



**Presentation to the Law Amendments Committee on
Bill #59, An Act Respecting Accessibility in Nova Scotia
March 2, 2017, NS Advisory Commission on AIDS**

The Nova Scotia Advisory Commission on AIDS (the Commission) thanks the Law Amendments Committee for the opportunity to speak to the proposed legislation. My name is Michelle Proctor-Simms, and I am the director of the office of the Commission. By provincial statute, the Commission is an arm's length advisory body to the Minister of Health and other ministers on matters relating to HIV and AIDS. Our purpose is to champion strong, informed government and public action on HIV/AIDS in Nova Scotia.

The Commission supports the need for and intent of the proposed legislation that will establish the framework and authority to develop accessibility standard and regulations to increase the health, well-being and independence of people living with disabilities. Because of advances in treatment, HIV/AIDS is now considered a chronic, manageable condition and is often experienced as an episodic disability.

We have carefully reviewed the Bill and attended a presentation on its contents. We recommend three amendments that we believe would help to ensure the legislation enables all Nova Scotians with disabilities to enjoy full and effective participation in society through greater access to critical income and employment supports:

1. **Include episodic disability in the definition of disability:** Clause **S 3(1, h)** currently states that *"disability' means a physical, mental, intellectual or sensory impairment that, in the interaction with a barrier, hinders an individual's full and effective participation in society."* *Episodic disability* is not specifically mentioned in this definition. However, the Commission recommends that the definition be revised to include episodic disability. The term episodic disability includes conditions like HIV/AIDS, multiple sclerosis, lupus, arthritis, diabetes, chronic pain, and mental illness to name a few. An increasing number of Canadians are living with such health conditions and disabilities that are lifelong and episodic. These conditions/disabilities are marked by fluctuating, recurrent and unpredictable periods and degrees of wellness and disability that can vary in severity and duration.

Many people living with episodic disabilities are in their prime working years. They often move in and out of the labour market in an unpredictable way, and have difficulty securing stable employment and/or income supports when they are unable to work. Current income and employment support programs do not adequately address the needs and realities of most people living with an episodic disability. These supports best meet the needs of either people with temporary disabilities/conditions who can return to employment and relinquish supports, or people with permanent disabilities or conditions (congenital or acquired) with some limitations or no capacity to enter or re-join the workforce.

People with episodic disabilities rely on a range of federal, provincial, and/or private programs with features that often exclude them or discourage them from entering and/or returning to paid employment when they are well. These restrictive features include:

- strict eligibility criteria and/or definition of disability, with each having their own criteria and definitions
- no allowance for variable work patterns (e.g., part-time)
- no partial benefits if working less than full-time
- unclear rules/policies that are sometimes subject to determination, or not transparent or communicated well
- lack of coordination or navigation support within and between the various programs

Benefit levels associated with the income support/replacement programs are also inadequate.

People living with episodic disabilities also may not want to “risk” entry or return to the workplace when they are well. This fear is often based on risks of: being (further) stigmatized; losing health benefits associated with a private or public disability, or an income support program, when a health plan is not associated with a potential employment opportunity or, if there is one, there is a waiting period or clause excluding certain pre-existing conditions; and losing a reliable source of income if/when they relapse. After an extended period of absence from the workplace, some people might also worry they are not able to “cut-it” and/or will be fired if they need to regularly take time off work to attend medical appointments.

For these reasons, many people living with episodic disabilities experience and are trapped in a downward spiral into poverty, social and economic exclusion, and reduced health and well-being. This increases the demand on health and social support systems.

Therefore, the Commission strongly recommends revising the definition to include episodic disability, and that specific accessibility standards (as per clause **S 29 [a,b]**) -- that would remove barriers to income security, employment, and workplace

accommodation in the context of a person's intermittent work capacity -- be developed in collaboration with public (provincial and federal governments) and private disability, employment and income support/replacement program providers.

2. **Include the Departments of Labour and Advanced Education (LAE) and Community Services (DCS) on the Accessibility Advisory Board:** The mandate of the Department of LAE is to *"provide fairness, safety and prosperity for all Nova Scotians by helping them live, learn and work to their highest potential."* In its mission statement, the DCS states that it *is committed to a sustainable social service system that promotes the independence, self-reliance, and security of the people we serve. This will be achieved through excellence in service delivery, leadership and collaboration with our partners.* Toward this end, the DCS is transforming and redesigning its programs to enhance effectiveness and efficiency in helping vulnerable Nova Scotians. Therefore, under the section "accessibility advisory board," the Commission recommends that clause **S 13 (4)** be amended to include the ministers of these departments, or their designates, on the proposed Accessibility Advisory Board.
3. The Commission further recommends **strengthening the authority of the Accessibility Advisory Board.** Clause **S 17(a)** currently states that the Board shall *"suggest measures, policies, practices, and requirements that may be implemented by the Government to improve accessibility."* The word "suggest" seems weak given the significance of accessibility issues. Changing this word to "advise," "urge," or "call on" may strengthen the ability of the Board to act on improving accessibility.

In conclusion, the Commission has been engaged in work related to episodic disability for more than a decade. We have developed extensive knowledge of the impact on income and employment, and of the barriers faced by people living with episodic disability; and of evidence-based, cost-effective solutions to increase access to critical services and supports. The Commission would be pleased to discuss or assist with any stakeholder engagement around the issues and recommendations, including future development of accessibility standards that relate to income security and employment for persons living with episodic disabilities, and accommodation in the context of intermittent work capacity. Again, the Commission thanks the Law Amendments Committee for the opportunity to put forth our concerns and recommendations regarding Bill #59.



BACKGROUND

Income Security and Employment for People Living with HIV in Nova Scotia

Purpose

The purpose of this Background is to provide an overview of issues in Nova Scotia related to income security and employment for people living with HIV (PHAs). It will demonstrate that PHAs often have specific income-related challenges and identify some key actions that could be taken by a range of stakeholders to improve their economic well-being.

What is the issue?

It's estimated that approximately 80,500 Canadians are living with HIV.¹ HIV is a lifelong illness, but the symptoms may come and go. As a result, it is referred to as an "episodic disability": periods of good health may be interrupted by periods of illness or disability. Like other episodic disabilities, such as multiple sclerosis, lupus, arthritis, diabetes, and mental health conditions, it is difficult to predict when episodes of disability will occur or how long they will last. Income security – a reliable and predictable source of adequate income – is a concern for all people with episodic disabilities.

Common sources of income for PHAs are partner support, part-time work and retirement income, and health and disability benefits, such as:²

- ⊙ Employment Support and Income Assistance (ESIA)
- ⊙ Employment Insurance (EI) sickness benefits
- ⊙ Long term disability (LTD) and extended health benefits (vision, dental, prescription drugs, physiotherapy, etc.) provided by employee group insurance plans and NS Pharmacare
- ⊙ Canadian Pension Plan Disability Program (CPP-D).

Many people relying on these income supports face financial hardship as these sources of financial support are generally insufficient to cover rent, food, telephone and heating. It is even more of a strain to make ends meet for some PHAs and others with special medical needs as they must also cover over-the-counter medications, transportation (e.g., for medical appointments), alternative therapies, rehabilitation services, dental services, and other essentials (e.g., special diets).

In addition to living well below the poverty line, people living with episodic disabilities, including HIV, face a number of common barriers to income security from within income assistance and disability programs, including a lack of coordination. Those who are hardest hit by HIV are youth, seniors, and injection drug users as they are the least likely to have supportive employer-provided benefits.

Due to the strict definitions and policies that govern these benefit programs, there are no provisions for half-time, part-time or episodic or cyclical reductions in workforce participation. CPPD and ESIA does allow some earned income before clawing back benefits within a calendar year, but the income threshold is limited. Under Canada's EI system and many disability insurance systems, workers need to make a choice: to be either "in" the workforce, or "out" of the workforce.

Why is this important for NS?

Lack of income security and workforce opportunities in the province present a major challenge for Nova Scotia's aging population (including PHAs). As of February 2016, the unemployment rate was 9.1% (above the national average of 7.3%).³ According to Statistics Canada Low Income Cut Off (LICO), in 2011 an estimated 64,000 of Nova Scotians were living in low income. Poverty costs the province between \$1.5 to \$2.2 billion dollars a year when social and economic costs are taken into consideration.

The biggest problems reported by PHAs in a Nova Scotia study⁴ were unemployment and the subsequent lack of income to meet even basic needs. Many PHAs said they had to leave employment because they had become too sick to work, or due to pressure from employers. Returning to work means cancelling disability benefits, something PHAs may not want to risk doing given the episodic and unpredictable nature of HIV.²

Besides it being in the best interest of all of Nova Scotia to have people who are able and willing to work employed, workforce participation contributes to the health and wellness of PHAs, increases feelings of self-worth, increases social inclusion, and decreases health care and social service costs.

What can we do to improve the situation and who needs to be involved?

We are committed to working with various government departments and relevant advocacy groups to improve the structure, coordination, and benefit levels of federal and private sector disability programs and the provincial ESIA program. This includes the development of a common definition of "disability" that takes into account the episodic, reoccurring nature of conditions like HIV/AIDS and allows for part- to full-time work during periods of good health with the option for partial income support.⁵

Nova Scotia's income security and workforce challenges are being addressed across the government of Nova Scotia. In 2009, the Province of Nova Scotia released its Poverty Action

Plan (PAP)⁶, which focused on breaking the cycle of poverty for low-income people, and those most vulnerable and at-risk of falling into poverty.

Two of the PAP's main goals are to "Enable and reward work" and "Improve supports for those in need." Many of the key action areas of the PAP^{7,8} would have positive impacts for people living with episodic disabilities (including PHAs), such as:

- ⊙ Employment assistance services and career development supports for unemployed or underemployed individuals
- ⊙ Skills training and workplace education programs
- ⊙ Increasing Income Assistance Personal Allowance and the annual Poverty Reduction Credit
- ⊙ Expanding the Independent Living and Alternative Family Support programs to enable persons with disabilities to live as independently as possible

Below are some examples of government departments which have a joint responsibility on the issue of income security and employment for PHAs:

Department of Seniors (DS)

The NS Department of Seniors is responsible for providing leadership related to the independence and well-being of older adults, including the increasing proportion of PHAs who are in their senior years. In relation to income security and employment, a key strategic direction for the DS is to enhance workforce participation of older workers and marginalized communities.⁵

Department of Community Services (DCS)

The DCS plays a key role in ensuring social and economic well-being for all Nova Scotians, including PHAs.

Benefit Reform Initiative (BRI):⁹ The DCS acknowledges that its income assistance programs are not transparent and individuals are forced to sacrifice long-term interests for the sake of satisfying immediate needs. As part of the BRI, the DCS will be reviewing all of its employment support programming and services to enable clients to find and maintain employment, support those who are "job ready", and provide wage subsidies or on-the-job training supports to obtain and maintain employment (especially for under-represented groups and persons with disabilities). In 2015-16, the DCS will also be developing an employment framework for persons with disabilities.

Disability Support Program: This program serves people with intellectual disabilities, long-term mental illness, and physical disabilities in a range of community-based, residential and vocational/day programs. According to the DCS, there will be increasing efforts to abide by the UN Declaration on the Rights of Persons with Disabilities through a number of ongoing initiatives.

Labour and Advanced Education (LAE)

The LAE works to provide fairness, safety, and prosperity for all Nova Scotians by helping them live, learn, and work to their highest potential. LAE has many areas of responsibility that have an impact on the income security and workforce participation of people living with HIV and other episodic disabilities. For example, the LAE is redesigning the NS employment services system to better meet the needs of job seekers¹⁰ and has the Options Work Activity Program through MetroWorks that helps adults develop essential skills required to move into further training or employment opportunities.¹¹ LAE also plays a key role in educating employers about the particular employment challenges experienced by people with episodic disabilities, and the benefits of, and strategies for, employee retention and managing a diverse workforce.

What are some key considerations to guide our joint efforts?

Effective public policy will enhance income security and workforce participation. Neither poverty nor income insecurity are inescapable facts of life. They are problems that can be addressed by effective policy.

Low income has health consequences, and poor health leads to insecure income: People with low incomes are more likely to become ill. They're also likely to suffer more adverse effects from illness than people with higher incomes. And as experienced by many PHAs, episodic disability creates income insecurity.

Insecurity about the future: The unpredictable nature of HIV and concerns about income security both contribute to the stress experienced by people living with HIV. Stress adversely affects health.

Social inclusion or exclusion: Long-term unemployment impacts self-esteem. Paid work, volunteer activities, and social interactions are key to health, confidence, and dignity.

¹ PHAC (2015). *HIV and AIDS in Canada: Surveillance Report to December 31, 2014*

² Canadian Working Group on HIV and Rehabilitation (CWGHR). (2016). *Work and Income*.

³ Nova Scotia Labour Force Update February 2016.

⁴ Lewellen D (2012). Understanding the Experiences of HIV-Patients in Nova Scotia - Final report

⁵ NS Advisory Commission on AIDS (2014). *Review of Nova Scotia's Strategy on HIV/AIDS: Looking Back & Moving Forward*

⁶ Nova Scotia Poverty Progress Profile Update - Canada Without Poverty, 2013

⁷ NS Department of Community Services (2013). *Enable and Reward Work*.

⁸ NS Department of Community Services (2013). *Improve Support for those Most in Need*

⁹ NS Department of Community Services *Statement of Mandate 2015-2016*

¹⁰ NS Labour and Advanced Education (2016). *Providers Selected to Lead New Employment Services System*

¹¹ NS Labour and Advanced Education (2015). *Finding Fulfillment in Lifelong Learning*