

# A SYNTHESIS OF CANADIAN HIV / AIDS RELATED EVALUATIONS, 1998-2003

# Presented to

Health Canada Departmental Audit and Evaluation Committee

October 14, 2004

# **CANADIAN STRATEGY ON HIV/AIDS (CSHA)**

# SYNTHESIS EVALUATION: RECOMMENDATIONS AND REQUIRED ACTIONS Drafted: Feb10, 2004

Evaluation: Recommendations	Program Response: Current Status	Program Response: Action Required	Due Date for Completion	Contact Person
Develop a vigorous national evaluation strategy and apply it to new and existing initiatives. This strategy should distinguish between different types of evaluation (ex. activity reports vs. impact evaluations).	The development of a Results- based Management and Accountability Framework (RMAF), including an evaluation strategy, for the CSHA is currently underway.	Integrate the findings from the Synthesis Evaluation into the CSHA RMAF, including its evaluation strategy.	06/2004	Marsha Hay Snyder A/Manager HIV/AIDS Division Health Canada 613-946-3565
Responsibility for the national evaluation strategy should rest within a single centre.	Complete. Health Canada's Departmental Program Evaluation Division (DPED) has been designated the responsibility centre and has secured adequate funding and confidence of those funding, managing and using the evaluations.	N/A	N/A	Karen Gittens Analyst DPED Health Canada 613-941-0704
The responsibility centre should encourage and fund evaluations, set research standards, promote the use of rigorous methodologies and provide technical assistance.	Ongoing.	Develop an evaluation toolkit based on the model prepared by INAC, HRDC and FNIHB.  DPED has developed assessment criteria for evaluation studies which should be disseminated widely.  DPED provides technical assistance and will continue to do so.	Ongoing.	Karen Gittens Analyst DPED Health Canada 613-941-0704
The responsibility centre should work to strengthen the evaluation skills of community-based researchers.	Training of community-based researchers is now done on an <i>ad hoc</i> basis, depending upon the particular region.	Working with the CSHA program consultants, provide training to community based researchers by providing training in research design and both qualitative and quantitative methods.	2005	Karen Gittens Analyst DPED Health Canada 613-941-0704

# **CANADIAN STRATEGY ON HIV/AIDS (CSHA)**

# SYNTHESIS EVALUATION: RECOMMENDATIONS AND REQUIRED ACTIONS Drafted: Feb10, 2004

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Ensure that reliable knowledge with practical application is gained and shared. This will result in better analysis in the short term and better programming in the longer term.	An evaluation of the CSHA and a study of cost-effectiveness approaches have been completed in 2003-2004. Both reports have been shared within the CSHA and beyond.	Build partnerships among program managers, project organizers and professional evaluators so that each group can share its strengths and skills. Future evaluations and performance measurement strategies will ensure that best practices are highlighted and that recommendations to improve programming are practical.	Ongoing	Karen Gittens Analyst DPED Health Canada 613-941-0704
The responsibility centre should disseminate knowledge and encourage organizations to build this knowledge into their programs and projects.	DPED works closely with several funding streams of the CSHA to disseminate knowledge and use it to improve programming. For example, DPED has recently worked with the AIDS Community Awareness Program (ACAP) to develop a national questionnaire, the results of which will be rolled up, analyzed and communicated to projects for implementation of program changes, where appropriate.	Identify the most appropriate repository for all relevant evaluations undertaken in Canada and organize these evaluations so they are accessible.  Integrate the evaluation findings and draw more generalized conclusions from them.  Integrate evaluative research with other cohort or observational studies.  Provide training in evaluation methodology to program consultants.	Ongoing	Karen Gittens Analyst DPED Health Canada 613-941-0704
The responsibility centre should focus its evaluation efforts on a small number of research issues about which there are serious questions.	Some evaluative research has been done around the question of how to measure the cost-effectiveness of HIV/AIDS interventions.	Engage in a partnered priority-setting exercise for determining what to evaluate when.	01/2005	Karen Gittens Analyst DPED Health Canada 613-941-0704

# Building Knowledge

A Synthesis of Canadian HIV/AIDS-Related Evaluations, 1998-2003

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## **Executive Summary**

Evaluation is vital for improving the planning, operations, impact and cost-effectiveness of HIV/AIDS-related projects in Canada. The Canadian Strategy on HIV/AIDS (CSHA) has long promoted evaluation and the purpose of this *Building Knowledge* synthesis evaluation is to:

- understand what has been learned about the outcomes, impact and costeffectiveness of HIV/AIDS-related projects in Canada and to consider how these support the CSHA logic model; and
- ➤ to understand what these evaluations indicate about appropriate methodologies for evaluating HIV/AIDS-related projects and what is needed in way of an improved evaluation strategy and further research.

#### Methodology

The project identified approximately 165 evaluation reports undertaken in Canada between 1998 and 2003. None were outcome or cost-effectiveness evaluations in the true sense of the terms and most were activity reports prepared for accountability purposes although often including some consideration of short-term outputs.

The synthesis assessed all the evaluations on the basis of certain methodological standards and relied most heavily upon those that employed a reasonable level of rigour. Importantly, however, the synthesis did not restrict itself only to those evaluations. Instead it assumed that the other less rigorous work might also offer some important insights.

#### Reflections

There are a number of significant methodological challenges inherent in evaluating HIV/AIDS-related projects. Few evaluations had access to or employed those research tools that would have enabled them to attribute outcomes to activities, to measure whether their short-term outputs had any lasting impact, or to assess cost-effectiveness.

These shortcomings sorely limited their contribution to the CSHA knowledge base.

Outcome and cost-effectiveness evaluation is serious business that requires a robust, well-defined and reasonably sophisticated research strategy. Community-based projects, meanwhile, exist not for the purpose of evaluation but rather to provide supports and services, and to address the epidemic. Furthermore, projects are rarely if ever required, requested or funded to undertake rigorous outcome or cost-effectiveness evaluations or to be part of a coherent evaluation strategy. Instead funders ask them to report on what they did, how well they did it, how they spent their funding and – in a general way – what they accomplished.

#### **Findings**

Most often the evaluations identified outputs rather than outcomes and focused very narrowly on specific activities, for example the impact of an HIV testing project operating in federal correctional institutions. Nevertheless these had value and one evaluation, for example, identified how comprehensive community-based projects addressing women's needs could improve participants self-esteem and health, lead to less involvement with the criminal justice system, reduce or end completely their use of injection drugs and improve their knowledge of the risk factors associated with both injection drug use and HIV.

The evaluations – regardless of their limitations – provide some important lessons. One is that we should be realistic in terms in terms of what we can expect given the context in which they were undertaken. At present, the evaluations' greatest value may be in identifying how to improve project effectiveness in the short term and how to ensure that these projects respond effectively to client, sponsor and community need in the longer term.

Another lesson is that the projects appear to contribute toward the achievement of some of the CSHA logic model's immediate and intermediate outcomes. Certain evaluations, for example, suggest their projects provided reliable information to a range of community audiences. Others documented the new partnerships being forged among various community-based organizations, thereby addressing the logic model's immediate outcome of "increased involvement, participation and partnership." Others still appeared to enhance "access to effective prevention initiatives."

The evaluation reports also provided a number of methodological lessons. One is that Health Canada and the HIV/AIDS-related projects need to strengthen their evaluation efforts, processes and methods. Importantly, evaluations should adhere to certain well-

established standards for gathering and analyzing information and for reporting on findings. If agencies are not required to apply certain minimum standards to their evaluation efforts or to invest an appropriate level of resources, then they will not have useful results or reliable conclusions upon which to build ever more effective programs.

Another lesson is that new approaches may be required to evaluate HIV/AIDS-related projects given the complexity of the issues and people involved. It may well be important, for example:

- to involve both the community and professionals in every aspect of the evaluation process, and to determine when agency self-evaluation is appropriate and when independent evaluators are required for ensuring objectivity and for enhancing the final report's credibility.
- to enhance the degree of methodological rigour characterizing HIV/AIDSrelated evaluations in Canada, to ensure that baseline data are gathered prior to the project, to undertake longitudinal studies focusing on impact, to more fully investigate ethnographic and gender differences, and to ensure that clear standards are established, articulated and respected. There may be no value in investing always scarce evaluation resources in efforts that do not meet these standards.
- to place greater emphasis on qualitative research as a methodology and on improving researchers' skills in this regard. Qualitative research methods are entirely appropriate for this complex field of human activity and certainly reliable in their findings. It has to be emphasized and recognized, however, that this form of research is more than simply reporting on what people said and accepting their views as valid.

#### Conclusions

The reports considered for this synthesis evaluation suggest that the different HIV/AIDS-related projects are contributing, each in their own way, to addressing the epidemic in Canada. They suggest the value of the work being done and often identify the short-term results of that work. It may be entirely reasonable to assume that the projects, taken together, have had an impact on the HIV/AIDS epidemic in Canada. However we cannot be entirely confident in that assumption since most of the work does not have the methodological rigour that would instil confidence. To achieve this confidence requires:

- a significant level of commitment from program administrators and funders, and from project managers. They have to want the knowledge and the certainty that can flow from rigorous evaluations. And they have to understand the difference between year end activity reports and program reviews on the one hand and evaluation on the other.
- experienced evaluators with the specialized skills necessary for analyzing project or program impact and the role of these programs and projects in addressing the HIV/AIDS epidemic in Canada.
- particular tools to attribute outcomes to inputs and to analyze costeffectiveness.
- program funders and project administrators who are willing to commit adequate resources to support the research and sufficient time to track and measure outcomes. At present adequate resources and time are rarely provided.

#### Recommendation – An Invigorated National Evaluation Strategy

If Canada wishes to know about outcomes, impact and cost-effectiveness – with regard, for example, to the new safe injection site in Vancouver – it may well require a reinvigorated national evaluation strategy that incorporates the elements described above and applies them to existing or new initiatives. This strategy could direct and shape evaluation efforts, focus the research issues and ensure there is a body of evidence rather than a single report addressing certain key issues.

A single centre could be responsible for this strategy and for encouraging and funding outcome and cost-effectiveness evaluations, for setting research standards and promoting the use of rigorous methodologies, and for providing technical assistance. It could also undertake to strengthen the evaluation skills of community-based researchers by providing training in research design and both qualitative and quantitative methods.

The centre could also be responsible for disseminating knowledge and for encouraging organizations to build this knowledge into their programs and projects. It could organize the evaluations so they are readily accessible to those policy, project and program people who could benefit from their findings. It could also endeavour to integrate the

evaluation findings and to draw more generalized conclusions from them. It could endeavour to integrate evaluative research with other cohort or observational studies.

Health Canada, the Canadian Institutes for Health Research, a Centre for Excellence, a university or an HIV/AIDS-related non-governmental organization could become this responsibility centre. Who serves this function does not much matter. What does matter, however, is a recognition that its success will depend upon having both adequate resources and the confidence of those funding, managing and using the evaluations.

A new more clearly focused and more rigorous evaluation strategy may well be vital if Canadian efforts to address the HIV/AIDS epidemic are to be founded upon knowledge and rooted in practices that have proven their effectiveness. Program funds are always limited and rarely adequate to address the challenges presented by HIV/AIDS. A new, comprehensive and well-directed evaluation strategy could help to ensure that these funds are spent in a cost-effective manner.

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#### 1. Introduction

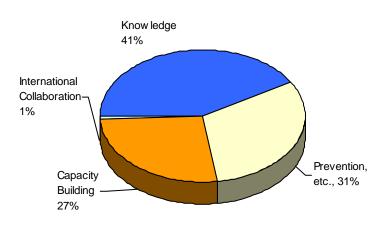
HIV/AIDS has been responsible for the death of over 20 million people around the world while in Canada it has cut a swath through vulnerable communities, leaving 13,000 deceased and 56,000 coping daily with its effects and impact. In 1998, the Government of Canada introduced the Canadian Strategy on HIV/AIDS (CSHA) to provide a coherent, on-going national framework for governmental and non-governmental organizations endeavouring to address the epidemic.

The CSHA enhanced public awareness of HIV/AIDS, built capacity through the more than one hundred community-based projects funded annually by the AIDS Community Action Program (ACAP), developed prevention programs for First Nations people and the Inuit, supported peer education among inmates in the federal correctional system, and provided quality assurance of HIV tests. As illustrated below, the CSHA also invested heavily in developing and disseminating

new knowledge, for example through both mainstream and Aboriginal research initiatives, surveillance, the Clinical Trials Network and the Canadian Youth, Sexual Health and HIV/AIDS Study (2003).<sup>1</sup>

The CSHA also endeavoured to build an evidence-based foundation for effective programming by including an evaluation component in its national and ACAP-funded activities. Evaluation – and its underlying monitoring, research and analysis – are vital for ensuring accountability and improving

#### **CHSA Funding Allocations by Activity Area**



the planning, operations, impact and cost-effectiveness of HIV/AIDS-related projects.<sup>2</sup>

# 2. Purpose and Objectives

In spite of the interest in evaluation, there have not been efforts to systematically integrate the knowledge accruing from the HIV/AIDS-related project evaluations addressing impact and cost-

<sup>&</sup>lt;sup>1</sup> For a review of the CSHA and its funding, see Spigelman, 2003.

<sup>&</sup>lt;sup>2</sup> See Health Canada, 1996:4/64.

effectiveness issues. The purpose of this *Building Knowledge* project, therefore, is to use a synthesis evaluation methodology for precisely that purpose.

A synthesis evaluation examines a range of different studies undertaken by different people at different times possibly using different methods. The synthesis evaluation has three important strengths. First, it adds to the knowledge base by drawing upon a number of sound studies with consistent findings. Second, when studies are methodologically weak, the knowledge that there exists no firm basis for action introduces an appropriate measure of caution. Third, a synthesis evaluation can integrate findings from studies employing both qualitative and quantitative methods.<sup>3</sup>

Focusing on evaluations undertaken in Canada between 1998 and 2003, this *Building Knowledge* synthesis endeavoured to:

- understand what has been learned about the outcomes, impact and costeffectiveness of HIV/AIDS-related projects;
- understand the gaps and limitations of the current CSHA logic model;
- understand what has been learned about appropriate methodologies for evaluating HIV/AIDS-related projects and help to build a new evaluation strategy; and
- guide further research on project impact and cost-effectiveness.

The expectation was that this synthesis would ultimately support Health Canada efforts to strengthen the CSHA through evaluation.

# 3. Methodology

#### 3.1 Evaluation Search

The project's first step was to identify and gather those evaluations examining impact and costeffectiveness undertaken in Canada since 1998. In addition to an internet search of many

<sup>&</sup>lt;sup>3</sup> United States, General Accounting Office, 1992.

different organizations and sources, a project Overview (Appendix A) and exploratory emails were sent to:

- representatives of the Health Canada branches involved with HIV/AIDS as well as Correctional Service Canada, the Canadian International Development Agency, the Ministerial Council on HIV/AIDS and the Federal/Provincial/Territorial Advisory Committee on AIDS;
- ➤ representatives of the Canadian AIDS Society, the BC Centre for Excellence in HIV/AIDS, the Canadian HIV/AIDS Legal Network, the Canadian Treatment Action Council, the Clinical Trials Network, the Canadian Association for HIV Research, the Canadian Institutes of Health Research, the Canadian Aboriginal AIDS Network and the Canadian HIV/AIDS Information Centre;
- > staff with government offices responsible for HIV/AIDS and selected community-based agencies in Quebec, Ontario, Manitoba, British Columbia and the Yukon; and
- ➤ approximately 80 participants in the 2002 Montreal Direction-Setting Follow Up meeting as well as another 30 academic and community-based researchers identified through the course of this work.

As a second phase in the search process, Health Canada and the principal investigator distributed the project's preliminary bibliography and requested recipients to identify any additional studies. The search produced approximately 165 reports.

## 3.2 Assessing Rigour and Selecting Studies

A major challenge in every synthesis evaluation is to assess the appropriateness, strengths and limitations of each report's methodology as well as the soundness of its conclusions and recommendations. This assessment is vital for ensuring that the synthesis' own conclusions rest upon a solid foundation. *Building Knowledge* assessed each evaluation on the basis of the following methodological tests.

Who evaluated the project and what were their qualifications or association with the project? Does the evaluation appear to be reasonably objective?

- Was the evaluation's methodology appropriate to the task? Were baseline data available and utilized? Did the evaluation focus on short-term outputs or did it track impact and outcomes through a reasonable period of time? Did the evaluation use control or comparison groups to identify project outcomes, to assess impact or to attribute impact to the project itself? These factors were particularly important given the synthesis' focus on outcomes as opposed to activities and outputs.
- ➤ What indicators were used to assess cost-effectiveness? Did the evaluation track these indicators through a reasonable period of time? What other programs were used for comparative purposes?
- Were the data fully explained and analyzed and were the conclusions and recommendations clearly rooted in the data and the analysis? Did the evaluation use triangulation or chain of evidence techniques?
- Were the conclusions reviewed and validated in any way, for example by the sponsoring organization or research peers?

A further test involved considering whether the reports themselves included some or all of the following:

- adequate descriptions of the project and of the evaluation's objectives, research issues, indicators and methodology;
- > a review and some incorporation of the relevant literature;
- ➤ a full presentation and analysis of the data relative to the evaluation's research issues as well as conclusions and recommendations that were clearly linked to the data and analysis; and
- appendices presenting the various research instruments and any other relevant materials.

The synthesis, in other words, established relatively high standards and then relied most heavily for its own analysis upon those evaluations that met at least some of these standards. Importantly, however, the synthesis did not restrict itself only to those evaluations that met the criteria identified above. Instead it assumed that the other less rigorous evaluations and reports

might also offer some important insights for shaping the future of HIV/AIDS-related programming in Canada.

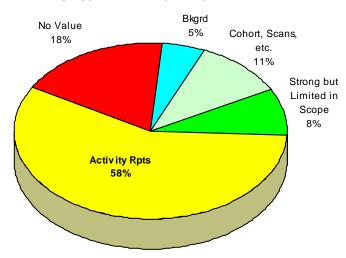
Of the 165 studies gathered for the synthesis evaluation – most of which were funded through the CSHA – approximately 30 were set aside because of their very limited value. Another eight were background studies supporting the synthesis evaluation itself. Of the remaining evaluations:

- none were outcome or cost-effectiveness evaluations in the true sense of the terms.
  This posed a significant challenge given the synthesis evaluation's objectives.
- approximately eighteen were not evaluations at all but rather observational or cohort studies, needs assessments or environmental scans. Generally, however, these were of a high quality.
- approximately fourteen used a credible approach and a reasonable methodology. Invariably, however, they focused on short-term outputs and on operational issues rather than on outcomes or cost-effectiveness.
- ninety-five were, by and large, activity reports prepared for accountability purposes although often including some effort to document short-term outputs.

The distribution of these studies by type is presented below. Most of these studies were useful

in their own way. They were not, however, consistent with the synthesis evaluation's focus on outcomes and cost effectiveness, or with the issues relating to the CSHA evaluation framework and strategy. A template (see Appendix B) was completed for those 105 evaluations that were relevant to this project.

#### Studies Review by Type & Value (n=165)



### 4. Reflections on the Evaluation Reports

The evaluation reports provide few insights into the outcomes flowing from or the costeffectiveness of HIV/AIDS-related projects in Canada.

In part this is due to the methodological challenges inherent in evaluating HIV/AIDS-related projects. These projects, for example, are invariably endeavouring to address a complex web of behavioural, social and economic factors that influence vulnerability, behaviour, service, support and outcomes. Projects intended to prevent HIV infection among injection drug users may make information, clean needles, counselling and on-going support available. Rarely, however, can they address the full range of conditions – including violence experienced as a child, stigma and discrimination – that contribute to drug use. One evaluation noted that "evaluating an HIV/AIDS prevention strategy with young marginalized women is too complex an undertaking for a simple pre-test/post-test approach...."

It is also methodologically challenging to attribute outcomes to activities. If incidence rates decline in the project's host community, for example, it may be a project outcome. Alternately it may be due to factors quite unrelated to the project itself, for example national HIV/AIDS prevention campaigns, provincial/territorial efforts to prevent discrimination, or local efforts to educate youth on sexually transmitted diseases. Furthermore, incidence rates have declined significantly across Canada and in other countries as well. It would be very difficult to evaluate whether the clients of a particular project are indeed responding to that project or simply are part of the larger trends.

To attribute outcomes to a project, evaluators require:

- baseline data on the situation prior to the project;
- an experimental group whose members participated in the project and a control or comparison group whose members did not participate but for whom everything else is identical; and
- the resources necessary to track both the experimental and control/comparison groups through an extended period of time.

<sup>&</sup>lt;sup>4</sup> Kinasevych, 2001:3.

By comparing the experimental and control/comparison groups over time, an evaluation may be able to ascribe observed differences to the project itself and there are certain econometric and other tools that can contribute to this effort. However HIV/AIDS-related project evaluators have not yet adopted these tools, and many may not have the skills or experience needed to use or explain them clearly.<sup>5</sup> Furthermore, the use of control groups would be ethically questionable in this realm of activity given that they would require projects to deny some people what are perhaps life-saving interventions for the sake of research.

Additionally, some evaluations may conclude that a project enhanced awareness of safe sex practices, developed certain skills or improved compliance with a particular treatment regimen.<sup>6</sup> The real issue, however, is whether these improvements had any continuing impact.

One evaluation, for example, noted the self-described impact of an ACAP-funded conference on participants' work with clients. However the evaluation team did not have either baseline data or the ability to survey participants 6 months or 12 months later to see if the conference had any continuing impact. The evaluation, in other words, measured short-term outputs rather than outcomes. This shortcoming characterized all of the studies under review.

Cost-effectiveness evaluation, meanwhile, is also a complex undertaking. Cost-effectiveness evaluations ask whether a project's approach is the most efficient way to achieve certain goals. In essence, these evaluations ask about value for money. They are broader than audits and different – "an evolution and in some sense a retreat" – from cost/benefit analyses.

In the reports under review, the evaluators often identified what funding was received from whom, the expenditures made and the purpose of such expenditures. In some cases they also documented that the project engaged volunteers and benefited from their contribution, or that ACAP contributions enabled the organization to leverage funds from other sources.

These may be used as indicators of or proxies for cost-effectiveness but they need to be accompanied by other considerations, namely a comparison of expenditures and outcomes across projects and some analysis of alternative means for progressing toward the same policy

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<sup>&</sup>lt;sup>5</sup> See Social Data Research, 2003: Executive Summary. This discusses the methodological challenges inherent in such work.

<sup>&</sup>lt;sup>6</sup> For example, see Strike, Myers and Millson, 2003.

<sup>&</sup>lt;sup>7</sup> Canada, Treasury Board of Canada, Results-Based Management, n.d.(a).

<sup>&</sup>lt;sup>8</sup> EKOS Research Associates, 2001.

Ost/benefit analysis endeavours to compare the economic costs and returns associated with a particular intervention, and often assesses this relationship from the perspective of clients, funders and society as a whole. See Social Data Research Ltd., 2003, for a discussion of methodologies used to make these assessments.

objectives. Yet there does not appear to be any generally accepted methods, formula or standards for assessing cost-effectiveness.

All in all, outcome and cost-effectiveness evaluation is serious business that requires a robust, well-defined and reasonably sophisticated research strategy. Community-based projects, meanwhile, exist not for the purpose of evaluation but rather to provide supports and services, and to address the epidemic. Project staff invariably believe their work has had a positive impact but this belief is based largely on intuitive logic and short-term outputs. This is not intended as a criticism. Indeed, it must be appreciated that projects are rarely if ever required, requested or funded to undertake rigorous outcome or cost-effectiveness evaluations or to be part of a coherent evaluation strategy. Instead funders ask them to report on what they did, how well they did it, how they spent their funding and – in a general way – what they accomplished.

As a consequence, most of the studies under review should be characterized as activity reports rather than program evaluations. As activity reports, many were reasonably good even though the methodologies they employed meant they could contribute little to the *Building Knowledge* objectives. Interestingly, this shortcoming is not unique to this particular synthesis evaluation. Lynne Leonard, for example, describes her:

... systematic review of 23 relevant, but largely methodologically weak primary studies and associated commentaries from 1997-1999 .... Of the 23 identified relevant studies for this project, none was assigned a global quality assessment rating of "strong," one was assigned a "moderate" rating and the remaining 22 relevant primary studies received a global quality assessment rating of "weak." ... The majority (55%) of the 22 weak studies were assigned weak ratings on five or more of the six component criteria. <sup>10</sup>

Similarly Yamada et al. identified 24 randomized or controlled trials of primary prevention programs designed to prevent sexually transmitted infections. The methodology employed by each was rated strong, moderate or weak. None of the evaluations received a strong rating, only four received a moderate rating and twenty (83%) were rated as "weak." None of these studies considered cost-effectiveness.<sup>11</sup>

Evaluation is hard work. It cannot be done from the corner of one's desk, secondary to a project's main service activities. Adequate resources have to be committed, time given and

<sup>&</sup>lt;sup>10</sup> Leonard, 1999:16.

<sup>&</sup>lt;sup>11</sup> Yamada, 1999:7,15.

special skills developed and applied. Analyzing the evaluation reports gathered for this synthesis would suggest these were not available to HIV/AIDS-related projects during the period 1998-2003. The HIV/AIDS and Pregnancy project evaluation in Prince Edward Island, for example, noted the absence of a national evaluation framework and the limited time and resources available for its own evaluation work. The evaluations of the HIV/AIDS Labrador project and the Promoting Positive Attitudes project also noted how their budget restricted their investigations. 13 Thus the knowledge that has accrued or can be gleaned from the evaluations conducted in this period is very limited.

Both funders and community-based project staff may appreciate the value of evaluation but their primary concern is with meeting the needs of those vulnerable to HIV infection or living with HIV/AIDS. Analysis and evaluation reports are a less pressing priority than quality service or even the activity reports needed to meet accountability requirements and to retain funding. Indeed one organization noted that its research "is more properly a program monitoring exercise than a summative evaluation.... [It provides] suggestions and indications rather than findings and conclusions."14

The consequence of these factors – the challenges inherent in rigorous evaluation, the lack of funding for evaluation and, possibly, the lack of commitment to evaluation – is a significant gap in what is known about the outcomes and cost-effectiveness of HIV/AIDS-related programming in Canada.

#### 5. **Findings**

This knowledge gap is exacerbated by the evaluation reports being so very project-focused. There are few reports examining the same types of projects or the same research questions, and the findings presented below are often based upon only one report, albeit a credible study that employed a reasonably rigorous methodology and met at least some of the selection criteria established in Section 3 above. This sorely limits the certainty with which the synthesis evaluation can speak to its objectives.

Bearwood, 2000:5.CMJ Consulting, 2003:4; Rodgers, 2002.

<sup>&</sup>lt;sup>14</sup> Wachtel, 1992; Abstract.

#### 5.1 What have we learned about outcomes, impact and cost-effectiveness?

#### **Outcomes and Impact**

Outcomes are described as significant consequences that can be attributed to an organization, policy, program or initiative. Outcomes may be immediate, intermediate or long term, direct or indirect, intended or unintended. 15 As described in Sections 3 and 4, most of the evaluations and reports gathered for this synthesis did not employ methodologies that allowed them to attribute outcomes to activities and/or did not describe their research in such a way as to create confidence in their findings. Most often the project reports addressed outputs, namely the products or services stemming from the activities of a policy, program or initiative, and delivered to a target group or population.<sup>16</sup>

Consequently there are only a small number of outcome and impact-related insights that can confidently be drawn from the methodologically stronger evaluations and activity reports.

- In a rigorous meta-evaluation of needle exchange programs, Lynne Leonard from the University of Ottawa concluded there is "compelling evidence that transmission of HIV from an infected woman to her unborn child or infant can be significantly interrupted through prophylactic treatment or medical interventions ...."

  17 Projects offering prenatal HIV counselling and testing have the potential to successfully increase the number of pregnant women who accept HIV testing as the first step in accessing treatment or other interventions. This meta-evaluation suggested that almost 75% of women offered prenatal testing for HIV will accept the offer with the most common reason being a concern for the health and well-being of their child.<sup>18</sup>
- DiCenso, Dias and Gahagan concluded that take up is high when correctional institutions offer HIV and/or hepatitis C testing in a manner that respects client concerns and confidentiality. They also conclude that such testing projects can effectively address vulnerability issues. 19 In this study, the researchers interviewed 156 women or almost 40% of the total female population incarcerated in nine federal correctional facilities, and used a study protocol approved by Dalhousie University.

<sup>19</sup> Dicenso, 2003:4.

<sup>&</sup>lt;sup>15</sup> See Treasury Board of Canada, Lexicon of Terms Used in the RMAF, n.d.(b).

<sup>&</sup>lt;sup>16</sup> See Treasury Board of Canada, Lexicon of Terms Used in the RMAF, n.d.(b).

<sup>&</sup>lt;sup>17</sup> Leonard, 2001:vi.

<sup>&</sup>lt;sup>18</sup> Leonard, 2001.

> An evaluation undertaken by Roberts et. al, from the Queen's University School of Nursing, suggests that comprehensive projects addressing the range of women's needs can improve their self-esteem and health, lead to less involvement with the criminal justice system, reduce or end completely their use of injection drugs and improve their knowledge of the risk factors associated with both injection drug use and HIV.20

The study group included 21 women who participated in the program through the course of one year, of whom 7% tested positive for HIV and 87% for hepatitis C. The evaluation indicated that 55% of participants stopped injecting drugs with 45% of these beginning methadone treatment. Among those who continued to inject drugs, 65% reported reduced use.

The study did not construct a comparison group but relied upon pre-test assessments and a post-test qualitative questionnaire. The research protocol was approved by the Queen's University Research Ethics Board.

- The Rainbow's End Consulting evaluation concluded that the Yukon project's activities were having an impact on their target populations, including those who have been relegated to the margins of Canadian society. The authors found that these particular individuals are "less isolated," "back in the human race," and benefiting from both the interaction and the prevention programming.<sup>21</sup>
- > Several evaluations identified as project outcomes the important and productive partnerships that emerged among community-based organizations and between governmental and non-governmental organizations. Roberts, for example, identified the importance of a comprehensive approach that integrated the efforts of number of community organizations. Similarly, the AIDS Coalition of Nova Scotia evaluation identified its success in building partnerships with other groups and suggested that "as a result of this collaboration, there is [now] a diverse population of speakers/educators across the province ... that can assist in the development of a response in their community." The Coalition evaluation employed questionnaires, interviews (12), four focus group meetings with 27 people, a review of 16 documents and many hours of project observation (190 hours).<sup>22</sup>

Roberts, 1998:71, 74.
 Rainbow's End Consulting, 2002:29.

<sup>&</sup>lt;sup>22</sup> AIDS Coalition of Nova Scotia, 2002:18. See also Rainbow's End Consulting, 2002 and Roberts, 1998.

#### **Cost-Effectiveness**

Cost-effectiveness analysis has been described as "a straightforward analytical procedure. Outcomes, in the form of measurable changes produced in the target group, are identified and compared to the costs required to produce these outcomes." The analysis then develops cost per client ratios as a measure of efficiency and compares these ratios across programs, thus identifying "which activity produces the most service per dollar spent, or which alternative is the least expensive way of achieving a given level of service."

While conceptually the procedure may be "straightforward," the research and analytical processes required to reach conclusions about cost-effectiveness are by no means so. They tend to be very complicated and, at present, not entirely applicable to the field of HIV/AIDS-related research given:

- the need for and absence of quantifiable outcomes;
- the need to compare the project with equivalent programs having similar goals and objectives; and
- the complexity and scope of the programs addressing the HIV/AIDS epidemic, of the populations to whom such programs are directed, and of the myriad of forces influencing outcomes and impact.

The activity reports assembled for this synthesis do indicate that the projects are undertaking the activities outlined in their proposals and are meeting their funding commitments. Some of the reports have an audit component, documenting expenditures and providing indications that they are being administered in an accountable manner.

None of the evaluations or activity reports, however, address cost-effectiveness issues using the methods described above although some of the observational and cohort studies do so. Jahnke, for example, describes the lowered risk of HIV progression and of AIDS associated with certain triple-drug therapies. This examination was a methodologically rigorous cohort study that noted a very significant "cost-effectiveness ratio of dual to triple drug therapy ... [of] \$39,047 per year of life gained."<sup>24</sup>

<sup>&</sup>lt;sup>23</sup> EKOS Research Associates Inc., 2001.

<sup>&</sup>lt;sup>24</sup> Jahnke, 1999:59.

Other studies use a cost-benefit as opposed to a cost-effectiveness methodology<sup>25</sup> to address somewhat similar issues. Anis et. al., for example, use time-series data to reaffirm the association between disease progression and increased health care costs in individuals with HIV.<sup>26</sup> Similarly, studies by Liviana Calzavera et. al. associated injection drug use with a number of blood-borne diseases and other adverse health and social effects. The authors note that the social and economic costs of caring for individuals with blood-borne diseases can be minimized by ensuring that:

- people do not start injecting;
- people are provided with the resources to stop injecting;
- those who continue to inject remain healthy; and
- ➤ those who are unwell are detected early and provided with care, treatment and support to eliminate ill-effects and to reduce transmission.

The authors conclude that "ignoring the issue [of drug use] or penalizing those who engage in the behaviour ... increases the social and economic costs as these individuals become more marginalized and hidden..."<sup>27</sup>

Overall, then, the evaluations gathered for this synthesis were not designed to address cost-effectiveness issues and indeed do not. Nevertheless the pattern may reasonably be expected to be similar to that for sexual health promotion more generally. In this area, "the cost-effectiveness and cost/benefit literature is small, [but] recent evidence is more clearly illustrating that well-designed, behaviourally effective interventions, even those that result in modest levels of behaviour change, are economically cost effective."

With regard to the synthesis evaluation's first objective, then, **we have learned** that we cannot rely upon the existing reports to provide a conclusive picture of outcomes, impact or cost-effectiveness. For the most part, the review efforts underway in agencies across Canada were not designed for that purpose and have not produced that knowledge. Special efforts, new resources and a renewed and refocused evaluation strategy will be required if governments and

<sup>27</sup> Calzavera, 2003: Executive Summary.

<sup>&</sup>lt;sup>25</sup> Cost-benefit analysis can to used to evaluate individual programs by comparing the costs of a program to the identified or anticipated benefits. See EKOS Research, 2001.

<sup>&</sup>lt;sup>26</sup> Anis, 1998(a).

<sup>&</sup>lt;sup>28</sup> McKay, 2000:part 8, 2 of 5.

agencies, ultimately, are to understand what impact they have had, what outcomes they have achieved and whether they have worked in the most cost-effective manner possible. That strategy will have to include a variety of components, including longitudinal studies involving a large number of people engaged in both experimental and comparison groups.

**We should also learn** to be realistic in terms of what we can expect from evaluations given the context in which they have been undertaken. At present, the evaluations' greatest value may be in identifying how to improve project effectiveness in the short term and how to ensure that these projects respond effectively to client, sponsor and community need in the longer term. Indeed the existing reports imply that greater emphasis should be placed on process evaluations "that focus on finding ways to enhance services" as a first step toward the more elaborate efforts needed to measure impact and outcomes.

#### 5.2 What have we learned about the CSHA Logic Model?

Usually displayed as a flow chart, logic models illustrate the relationship between the immediate, intermediate and long-term outcomes that are expected to result from certain activities, policies, programs or initiatives.<sup>30</sup> The CSHA logic model identifies:

- ➤ as *immediate outcomes*, scientific advancements, increased use of reliable information, strengthened HIV/AIDS policy coordination and programming, increased capacity and increased involvement, participation and partnership;
- as intermediate outcomes, finding vaccines and therapies, access to effective care, treatment and support (CTS) initiatives, minimizing the adverse impact of HIV/AIDS on individuals and communities, minimizing social and economic risk factors and access to effective prevention initiatives; and
- as long-term outcomes, finding a cure for HIV/AIDS, preventing the spread of HIV and provision of care, treatment and support.

<sup>&</sup>lt;sup>29</sup> Strike, Myers and Millson, 2003.

<sup>&</sup>lt;sup>30</sup> Canada, Treasury Board of Canada, n.d.(b).

#### **Immediate Outcomes**

Few of the reasonably rigorous activity reports and evaluations spoke directly to the CSHA logic model and none addressed its immediate outcomes relating to "scientific advancements" or "strengthened HIV/AIDS policy coordination and programming." However, in a rather indirect way, several evaluations – taken together – imply progress toward the other immediate outcomes.

Some evaluations, for example, suggest their projects provided reliable information to a range of community audiences. In Ontario, the ACCKWA Positive Approaches Program spoke of the volume of community presentations made by the organization and of the demand on its Speakers' Bureau. The evaluation noted that audiences felt the information being provided was easily understood and enabled them to better understand both the threat and the impact of HIV/AIDS.<sup>31</sup> Disseminating reliable information in this way characterized a number of the project reports including:

- > the AIDS Prince Edward Island HIV/AIDS and Pregnancy project;
- the Stepping Stone Association HIV/AIDS Prevention Strategies for Sex Trade Workers project;
- the HIV/AIDS Prevention for Young Women project delivered by the Women's Health clinic in Winnipeg; and
- > the online service of the Canadian HIV/AIDS Legal Network.

Some reports also documented their new partnerships with other community-based organizations and thereby addressed the logic model's immediate outcome of "increased involvement, participation and partnership." Direction 180 in Halifax provides an example of building such partnerships and engaging a range of community agencies in the effort to serve those living with HIV/AIDS and to address the HIV/AIDS epidemic.

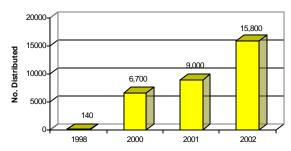
#### **Intermediate Outcomes**

The situation was similar with regard to the logic model's intermediate outcomes. None of the evaluations addressed "finding vaccines and therapies." Several projects, however, served to

<sup>&</sup>lt;sup>31</sup> Centre for Research & Education in Human Services, 2001:21.

enhance "access to effective prevention initiatives." The report on the Peer Outreach Project in Ontario, for example, indicated the organization's success in distributing an ever greater number of clean syringes to injection drug users in that area. It also distributed 720 condoms in 1999 and almost 3700 in 2002. It is reasonable to assume that these efforts and successes contributed to two other intermediate outcomes identified in the logic model, i.e.:

# Peer Outreach Project, Number of Syringes Distributed, by Year



- minimizing the adverse impact [of HIV/AIDS] on individuals and communities; and
- minimizing social and economic risk factors.<sup>32</sup>

Similarly the Direction 180 project review in Halifax described its effort to refer clients to appropriate services, in part by building community-based partnerships. This may be consistent with the logic model's anticipated outcome of improving "access to effective care, treatment and support initiatives."

We have learned therefore – albeit from a very small number of project reports – that the ACAP-funded project outcomes are contributing in some way toward some of the logic model's immediate and intermediate outcomes. The nature of the evaluation or activity reports do not permit any stronger conclusions to be drawn. It is certainly not clear, for example, that the projects are familiar with that logic model or that they can place their efforts into a larger ACAP or CSHA context. In essence, it appears that the projects are responding to a local need rather than consciously filling a role within the larger Canadian effort to address the HIV/AIDS epidemic in all its manifestations.

Given the shortcomings evident in these reports and in the evaluation process, **we have also learned** that a European as opposed to the American approach to program design and operations may be of more practical value relative to the CSHA, at least in the short term. European governments and programs appear willing to build and support projects on the basis of their intuitive logic. It simply makes sense, for example, that well-designed, community-based projects increase community capacity and involvement, or that community-based referral services enhance access to care, treatment and support initiatives. The absence of clear

<sup>&</sup>lt;sup>32</sup> Hammond, 2002.

evidence – derived from methodologically rigorous evaluation – is not necessarily evidence of absence.

# 5.3 What have we learned about appropriate methodologies for evaluating HIV/AIDS-related projects, about what is needed in a new evaluation strategy, and about further research requirements?

As discussed in Section 4 above (Reflections), few of the projects had the mandate, resources, time or data necessary to evaluate, in a methodologically rigorous manner, either the outcomes or cost-effectiveness of their endeavours. Nevertheless, there is evidence that some projects certainly took their evaluation work seriously. In 2002, for example, the AIDS Coalition of Nova Scotia (ACNS) began its review process with a half-day orientation to the ACAP evaluation framework. ACNS Board members and staff attended this meeting and committed "Approximately 120 hours [to] developing success indicators, [and] data collection and analysis processes."

Importantly, they worked in partnership with academics from Mount Saint Vincent University in Halifax to develop their evaluation plan. Ultimately they associated success indicators with each of their project's objectives, and their methodology included observation, questionnaires, interviews, focus group meetings and document reviews.

Similarly, the *Creating a Better Life* project in Kingston clearly identified its objectives and associated as many as eight indicators with each. For example, its objective of assisting "women dependent on injection drugs to improve their skills in parenting children at various stages of development," used the following as indicators:

- active participation of women and children in the Child Focus Project and the Nobody's Perfect Program;
- > more mature parenting attitudes following one year of participation in the project; and
- improved knowledge of and positive interaction with community services targeted toward parents and children.<sup>34</sup>

<sup>&</sup>lt;sup>33</sup> AIDS Coalition of Nova Scotia, 2002:3.

<sup>&</sup>lt;sup>34</sup> Roberts, 1998:10.

These projects and others adopted a participatory process for their evaluations, with the reviewer consulting extensively at every stage with project managers and staff. This approach appeared to be well-appreciated and may have contributed to the review's findings ultimately being incorporated into the project's operations.

Invariably the evaluations used qualitative rather than quantitative methods. Qualitative research studies people and their organizations in their natural settings. It describes in words rather than numbers, does not rely upon statistical procedures and is particularly useful in areas where there is little pre-existing knowledge, where it is difficult or inappropriate to generate hypotheses and where issues are complex and require in-depth explorations. Importantly, conclusions drawn from qualitative research are as valid and sound as those from quantitative research.35

Within this qualitative framework, the different evaluations and reviews employed a diverse array of standard methods for assessing their projects. The Blood Ties project in Whitehorse, for example, interviewed a broad range of stakeholders.<sup>36</sup> Others used stakeholder interviews, telephone or mail surveys, participant feedback forms, focus group or other meetings, and document reviews.

It appears, however, that none of the evaluations developed new methodological tools to address the particular evaluation challenges associated with HIV/AIDS-related programming. Nevertheless the methods employed were certainly reasonable given that their primary mandate was to report on activities and outputs. Whether these methods would be appropriate or adequate for addressing outcome or cost-effectiveness issues remains a question.

Overall, the evaluation activities and reports have provided a number of important methodological lessons. We have learned, for example, that Health Canada and the HIV/AIDS-related projects need to strengthen their evaluation efforts, processes and methods. Evaluation involves asking questions and gathering a broad range of data and other information in order to assess what the projects have achieved. It should include a series of well-defined steps and procedures, and should adhere to certain well-established standards for gathering and analyzing information and for reporting on findings.<sup>37</sup> If agencies are not required to apply certain minimum standards to their evaluation efforts or to invest an appropriate level of resources, then they will not have useful results or reliable conclusions upon which to build ever more effective programs.

<sup>37</sup> Health Canada, 1996.

See United States, General Accounting Office, 1987 and 1990; Strauss and Corbin, 1990.
 Blood Ties, 2002:5.

**We have further learned** that certain approaches may be required to evaluate HIV/AIDS-related projects given the complexity of the issues and people involved, given the CSHA commitment to partnership and given the need to have a strong evidence-based foundation for future programming and funding. It may well be important, for example:

- ➤ to build community support for the research and to involve both the community and professionals in every aspect of designing and conducting the research, and in both analyzing the findings and developing conclusions. Community involvement, professionalism and rigour can be entirely complementary.
- ➤ to assess whether agency self-evaluation is appropriate or whether independent evaluators are required for ensuring objectivity and enhancing the final report's credibility. There are both advantages and disadvantages to separating the "doing and reviewing" functions although a balance can invariably be struck between the two. It may well be that there is both an appropriate place for self-evaluation and a time when independent evaluators are essential.
- to enhance the degree of methodological rigour characterizing HIV/AIDS-related evaluations in Canada, to ensure that baseline data are gathered prior to the project, to undertake longitudinal studies focusing on impact, to more fully investigate ethnographic and gender differences, and to ensure that clear standards are established, articulated and respected. All research activities should be conducted in a professional, ethical and respectful manner and confidentiality should certainly be protected wherever appropriate. There may be no value in investing always scarce evaluation resources in efforts that do not meet these standards.
- to ensure that the data gathered and conclusions reached are then used to shape and improve the projects themselves. Knowledge transfer is vital if evaluation is to be more than an academic exercise, and if the evaluation itself is to be a cost-effective exercise. There is little sense in committing resources to evaluation efforts that have no substantive outcomes.

**We have also learned** that rigorous evaluation should be a staged process. There is a process that should be pursued in order to ensure that the evaluation's findings are accurate and its conclusions are valid.

- First, the project's design should include efforts to articulate clear and quantifiable objectives that will ultimately serve as the evaluation's focus, and to gather the client, financial and other data that ultimately will be required for evaluation purposes.
- ➤ Second, a process evaluation should be used to establish that the project is operating as intended and to identify and resolve operational problems.
- Next, activity reports and project reviews should be used to document program operations and outputs.
- Finally, there should be a longer-term evaluation of project impact, outcomes and cost-effectiveness that uses baseline, participant and comparative data.<sup>38</sup>

As well, **we have learned** that greater emphasis should be devoted to qualitative research as a methodology and that researchers' skills in this regard should be honed. Qualitative research methods are entirely appropriate for this complex field of human activity and certainly reliable in their findings. It has to be emphasized and recognized, however, that this form of research is more than simply reporting on what people said and accepting their views as valid. Qualitative studies should:

- use multiple methods and sources of evidence to capture the situation at different times in the project's evolution. This could include methods such as literature reviews, file and case reviews, direct observation, focus group meetings, surveys and questionnaires, and open or structured interviews. The methodology should certainly capture the views of participants, including those who benefited from the project and those who did not. It should also capture the views of a wide range of stakeholders including both project advocates and detractors. Using a variety of methods and sources will provide the "thick" descriptions that can illuminate patterns, trends and outcomes.
- ➤ use "triangulation" techniques to corroborate findings, rule out competing explanations and maximise confidence in the evaluation's findings. Triangulation refers to using a combination of methods and information sources to study the same issue. This technique cannot be a rigid requirement, however, since different methods and sources often provide different insights rather than contribute to a single, accumulating picture.

<sup>&</sup>lt;sup>38</sup> See Social Data Research, 2003.

➤ use the "chain of evidence" approach whereby an independent reviewer could follow the evaluator's evidence and logic to arrive at the same conclusions. This requires that the evaluator carefully organize, document and report upon their observations and data. The report's presentation should be logical, clear and intelligible. This approach serves to make the project both transparent and, in theory, reproducible.

Furthermore, qualitative research invariably makes extensive use of key informant interviews and stakeholder meetings to elicit information. The evaluation's strength, therefore, depends upon asking "good questions." These should:

- be linked to what we want to know and must lead to something of importance that we need to know.
- ▶ be free of bias and presumption, be stated in common language and be characterized by both simplicity and elegance.
- > have an open quality that invites participants to tell all they know and to raise issues that they believe are important for the researcher's understanding.
- invite participants to participate in the process of drawing conclusions and offering recommendations.<sup>39</sup>

### 5.4 What have we learned about project operations?

Overall, the methodologically stronger activity reports gathered for this synthesis evaluation suggest that the different projects are doing what they said they would do in their funding applications and are reaching their target populations. Meeting their own specific objectives, in other words, does not appear to be an issue. These reports – the strongest in the group – also provide some important insights into project operations and some important lessons as to what may well be effective practices for HIV/AIDS-related programming. These lessons are presented below.

<sup>&</sup>lt;sup>39</sup> International Association of Public Participation Practitioners, 1995.

#### **Approach**

- Incorporate a holistic approach and offer clients an array of services including education, counselling and on-going support.<sup>40</sup>
- Adapt messages and activities to the client group's culture and customs, and ensure that information is provided in a manner that accommodates different learning styles. Information should be provided in a plain language format suitable for the intended audience.41
- ➤ Endeavour to build trust with the client group, in part and importantly by being respectful of their particular situation and by ensuring client confidentiality.<sup>42</sup>
- > Provide services that are supportive but not judgemental. This is perhaps best manifested in needle exchange programs where some projects trade old for new needles on a one-to-one basis while others provide as many needles as individuals may want regardless of the number returned. The latter approach does not judge what clients should be doing but is simply accommodating the reality of what they are doing.

#### **Training and Staffing**

- > A number of evaluations speak of the importance of having knowledgeable, professional, positive, friendly and caring" staff. 43 They suggest that professionalism and competence are important for providing quality service and achieving the project's objectives.
- > Two studies suggest that health care professionals need training that focuses on the particular needs of women who inject drugs and/or engage in the sex trade. The reports also suggest the importance of strengthening physician support for projects directed at preventing the transmission of HIV from mother to infant, and of providing appropriate training to physicians and other health care providers.<sup>44</sup>

 <sup>40</sup> Leonard, 2001; Dicenso, 2003:37.
 41 Dicenso, 2003:19; Bearwood, 2000:13.

Dicenso, 2003:17,
 Dicenso, 2003:17.
 Rainbow's End Consulting, 2002:3.
 Leonard, 2001. Roberts, 1998.

Some project reports appear to suggest that understaffing can compromise project objectives and operations. The Blood Ties project in Whitehorse, for example, expanded its mandate so as to include those infected with hepatitis C but then did not have the "additional funding or staff ... [necessary] to support these additional services." Similarly it had to scale back its plan to produce a quarterly newsletter due to funding restraints.<sup>45</sup> Another study stated that certain of its project's objectives were not realized because they "were not afforded the same priority as direct support to clients." The organization had funding for only a part-time staff position.46

#### **Reach and Consistency**

- > Two studies suggest that clear policy is required to ensure the broad and effective implementation of prevention measures such as prenatal testing for HIV. It states that there should be measures in place to ensure service providers understand policy goals and directives.<sup>47</sup> Consistency and accessibility, "both within individual institutions and across the system as a whole" are vital, it says, for the successful implementation and comprehensive application of these policies.<sup>48</sup>
- One study suggested that "pregnancy was not the best time to raise with women the possibility of HIV counselling and testing." Instead preconception counselling and testing is the ideal.<sup>49</sup> Another study, however, indicated that "childbirth and mothering were major turning points for women" and hence a good time to reach out with support and prevention measures.<sup>50</sup> The key may be to have a variety of services available to reach people whenever they are ready to receive the message.
- Location may be crucial for ensuring accessibility. The Direction 180 methadone and modelling project located its operations in North End Halifax "where the majority of clients live, in order to improve access to the program." It also appears important to have appropriate facilities. Direction 180 did not have sufficient space to allow for

<sup>48</sup> DiCenso, 2003:1.

<sup>&</sup>lt;sup>45</sup> Rainbow's End Consulting, 2002:11, 4. It is not clear whether these objectives constituted part of the project's funding request.

46 Uhryniw, 2002:1.

<sup>&</sup>lt;sup>47</sup> Leonard, 2001.

<sup>&</sup>lt;sup>49</sup> Leonard, 2001.

<sup>&</sup>lt;sup>50</sup> Roberts, 1998.

private conversations between staff and clients, or to allow the project to expand to meet the level of community need.<sup>51</sup>

Another study suggests the importance of both adequate funding and consistent funding. At present, it says, "Service providers are faced with inadequate financial resources [and] rigid rules ... [while] working with a stigmatized and untrusting population. This stressful work environment results in frequent staff turnover and lack of continuity. Little time or energy is left to conduct quality control, set standards, and to collect information to monitor and evaluate how programs are working...."52

#### **Program Awareness**

Findings from several studies suggest that many service providers may not be aware of public policies designed to guide their practices. In one study, for example, 43% of physicians did not know that, by policy, HIV testing was to be offered to all pregnant women. Another study suggested that many women incarcerated in correctional institutions were not aware that HIV and hepatitis C counselling was available.53

#### Comprehensive Programming

Certain project reports suggest that special interventions are needed to address the needs of women dependent upon injection drugs or, by implication, others at high risk of HIV infection. A single dose of programming, or very narrowly focused programming will not effectively address their range of needs. Blood Ties in Whitehorse provided a model in this regard by offering a range of services funded both by Health Canada and the Yukon government, i.e. general prevention efforts, a needle exchange, a Positive Persons Support Program, the Yukon Outreach AIDS project, a newsletter, a Volunteer and Events Program, and a Youth Supper Club.54

<sup>&</sup>lt;sup>51</sup> Chaytor, 2002:2.

<sup>&</sup>lt;sup>52</sup> Calzavera, 2003(a): Executive Summary.

<sup>&</sup>lt;sup>53</sup> Leonard, 2001; Dicenso, 2003:16-17.

<sup>&</sup>lt;sup>54</sup> Roberts, 1998; Rainbow's End Consulting, 2002:11.

#### 6. Conclusions and Recommendations

The reports considered for this synthesis evaluation suggest that the different HIV/AIDS-related projects are contributing, each in their own way, to addressing the epidemic in Canada. They suggest the value of the work being done and often identify the short-term results of that work. It may be entirely reasonable to assume that the projects, taken together, have had an impact on the HIV/AIDS epidemic in Canada:

- by providing reliable information to vulnerable groups and to the community, and by ensuring that such information is widely available in communities across Canada;
- by helping some people avoid activities that place them at risk of HIV infection, for example pregnant women and women incarcerated in federal correctional institutions;
- by enhancing community capacity and building partnerships across agencies, for example between certain projects and local health clinics; and
- by referring some people to care, treatment and support services.

However we cannot be entirely confident in that assumption no matter how reasonable it is. By and large, the evaluations do not have sufficient methodological rigour to instil confidence. Consequently – and unfortunately – they do not contribute very much to a larger understanding of what outcomes have resulted from the projects' efforts and funding.

It may be that these projects and their reviewers did not have the time or resources necessary to evaluate their work in a rigorous manner. It may be that they did not have access to the skills and experience that are required to evaluate projects in such a complex field of endeavour. Furthermore, what evaluations do exist are scattered in their focus and there are too few studies examining the key issues to provide clear evidence of outcomes, impact or cost-effectiveness.

Since its inception, the Canadian Strategy on HIV/AIDS has emphasized the importance of building and disseminating new knowledge. There is now in Canada a strong body of research relating to HIV/AIDS, for example needs assessments, cohort studies, situational analyses and policy considerations. However there is not yet a substantive, solid body of evaluation knowledge that "would allow decision-makers to review alternative courses of action in light of resources and evidence-based outcomes." The importance of this synthesis evaluation,

<sup>&</sup>lt;sup>55</sup> Social Data Research, 2003: Executive Summary.

therefore, lies in what it could not find and in what it cannot conclude. This is a significant gap given the threat posed by HIV/AIDS and the need to use always-scarce resources in the most effective manner possible.

Building knowledge on the basis of evaluation is important for strengthening program effectiveness, planning, budgeting and indeed every aspect of the Canadian Strategy on HIV/AIDS. Rigorous evaluation, however, requires:

- a significant level of commitment from program administrators and funders, and from project managers. They have to want the knowledge and the certainty that can flow from rigorous evaluations. And they have to understand the difference between year end activity reports and program reviews on the one hand and evaluation on the other. The former are important for accountability and operational purposes and as a foundation for evaluation. But they are not evaluations upon which to build ever more effective programs.
- experienced evaluators with the specialized skills necessary for analyzing project or program impact and the role of these programs and projects in addressing the HIV/AIDS epidemic in Canada. Furthermore the evaluators must be entirely objective in their work and reporting so as to ensure their conclusions and recommendations are both valid and credible.
- particular tools to attribute outcomes to inputs and to analyze cost-effectiveness. Evaluation that can shape future programming is a complex business. It requires both qualitative and quantitative tools, for example case studies and perhaps econometric analysis.
- program funders and project administrators who understand that evaluation is a comprehensive, rigorous and careful process that may involve several phases. They must be willing to commit adequate resources to support the research and sufficient time to track and measure outcomes. At present adequate resources and time are rarely provided. One study of the Clinical Trials Network, for example, had to be completed in six weeks as did another potentially important study of the Canadian Institutes for Health Research.<sup>56</sup>

<sup>&</sup>lt;sup>56</sup> See Canadian HIV Trials Network, 2002; PRA Inc., 2002.

If Canada wishes to know about outcomes, impact and cost-effectiveness – with regard, for example, to the new safe injection site in Vancouver – it may require a vigorous national evaluation strategy that incorporates these elements and applies them to existing or new initiatives. This strategy could direct and shape evaluation efforts, focus the research issues and ensure there is a body of evidence rather than a single report. It could distinguish between the different types of evaluations and determine which projects require only activity reports for accountability purposes and which require formal evaluation. It could ensure that process evaluations precede efforts to evaluate impact.

A single centre could be responsible for this strategy and for encouraging and funding outcome and cost-effectiveness evaluations, for setting research standards and promoting the use of rigorous methodologies, and for providing technical assistance. It could also undertake to strengthen the evaluation skills of community-based researchers by providing training in research design and both qualitative and quantitative methods.<sup>57</sup> Indeed the centre could build an evaluation toolkit on the model of those prepared by Indian and Northern Affairs Canada, Human Resources Development Canada and the First Nations and Inuit Health Branch in Health Canada itself.<sup>58</sup>

This approach does not preclude the possibility of collaborative working partnerships among program managers, project organizers and professional evaluators. Each would bring their own strengths and skills to the effort and the result would be better analysis in the short term and better programming in the longer term. Indeed these partnerships – and the symbiotic relationship that could ensue – are vital for ensuring that the knowledge gained is reliable and has practical application.

The centre could also be responsible for disseminating knowledge and for encouraging organizations to build this knowledge into their programs and projects. It could identify the most appropriate repository for all evaluations undertaken in Canada and could organize these evaluations so they are readily accessible to those policy, project and program people who could benefit from their findings. It could also endeavour to integrate the evaluation findings and to draw more generalized conclusions from them. It could endeavour to integrate evaluative research with other cohort or observational studies.

Health Canada, the Canadian Institutes for Health Research, a Centre for Excellence, a university or an HIV/AIDS-related non-governmental organization could become this

<sup>&</sup>lt;sup>57</sup> See Healing Our Spirit BC First Nations AIDS Society, 2000; Trussler and Marchand, 1999.

<sup>&</sup>lt;sup>58</sup> For example, see Health Canada Population Health Directorate, 1996.

responsibility centre. Who serves this function does not much matter. What does matter, however, is a recognition that its success will depend upon having both adequate resources and the confidence of those funding, managing and using the evaluations.

Similarly – and without diminishing the responsibility of organizations to report on their activities – there may well be value in focusing the evaluation effort on a small number of research issues about which there are serious questions. This approach could ensure that resources are not wasted pursuing issues for which answers already exist, either because of research undertaken elsewhere or because of their strong intuitive logic. The responsibility centre could engage in a partnered, priority setting exercise for determining what to evaluate when.

A new more clearly focused and more rigorous evaluation strategy may well be vital if Canadian efforts to address the HIV/AIDS epidemic are to be founded upon knowledge and rooted in practices that have proven their effectiveness. Program funds are always limited and rarely adequate to address the challenges presented by HIV/AIDS. A new, comprehensive and well-directed evaluation strategy could help to ensure that these funds are spent in the most cost-effective manner possible.

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## Appendix A – Overview

Building Knowledge: A Synthesis of Canadian HIV/AIDS Program Evaluations **Project Overview** 

In 1998 the Government of Canada introduced the Canadian Strategy on HIV/AIDS (CSHA) with an annual budget of \$42.2 million. This funding has supported a great many activities at the national, regional and community levels, and has had considerable impact upon the spread of the HIV/AIDS epidemic in Canada and on the response of Canadians to the epidemic.

As the federal government prepares to renew the CSHA, it needs a clearer picture of what outcomes have resulted from these efforts. Similarly, provincial and community partners need to know what works and what does not if they are to continue improving their programs and making them ever more effective. This *Building Knowledge* project will gather, summarize and synthesize the various outcome and process evaluations conducted in Canada since 1998 by governments, academic and other research institutes, and community-based HIV/AIDS-related organizations. Using these studies, the project will identify and analyze:

- what has been learned about the impact and cost-effectiveness of HIV/AIDS-related programs;
- what has been learned about appropriate ways for evaluating HIV/AIDS-related programs;
- the gaps and limitations of the evaluation framework and strategy currently in place for the CSHA; and
- what further program effectiveness research is needed in order to achieve the CSHA prevention, care, treatment and support objectives.

Health Canada has selected Dr. Martin Spigelman to undertake this project. Martin has extensive experience with program evaluation and with HIV/AIDS-related issues and organizations. Martin Spigelman Research Associates, for example, prepared the *Taking Stock* report on funding adequacy for the Ministerial Council on HIV/AIDS and, more recently, the *Five-Year CSHA Review* for Health Canada. For more information on this project or to contribute your views, please contact either:

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# Accroître nos connaissances : une synthèse des évaluations du programme canadien de prévention du VIH/SIDA **Apercu du Projet**

En 1998, le gouvernement du Canada a déposé la Stratégie canadienne de lutte contre le VIH-Sida et lui a donné un budget annuel de 42.2 millions de dollars. Ces fonds ont permis d'appuyer un nombre important d'activités aux niveaux national, régional et communautaire. Ils ont également eu un impact considérable pour limiter la propagation de l'épidémie de VIH-Sida au Canada ainsi que sur façon dont les citoyens canadiens ont réagi devant l'épidémie.

Alors que le gouvernement fédéral s'apprête à renouveler la Stratégie canadienne sur le VIH-Sida, il lui est nécessaire d'avoir une vision plus nette des résultats qu'ont donnés tous ces efforts. Les partenaires provinciaux et communautaires doivent eux aussi savoir ce qui est efficace et ce qui ne l'est pas s'ils veulent continuer à améliorer leurs programmes et les rendre plus efficaces. Ce projet ayant pour titre "Building Knowledge" recueillera, analysera et fera la synthèse d'un éventail d'évaluations effectuées par les différents gouvernements, les organisations communautaires, les institutions de recherche et autres organisations sur le VIH-Sida à l'étendue du Canada depuis 1998. À partir de ces études, ce projet déterminera et analysera:

- ce qu'on a appris sur l'impact et le rapport coût-efficacité des programmes sur le VIH-Sida;
- ce qu'on a appris sur les façons les plus appropriées d'évaluer les programmes sur le VIH-Sida;
- les lacunes et les limites de la stratégie et du cadre d'évaluations actuellement utilisés par la Stratégie canadienne sur le VIH-Sida, et
- quelle recherche plus avancée sur l'efficacité du programme est nécessaire afin d'atteindre les objectifs que s'est donnée la Stratégie canadienne sur le VIH-Sida dans le secteur de la prévention, des soins, des traitements et du soutien.

Santé Canada a désigné le D. Martin Spigelman pour entreprendre ce projet. Martin a une longue expérience dans l'évaluation de programmes ainsi que dans les organisations et les questions touchant le VIH-Sida. À titre d'exemple, la firme Martin Spigelman Research Associates a préparé le rapport *Taking Stock* qui abordait la question de la suffisance des fonds alloués et, plus récemment, le rapport *Five-Year CSHA Review* à l'attention de Santé Canada.

Pour plus de renseignements sur ce projet ou pour nous faire part de vos opinions, veuillez contacter:

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## **Appendix B Evaluation Review Template**

Author, Date, Title.	
Issue	Notes
Type of intervention/program evaluated	•
Evaluation type and purpose/objective	•
Evaluator	•
Organization, funder and sponsor	Organization: Funder: Sponsor:
Methodology	
Period of time available for the evaluation	•
Key research issues and indicators	•
Methodology	•
Strengths, challenges and limitations	•
Conclusions	
Operations	•
Impact/outcomes	•
Cost-effectiveness	•
Other	•
Recommendations	
Summary re operations, impact and cost- effectiveness	
Relevance to CSHA Evaluation Framework and Strategy	
Lessons for effective programming?	•
Lessons for the CSHA Logic Model?	•
Lessons for a CSHA Evaluation Strategy?	•
Issues for further research?	•

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