



Nova Scotia Advisory Commission on AIDS

Review of Nova Scotia's Strategy on HIV/AIDS:

*Looking Back &
Moving Forward*

Executive Summary

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Prepared by:

Nova Scotia Advisory Commission on AIDS and Collective Wisdom Solutions

For questions or to request copies of this report contact the:

Nova Scotia Advisory Commission on AIDS

Phone: (902) 424-5730

Fax: (902) 424-4727

E-mail: aids@gov.ns.ca

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Introduction

For over 30 years, the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have been serious public health concerns for Nova Scotia, Canada, and the entire world^(1,2,3,4). While the overall reported incidence of new HIV infections and AIDS diagnoses have decreased, the virus continues to spread, particularly among marginalized populations^(4,5,6). The number of new diagnoses has decreased; however, the estimated number of people living with HIV/AIDS (PHAs) in Canada has risen by 11.4 per cent—from approximately 64,000 in 2008 to 71,300 in 2011⁽⁷⁾. This change has been attributed to both new infections and fewer HIV/AIDS-related deaths as treatments increase the survival of those already diagnosed. An estimated 25 per cent (17,980) of those living with HIV (71,300) were unaware of their HIV infection in 2011⁽⁷⁾.

Factors like stigma, discrimination, living in rural/remote areas, and poverty help explain why some communities and individuals are more strongly affected by HIV and have more difficulty accessing prevention, testing, treatment, and support services⁽⁴⁾. There is still no cure or vaccine for HIV/AIDS.

Nova Scotia's Strategy on HIV/AIDS (the Strategy) was released in December 2003⁽¹⁾. This document—*Review of Nova Scotia's Strategy on HIV/AIDS: Looking Back and Moving Forward* (the review)—assesses the implementation and outcomes of the Strategy.

Background to the Strategy

The Strategy is a provincial plan made up of 19 recommended actions under four strategic directions and four overall goals⁽¹⁾. It is based on a comprehensive consultation and strategic-planning process undertaken by the former provincial HIV/AIDS Strategy Steering Committee. A population health approach was the foundation for the Strategy. Integrating a gender and social inclusion approach was a major focus and priority for implementation. Ownership and accountability for the Strategy is shared among many stakeholders and partners, with the Nova Scotia Advisory Commission on AIDS (the Commission) as the coordinating agency for implementation, monitoring, and evaluation.

In 2004, the Commission established and provided secretariat support to four inter-sectoral working groups to facilitate the development of action plans to address the Strategy's recommended actions. Participation in the working groups gradually diminished, and they eventually disbanded. Since 2008, the bulk of the work has been carried out by project-specific committees led by either the Commission or another organization. Issues related to the implementation process are addressed in the main report of this document.

The Commission produced and disseminated annual updates on implementation activities up to the end of 2010⁽⁸⁾, after which it began planning the review. An evaluation framework⁽²⁾ for the Strategy was developed in 2007 and was the foundation for the design and implementation of this review.

Purpose and Priorities of the Review

The purpose of the review is to

- document and assess the outputs and outcomes of the key implementation activities associated with the Strategy
- determine the areas and key elements of success
- identify gaps and unmet needs as well as any implementation processes requiring revision

The logic-model components of the evaluation framework were based on the Strategy's four strategic directions and were used to structure and design the implementation plan. Priorities were selected from across the following components:

- **Care, treatment, and support**

- Availability and coordination of care for PHAs
- Cultural competency
- Availability of income and related support for the medical and non-medical needs of PHAs
- PHA workforce participation
- Stigma and discrimination

- **Health promotion, prevention, and harm reduction**

- Access to harm-reduction services (e.g., needle exchange, methadone maintenance treatment, anonymous testing, barrier protection)
- Public-awareness initiatives and learning opportunities for media

- **Knowledge development and exchange**
 - Mechanisms/capacity to collaboratively identify priorities and conduct research
 - Mechanisms to build linkages among researchers across disciplines
 - HIV/AIDS surveillance, especially for priority populations
- **Coordination, planning, and reporting**
 - Awareness of and stakeholder engagement with the Strategy, including PHA participation
 - Integration of gender and social inclusion (GSI) approach
 - Sustainable funding for AIDS service organizations (ASOs)
 - Responsiveness to new or changing issues/monitoring and evaluation

Approach and Methodology

The review was initiated in the fall of 2012. It was undertaken by the Commission with the assistance of Collective Wisdom Solutions (CWS), a private consulting firm. The report was jointly prepared by the Commission and CWS. This was a review rather than a full evaluation, and a detailed initiative-by-initiative assessment was not undertaken. The focuses were on obtaining an overview of the actions, achievements, gaps, challenges, and issues within the four components of the Strategy and identifying priorities and opportunities for future collaborative action and policy direction. The review is rigorous and extensive, covering a cross-section of key priorities related to many of the recommended actions.

Stakeholder views on processes and outcomes within the four components were gathered by CWS in the following ways:

- Surveys with three stakeholder groups, including PHAs
- In-depth interviews with 15 key stakeholders
- Focus groups with two groups of key stakeholders

This information was consolidated and summarized by CWS to ensure confidentiality.

A document review of a wide variety of types of documents was undertaken by the Commission staff to validate and add more depth to the information gathered from the surveys and interviews and, in some cases, to fill in information gaps.

In the spring of 2012, the Commission partnered with Dr. Denver Lewellen (who was the Canadian Embassy Research Scholar and Fulbright Research Chair in Society and Culture, Sociology and Social Anthropology, Dalhousie University in 2012) to conduct key informant interviews with PHAs in Nova Scotia. An analysis of these interviews was used to support and add depth to many of the findings in this report.

Summary of Findings

Due to the variety of stakeholders surveyed or consulted, there were many viewpoints. On some issues there was a broad consensus, and on others there were differences of opinion.

Progress has been made, including some reduction in HIV stigma (especially within health-care settings) and the establishment and/or expansion of collaborative programs and health services (e.g., Mobile Outreach Street Health, methadone maintenance treatment programs, anonymous HIV testing, needle exchange). However, more work is needed to increase access to such services, particularly outside the Halifax Regional Municipality and in rural areas. There has been some increased capacity for culturally competent services, with some informants suggesting that such services have improved for women, aboriginal people, gay men, and youth. That being said, culturally competent services are often ad hoc and not available equally across the province.

The review reveals significant resource and systemic challenges to addressing the recommended actions in the Strategy. A lack of resources was the biggest challenge identified by an overwhelming proportion of respondents. The Strategy is regarded as underfunded, with inadequate resources and supports for implementation, including stable and sufficient funding for community-based AIDS services and other organizations.

Data from all sources demonstrate the range of complexity and potential difficulties for PHAs and those at higher risk who lack sufficient economic resources and community or social support. Overall, the review suggests that health and social service systems do not respond well to chronic illness, and that stigma continues to be a barrier to service.

There is an overall need to build capacity for culturally competent and holistic approaches to care, increased system coordination/navigation, and advocacy, especially for marginalized populations. More work is needed to increase access to education, testing, and prevention-related services in a way that connects with other related sexual-health and social determinants of health issues and sectors.

As the HIV/AIDS policy landscape is shifting toward integration with other sexually transmitted and blood-borne infections (STBBIs) and/or chronic diseases, a re-examination of the scope of the Strategy and which issues should be integrated and which should be addressed separately is needed. Serious consideration is needed for how to best position the Strategy to achieve greater shared accountability and ownership; multi-stakeholder engagement and partnership; better use and leveraging of existing resources; and increased funding for implementation, ASOs and other community-based service providers, and PHA needs.

The following are identified as **priorities** for the future:

- ***Address the issue of integration.*** Respondents reflected on the need to address how HIV/AIDS is nested within these other issues while also noting the importance and necessity of HIV/AIDS-specific needs, especially around the issues of testing, treatment, and stigma. There are mixed views around whether treating HIV/AIDS as exceptional increases or decreases stigma and isolation.
- ***Reflect on and reimagine the role of the Strategy.*** Given the changing context in which HIV/AIDS work will be happening, respondents are asking many questions about the role of the Strategy, accountability, stakeholder engagement, role clarity, resources, and funding.
- ***Expand access to prevention, testing, and treatment.*** Continue to increase the accessibility to testing and needle exchange services and treatment that is culturally relevant and person-centred across the province, especially in rural areas.
- ***Improve education to reduce stigma.*** Invest in promoting sexual health through a harm-reduction approach, the education of medical doctors and other health professionals on HIV and HIV and aging and increasing public awareness around stigma.
- ***Increase social inclusion and cultural competency.*** Continue to ask, Who is missing and how can we best serve diverse and/or marginalized populations? This could be facilitated by increasing the use of tools such as intersectionality research and analysis⁽⁹⁾, expanding training to enhance inclusion and cultural competency, increasing outreach to diverse groups, and enhancing the collection and reporting of ethno-racial data in HIV/AIDS surveillance.

A more nuanced picture of progress and the areas for improvements is provided in the main report of this document.

Concluding Remarks

This review provides direction for a revisioning and renewal of the provincial Strategy for HIV/AIDS within a changing policy, service, and funding context. Stigma and marginalization remain key drivers of the epidemic—creating barriers to services—and must be addressed.

The review makes nine recommendations. Addressing the fundamental questions within the first two recommendations—questions related to integration, accountability, stakeholder engagement, resources, and funding—will pave the way to addressing the remaining seven recommendations. Moreover, addressing these questions will result in the shared commitment and ownership that is necessary to address the root causes and reduce the impact of HIV/AIDS in this province.

Recommendations

1. **By March 2015, the Commission and the Department of Health and Wellness (DHW) will convene a process to reimagine and renew the provincial response to HIV/AIDS in Nova Scotia.** This process will include the following:
 - a. *Address the issue of integration.* This includes what a renewed Strategy should be in order to reflect the movement toward integrated funding, policies, and services. Resource/capacity implications for ASOs and other service providers (including those who have not been significantly involved in HIV/AIDS work) and the impact on PHAs and those who are marginalized must be thoughtfully explored and analysed.

Given the prevailing stigma and discrimination and overlap in the populations affected, it is important to determine what issues and services would benefit from an integrated STBBI and/or chronic disease approach and those that would benefit from an HIV/AIDS-specific focus. Further, this work should be linked to and informed by the research project “Exploring the Landscape of Communicable Diseases in Atlantic Canada,” which will be completed by March 31, 2014.[†]

[†] Led by the Atlantic Interdisciplinary Research Network (AIRN) and funded by the Public Health Agency of Canada (PHAC), this project is a collaborative investigation into the current state of communicable diseases, affected populations, and associated service delivery needs in Atlantic Canada.

- b. *Address the issue of accountability and ownership.* This includes determining the roles and responsibilities of various stakeholders and identifying mechanisms to enhance engagement and collaboration and give the Strategy “teeth.” Questions should include the following:
 - i. What should be the role of the Commission given the evolution of HIV/AIDS work?
 - ii. What should be the role of the DHW (e.g., public health, primary care) and other provincial government departments in relation to the Strategy?
 - iii. How can shared ownership across the health, social, justice, and education systems for better-integrated policy and service delivery be achieved?
 - iv. What is the best way to re-establish and/or strengthen linkages with and engagement of ASOs, PHAs, and other stakeholders?
 - v. Given the complexity of issues relative to the social determinants of health, what is the best way to monitor and evaluate the Strategy?
 - c. *Address funding and resource requirements for supporting a renewed Strategy and to increase accessibility to prevention, testing, care, treatment, and support.* This includes increases in funding and support to ASOs and other front-line service providers who assist PHAs and/or those most vulnerable (e.g., people who are street-involved and/or living with concurrent mental-health issues and addictions).
2. Concurrently with recommendation #1, **the DHW and the Commission will convene a review of provincial HIV testing policies (including prenatal screening guidelines) as part of the continuum of quality health care for Nova Scotians that is aligned with the new national guidelines for HIV screening and testing released by the PHAC⁽¹⁰⁾.** This needs to take into account strategies to make HIV/STBBI testing and counselling services accessible to Nova Scotians in all of their diversity, innovations in testing technology (e.g., point-of-care testing), stigma and criminalization, and infrastructure to respond to potential increases in HIV screening and support needs for new diagnoses.

Once the fundamental issues have been resolved through acting on recommendations #1 and #2, the following additional seven recommendations should be addressed:

3. **The Commission, in partnership with the DHW, ASOs, and the Hepatitis Outreach Society, will develop innovative strategies for the coordination and navigation of services for PHAs and people with hepatitis C and/or co-infected, particularly those outside the Halifax Regional Municipality.** Collaboration with the district health authorities (DHAs) and a wide range of health professionals and relevant cultural and/or support organizations is required to ensure access across the province.
4. In keeping with the recommendations of the Episodic Disabilities Network⁽¹¹⁾, other relevant advocacy groups, and other documents completed for the Strategy, **the Commission will work with the Department of Community Services and relevant advocacy groups to improve the structure, coordination, and benefit levels of federal and private sector disability programs and the provincial Employment Support and Income Assistance 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. **The Commission will work with the DHW to address specific concerns of diverse PHAs living on assistance or low incomes related to Pharmacare, including copayments, the cost of over-the-counter medications, and coverage of prescribed drugs not on the formulary.**
6. **The AIRN and the Commission will work with the DHW to identify mechanisms that can sustain and facilitate collaboration among academics, community/service providers, and policy-makers in the identification of important research questions and increase uptake of results at the service delivery and policy levels.** There is a need for an intersectional approach to research and policy analysis⁽⁹⁾ to understand the implication of policy decisions on different population groups.

7. **The DHW and other key stakeholders will invest in and develop education/training and awareness campaigns for key audiences to increase cultural competency and inclusion, reduce stigma, and build awareness of HIV/AIDS as a concern for all Nova Scotians.** This process will include the following:
 - a. The DHW, professional organizations, and universities will identify opportunities (e.g., Continuing Medical Education, professional conferences) to increase the training of medical doctors and other health professionals and/or front-line providers around stigma, cultural competency, harm reduction, and the basics of HIV and HIV and aging.
 - b. The DHW and the Department of Education and Early Childhood Development (DEECD) will increase the capacity and resources of youth-serving organizations (including youth health centres), parents, and educators to address issues related to sexual health, mental health, and addictions.
 - c. The DEECD and school boards will work with the DHW and other relevant partners to monitor, evaluate, and revise as required the sexual-health components of the public school learning outcomes framework⁽¹²⁾ and ensure ongoing access to training and support for teachers responsible for delivering these components.
 - d. The DHW and the Commission, in partnership with ASOs, will develop a public-awareness campaign to increase knowledge of HIV/AIDS and related STBBIs and reduce stigma.

8. **The DHW, the PHAC, the Commission, and other key stakeholders will work together to strengthen and support (including providing funding and increased collaboration) networks and organizations such as the Canadian HIV/AIDS Black African Caribbean (CHABAC) Network, the Health Association of African Canadians, Healing Our Nations, and others to address and make visible HIV/AIDS within their respective communities and increase collaboration with mainstream services and organizations.** Training and other skills-building initiatives need to be supported and expanded in order to increase the cultural competency of providers to more effectively work with and respond to the needs of diverse populations.

9. **The DHW and other key stakeholders will enhance the collection and reporting of HIV and other STBBI surveillance data.** This process will include the following:

- d. The DHW, NS Public Health Laboratory, and PHAC will work together to facilitate timely access to enhanced surveillance data to better understand trends in HIV/STBBI testing uptake, co-infection, risk factors, and behaviours within diverse population groups.
- e. The DHW, PHAC, and testing providers will improve the completeness of demographics data collected at the time of testing and during HIV-positive case follow-up, including information related to the social determinants of health.

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