for members to express needs and concerns.
- provides relevant, accurate and up-to-date information on issues facing Aboriginal people living with and affected by HIV/AIDS in Canada.
- is governed by a twelve member National Board of Directors and operated by a four member Executive.

The Canadian Aboriginal AIDS Network (CAAN)



Mission Statement

The mission of the Canadian Aboriginal AIDS Network is to provide leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS regardless of where they reside.

Disclaimer

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Recent advances in the clinical treatment of HIV/AIDS have improved health and longevity for many people who live with the disease. As a result, some Aboriginal Persons with HIV/AIDS (APHAs) may consider finding work, returning to work, or remaining in the work force despite HIV-related disabilities.

It is important not to overemphasize the success of current treatments. It must be remembered that the long-term effectiveness of treatments is unknown and that no cure is in sight. As well, clinical data is uncertain regarding the success of immune reconstitution, even among people who respond well to combination therapy. The trauma of being gravely ill and/or near death can affect a person mentally, emotionally and spiritually long after physical recovery from therapies. Modern medicine is finally beginning to recognize that it is the balance between the physical, the mental, the emotional, and the spiritual that defines health.

There has been little research to assess the needs of APHAs in the workforce or to evaluate the ability of existing public and private sector programs to respond to those needs. It is extremely important for APHAs to consult widely and assess the impact of returning to work through discussions with family, friends, counsellors, medical professionals, and AIDS Service Organizations (ASOs). There are many questions to consider before a decision can be made.

PERSONAL CIRCUMSTANCES ...

- Is there a desire for greater variety, challenge, participation and satisfaction in life?
- Is income security an issue (e.g. Pension Plan, Social Assistance, Unemployment Insurance)?
- Are basic needs being met adequately (e.g. food, clothing, shelter ...)?
- Are social needs being met adequately (e.g. support of family, friends, community ...)?

- Are there problems with life skills or social skills?
- Are there problems with self-esteem and/or confidence?
- Is there fear of failure or other anxiety associated with returning to work?
- Are there already too many demands on time and energy from dependants (e.g. children, elders ...)?

PHYSICAL HEALTH ...

- Is there a desire for greater physical activity?
- Do healthcare professionals recommend a return to work?
- Are physical health needs being met adequately (e.g. access/quality of medical care, medications ...)?
- Are current levels of physical health likely to continue next week, next month, or next year?
- Are energy levels high enough to tolerate the physical demands of work?
- Are there problems with eating or sleeping habits?
- Are there problems with the side effects of medications (e.g., nausea, fever, digestive disorders ...)?
- Are there problems with vision, balance, coordination, or dexterity?
- Are there problems that would impact personal safety and/or the safety of others?

MENTAL HEALTH ...

- Is there a desire for greater mental challenge?
- Do healthcare professionals recommend a return to work?
- Are mental health needs being met adequately (e.g. access/quality of mental health care, medications ...)?
- Are current levels of mental health likely to continue next week, next month, or next year?
- Are energy levels high enough to tolerate the mental demands of work?

- Are there problems with eating or sleeping habits?
- Are there problems with the side effects of medications (e.g. drowsiness, absent-mindedness ...)?
- Are there problems with fatigue, memory, concentration, planning, organizing?
- Are there problems with communication skills, problem solving skills, or decision making skills?
- Are there problems that would impact personal safety and/or the safety of others?

EMOTIONAL HEALTH ...

- Is there a desire for greater emotional satisfaction?
- Do healthcare professionals recommend a return to work?
- Are emotional health needs being met adequately (e.g. access/quality of emotional care, medications ...)?
- Are current levels of emotional health likely to continue next week, next month, or next year?
- Are energy levels high enough to tolerate the emotional demands of work?
- Are there problems with eating or sleeping habits?
- Are there problems with the side effects of medications (e.g. depression, helplessness, hopelessness ...)?
- Are there problems with fatigue, memory, concentration, planning, organizing?
- Are there problems with communication skills, problem solving, decision making?
- Are coping skills adequate (e.g. dealing with deadlines, stress, anxiety, change ...)?
- Are there problems with stability of mood or emotions?
- Are there problems that would impact personal safety and/or the safety of others?

SPIRITUAL HEALTH ...

- Is there a desire for greater spiritual balance?

- Do spiritual advisors recommend a return to work?
- Are spiritual health needs being met adequately (e.g. access to spiritual teachings, helpers ...)?
- Are there problems that would impact personal safety and/or the safety of others?

There are many positive factors (physical, mental, emotional, and spiritual) as well as financial advantages to employment. However, while the benefits of working are important, there may also be some negative factors requiring careful consideration.

PRACTICALITY ...

- Are there appropriate employment opportunities within commuting distance?
- Are there better options (e.g. self-employment, working at home, traditional hunting & fishing ...)?
- Will there be problems with fatigue?
- Will there be problems with drug benefits?
- Will there be problems with income stability?
- Will there be problems with safety for oneself or others?
- Will there be problems with stigma and/or discrimination?
- Will there be problems with transportation to and from work?
- Will there be harmful disruptions in eating and/or sleeping habits?
- Will there be a need to move away from the community or the province?

EMPLOYER ...

- Will the employer require full-time, part time, or casual hours?
- Will the employer be accommodating re: time off around episodic illnesses?
- Will the employer be accommodating re: physical modifications to the workplace?

- Will the employer be accommodating re: modification of tasks and/or work schedules?
- Will the employer be accommodating re: “flex time” in consideration of fluctuating health status?
- Will the employer be accommodating re: therapeutic regimens (e.g. medical appointments, follow-ups ...)?
- Will there be hazards that may have a negative impact on health?
- Will there be problems with universal precautions/protocols?
- Will there be problems with confidentiality, stigma, racism ...?
- Will there be problems with getting support in the workplace?
- Will there be problems if a previous job is no longer available?
- Is there a risk of becoming unemployed?

MOVING ...

- Will there be overwhelming stress due to relocation?
- Will there be access to traditional medicines and teachings?
- Will there be access to a provincial drug plan or other assistance?

ALTERNATIVES

In spite of the physical, mental, emotional, and spiritual benefits of working, there are times when employment is not the best choice. Productive daily activities may provide some of the same therapeutic benefits as paid employment without endangering health and/or essential private/public disability benefits. APHAs may want to consider volunteer work, education, or training. As social beings, we all yearn to find our place in society. A large part of our identity comes from how we spend our time; what we consider important; where and with whom we share our many gifts and skills ...

VOLUNTEERING

Volunteering is a practical way for APHAs to build stamina, confidence, and a sense of place in the community. Aboriginal organizations, businesses, and communities benefit as APHAs further themselves by meeting people, interacting, networking, refining old skills, and developing new ones.

EDUCATION OR TRAINING

Access to education, training, and funding varies from province to province.

REHABILITATION SERVICE PROVIDERS

APHAs in small First Nation Reserves, Inuit Hamlets, or Metis Settlements have limited employment opportunities, if any. The continuing challenges of homophobia, stigma, and discrimination take on greater proportions in communities where everyone knows each other, often further reducing employment options. Strategies must be developed for these people; as well as for those who live more traditionally (i.e. off the land). It is essential to keep in mind that a number of Aboriginal people living with HIV have little or no work experience and need access to training opportunities at all levels.

When addressing vocational rehabilitation for APHAs, it is important to understand the cyclical nature of the illness; the needs of APHAs in the workforce; the ability of existing public and private sector programs to respond to those needs; as well as the mental, physical, emotional, and spiritual components of the illness itself. Despite pressure from private or public insurers, the decision of whether or not to work cannot be decided solely on markers such as CD4 count or viral load. APHAs must be free from coercion. Work should be an option for those who wish

it; however, APHAs must be at the centre of the decision making process; and, they must be able to access culturally appropriate vocational rehabilitation programs.

An Aboriginal person may take advantage of, for example an Ontario model of support:

Should the Aboriginal person be receiving the Ontario Disability Support Program (ODSP) Income Supports or ODSP Employment Supports, s/he must show that s/he has a physical or mental disability that is expected to last for one year or more, and be verified by a doctor or someone else who has the prescribed qualifications under the ODSP Act. The effect of the disability must make it hard to find or keep work.

If a person is already employed, but is having difficulty in meeting the requirements, s/he may be eligible for Employment Supports. The kinds of situations that would be considered to be a “crisis” and establish eligibility for ES include:

- risk of losing a job because one cannot perform the essential duties
- erratic work history;
- employment can no longer support the person or the person and his or her family;
- work seriously aggravates the person's disability;
- nature of the disability will mean that at some point in the future, the person will have to change
- person is now employed in a capacity below a previous level (i.e., different duties or fewer hours of work) because of the disability, or
- employment supports would increase earning capacity and eliminate or reduce reliance on social assistance.

Should you find this overwhelming to look into you can also contact Employment Action at Tel: (416) 340-2437 or by E-Mail at solutions@employmentaction.org.

They will review your current situation and advise you of their services they can offer such as: Assessment & Career Planning, Benefits Counselling, Resume Preparation, Training Opportunities and Search and Planning Assistance in dealing with lifelong episodic illness. In addition they can also help to arrange temporary, unpaid work trials with employers to help build your skills and confidence and gain valuable references, all the while promoting Employment Action to agencies and businesses that understand and support the needs of people living with HIV/AIDS and work with them to secure leads and placements. They will work with you in the first few months of employment to ensure that the transition back to work is a healthy experience and will intervene with employers should an issue arise.

Lifelong episodic illness:

The long-term economic forecast for many Aboriginal people with lifelong episodic illness is an ongoing struggle. The phrase ‘income security’ assumes that there will be a reliable and predictable source of income. While income support and security is a concern among all Aboriginal people with disabilities, the unpredictable nature of episodic illness poses unique challenges in terms of maintaining a steady income. If your main source of income is a disability pension (tied directly to your health status) and your health status is changing frequently due to the nature of your condition, then income security is challenging, at the best of times. Disability benefits may be “cut off” during periods of improved health status, and then be difficult to reinstate later, when your health status takes a turn for the worse. There is an acknowledged need for a holistic health approach, which includes social policy and service provision relating to income support. A number of issues in relation to long-term disability insurance are brought forward as Aboriginal people with chronic and unpredictable conditions seek financial support from insurance plans, in both the public and private sectors. There is a complex ethical dilemma regarding disclosure of health

information, and an agreement that the system itself often provides disincentives to return to work (i.e. Danger of loss of benefits if you return to work is not the only concern). A common fear was expressed as, “I’m feeling fine now, but I am afraid of what might happen if I go back to work and then I get sick again.”

The claims process is a very complicated and laborious; and there is consensus that it needs simplification. If a claimant’s health status is changing frequently (unwell/very unwell/now feeling better) ‘new’ forms must be constantly filed to reflect changes in health status. There is a requirement to continually prove (or re-prove) your illness. It has been stated, “It feels strange to be trying to heal and get better while at the same time trying to convince insurers that you are at death’s door!” This becomes unwieldy not only for the Aboriginal person, but also his/her health care provider(s) — especially the family physician who often functions as ‘gatekeeper’ for both the public and private sector insurance providers.

There is the impression that APHA’s who “look healthy to me” (as viewed by employers, co-workers, social workers, etc.) do not have ill health.

There is also a perceived lack of understanding on the part of many government assistance assessors and private insurance claim adjudicators in regards to the unique circumstances of claimants living with episodic illness.

Aboriginal people can access a retirement income system by the following three levels:

- Old Age Security (OAS) provides the first level, or foundation. If you meet certain residence requirements, you’ll be entitled to a modest monthly pension once you reach the age of 65.
- The Canada Pension Plan (CPP) is the second level of the system. It provides you with a monthly retirement pension as early as 60, if you have paid into it. The

Canada Pension Plan also offers disability, survivor and death benefits. Quebec has a similar plan, called the Quebec Pension Plan.

The first and second levels of Canada’s retirement income system make up Canada’s public pension system. Today, these pensions form a significant part of the income of Canada’s seniors. But public pensions are not intended to meet all of your financial needs in retirement. Rather, they provide a modest base for you to build upon with additional, private savings.

- The third level of the retirement income system consists of private pensions and savings.
- Many employers help you build your retirement income by providing pension plans. But perhaps you are self-employed or have no employer plan. Maybe you want to supplement your pension income.

You can build your own nest egg through Registered Retirement Savings Plans (RRSPs). Or you can earmark for retirement other investments such as mutual funds or the equity in your home.

The Government of Canada provides tax assistance on savings in Registered Pension Plans (RPPs) and RRSPs, which encourages and assists saving for retirement.

One of the strengths of Canada’s retirement income system is that the risks and responsibilities are shared by individuals, employers and governments. The result is a balanced, flexible system that responds to the different financial needs of individuals and families over the course of their lifetime.

Employers, assisted by advocacy from AIDS service organizations and incentives and regulations from governments, can reduce some of the risks of and barriers to returning to work. Workplace education and information initiatives could seek to reduce discrimination related to HIV/AIDS, which would in turn reduce the fear of loss of employment (Grubb &

McClure, 1997). Employers could provide information about their benefits packages to potential employees at their first interview. Not providing such information unless requested can be seen as an indirect form of discrimination. Employers could also join together to create an employment bank for APHAs who would like to take on short-term positions if they felt up to it on a given day or in period of time, which would address barriers to health fluctuations or uncertainty and to medication side-effects.

Disability compensation plan administrators, again helped along by advocacy from AIDS service organizations and incentives and regulations from governments, could also make an important contribution to facilitating return to work for APHAs. The status quo is a lose/lose proposition in the context of HIV/AIDS and other chronic illnesses with a fluctuating or uncertain course. Disability compensation plans lose because only a small sub-set of APHAs will take what constitutes a very risky leap; APHAs lose because they never get the opportunity to receive the incremental benefits of paid work. As an important first step, disability compensation plans could allow APHAs to undertake volunteer work, to attempt a trial of paid work, and to attend training and resume-writing programmes, which remove APHAs' fear of losing their disability compensation and medication coverage if they even experimented with these activities.

These plans could also be very beneficial to increasing incremental benefits of work by guaranteeing that APHAs' base income will remain steady if they undertake paid work and that a reasonable level of additional income will be provided for their efforts. Private/government plans could also guarantee portability of medication coverage through, for example, a guaranteed drug card. This new initiative would remove a lot of stress of losing their medication coverage if they lose their jobs and remove the need to find ways to assess workplace benefits. Plans could also guarantee an immediate return to disability compensation and medication coverage if an APHA loses his/her job or must leave it for

health-related reasons. The traditional approach of dealing with a re-opened claim, which involves a waiting period, especially if they are moving from one province to another, and dealing with the real possibility of being turned down for disability compensation and medication coverage, is clearly as unacceptable to most APHAs as it is to most injured workers. There is a definite need for Aboriginal people to have barrier free legislation and an enabling environment for people living with the unique challenges of episodic illness. Human rights legislation is an important vehicle for effecting and enforcing change. Another area is to use education for better awareness at many levels: the Aboriginal person living with the illness; the caregiver(s) and family of the Aboriginal person; healthcare providers; employers; insurance companies and funders; and, policy makers at various levels of government, regarding the unique needs of Aboriginal people living with episodic, unpredictable illness and disability.

Recommendations for consideration/follow-up:

- Clearly state why lifelong episodic illness is different from other chronic illness/disabilities for Aboriginal people.
- National Aboriginal organizations undertake shared work on developing useful common definitions.
- Define Aboriginal similarities pertaining to long-term episodic illness among disability groups and define common goals re: policy, research and programming.
- Create flexible alliances to address public education, public action, and support for Aboriginal people.
- Continue to explore Aboriginal organizational support for ongoing collaboration.
- Investigate funding sources to support collaborative work in regards to episodic disability issues.

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- Encourage an Aboriginal environmental scan re: programs and strategies (Canada and abroad) that addresses long term, episodic illness in an integrated manner.
 - Encourage Aboriginal research re: early intervention and relapse prevention.
 - Encourage Aboriginal research on the economic benefit of best practices (i.e. cost savings of effective management of episodic illness).
 - Encourage a comprehensive review of existing studies pertaining to labour force involvement of people living with episodic illness/disability.
 - Advance the Aboriginal agenda on workplace accommodations/workforce involvement.
 - Advocate for change with insurance providers (public and private) regarding current claim management and criteria. Re-establish a formal means of communication with the “Disability Insurance Committee” of the Canadian Life and Health Insurance Association (CLHIA).
 - Consider forming a national Aboriginal consumer-provider task force to address insurance policy issues overall.
 - Consult widely with APHA’s all across Canada to provide personal challenges, insights, and expertise; and involve APHA’s at all levels and in all areas from the ground up.

Notes:

A number of sources were consulted in preparing this position paper. The Canadian Aboriginal AIDS Network acknowledges the contribution of the following sources:

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Grubb I, McClure C, "Back to the Future: A Feasibility Study on Return-to-Work Programming