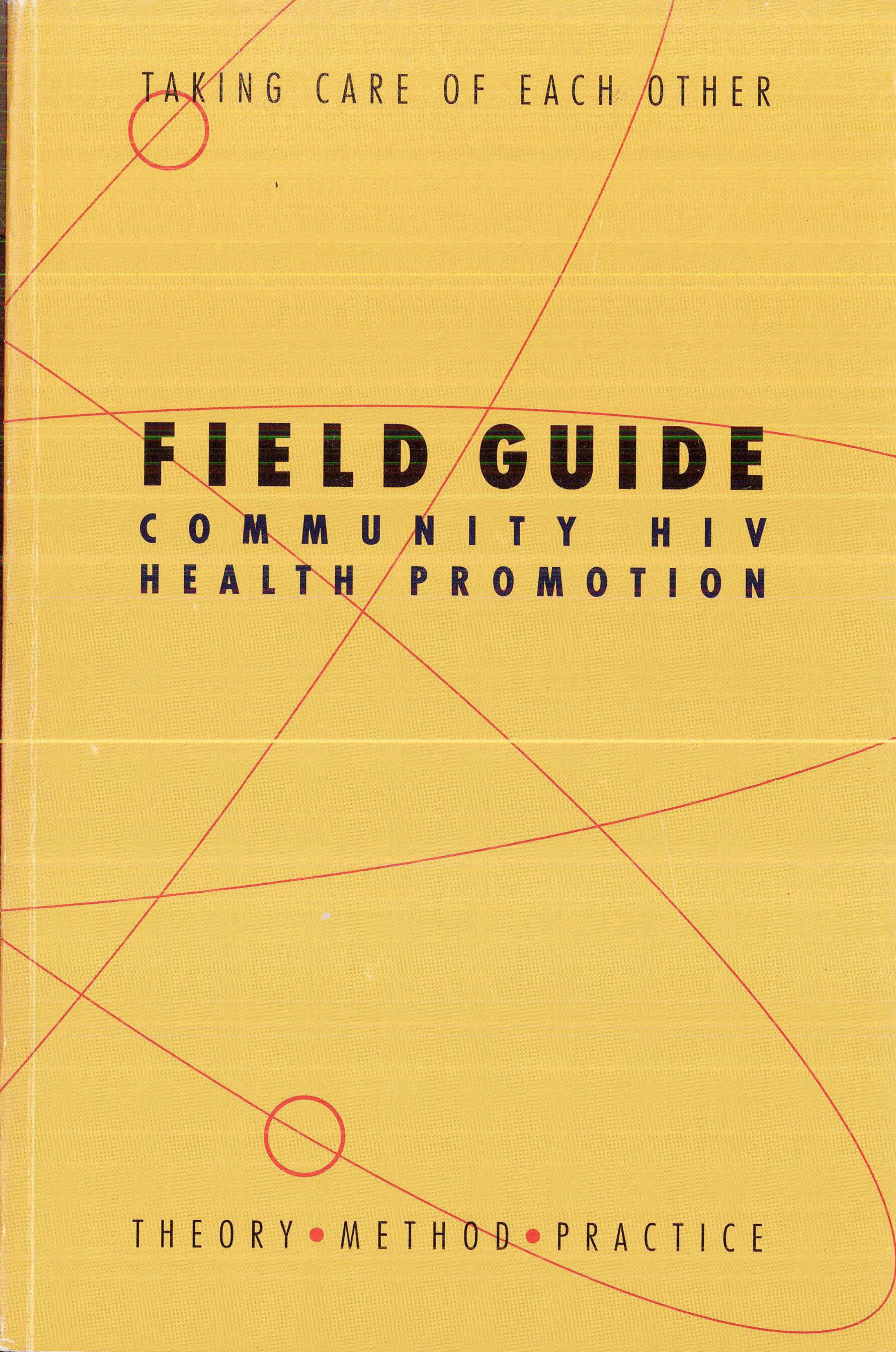

TAKING CARE OF EACH OTHER

FIELD GUIDE

COMMUNITY HIV HEALTH PROMOTION

THEORY • METHOD • PRACTICE

TAKING CARE OF

EACH OTHER

FIELD GUIDE

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COMMUNITY HIV
HEALTH PROMOTION

THEORY, METHOD & PRACTICE

TERRY TRUSSLER, EdD
RICK MARCHAND, PhD

VANCOUVER, BRITISH COLUMBIA

AIDS VANCOUVER
TAKING CARE OF EACH OTHER

Health Canada Santé Canada

Canadian AIDS Society
Société canadienne du sida

General Editors: Erik Ages, Casper Communications
Yvonne Van Ruskenveld, West Coast Editorial Associates
Copy Editor: Barbara Tomlin, West Coast Editorial Associates
Proofreader: Yvonne Bondarchuk
Indexer: Yvonne Bondarchuk
Translation: Murielle McCabe

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Collaboration is a necessity of life in AIDS work, and writing about it is always an adventure in sharing and shaping ideas. It's not always easy, though, to find the time it takes to contribute, to review and to dialogue. Without this willing suspension of personal and professional boundaries to accomplish such things, nothing of consequence would happen to advance the health field. So, it is a tribute to the collaborative spirit of the community of people working with AIDS in Canada that this *Field Guide* has materialized from the experience.

PROJECT STEERING COMMITTEE
Brent Allan, AIDS Vancouver
Russel Armstrong, Canadian AIDS Society
Barbara Jones, Health Canada
Rick Marchand, AIDS Vancouver
Robert Shearer, Health Canada
Terry Trussler, AIDS Vancouver

CONTRIBUTORS
Shane Borley, AIDS Vancouver
Gregg Brown, AIDS Vancouver

Ken Burke, AIDS Vancouver
Thomas Dolan, AIDS Vancouver
Marcel Dubois, Urban Aboriginal AIDS Awareness Project
Michael Graydon, Canadian AIDS Society
Erin Harvey, St. Paul's Hospital, Vancouver
Terrah Keener, AIDS Vancouver
Rodney Kort, Canadian AIDS Society
Ross MacDonald, AIDS Coalition of Nova Scotia
Maurice McDonnell, Toronto
Nancy McPherson, Edmonton Board of Health
Karen Schell, YouthCo AIDS Society
Juanita Smith, Black Coalition for AIDS Prevention
Marcie Summers, Positive Women's Network
Margreth Tolson, AIDS Vancouver
Anne Wyness, University of British Columbia School of Nursing

REVIEWERS

Erik Ages, AIDS Vancouver Island
Brent Allan, AIDS Vancouver
Russell Armstrong, Canadian AIDS Society
Christopher Barnes, YouthCo AIDS Society
Claudia Brabazon, Research Consultant
Sheena Campbell, Village Clinic, Winnipeg
Theodore de Bruyn, Health Canada
Beth Easton, United Nations AIDS Program
Howard Engel, Canadian AIDS Society
Dionne Falconer, Black Coalition for AIDS Prevention
Irene Goldstone, British Columbia Centre for Excellence in HIV/AIDS
Peter Granger, Downtown South Community Health Centre, Vancouver
Jackie Haywood, British Columbia Persons With AIDS Society
Alison Ivan, AIDS Vancouver
Ralf Jurgens, Canadian HIV/AIDS Legal Network
Ron Labonté, Research Consultant
Roseanne LeBlanc, Nova Scotia Ministry of Health
Heidi Liepold, Health Canada
Wendy McCulloch, AIDS Vancouver

Craig McLure, Community AIDS Treatment Information Exchange
Ken Morrison, XIth International Conference on AIDS
Warren O'Briain, AIDS Vancouver
Paul Perchal, AIDS Vancouver
Jeea Saraswati, Canadian AIDS Society
Arn Schilder, British Columbia Persons With AIDS Society
Ron Silvers, Ontario Institute for Studies in Education
Steffanie Strathdee, British Columbia Centre for Excellence in HIV/AIDS
Darien Taylor, AIDS Committee of Toronto
Micheal Vonn, AIDS Vancouver
Elisse Zack, Canadian AIDS Society
Julia Zarudska, AIDS Vancouver

FOREWORD

The making of the *Field Guide* is a story of many layers and connections. While our earliest work – *Taking Care of Each Other* – was still in production, an unproofed version found its way to Health Canada. As an example of what could be done with community-based research, *Taking Care of Each Other* sparked the imagination of several insiders who were eventually to become key players in further developments. Barbara Jones, Kim Elmsley and Bob Shearer were among the first to recognize the vision of an educational program to develop the practice of health promotion in community AIDS work. They laid the groundwork for the project and committed themselves to the long-haul of the creative process. Their colleague, Heidi Liepold, set the project in motion, encouraging further research (published in *More Reflections on Taking Care of Each Other*) and the creation of a text (eventually the *Field Guide*) expressly written for people working with community AIDS agencies.

Establishing a national project in a community agency, however, took more effort than we had assumed. Rodney Kort came on the scene and lent considerable energy to setting up the office, the quarterly newsletter *Taking Care*, local educational activities and eventually many of the field interviews used in background research for the *Field Guide*. Claudia Brabazon, who had been contributing at the community level in Vancouver, moved to

Ottawa, which enabled her to spearhead national involvement with the Canadian AIDS Society.

As the project developed, AIDS Vancouver was undergoing a major transformation. Brent Allan arrived from working on the national scene to become the Director of Education of AIDS Vancouver. One of his first moves was to partner with Phillip Hannan to develop a community support campaign in which they positioned *Taking Care of Each Other* as the motto. Brent also took a keen interest in integrating the ideas of the developing *Field Guide* directly into education and outreach activities. In that vein, Shane Borley created "Victor Vancouver," a highly creative community development project for young gay men that showed us the future. The AIDS Vancouver Board, especially Andrew Johnson, Ed Lee, Dianne Richards and Don Seaton, took up the momentum in recognizing *Taking Care of Each Other* as the central vision of the agency.

As the text of the *Field Guide* developed, attention shifted from content to how to deliver it. Micheal Vonn took an early interest while in the midst of developing AIDS Vancouver's Training Institute. She contributed much wisdom and experience to designing and planning a program suitable for the community AIDS environment. Paul Perchal volunteered to help facilitate our first efforts. Their subsequent collaboration, spanning three pilots, brought together a vibrant creative engagement in the design of a transportable workshop called Study-Plan-Do, based on the *Field Guide.*

Throughout the writing, several important relationships shaped the text across months and years of dialogue. Irene Goldstone contributed her vast knowledge of the depth and breadth of the AIDS care world. Arn Schilder played a focal role in the attention to the social environment, HIV vulnerability, and the implications for research and policy. Steffanie Strathdee turned our attention to the role community agencies could play in HIV epidemiology. Howard Engel confirmed the link between community fieldwork and policy advocacy. Peter Granger bolstered our confidence by showing the transferability of our work to many aspects of community health and medicine. Ron Silvers, our long-time intellectual mentor, saw the potential for social-health studies in the developing world. Vivian Darroch-Lozowski encouraged our exploration of the vital connection between language and health of the body. Theodore de Bruyn saw the policy implications of community-based research and helped to bring its potential to the attention of the HIV/AIDS research community. Anne Wyness helped us make the connection between community and professional education. Julia Zarudska affirmed the spiritual path in social transformation.

The *Field Guide* has a talented cast of characters in Gregg Brown, Mike Graydon, Erin Harvey, Terrah Keener, Rodney Kort, Nancy McPherson, Ross MacDonald, Karen Schell and Juanita Smith. They are the stars of the show and their stories are the core of text. Many more have contributed interviews, reading and reflections. Informal chats in the halls and notes in the margins add up to real substance in the course of writing. Thanks to all.

Finally, *Taking Care of Each Other* is the inspiration of a partnership in life as well as in thought. It was all Rick's idea. I just took care of the details.

Terry Trussler and Rick Marchand
Vancouver, Fall 1997

INTRODUCTION

First, do no harm
— HIPPOCRATES

Originally, the objective was simple: to create a practical guide to HIV health promotion—what works, why and how to. But the situation demanded more. Global experience had exposed the root cause of the persistence of HIV/AIDS in underlying social factors. On the horizon was a reinterpretation of the ideas on which community AIDS work has been based.

The concept of health promotion offered a useful frame for this reinterpretation. An international public health movement, health promotion is the process of enabling people to increase control over and improve their health. The *Field Guide* would need to represent the insights from the social reinterpretation of AIDS and provide the means for the field of HIV health promotion to advance. So began a wide-ranging discussion on

- the nature of health in the era of HIV/AIDS;
- the impact of society and culture on health;
- the education of care providers;
- the adverse effects of social environments;
- the place of health policy;
- the capacities of community AIDS agencies to influence these issues.

These are the expanding boundaries of HIV health promotion.

The observations and suggestions in the *Field Guide* are aimed at inspiring innovation, enhancing the quality of service, expanding effort and increasing capacity in AIDS agencies. While it is not a manual on how to run a community-based AIDS agency, the *Field Guide* presents material that may well reshape many facets of organizational life, including prevention, outreach, community care, advocacy in the health system and internal administration.

GLOBAL DEVELOPMENTS

The *Field Guide* addresses several important global developments in the HIV/AIDS field, especially the recognition of significant health realities such as

- HIV vulnerability (the state of diminished control over the risk of HIV infection or the development of subsequent illness);
- the adverse impact of AIDS on HIV-vulnerable communities;
- the disproportionate impact of HIV/AIDS on individuals and communities already confronted by other health, social and economic issues.

These developments confirm a growing awareness that the social environment must be considered in developing effective strategies for dealing with HIV transmission and illness at the community level. Global experience has shown that the people who are most vulnerable to HIV/AIDS have always been subject to various forms of discrimination based on race, religion and sexual orientation, even before the epidemic.

HIV is now recognized to be endemic in many areas of the world. HIV is with us and cannot be eradicated by known science. The collective vision of community AIDS work that exists so far has developed from hard-won experience coping with tragedy. Still, the epidemic continues to expand. We need a shared vision, a commonly understood set of organizing tools, disciplines and working arrangements to address the emerging conditions of the epidemic.

TURNING VISION INTO REALITY

Community AIDS agencies need a way of building on their field knowledge to increase their capacities and expand their response. Otherwise, the development value of experience from everyday frontline prevention, support, education and advocacy work will be lost. Meetings, conferences and organizational collaboration may help to ensure the development of some form of common ground. But the methods and practices of community AIDS work need consolidation into a commonly understood system of practical knowledge. The *Field Guide* presents a way of thinking about community AIDS work, a way of proceeding and a way of evaluating the effects.

The methods described in the *Field Guide* did not grow out of idealized conditions—AIDS work as it ought to be—but from the work as it really is in the field. The *Field Guide* is a living reality represented in case stories from across the Canadian landscape. It is not meant to be the last word on the community response to HIV. Take it, instead, as a foundation to build on.

BEFORE THE *FIELD GUIDE*

The *Field Guide* is the product of an intensive, three-year involvement in the life of the Pacific AIDS Resource Centre (PARC), a consortium of independent-but-related agencies housed in one building in downtown Vancouver on the west coast of Canada. AIDS Vancouver, the British Columbia Persons With AIDS Society, the Positive Women's Network and Wings Housing Society are partners in the centre and share responsibility for the overall management of the building and its administrative operations.

The shared management of PARC has, in itself, proven to be a productive model of community AIDS work. The complexity of relationships in a workplace of mixed gender, sexual orientation, racial and HIV-serostatus has provided fertile ground for experience, reflection and analysis in the development of the *Field Guide.*

The project began with an informal inquiry into the meaning and potential of health promotion in community-based AIDS work. The process developed from qualitative studies of life at PARC, informed by participant observation, focus groups, intensive interviews and a review of health promotion literature. The product was presented in a monograph entitled *Taking Care of Each Other.*

Taking Care of Each Other stimulated a rich discussion about the ideas on which community AIDS work is based, across Canada and beyond.

Small print runs turned into thousands. This interest caught the attention of Health Canada, which provided the necessary support to pursue the work further. The result, *More Reflections on Taking Care of Each Other*, made an intensive study of the social determinants of health as applied to HIV/AIDS and the implications for prevention in HIV health promotion.

THE *FIELD GUIDE* DEVELOPS

While work continued on *More Reflections*, a full-scale nationwide project to develop the organizing principles, methods and practices of HIV health promotion began to take shape. The outcome would be the *Field Guide.* A plan was also set up to enrich the text with a wide range of experiences of HIV health promotion in actual practice. The plan involved interviews across the country, action research in the PARC agencies, program evaluation, collaboration with care-providing professional groups, case history retrieval, focus groups, conferences, position papers, a quarterly publication, several community-based health promotion initiatives and mentoring of individual researchers.

The most intensive involvement developed from the project's insertion into the everyday life of AIDS Vancouver, which included an office and a staff presence. This brought the project, its analysis and theory-building directly into the practice realities of an AIDS agency. The work also provided close-up opportunities to observe and influence agency development through program consulting and strategic planning.

The project launched a series of in-service forums on the nature and conduct of HIV health promotion, called PARC Rounds, which were open to all participants in PARC. These taped and transcribed sessions provided a hot-house environment in which to listen, address issues and concepts and test how well the project's analysis was connecting with the real life of the organization. See Chapter 7: Agency—Transformative AIDS Organizations for the full case story.

The project also established a quarterly newsletter, *Taking Care*, featuring interviews with fieldworkers, milestone reports and regular editorials examining key concepts in HIV health promotion. The intention was to keep everyone interested in the project's developments while the *Field*

Guide was being written.

While consulting on qualitative methods, the project made an effort to stimulate research interests in the community. Eventually, several field studies were linked into the project's theory-building framework. These included

- an evaluation of a fourth-year senior nursing AIDS elective at the University of British Columbia;
- a preliminary investigation of the role of early abuse in the HIV vulnerability of gay men;
- a self-guided qualitative study of the barriers youth experience with safer sex;
- an evaluation of support services offered by AIDS Vancouver.

The project also invited submissions of "community breakthrough" stories from AIDS agencies nationwide. Some of these case stories are featured throughout the *Field Guide*.These vivid descriptions build a picture of the real-life experience of HIV health promotion.

The project prompted several presentations at conferences. Each was a fresh opportunity to advance the analysis and build theory. The sequence of titles illustrates our progress:

- "How can we be sure we aren't creating the risk conditions we're trying to avoid?"
- "Revisioning AIDS work"
- "The case for participatory evaluation in HIV health promotion"
- "Participatory research, empowerment and community transformation"
- "Methodological foundations for a participatory model of research in HIV health promotion"

Several international experiences contributed to the expanding dialogue: the Xth International Conference on AIDS in Yokohama (1994); the 1st International Conference on Health and Human Rights, held at the Harvard School of Public Health (1994); the Cultural Competence Program of the AIDS Education Project at the University of Hawaii; and ongoing dialogue with colleagues in Australia.

As with any production, the *Field Guide* has gone through several drafts, readings and reviews, all of which have helped to bring its message into clearer focus. Early drafts were distributed to a national panel of readers. Subsequent drafts have been used in workshop experiences. As a result, the *Field Guide* is a rich resource poised to influence the next advance in HIV strategy.

TWO LETTERS FROM THE FRONT

The experience of health is deeply personal but strongly affected by social environment. The following two passages written by different people coping with HIV illustrate the wide variation in states of being associated with their different perspectives and living conditions. Both are real experiences of life with HIV under treatment. Note that we can only know the state of wellness each is experiencing by appreciating the inner life associated with the events they are living through.

IN THE SHADOWED VALLEY

Hi from the Swiss Chalet where you can get full for less than $10. There is a 2.5-kid family sitting beside me who haven't said a word to each other in the last hour. I'm a bit stoned at the moment. I'm taking Emivane to go to sleep and Ritalin to wake up. Turning into a regular Judy Garland, living in the Valley of the Dolls.

Ritalin isn't bad but it doesn't do what I had hoped. Still physically tired but mentally alert. I've just started, so we'll give it a month. Damn good laxative though.

It's been really cold here although very little snow. Not complaining, but I'm eager for spring, even though we've still got February to finish yet.

Christmas was okay. Boring. You know how it is. You go from the kitchen chair to the living room and back to the kitchen again. Went on walks for relief. Imagine—I actually went to the mall for something to do. New Year's was okay too. Spent it at this cheesy gay place; it was free. There was a really lame band that played disco from the 70s. Ugh. I had a real laugh watching the old gang dancing to "Macho, Macho Man" though. Stayed out until 3 a.m. Not that I was really into it but I was glad to be out.

Haven't been doing much. Movies, coffee, lunches, dinners, TV. I was pretty depressed after Christmas, and it took a while to get it under control. Okay now—more or less. Nothing has changed. My life sucks and I have no future. But sometimes I feel better about it.

Health is okay. Have been stable since the summer. The vision in my good eye is worsening. Apparently, there is nothing major wrong with the eye.

The symptoms are strange. I can't read very well any more, which is a major drag. So what is it? The brain?

I spoke at an AIDS conference to 150 doctors a week ago. I was astonished at their reaction. They laughed at all my jokes, to the point where I had to stop speaking until they calmed down. I wasn't nervous at all. I was dramatic, poignant and funny—with a whopper of an ending!

Well I'd better go before I go on too long and this letter sits unfinished on my desk.

AND IN ANOTHER EXPERIENCE

Late in April, I attended the "Living Fully" conference at Breitenbush Hot Springs in central Oregon, high in the Cascade Mountains in the midst of an ancient old-growth forest. The conference brought together experts from a variety of holistic healing fields and people living with HIV and AIDS.

The compound is so naturally situated it's almost unnoticeable at first glance. The main lodge is in a meadow with picture windows overlooking terraces, an impressive stone fireplace, library, reading lounge and cafeteria. In the cafeteria line, I realized I'd be eating gruel and leaves for the next few days because they serve only a macrobiotic diet—no coffee or caffeine of any kind. I was already feeling tremours and we hadn't even started.

The first evening opened with introductions to an array of highly accredited practitioners and therapists: everything from aromatherapy to acupuncture and psychodrama. There were about 100 other men and women participating, representing just about every part of the HIV/AIDS continuum and every social, economic and ethnic background.

The first workshop called "The Hero's Journey" was based on *The Wizard of Oz*—only the yellow brick road was HIV. Battling all kinds of adversity, Dorothy eventually completes her journey, which is what allows her to return home. Similarly, as people living with HIV/AIDS, our determination to survive can lead us on a journey, down a path of knowledge, which allows us to live fully and find the true hero within ourselves. (And our little dog "T-cell" too!)

We went through a guided meditation to get in touch with deeper levels of consciousness. Then we wound up with a ceremony called "Ritual of Intentions." There were two tables at the front of the room, one representing life and the other death. We were each to approach the table we thought we were closest to and light a candle representing our intention to heal. What fear! What self-recognition! What empathy! What a way to bond!

Sleeping in the cold mountain air was a treat. Over breakfast the second day, people were just as excited and seemed to accept the dietary restrictions. However, there was an eddy of rebellion at the Smoking Temple, where rumours abounded about a secret stash of M&Ms and Folger's Instant.

The keynote speaker was Dr. Jon Kaiser, a certified naturopath who combines herbs, nutritional supplements and body work with western medicine. Later, I opted for the Native American sweat lodge workshop. I can't say I had a spiritual experience but I did become disoriented. My mind must have scrambled in the intensity of the heat and smoke in that dark, womb-like enclosure. Perhaps I was dying in there and was reborn again. When I collapsed on the damp grass outside, I did feel a little like a helpless infant. So I followed that up with a session of acupuncture and then a short "nap" that lasted fourteen hours.

At closing the next morning, we had an "Ecstatic Dance" session that I am sure raised the temperature of the room 20° and must have caused structural damage to the building—a touching ending with many seeds of new friendships in the making.

Personally, what I got out of the experience was a feeling of renewed energy and determination to control my own destiny. That brought home an insight. All life contains the same basic energy. When we weave our lives together like threads, we create a strong and comfortable fabric that is community, and the value of this is vast and immeasurable.

KEY TERMS

HIV AND HEALTH

HEALTH

Health is an experience not a behaviour. The World Health Organization definition in the Ottawa Charter for Health Promotion describes health as a state of complete physical, mental and social well being. Some models of health limit themselves to measurable indicators such as absence of disease. Because health promotion emphasizes a complete state of well being, people's vulnerabilities can be adequately influenced only by addressing the total experience, not just individual behaviour. The way toward health improvement must include strategies to influence the surrounding environment—particularly the social environment—for threats such as HIV/AIDS.

HEALTH PROMOTION

Health promotion is a recognized practice throughout the world and includes many kinds of human services taking a similar approach toward improving health: enabling people to increase control over the conditions affecting their health. Some practitioners believe that health promotion should be a distinct form of community action separate from activism around particular diseases such as cancer and AIDS. Experience has shown, however, that concern about a particular disease is often the entry point to participation in health promotion. It is also the real historical path of HIV health promotion.

HIV HEALTH

HIV health is a way of thinking about wellness and prevention in conditions where HIV is a pervasive threat. This way of thinking includes a wide range of strategies between remaining HIV-negative and living with HIV or AIDS. A key question health promoters must ask themselves continually is: What strategy would improve HIV health in this situation? Pursuing HIV health may include individual, community and societal action. The health emphasis throughout is on achieving well being by taking into consideration people and their environment. HIV health acknowledges vulnerability: people may be subject to HIV infection or illness by connection with their social and cultural environment, often regardless of their personal health efforts.

HIV HEALTH PROMOTION

Health promotion for HIV and AIDS has a history of profound burdens because of the stigma attached to the disease itself, discrimination and heterosexism. This history places special demands on practices specific to HIV, such as dealing with moral conflict around drugs and sexuality. HIV health promotion deserves a specific definition: any strategy that enables people to increase their control of conditions affecting HIV/AIDS. This can mean working on the interpersonal, group, organizational or societal level on any issue affecting the whole range of HIV/AIDS issues, from primary prevention to treatment and social policy.

DETERMINANTS OF HEALTH

Our knowledge of environmental factors affecting health is the product of investigations tracking the quality of life and life expectancy in various countries and regions of the world. Evidence from such studies has indicated that health is affected by a complex of interrelated factors. Surprisingly, biological factors such as genetic endowment and the presence of microbes such as HIV comprise only a small fraction—about 15%—of the overall influences on health. Factors such as health services, clinical research and medicine appear to contribute as much as 25%, although some observers believe that this portion is possibly as low as 10%. The physical environment, accounting for such factors as clean air and water, contributes another 10%. The remaining 50% appears to result from the influence of the social/cultural and economic environment on personal coping and life choices.

SOCIAL DETERMINANTS OF HEALTH

One of the key findings from the determinants of health research was that "the health effects of social relationships may rival the effects of well-established health risk factors such as smoking, blood pressure, obesity and physical activity." Social effects are thought to operate on both the societal and local levels. Societal effects include such factors as class, employment status, position in organizational hierarchies and systemic discrimination. Local factors include interpersonal relations in families and social networks, as well as regional, cultural and community influences.

VULNERABILITY

Vulnerability is increasingly being used to describe how social determinants increase HIV risks for both infection and illness. The term is defined in the UN AIDS *Strategic Plan* as follows: "The net result of the interplay of many factors, both personal and societal, vulnerability can increase by a range of cultural, demographic, legal, economic and political factors." To be vulnerable in the context of HIV/AIDS means to have little or no control over one's risk of acquiring HIV infection or, for those already infected, to have significant barriers to obtaining care and treatment.

APPROACHES TO PRACTICE

Health promoters use the flow of water to describe how, when and where to apply their strategy.

UPSTREAM—PRIMARY PREVENTION

In HIV terms, upstream means "before infection." Upstream HIV health promotion involves any initiative that would enable people to control their vulnerability to primary infection. That would include initiatives that improve social and environmental factors such as discrimination and impoverished neighbourhoods, or interpersonal factors affecting the classic prevention behaviours of safer sex, clean needles and universal precautions.

MIDSTREAM—SECONDARY PREVENTION

The idea of midstream HIV health promotion is to enable "living with HIV." This includes any initiative that helps people gain control of factors that would optimize their length of life and overall well being. A range of factors is involved including basic supports such as enhanced nutrition, clean water and adequate shelter. The next most significant factors are supportive social networks, healthy living environments and freedom from discrimination.

DOWNSTREAM—TERTIARY PREVENTION

Downstream HIV health promotion is about "living with AIDS"—supporting people through treatment and their experience with the health-care system to ensure optimal quality of life under whatever circumstances AIDS may bring. Downstream health promotion includes such initiatives as advocacy on social and health policy to ensure the provision of the best current medications, educational initiatives for care providers and community care team support.

HARM REDUCTION

HIV realities often require health promoters to suspend their personal judgment to get to the root causes of vulnerability. Taking a harm reduction approach means accepting that abstinence from risk behaviour may not be desired or even possible in some life circumstances. The goal of harm reduction is to reduce the negative health effects of risk behaviour or environments. Harm reduction can be either "micro" or "macro" depending on how you locate specific problems. It can mean big things such as running a needle exchange or a condom program. Or it can mean smaller things such as supplying bleach or recommending urination directly after sex.

RISK CONDITIONS

In accepting environmental influences on HIV vulnerability, health promoters recognize that HIV risks extend beyond individuals. Identifying risk conditions provides a way to list environmental factors that may increase the chances of HIV risk behaviour or illness progression. HIV risk conditions can include a wide range of environmental influences such as growing up in a repressive atmosphere that denies open discussion of sexuality or living in a community marred by unemployment, illness and hopelessness.

PART ONE

THEORY

Health promotion is a mind-set. To get into the health promotion frame of mind, you have to think about individuals relative to their environment. When you see a health dynamic working between people and the environment, you can see that health is more than personal choices such as diet, exercise and prevention. Health is strongly influenced by environmental factors: physical, such as home and neighbourhood living conditions, and social, such as work life and interpersonal relations. The social environment is particularly important because of stress, its direct impact on health and its less-direct influence on individual learning, experience and decisions, factors that ultimately govern health-related behaviour. To understand and influence health threats such as HIV, you can use health promotion as an important frame for thinking and working, based on the effect of environment on people's vulnerability to both HIV infection and illness progression. Knowing the language of health promotion is the key to achieving the mind-set you need. ■

CHAPTER 1

HEALTH

health promotion and the language of practice

The everyday challenges of life in a community AIDS agency—the mounting demand for services, the uncertainties of the epidemic—create a demand for an easy-to-grasp presentation of the major ideas in the health field that can help to refine the community response to HIV/AIDS.

The *Field Guide* is influenced by several models or conceptions of health. All are helpful in expanding a general understanding of health and health promotion. They also contribute toward a strategy for health improvement. They are not necessarily competing models, although they do at times critique each other's perspectives. Their real contribution to the HIV/AIDS field is the way in which each helps to advance the theory and method for the practice of HIV health promotion.

This chapter reviews the existing models and introduces a new model for HIV health promotion that is expanded and explained in the remaining chapters of the *Field Guide.* The chapter begins by considering the predominant models together in a way that brings out their contributions to understanding the health perspectives on HIV/AIDS, the language and, ultimately, the practice of HIV health promotion.

SPEAKING THE LANGUAGE OF HEALTH

Health has a language that is surprisingly diverse. The meaning of terms can vary enough that even professionals sometimes have difficulty understanding each other on crucial points. Think about the definition of health itself: Is health a lack of illness or is it wellness?

The meanings people associate with health can also have an impact on their experience. As HIV/AIDS has shown so clearly, the difference between living with HIV and coping with terminal illness is more than subtle. A good reason to learn the technical language of health—what we'll call "health-speak"—is that the change of thinking and being that comes with understanding it can actually affect how well you are.

Having a good grasp of health-speak is also helpful for getting around the health system. Those who are confident with this technical language of health are better able to focus their work within the system, and have a better idea of where they fit in the "big picture."

An experience in a mixed meeting of health academics and community AIDS workers illustrates these points very well. Participants in the meeting were discussing an exciting development—the design of an HIV/AIDS stream to run through a four-year undergraduate medical curriculum. When the discussion drifted into a critique of physician-patient relations, a professor of medicine exclaimed, "What's the bottom line? What do you really want?" The seropositive community activist parried confidently with "Health!" That remark silenced the room.

Of course, there is more to knowing the language of health than slipping in a well-turned retort. Learning the language will also affect the way you practise health promotion. Practice is everything in *Taking Care of Each Other*. Language brings it into focus: with whom, how, when and where.

Some may argue that everything in community AIDS work could be called "health promotion," but there are, as you will see, distinct orientations and practices. Knowing what they are and gaining facility with the language will enhance your performance. And, as in knowing any language, your facility with the language of health will influence how much you can participate in the ongoing professional dialogue of the field. That dialogue is the key to HIV/AIDS advocacy in the health and social policy system.

The discussion that follows relates community HIV experience to five models of health:

- The Ottawa Charter for Health Promotion
- Precede-Proceed Health Promotion Planning
- Socio-Environmental Health
- Population health
- Health and Human Rights

It is important to recognize that each model reflects different experiences. The intent of this discussion is to describe these models in a way that helps you better understand the language of health. These descriptions eventually build a comparative framework that exposes some widely discussed, but still not fully understood, themes surrounding health, HIV health and the public health system, such as the social determinants of health. From there, you will be able to see and understand how the ideas converge to frame a productive strategy for HIV health promotion.

ACCORDING TO THE CHARTER . . .

The Ottawa Charter for Health Promotion of 1986 is widely recognized as a foundation document for the practice of health promotion, although the field of health promotion practice is much older. The Charter focuses on health, not disease, and develops the concept of health for all. Like any statement of its kind, the Charter attracts its share of debate on the precise meanings of its terms. Yet the very fact that it attracts such attention provides the Charter with its position and strength within discussions going on among health practitioners and policy makers worldwide. To understand why requires a close examination of some of its principles.

The first thing you notice about the Ottawa Charter is its voice. It sounds like a manifesto and it is. The Charter was the mission statement of the

KEY STATEMENTS FROM THE OTTAWA CHARTER

Health promotion is the process of enabling people to increase control over and to improve their health.

To reach a state of complete physical, mental and social well-being, individuals must be able to

- identify and realize their aspirations;
- satisfy their needs;
- change or cope with their environments.

Prerequisites for health are peace, income, shelter, a stable ecosystem, education, social justice, food, equality.

PRINCIPLES OF PROMOTING HEALTH

ENABLE Health promotion focuses on achieving equity. It ensures equal opportunities and resources to enable people to achieve their fullest health potential. It secures the foundation in a supportive environment, with access to information and opportunities to enhance personal skills.

ADVOCATE Health promotion aims at making the following conditions favourable through advocacy: political, economic, social, cultural, environmental, behavioural, biological.

MEDIATE Professional groups, social groups and health personnel have a major responsibility to mediate between differing interests in society in the pursuit of health. Health promotion strategies should be adapted to local needs and possibilities.

"new public health" crafted for a conference sponsored by the World Health Organization in 1986. The document was endorsed by representatives from public health agencies all over the world.

The next thing you notice is the perspective. The Ottawa Charter reads like a set of instructions to reinvent the health system. That impression, apparently, was also intended. The HIV/AIDS experience is certainly one of the best examples of the degree to which system change can actually happen.

KEY STATEMENTS FROM THE OTTAWA CHARTER

ACTION STEPS FOR HEALTH PROMOTION

BUILD HEALTHY PUBLIC POLICY. Health promotion puts health on the agenda of all policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health.

CREATE SUPPORTIVE ENVIRONMENTS. The overall guiding principle for the world, nations, regions and communities alike is the need to encourage reciprocal maintenance—to take care of each other, our communities and our natural environment.

STRENGTHEN COMMUNITY ACTION. Health promotion works though concrete and effective community action in setting priorities, making decisions and planning and implementing strategies to achieve better health.

DEVELOP PERSONAL SKILLS. Health promotion supports personal and social development through providing information and education for achieving health and enhancing life skills—increasing the options available to exercise control over health and make choices conducive to health.

REORIENT HEALTH SERVICES. Reorienting health services requires stronger attention to health research. It also requires professional education and training leading to a change of attitude and organization of health services that refocuses on the total needs of the individual as a whole person. Reorienting health services is a responsibility shared among individuals, community groups, health professionals, health service institutions and governments.

Then you notice that the Charter is a framework. It is an outline of a path toward a way of thinking and acting on health, but is never specific about how to *practise* this new way of doing things. That has been an important point of confusion on the perspective of the Charter. It was obviously written to argue the policy framework for community involvement in health but not the specific practices of community health work. This was a significant point of departure for the *Field Guide.*

An example of the Charter's influence is the AIDS Community Action Program created by Health Canada, in the spirit of the Charter, to allow public support of community efforts.

Moving from the Charter to everyday AIDS work turns out to be more complicated than it appears on the page. And yet, what the Ottawa Charter has to say is truly inspirational. The Charter is a public document that actually encourages individuals, groups and communities to challenge the health system in order to improve the health of society.

"Reorienting health services" continues to be one of the key challenges of AIDS work. Advocacy to protect the health, rights and dignity of people affected by and living with HIV/AIDS is required at the local level virtually everywhere. Effectively, the entire health system is, in one way or another, touched by the need to reduce vulnerability and harm related to HIV/AIDS. Yet, curriculum for the formal education of health-care providers is only just developing. In spite of appreciable progress, the reorientation of health services to enable the Charter's goal—to increase the patient's control of health—has only begun.

The Ottawa Charter defines health promotion in a simple and direct way that can be understood by everyone:

> Health promotion is the process of enabling people to increase control over and to improve their health.

The power of this language becomes clear when you realize that "enabling" describes a practice that frees people to improve their own health. The location of the control is the important issue. People who feel controlled by illness fare worse in terms of pain, damage and disability than those who live their lives beyond their symptoms. Enabling makes it possible to help people make this crucial shift in thinking.

The process of enabling people to increase their control applies to many different levels: from individuals to groups to communities, organizations and whole populations. Admittedly, enabling others is easier to say than do. If we allowed it, an enabling approach would form the basis for all community

HIV practices—prevention, harm reduction, support and care, including face-to-face conduct within community organizations themselves.

The Charter neatly packages a set of core principles for this practice that speaks directly to the community HIV/AIDS field with its polyglot mix of participants:

- Focus on achieving equity.
- Secure the foundation in a supportive environment.
- Mediate between the different interests of society.

The Charter spells out a program for health promotion that could stand as the mission of community AIDS agencies:

- Take care of each other.
- Create supportive environments.
- Strengthen community action.
- Develop skills that increase health options.
- Reorient health services to respect the needs of the whole person.
- Put health on the agenda of policy makers at all levels.

This is the substance of the model of health embodied in the Ottawa Charter. It provides a broad set of health-promoting principles, a practical foundation for working with people affected by and living with HIV/AIDS, as well as an advocacy framework for the health system, governments and society.

Observation suggests that HIV-affected communities have only begun to recognize the full depth of the meaning of health and health promotion as outlined by the Ottawa Charter. Certainly, strong movement and change have occurred, but the routine focus continues on condoms, clean needles, safer sex and symptom management rather than on health strategies for the whole person and whole communities. Obviously, the "new public health" of 1986 is still new today.

PRECEDE BEFORE YOU PROCEED

The model used by the Institute for Health Promotion at the University of British Columbia is known as Precede-Proceed. Lawrence Green, the

THE PRECEDE-PROCEED HEALTH PROMOTION PLANNING FRAMEWORK

PRECEDE

1 SOCIAL DIAGNOSIS Assess quality of life by involving people in the study of their health needs and aspirations. Document and inventory the needs.

2 EPIDEMIOLOGICAL DIAGNOSIS Identify specific health problems by using available data generated by appropriate investigations and epidemiological findings. The following are key HIV epidemiological parameters: HIV sero-prevalence, HIV infection rates, HIV incidence, AIDS incidence, cumulative AIDS incidence and AIDS mortality rates.

3 BEHAVIOURAL AND ENVIRONMENTAL DIAGNOSIS Research and identify specific behavioural and social-environmental risk factors and issues in the local environment.

4 EDUCATIONAL AND ORGANIZATIONAL DIAGNOSIS Research appropriate health promotion strategies for your community by investigating

- Predisposing factors: Determine people's current knowledge, attitudes, beliefs and perceptions that could facilitate or hinder health promotion efforts.
- Enabling factors: Determine available skills, resources and barriers that may help or hinder health promotion.
- Reinforcing factors: Determine the kinds of feedback and rewards that will further the desired goals.

5 ADMINISTRATIVE AND POLICY DIAGNOSIS Review and assess the organizational and administrative capacities to develop and implement health-improving programs.

PROCEED

6 IMPLEMENTATION Design the programs. Align people, budgets, timelines.

7 PROCESS EVALUATION Observe and adjust the program to improve effectiveness.

8 IMPACT EVALUATION Research and describe the impact of the programs on the people for whom they are intended.

9 OUTCOME EVALUATION Research and describe changes to population's health status and quality of life.

institute's director, is the co-author of one of the leading and internationally recognized textbooks on health promotion, *Health Promotion Planning: An Educational and Environmental Approach*, which presents the model in detail.

Precede-Proceed is a community-health planning framework. The process involves a series of steps that *precede* a health intervention, which then *proceeds* through implementation and, eventually, outcome evaluation. Ideally, a mix of community members and professionals steer these efforts. According to this model, health promotion is "the combination of educational and environmental supports for actions and conditions of living conducive to health."

The health focus includes both risk factors and positive health or wellness—common ground with the community AIDS agenda against HIV infection and illness. In addition, health and health risks are seen to be caused by many factors—behavioural, environmental and social. Because of these many factors, health improvement requires co-ordinated efforts across sectors and fields. Such comprehensiveness has long been recognized as a key to enhancing action on HIV/AIDS at every level. Precede-Proceed suggests methods to put this intent into practice.

Precede-Proceed emphasizes *research before intervention* for reasons that are familiar in the community HIV/AIDS story. Prevention strategies, messages and programs have often been determined by the people responsible for them, following only their gut instinct rather than a systematic consultation with the intended audience. While it is possible such creativity got results, all too many actions had a low impact, or even worse, sent out the wrong message. The Precede-Proceed model advises: "Research everything before doing anything."

Precede-Proceed has been applied widely at the community level, as well as nationally and internationally. The model is relevant to community AIDS agencies because it inspires long-range thinking and strategic planning for the overall health circumstances of HIV-affected communities. To date, few AIDS agencies have taken up such comprehensive planning. See Chapter 4: Plan—Focusing on HIV Strategy in Evaluation and Planning.

HIV health planning, ideally, would take the health of the whole affected community into account, not just individuals or groups at risk for HIV infection and illness. As a device to help an AIDS agency through strategic planning, Precede-Proceed would be a useful way to look at HIV/AIDS in the context of a range of other health issues within an affected community. As AIDS experience has amply shown, there is usually more at stake in the health status of HIV-affected communities than HIV alone.

Following Precede-Proceed to the letter requires levels of research normally unavailable within community AIDS organizations. The agencies at the Pacific AIDS Resource Centre (PARC) have enjoyed the advantage of a close partnership with the British Columbia Centre for Excellence in HIV/AIDS, allowing access to epidemiologists and other health scientists. This situation is rare, in Canada at least, but the general idea of Precede-Proceed is to look for and recruit the best mix of professional and community resources available within the local health environment, such as public health data collections.

Another factor that limits the ability to plan HIV health promotion in community AIDS agencies is the state of HIV/AIDS epidemiology. Only AIDS is reportable in Canada at the national level. Knowledge of HIV incidence is limited to estimates and whatever can be derived from HIV test sites, the memberships of AIDS organizations and long-term follow-up studies of at-risk populations. Numbers of positive HIV test results are available in some Canadian provinces, but ethical problems—such as protecting anonymity—stand in the way of a better system.

A further complication stems from people's attitudes and beliefs about HIV testing in the first place. Even though current clinical research suggests that early HIV detection and subsequent early intervention have a significant effect on length and quality of life, there are still those who would rather leave their HIV status undetermined.

Reportability, as it currently exists, also makes it hard to know what is actually happening with seroconversion rates in any particular community. This affects the ability, at the agency level, to manage the future epidemic as people living with HIV develop symptoms. The epidemiological information to predict such trends in Vancouver was acquired almost accidentally.

Creative manipulation of statistics from a member survey of the British Columbia Persons With AIDS Society (BCPWA) produced a chart projecting the population curve entering symptomatic HIV disease in the region.

Precede-Proceed underscores the importance of research tools for health promotion planning. For example, by using a survey, AIDS Vancouver found that 52% of its HIV-positive clients were satisfied with existing services; another 25% were satisfied most of the time. Less than 2% of respondents had anything really negative to say. These results helped to put to rest a perception, held by some in the community, that the agency was doing its work poorly. The survey enabled AIDS Vancouver to proceed with confidence toward the further development of its HIV/AIDS support program. The results also proved the strategic value of research.

WELCOME TO MY SOCIO-ENVIRONMENTAL NIGHTMARE

The socio-environmental model is based on a view that health promotion operates within a distinct action zone in the health system that emphasizes analysis of the *quality* of both social and physical environments. This is the model used by the Institute for Health Promotion Research at the University of Toronto and appears in the writings of Ron Labonté and Irving Rootman.

The model's emphasis on environmental risk conditions in both the social and physical sense has been a continuing source of inspiration for the *Field Guide's* approach to HIV health promotion. Taking socio-environmental health into consideration affects a broad range of activities in an AIDS agency, from concepts of management and organizational development to community outreach and even community centre design.

The socio-environmental model also supports many observations about the negative health effects of the social environment made every day in AIDS work: the stigma of infection, the marginalization of affected groups, the impact of homophobia on prevention, the isolation of the ill and the constant stress of witnessing it all. The focus of the model in practice is to help groups affected by all this to draw on their own potential to rise to the challenge of health. See Chapter 7: Agency—Transformative AIDS Organizations.

SOCIO-ENVIRONMENTAL HEALTH PROMOTION

The following approaches to health operate simultaneously:

MEDICAL This approach focuses on disease and treatment. Prevention is defined by physiological risk factors such as obesity, high blood pressure, high cholesterol or early detection information such as spots, lumps and pains.

BEHAVIOURAL Chronic and degenerative diseases often result from behavioural risk factors such as smoking, high-fat diet and lack of exercise. Prevention, from a behavioural approach, is defined by healthy lifestyles and the promotion of physical well being.

SOCIO-ENVIRONMENTAL People's aspirations to health are affected by their circumstances and exposure to socio-environmental risk conditions such as discrimination, marginalization, isolation and poverty—homophobia in HIV-affected communities.

Health promotion operates in the socio-environmental field.

One contribution of the socio-environmental model is its attention to the way in which health promotion differs from health care and health education. In this framework, *health care* deals with illness and is governed by medical practice. *Health education* is the classic prevention model dealing with personal behaviour such as condoms, clean needles and safer sex. This puts health promotion into a category of action where the emphasis is on social, cultural and environmental change as a way of achieving health. It is important to recognize that all of these activities and ways of delivering health can occur at the same time.

In AIDS work, a socio-environmental approach would position both safer sex (primary HIV prevention) and nutrition information (secondary HIV prevention) as health education. Health promotion, from the model's perspective, might include community ventures such as food, money and housing initiatives, development outreach in risk environments and advocacy efforts against discrimination or homophobia. Beyond such direct approaches to HIV/AIDS, the model directs practice toward the range of other community issues that affect HIV health, such as the safety and livability of neighbourhoods.

PRODUCING HEALTH

	MEDICAL	BEHAVIOURAL	SOCIO-ENVIRONMENTAL
HEALTH	Absence of disease	Individual well-being; fitness	Complete state of physical, psychological and social well-being
DETERMINANTS	Physiological risks: high blood pressure Microbes: HIV, TB, HEP A,B,C	Behavioural risks: unsafe sex	Psycho-social risks: discrimination, abuse Environmental risks: poverty, pollution
TARGET	Individuals at risk	Risk groups	Vulnerable groups and risk environments
STRATEGY	Testing, treatment, health care and surgery	Information, education and social marketing	Personal empowerment, group and community advocacy and action
DEVELOPMENT	Professional education	Community planning and programming	Self-empowering community groups and organizations
PREVENTION	Tertiary: disease intervention	Primary-secondary: creating and improving healthy lifestyles	Primary-secondary: creating conditions conducive to health
SUCCESS	Decreased physiological risks, illness and death	Healthier lifestyles, fitness	Improved control over health and quality of life

The model shows that the social environment surrounding people at risk for HIV infection and illness is a potent contributing factor to the behaviour, and therefore the health, of individuals. The practical strategy resulting from that understanding is to mobilize affected communities to advocate for and to help make systemic changes that reduce their vulnerability to HIV/AIDS.

An Australian prevention campaign provides a good example of an HIV health message informed by socio-environmental thinking. "When my mother found out I was gay she blamed herself. Now she takes all the credit." Although AIDS is mentioned in the tag line, the strategic intent of the campaign was to secure a supportive environment for an HIV-vulnerable group. AIDS Vancouver took a similar approach in the development of an HIV/AIDS information campaign for the workplace. The message was oriented directly to employees: "We care about AIDS. We care about you. A message from your employer."

CREATING CONDITIONS FOR HEALTH

From the socio-environmental perspective, health problems are the result of social, political and economic impacts that degrade the environment and cause groups within a society to become dysfunctional, trapped by powerlessness and illness. People who have the least economic and social power, for example, often live in the most polluted or degraded neighbourhoods. Lack of power, self-blame and low self-esteem become enmeshed in a social pattern that contributes to illness and, more generally, to a state of low expectation of health. This is certainly the underlying story of the HIV epidemic among injection drug users. See Chapter 3: Study—Listening to HIV Experience with Research Skills.

SOCIO-ENVIRONMENTAL PRACTICE

The socio-environmental model relates living conditions to the way individuals feel and how motivated they are to care for their own health and that of others. In pointing out these relationships, the model sharpens the practical focus on where and how to act to create conditions more conducive to health. As a way to enhance HIV prevention, the socio-environmental model suggests the following practice framework for HIV health promotion:

- what to look for in the environment that may be affecting the general health of the community as risk conditions for HIV/AIDS

- how to see the linkage between environmental conditions, social behaviour and the HIV/AIDS health situation of the community
- what can be done environmentally to enhance health as a way to prevent HIV infection and illness

Practice from the socio-environmental perspective involves *direct experience* with people living in risk conditions. The process of enabling people to increase control of their health is interactive and intuitive, based on close contact, listening, documentation and reflection. The research is qualitative, requiring deep immersion in local culture—termed *ethnography* in the *Field Guide*. See Chapter 3: Study—Listening to HIV Experience with Research Skills.

The socio-environmental approach provides useful perspectives on primary HIV prevention. A repressive environment marked by homophobia and social stigma around HIV/AIDS affects the self-esteem of gay men and chips away at community and personal aspirations. Even more troubling, at least a third of HIV-positive gay men are thought to have histories of early abuse. Such widespread experience may be evidence of damage caused by homophobia. The statistics link HIV vulnerability to socio-environmental risk conditions in childhood. The effects of these conditions show up in the adult in a dangerous mix of low self-worth and a propensity for dysfunctional relationships and compulsive sex.

The socio-environmental approach provides a good basis for the outreach aspects of AIDS work. Intervention in public sex environments such as bath houses and parks has been shown to be more effective with friendly, face-to-face contact, normalized over time, than with pamphlets or condom blitzes.

The model applies to HIV/AIDS support and positive living equally well. In evaluating the focus of community support efforts, for example, the model demonstrates how inappropriate it would be to offer a pamphlet on nutrition when local environmental conditions are poverty and homelessness. Food, shelter and medicine are the more obvious priorities.

Clearly, there is more to health promotion in HIV-affected communities than HIV/AIDS alone. Yet, HIV/AIDS remains the main reason to advance the practice.

POPULATION HEALTH—A WHOLE-POPULATION MODEL

Population health is one of the more recent models to enter the field. A strong wave of interest in it is due to the powerful way in which the model explains some of the lesser known, but significant, phenomena that determine the health of whole populations. However, the use of the model in health strategy is untested, either in research or actual practice. Curiously, the significant history, international experience and field research in health promotion as a public health strategy appear to have been bypassed in the political embrace of the large-scale social perspective of population health.

The model is based on an influential global investigation into the range of factors that determine the health status of whole populations. Its key proponents and investigators are Fraser Mustard and John Frank of the Canadian Institute for Advanced Research. The findings of their research form the foundation for population health. Population health is the dominant model under discussion in health ministries across Canada, often overshadowing interest in health promotion. The reasons will become clear with further exploration.

POPULATION HEALTH

DETERMINANTS OF HEALTH

Personal health practices
Biological endowment and coping skills
Social and economic environments
Physical environment
Health services

TOOLS AND SUPPORT SYSTEMS

Research + Information + Public policy

The view of health proposed within the population health model is limited to the *absence* of disability or disease. More to the point, some supporters of population health see the definition of health embraced by the Ottawa Charter—a complete state of physical, mental and social well-being—as too broad. This suggests that if the factors that determine health (determinants of health) must be directly measurable, then the "quality of life" experience of health, so important to HIV health promotion, does not have a place within population health.

The implications of the population health model may well affect future advocacy initiatives for HIV-vulnerable groups and communities. Critical analysis of the model reveals that it is not a replacement for health promotion. In fact, population health offers little for actual field practice, emphasizing instead large-scale social and economic policy. The importance of population health for HIV strategy is in knowing where the HIV/AIDS experience fits into it.

RESEARCH OVERVIEW

An overview of the research on the determinants of health is the best starting point to understand the issues and implications. Investigators sought to determine whether or not increased investment in health care increases the health status of populations. Evidence from the research showed that health care itself comprises a relatively small fraction of health determinants. Further, increased spending on health care can actually *decrease* the health status of populations: less money is available to influence other important factors affecting health.

Not surprisingly, one of the key determinants of health found by population health analysis is prosperity. In this respect, the economic environment is shown by the study to be a significant determinant of health. Japan is the leading example of health status improvement coincidental with economic growth and success. The inference is that other nations would do as well under the same circumstances—an untested assumption.

Closer analysis of the wealth-equals-health equation, however, reveals insights more directly related to our developing knowledge of the socio-environmental causes of HIV/AIDS. One of the more interesting findings of the determinants of health research is Mustard and Frank's observation that "the health effects of social relationships may rival the effects of well-established health risk factors such as smoking, blood pressure, obesity and physical activity."

This observation emerges from a study of illness and mortality rates among men working in bureaucracy. The greater the freedom to make decisions, the study demonstrates, the better the health and longevity of the individual. This brings us to a central tenet of health promotion: "Enabling people to increase control over and to improve their health" is not simply a matter of health; it is also linked directly to the whole social system. The origins of limited control of the individual over health are rooted in a social landscape of status, stigma and dysfunction.

Insights into the social nature of health become clearer when determinants of health are weighted according to how much they are believed to contribute to the health status of a population. An interpretation of the population health model provides us with the following profile of the socio-environmental effects on any disease:

- physical environment 10%
- health services 25% (some estimates are lower: 10% to 12%)
- biological influences (genetic endowment) 15%

Importantly, the following factors make up the remaining 50% or more:

- coping skills and health choices
- social and economic environment

POPULATION HEALTH AND HIV STRATEGY

AIDS organizations have made substantial contributions toward enhancing coping skills and providing health choices and supportive social environments for both HIV-vulnerable populations and the general population. From a population health perspective, community AIDS organizations could be seen to provide frontline protection from the threat of overwhelming costs to health services, as well as the less immediate costs of the social burden of illness.

One clear potential of the population health model for HIV strategy is that population health opens the way for community AIDS agencies to work with government outside a strictly health-centred framework. The Ottawa Charter introduced this idea and population health confirms it. This collaboration would involve other sectors of public interest, including the economy, the environment, social services and law.

The weakness of the population health model compared with other health models is its largely untested "top-down" approach toward health improvement through large-scale policy initiatives. Personal, group and community development—central to health promotion—are not considered. Experience with worldwide health promotion and harm reduction efforts, by contrast, has shown that the social and political momentum needed for improvements in health often come from the affected communities themselves.

Careful reference to population health has advantages, however. The model's acknowledgment of the health consequences of the social environment gives the social focus of HIV health promotion efforts a significant edge in the public policy arena. This provides an important advocacy channel for the renewal of HIV strategy at local, national and international levels.

KNOW YOUR HEALTH AND HUMAN RIGHTS

The health and human rights model further exposes the social causes of illness. It grew out of the earliest experience of the AIDS epidemic and offers a framework for the analysis of risk conditions and public health decisions. It also provides a legal framework for action.

The main proponent of this model is Jonathan Mann of the Harvard School of Public Health. The link between health and human rights is clear with AIDS work because the model grew out of an appreciation for

HEALTH AND HUMAN RIGHTS

This legal framework to investigate and remedy health conditions consists of three core principles:

1 Health policies, programs and practice affect human rights: e.g. contact tracing, quarantine.

2 Violations of human rights affect health: e.g. gender violence, discrimination.

3 Promoting and protecting health are inextricable from promoting and protecting human rights.

the health consequences of human rights issues encountered in the Global Program on AIDS administered by the World Health Organization. The best way to access the model is through Professor Mann's own words:

> Public health officials became increasingly aware that when people suspected or confirmed to be HIV-infected were dismissed from work or school, denied health care, imprisoned or beaten or physically harassed, fears of such treatment became a major barrier to HIV prevention. For the first time in history, preventing discrimination toward infected and affected people became an integral part of a strategy to control an epidemic.

The health and human rights model focuses on the root causes of illness found in social, rather than physical, environments. Root causes need to be distinguished from the more obvious or "proximal causes" of illness, those we are likely to associate with individual behaviour or a disease agent such as HIV. The product of this analysis, in terms of public health, is the concept of *social vulnerability.*

Those who are exposed to social discrimination, isolation and abuse are known to be vulnerable to a range of illnesses, including HIV/AIDS. As Professor Mann observed at the Xth International Conference on AIDS in Yokohama in 1994, "AIDS, even before our knowledge of HIV, followed the path of least resistance, infecting those who were vulnerable to discrimination on the basis of race, gender and sexual orientation."

Social vulnerability proves to be a useful analysis on its own when evaluating social causes of HIV transmission and illness. For example, there is anecdotal evidence from the client intake process at the Pacific AIDS Resource Centre that powerlessness and low self-esteem experienced by street-involved youth are sources of profound vulnerability to the sexual transmission of HIV and, worse, to a quick transition to symptomatic AIDS. The British Columbia Centre for Excellence in HIV/AIDS has published research on this phenomenon, demonstrating that those who are poorer and have HIV die faster than those with connections and means.

Experience and research with health and human rights is a relatively new development. But it is one that will be increasingly valuable in the pursuit of HIV-related health. The model challenges us to reduce vulnerability through the use of human rights as a legal and analytical foundation.

"The new public health," Professor Mann suggests, "sees society and disease to be inextricably linked, so that society is very much part of the disease, and disease is very connected with society. Without a commitment to change the societal conditions which constrain health, the impact of public health work will be limited to those who already enjoy and realize their human rights."

Community AIDS organizations can act as important catalysts for social transformation in the path of an expanding and intensifying global epidemic.

CONVERGING IDEAS OF HEALTH

It is important to remember that each model explored in this chapter assumes a complete operating environment of its own. The point of comparing the models has been to demonstrate how AIDS work can fit into the powerful context of health-centred language and strategy.

Building a model of the models helps to show more clearly how the language, meaning and interests of different approaches can provide a comprehensive strategy for HIV-related health. It also leads us to consider how limited and ineffectual AIDS work would remain without a shared language of health.

One striking effect is the extent to which the language of health expressed through these models directs our attention to a social interpretation of health and illness. Consequently, this leads us to social methods and remedies for HIV-affected groups and communities. The social implications of the models suggest a broad range of possibilities for interventions in specific environments and in society itself:

- The Ottawa Charter promotes community action, the creation of supportive environments and equitable access to health.
- Precede-Proceed is an instrument of social planning and co-ordinated community activity, directed toward social change that leads to better health.
- The socio-environmental model provides a way of looking at health issues in a social framework where risk conditions are social in origin,

FIVE MODELS OF HEALTH PROMOTION

	HEALTH PRINCIPLE	HEALTH IMPROVEMENT	CONTRIBUTION TO HIV HEALTH PROMOTION
OTTAWA CHARTER	Physical, mental, social well-being	Enable increased control	Empowering practices and policies
PRECEDE-PROCEED	Wellness, behavioural risk factors	Research-do-evaluate	Community health planning method
SOCIO-ENVIRONMENTAL	Physical, mental, social well-being	Improve environmental risk conditions	Application to multiple practice environments
POPULATION HEALTH	Absence of disease	Target economic determinants	Social and economic policy advocacy
HEALTH AND HUMAN RIGHTS	Societal causes of health and illness	Decrease vulnerability	Human rights, legal remedies

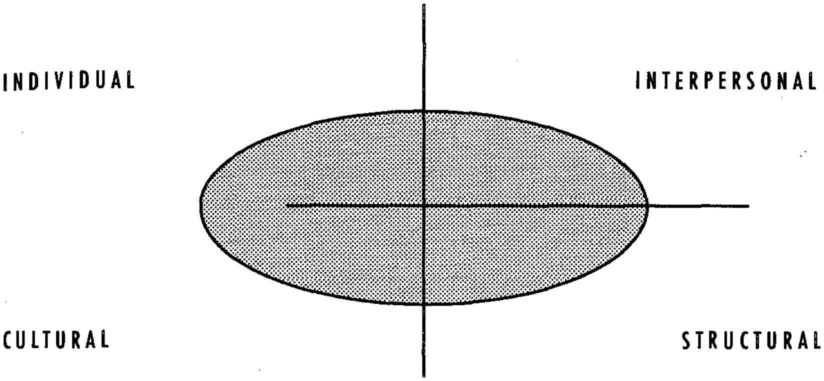
including industry-damaged physical environments.

- Population health shows that even the determinants of health depend on social conditions produced by the economic, cultural and social support systems of a society.
- The health and human rights model suggests that the root cause of illness is in social vulnerabilities.

Clearly, the *social-environmental* interpretation of HIV prevention that emerges from these converging ideas of health suggests the need for an analytical frame suited to a broader picture of HIV risks and vulnerabilities. Its wider range would focus strategy for more powerful outreach, targeted messages and advocacy work. This social-environmental focus would encompass four main points:

- **Individual:** Consider the mind-set and circumstances of the individual, not just his or her behaviour. Social environment governs how an individual behaves, as well as his or her overall health.
- **Interpersonal:** Account for how social power, in all of its uses and abuses, is negotiated between people and ultimately affects health.
- **Cultural:** Expose and change harmful cultural factors. Social experience is governed, in large part, by cultural habit, practice and rules of conduct that are rarely explicit and easily taken for granted.
- **Structural:** Account for the systemic nature of vulnerability that arises from existing economic, legal and social systems.

HIV VULNERABILITIES



The simple grid reproduced above helps to interpret the breadth of social-environmental factors affecting HIV vulnerability. (For the complete chart see p. 133.) It can be used to construct an inventory of HIV vulnerabilities affecting an individual, group, community or a whole population. See Chapter 3: Study—Listening to HIV Experience with Research Skills for an inventory of social-environmental risk factors affecting youth vulnerability compiled during the creation of the youth-directed video documentary, *You, Me & Reality*.

SHAPING HIV HEALTH PROMOTION

The models we have discussed provide important clues to how a more complete understanding of the social basis for HIV health can help us design a comprehensive model of HIV health promotion.

- The Ottawa Charter is a powerful expression of the interpersonal dynamics and ethics of practice required to enable people to have greater control over their own health.
- Precede-Proceed's emphases on research, planning and evaluation of action as essential parts of the action itself are valuable reference points in developing a strategy for health promotion.
- The socio-environmental model provides a practice framework of where to look and how to account for HIV health risks. It emphasizes the social dynamics and conditions that can influence the way individuals behave and, ultimately, how well they are.
- The population health model suggests a policy strategy to work on structural and systemic issues affecting HIV-vulnerability, both inside and outside the health field—such as those related to groups disadvantaged by economic inequity and discrimination.
- The health and human rights model provides a widely accepted set of legal principles that may be used for advocacy, as well as for broad social change.

A HEALTH PROMOTION MODEL FOR HIV/AIDS

Discussion of AIDS work and its relationship to the language of health would make little sense without practical ways to bring the theory into the field. The balance of the *Field Guide* is devoted to describing the working methods of an HIV-centred health promotion model. The five models included in the discussion so far have shaped a foundation, but there is a need for an easy-to-grasp, appropriate model for HIV health promotion. The term we will use here is *transformational health*, emphasizing the social change focus of HIV health promotion.

Transformational health is a model of practice to assist community AIDS agencies in expanding their role in HIV health promotion, for whatever challenges may be ahead. The model is *developmental*, meaning that the agency's capacity increases while working with the model in practice. The model is also *evaluative*, meaning that doing the practical fieldwork brings forward evidence of change. In its simplest terms, transformational health is learning while doing—a model of HIV health promotion suited to virtually everyone working in community-based AIDS work.

Transformational health is not an invention of the *Field Guide*. The model was "uncovered" by studying examples of excellence in HIV/AIDS fieldwork, refining the principles and testing them during the research and development phase of the *Field Guide*. These examples are presented here in impressive case stories from across Canada that describe breakthrough experiences resulting from the following actions:

- Study social risk conditions.
- Convert findings to a health strategy.
- Create supportive social networks and environments conducive to health.

As you read the case stories, reflections and practical advice in the remainder of the *Field Guide*, you will experience transformational health as a living model of HIV health promotion. The next chapter explores the model's main features and contributions to the development of HIV health promotion:

- a practical model of health promotion that emphasizes personal and social change in creating supportive conditions conducive to HIV health,
- a qualitative model that uses listening as a way to develop strategy to create supportive conditions,
- a portable model that can be used in any given situation where community-based strategy would enhance conditions for HIV health,
- a learning model that can guide fieldwork productively through multifaceted HIV/AIDS-related situations and conditions.

CHAPTER 2

A MODEL

transformational health—practical HIV fieldwork

Taking care of each other is the essence of transformational health. The model is a refinement of the health promotion theory, method and practice already found in community AIDS work. It emerged from valuable experiences in community AIDS work on prevention, harm reduction, support, treatment and care. Each of the case stories in the *Field Guide* documents these origins. The purpose of expressing "what works in the field" in the form of a model is to build on the spirit of excellence in those efforts, and to enable people working in community AIDS agencies to contribute even further.

The impulse to name the *Field Guide's* model of HIV health promotion "transformational health" arose from some of the earliest research in the development of the text. During an interview, a community opinion leader offered the following observation about the state of practice in community organizations:

> What we are looking for, in many respects, is *social transformation*, but we haven't got the theory to help us get there from the context of community AIDS work.

Since then, transformation has developed into a useful way of expressing the theory, method and practice of HIV health promotion.

The transformative basis of AIDS work has become a working reality. As described in Chapter 1, HIV vulnerability resulting from the effects of the social environment has become a major preoccupation of those in the field of HIV prevention and harm reduction. This has been, in itself, a considerable transformation in HIV prevention from the more limited version based on individual behaviour. However, there is still an urgent need to develop and apply methods of working with social risk conditions to keep HIV transmission rates low and to enhance supportive conditions for those infected.

The language and theory of health presented in the previous chapter provide the orientation and focus for this one, which is primarily about transformative practice. This chapter describes the transformational health model in detail and how it translates into practical fieldwork. It also offers some thoughts on, and symbols for, the idea of transformation.

WHY WE NEED TRANSFORMATION IN HIV/AIDS

Experience worldwide has indicated a need to expand and enhance the effectiveness of community-based efforts around HIV/AIDS. In Canada, about 3,500 infections continue to occur each year and indications point to rising rates. Meanwhile, the majority of people living with HIV are still undiagnosed with AIDS, suggesting that the worst impact of the epidemic may be still ahead.

So far the community-based response has moderated the impact of HIV/AIDS, but there are several significant threats to this situation:

- unstable political commitment to sustain support necessary for an effective nationwide community-based response to HIV/AIDS
- misinformation spread by opposing political forces: e.g., confusing HIV

population (42,500 to 45,000) with AIDS cases (11,192) [statistics from 1994]
- uncertain economic futures
- competition from other diseases for funding

To maintain an edge in these times, community AIDS agencies must be able to

- expand the practice capabilities of participants in HIV health promotion;
- increase knowledge of local risk conditions and vulnerabilities;
- evaluate and enhance local efforts to reduce HIV transmission;
- address underlying social and structural conditions to reduce HIV vulnerabilities;
- advocate increased quality and accessibility of treatment, care and support for people living with HIV and AIDS;
- advocate policies that sustain political and financial support necessary to promote the health of HIV-vulnerable communities.

Transformational health is a practical way to make progress on these initiatives, while continuing to manage the HIV/AIDS situation as it presents itself in the community.

The real point of transformational health is to enable AIDS agencies to keep on top of an unstable epidemic, to monitor developments and to increase their capabilities to manage emerging trends. They need a framework on which to build capacity to

- manage the local HIV situation by
  - reducing HIV transmission;
  - increasing the quality of and access to support treatment and care.
- promote the overall health of HIV-affected communities by
  - identifying and reducing the effects of structural vulnerabilities;
  - creating supportive spaces and social networks;
  - advocating policies that expand the political, social and economic opportunities of HIV-vulnerable communities.
- reduce the adverse effects of the HIV experience on the health and well being of individuals and their communities by
  - documenting harmful effects;
  - enabling healing.
- enhance advocacy efforts with documented local knowledge of underlying systemic and cultural effects by

- advocating for changes in society that will reduce HIV vulnerability;
- advocating for sustained commitment and investment in HIV prevention, harm reduction and health promotion.

TRANSFORMATIONAL HEALTH PROMOTION

Transformational health is a "process" model: it outlines a social learning approach to HIV health promotion. The process flows continuously through three phases: study-plan-do. This is not necessarily a step-by-step procedure but a way of describing cycles of listening, focusing and practising throughout a course of action. The process includes documentation and evaluation. Continuous evaluation through the cycles provides you with opportunities to increase the effectiveness of the action. Documenting the lived experience establishes evidence that enables you to track the effects of community HIV health promotion efforts on conditions affecting infection and illness.

HIV HEALTH PROMOTION TRANSFORMATIONAL HEALTH MODEL

STUDY	Listen to HIV/AIDS experience.
PLAN	Focus on a strategy.
DO	Create supportive social networks and environments.

EVALUATE THROUGHOUT

Analyze the impact of the determinants of HIV vulnerability on the local situation:

- individual
- interpersonal
- cultural
- structural

Apply the strategy to the full range of HIV/AIDS practice environments:

- interpersonal
- agency
- community
- society

TAKING CARE OF EACH OTHER— PRACTISING TRANSFORMATIONAL HEALTH

The core of transformational health is study-plan-do. Centred in practical fieldwork, the model is a useful description not only of the way things work, but of the way things *can* work.

STUDY Study HIV risk conditions and vulnerabilities by listening to the experience of the affected people in their own social context and situation.

PLAN Convert findings into a productive strategy to improve conditions for HIV health.

DO Build supportive networks by engaging people in creating an environment that promotes health.

Evaluation is continuous throughout the cycle, analyzing the influence of the determinants of HIV risk conditions and vulnerabilities at all levels:
- individual
- interpersonal
- cultural
- structural

In this way, you learn and apply new experiences.

Using the model helps you pursue creative ways to develop the social skills and productive potential to reduce harm, prevent infection and extend life by considering all the practice environments:
- interpersonal
- agency
- community
- society

The rest of this chapter provides examples and discussions of how transformational health practice can work in the field.

The first **Case Story** describes a study-plan-do experience from AIDS work in rural Nova Scotia. The example is particularly telling about practicalities in the field—a courageous story about practice, method and follow-through.

The **Reflections** section discusses the idea of transformation and its connection to health, and uses illustrations to represent the model.

The second **Case Story** demonstrates a study-plan-do experience in the community-based process of reorienting health services to improve the quality of HIV/AIDS care for women.

Practical Fieldwork is a summary of subsequent chapters, which describe each step in the study-plan-do model and applications to the practice environments defined in the model.

CASE STORY Rural Nova Scotia Outreach Experience

This is a story of one man's experience entering a known but largely invisible community health environment. Ross MacDonald discovers how to contact and eventually lead a previously hidden group through an inquiry about their HIV/AIDS vulnerabilities. It is a story that illustrates a sequence of steps toward transformation.

When Ross MacDonald was hired to develop AIDS Nova Scotia's prevention program for "men having sex with men" (MSM), he had little to work with. The provincial department of health had provided some funding a few years earlier to run "talking sex" (safer sex) workshops. The program operated for a year and was considered successful within the Halifax gay community. But when the grant concluded, the workshops had to be discontinued for lack of funds. AIDS Nova Scotia reverted to distributing pamphlets as a way to get safer sex information out to mainstream gay men.

As the focus of prevention efforts shifted to MSM—men with little association to the openly gay community—more funding appeared. Trying to reach this group, however, proved difficult. The agency placed ads in the newspaper announcing workshops for MSM, but few showed up. Those who did attend required counseling to deal with repressed personal histories before they were ready to discuss their sexuality, let alone safer sex or HIV/AIDS.

The workshops failed, but the organization learned from the experience. Issues more complex than condom use and safer sex practices had to be addressed to make any progress—issues such as homophobia and heterosexism.

When Ross arrived on the scene, he brought with him an interest in rural outreach. He was raised in a small fishing village up the coast from Halifax. At university, he pursued a program in international development. He was eager, therefore, to see what inroads he could make among gay youth and MSM in small-town Nova Scotia. He knew from his own experience that sexual histories begin at home—long before young men beat a path to the nearest city. But how do you begin to locate groups of men in hiding?

"We did quite a few months of information gathering, trying to develop and design a project into something we felt would really meet the needs," Ross recalls. "I started just touring around, meeting people, making contacts in communities, seeing if there was any willingness to get involved." This search for predisposed individuals and a personal investigation of the scene preceded any kind of strategy.

Eventually, as Ross met people in various small towns, an idea began to take shape on how to get the men he was meeting involved in knowing more about their vulnerability to HIV and AIDS. He decided to involve them in creating a "community profile" of their local HIV health scene. "It would be just a profile of the community from the perspective of the gay men living there."

The questions were basic and the inquiry geared to management by the participants themselves:

- What type of health resources do you rely on?
- Who knows about your sexuality?
- Whom do you trust?
- Where do you get HIV information?
- Is there any local support for gay/seropositive men?
- Do you need to go to Halifax for gay/HIV information?
- What is your relationship to the gay community in Halifax?
- What is your opinion of the gay community in Halifax?
- Have there been any problems with gay "outings" or gay bashing in the community?
- Can the police be trusted?
- Is there a gay cruising area in the community?

By tapping into informal social networks, Ross was able to bring together groups of men in six rural communities in Nova Scotia to develop profiles of their own local scenes. The communities were Middleton in the Annapolis Valley, Lunenburg on the south shore, Truro in central Nova Scotia, Pictou on the northwest shore, Sidney on Cape Breton Island and Antigonish on the northeast shore.

"We were basically asking men to come together and talk about themselves, anything about their own lives, really. They didn't even have to tell us their names."

Ross found that the responses varied, but generally the effort was worthwhile. "Some groups really responded, especially the ones that had no other venue for getting together. They tended to react more quickly, which was interesting.

"The student group in Antigonish (Francis Xavier University students) was kind of an experiment that didn't work. The approach didn't fit the frame of a Catholic school.

"But, on the whole, we got a lot of information about the rural scene, about who was available for AIDS work, about who could be trusted to continue development, information on schools, counselors, doctors and nurses in those communities."

Ross noted, "There's not much out there. But there are some people—doctors, public health nurses and counselors—who would help to do some of the work. We found out that, more often than not it was women who could be trusted.

"We also discovered that there was gay porno available in every community, so there must be men buying it. We got some men to count up the men they knew who have sex with men in the local area. The numbers were high—as many as 70 in one place. We found out about some cruising areas we didn't know of.

"I guess the assumption, initially, was that everything happens in the urban gay community. But that's not necessarily the case. There are a lot of gay men who have removed themselves from 'the community.' Even though they're comfortable with their sexuality, they are not comfortable with being identified with any particular community."

Ross proceeded to identify some of the natural leaders in the communities motivated by the "community profile" experience. He invited these men to a weekend workshop at a retreat centre.

"We had about 23 people there and the response was overwhelming. It was an 'encounter' weekend that I had thought would be much more superficial. It was wonderful because it really did take a step beyond what we had hoped for."

REFLECTIONS On Transformation

The appeal of this story is in its description of how research was used first to interest, and then to mobilize people to connect on HIV as a community health issue—even before a functioning community really existed. The interviewer might have asked for more detail about the previous step: how to identify and meet these men in the first place. It was assumed that Ross already knew the proper codes and eye contact from growing up in the region. The work of establishing face-to-face connections, the enablement of participants, the exchange of practical knowledge, the creation of a multidirectional flow of information, the assessment of vulnerabilities and the community-building action make this an exemplary story of transformative action in HIV health promotion.

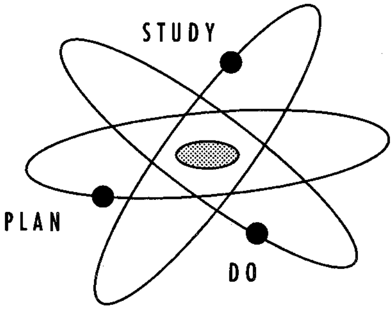
The original agents of transformation in ancient societies were the shamans or traditional healers. Later the alchemists of medieval Europe developed transformational practices. Unlike the popular conception of alchemy—focused on turning base metals to gold—the alchemists were more interested in the internal process of personal transformation. The modern practice of psychiatry is the contemporary offspring of alchemy. One of Carl Jung's most influential works, *Psychology and Alchemy*, laid the foundation for his theory of the collective unconscious—the invisible source of primal change. Lately, interest in transformation has been taken up by adult educators and other social development workers. Transformational learning theory has evolved from the effort to describe the kinds of changes that take place when people critically examine the relationship between themselves and their social environment.

Health promotion also has deep roots in human experience; it is sometimes cited as the oldest form of health care. The transformational health model is a recent development that makes use of transformational learning theory to explain and describe the practice of HIV health promotion. The model is based on underlying principles found within the "best-practice" examples of HIV health promotion gathered during research for the *Field Guide*. Describing the model in this detailed way makes transformational health available not just to people exploring the cutting edge of HIV health promotion but to everyone doing AIDS work.

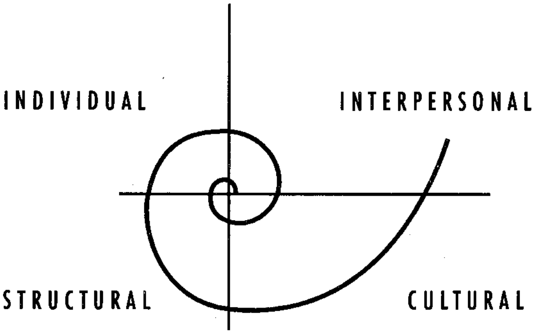
TRANSFORMATIONAL HEALTH ILLUSTRATED

The many different ways in which health promotion may be applied in the field makes the wider understanding of its practice difficult to express in a few words. The enabling principle, for example, can apply to an individual, a group, a community or a population. Experience has shown that a few simple illustrations help where words flounder. The following graphic ideas were influenced by symbols used in alchemy, handed down through time and given a contemporary interpretation to illustrate the transformational model.

THE STUDY-PLAN-DO PROCESS

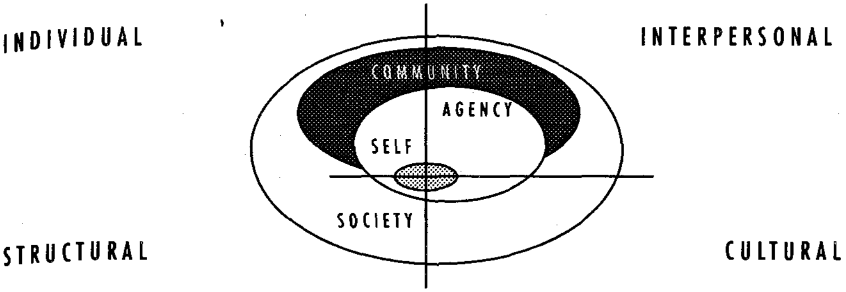


METHOD This illustration emphasizes *action* in health promotion using study-plan-do to operate effectively on the many dimensions of an HIV situation.



PROCESS This illustration shows how study-plan-do is an unfolding process rather than a rigid procedure. As the listening process unfolds, your knowledge of the situation expands, giving you a better appreciation of what to do at every new challenge.

THE PRACTICE ENVIRONMENTS: NESTED SPHERES



Spheres symbolize fields of action. The spheres illustrated here represent the critical practice settings of HIV health promotion. Nesting conveys the idea that work in one field affects others. This suggests that practice in one setting would be incomplete without at least considering the impact of the others and, at best, applying an appropriate strategy to account for all of them.

THE INTERPERSONAL ENVIRONMENT: The sphere at the core illustrates where health promotion practice must start—from within. But health promotion as a practice for individuals really occurs in the interpersonal sphere of action. It is fundamentally about supportive practices between people.

THE AGENCY ENVIRONMENT: The next sphere symbolizes the agency context of health promotion, the community AIDS organization. It is both a refuge for health promotion and a practice environment of its own. This sphere breaks out from its nest, which illustrates that the agency environment bridges between practice environments.

THE COMMUNITY ENVIRONMENT: The next sphere represents community and illustrates how a community contains an AIDS agency. Agency is the best expression of community intentions and leadership for HIV health. The action is not only on the community but also from the community acting on the surrounding environment.

THE SOCIETAL ENVIRONMENT: The largest sphere symbolizes society. The surrounding societal environment is a potent source of HIV vulnerability in the form of underlying social stresses such as stigma and discrimination. Practice in society is thus an essential reality for HIV health promotion.

CASE STORY Positive Women Transforming Care

Ideas begin informally before you really know what you are doing.
—Terrah Keener

This story describes HIV health promotion in the pursuit of access to quality care—"reorienting health services" in the language of the Ottawa Charter. The process developed over three years with extensive participation from a wide range of groups and individuals.

Primary care physicians are in need of both support and current information on HIV diagnosis and treatment issues for women: that much was clear to everyone who had spent any time listening around the kitchen table at the Positive Women's Network (PWN) in Vancouver—one of the partner agencies in the Pacific AIDS Resource Centre (PARC). Women with well-founded fears had been refused testing—told to go home and stop thinking about AIDS. Others were flatly told to expect to die soon when they tested positive. It was all anecdotal information at this point, but insensitivity was a common theme. The board of PWN felt something should be done about this obvious weakness in the health-care system, so they created a committee to focus on medical education.

This committee needed to be a mix of physicians, HIV-positive women and community members who would be willing to do whatever was necessary to improve health-care conditions for women around HIV/AIDS. Because PWN had been on the scene for several years, the right group seemed to come together at the right moment.

STUDYING

The first order of business for the committee was to get more information in a form that was appropriate for the audience. They wanted research and realized it would have to be rigorous to satisfy physicians. Two studies were launched, one looking at the experience of HIV-positive women, the other assessing the needs of primary care physicians.

Two of the physicians on the board volunteered to do the Positive Women's Survey. They wanted a detailed profile of HIV-positive women in British Columbia and answers to their questions about relations with physicians—information that would help to focus initiatives. This information included

- demographic information
- risk factors for HIV infection
- circumstances around HIV testing
- assessment of the stage of HIV disease
- current use of antiretrovirals
- level of satisfaction with health care
- assessment of the most common psycho-social stresses

To reach women throughout the province, they designed a self-administered questionnaire. PWN called on its alliances with clinics, hospitals, family physicians, street nurses and dentists to distribute the forms.

Another physician volunteered to look after the physician survey. The questionnaire was limited to just a few pertinent questions about their knowledge of HIV/AIDS and the kind of resources they would need to feel more comfortable with handling HIV/AIDS in their practices.

The results of the two surveys combined to paint a powerful picture of the need to enhance HIV/AIDS knowledge at the primary-care level in British Columbia. But the medical education committee decided to probe even deeper. They convened a focus group composed of women living with HIV/AIDS and gave them an opportunity to talk about how they felt about their doctors, their experiences in the health-care system and what they would like to see changed.

The focus group more than confirmed what the questionnaires had already said. The session had a strong message. Women talked about being dropped by their physicians after their HIV diagnosis. They repeated statements made by their physicians such as: "You got yourself into this!" There were painful stories of insensitivity in pregnancy and childbirth.

PLANNING

The evidence was clear to the medical education committee. There were huge gaps in the health-care system for women living with HIV/AIDS. So the question became: What should we do about it?

As a starting point, the committee outlined the fundamental needs of women living with HIV/AIDS:
- information and education
- support services
- access to sensitive, responsive health care
- treatment information
- increased access to clinical drug trials
- reduction of isolation
- ongoing quality of life management

From there, the committee realized that there were too few general practitioners in British Columbia familiar enough with HIV/AIDS to ensure those fundamental needs could be met. The target was obvious and so the Physician Education Project was launched. The goals were ambitious but realistic. The program would
- be designed and delivered by family physicians in partnership with women living with HIV/AIDS;
- provide testing information, stressing pre- and post-test counseling;
- provide basic information on epidemiology, pathophysiology, treatment and palliative care for HIV disease in women;
- address psycho-social issues relevant to women with HIV disease;
- enable family practitioners to look after women with HIV/AIDS in their own practices.

Then the question became how to deliver such a program to reach the widest possible audience of physicians. The easiest way seemed to be to set up a presentation that could be delivered at Grand Rounds (educational sessions that regularly feature such presentations) in hospitals throughout the region. The logistics were demanding but not overwhelming. If a few teams were geared up for the presentations, they could share the load and no team would have to present too many times.

DOING

By this time, the committee needed support, so they hired Terrah Keener as their consultant and project organizer. As ideas developed, the committee decided to create and produce the session as a one-weekend workshop.

There was a word-of-mouth recruitment program to find physicians and HIV-positive women who could attend the development workshop and deliver the presentations afterward. When the group came together for the development workshop, Terrah acted as facilitator.

The group split into two sections for the first day to prepare the content. The physicians had established roles in advance so that each would be responsible to review literature in various areas of focus, such as the natural history of HIV/AIDS in women and gynecological issues.

Terrah feels that the decision to split the doctors from the positive women was the right thing to do. She could tell that the positive women had things on their minds and it turned out that the first three hours were spent venting these issues. Terrah was able to focus all their anger into lists of helpful and unhelpful practices around HIV/AIDS to communicate to physicians.

Life in the physician's group was no holiday either. They had decided that the presentation should be composed on slides to fit what people usually expect to see at Grand Rounds. Narrowing the vast amount of information onto a few points for each slide led to heated discussions. Generating the slides was made possible by having someone with a laptop computer compose them as the group worked through the discussions and arguments.

All things considered, the development workshop turned out extremely well. The overall Grand Rounds presentation was set up to be about an hour: the physician segment 30 minutes and the positive women's segment 20 minutes. The physicians would deliver their material as a lecture, and the positive women would weave their message into their own testimonials. They decided on six key points that they wanted participants to get from the Grand Rounds session:

- Women get HIV and AIDS.

- Women are a rapidly growing HIV/AIDS population within Canada.
- Physicians should consider testing and not refuse it.
- Pre- and post-test counseling are essential.
- HIV disease can present differently in women.
- HIV is a family practice disease.

Lining up the presentation schedule turned out to be more than a simple exercise as well. The hospital staff responsible for organizing the schedules changes from year to year. Much more time than expected was spent in locating the person responsible. Eventually, Grand Rounds presentations were set up in 19 hospitals in the Vancouver region. Eight pairs of physicians and positive women would present. They held a dress rehearsal night to give everyone a final chance to perform for a supportive audience.

Once the show was on the road, there were many experiences that confirmed the needs everyone had been hearing about. Doctors apparently did not even know that HIV/AIDS was an issue for women and certainly did not feel competent to handle it in their practices. Even so, the Rounds presentation was just the germ to get physicians started, enabling them to begin their learning.

EVALUATING

To ensure feedback, the presentations ended with an evaluation form. The hospital environment is tough on consistent returns, but out of 380 evaluation forms handed out, 127 came back—enough to get a feel for what was on the minds of people who attended. Results indicated that, although physicians feel more counseling is necessary for HIV/AIDS patients, it puts excessive pressure on their practices.

By now, it has become clear to everyone at PWN that Grand Rounds made a solid impression. Although the presentation was designed for physicians, PWN receives calls from representatives of all health-care professions in the region who are apparently hungry for HIV/AIDS knowledge. More presentations are being given.

PRACTICAL FIELDWORK Process and Environment

Several cycles of listening, planning and doing are featured in this story. Terrah points out that early listening can be quite informal: simply noticing similarities in people's experiences and picking up from there. The collaboration of positive women and physicians is a significant contribution toward building informed support within the health-care environment. The rich engagement between positive women, a community agency, the medical profession and regional hospitals demonstrates the transformative potential of HIV health promotion and the practical value of study-plan-do as a method.

Transformational health is an adaptable community strategy to deal with an unstable epidemic in uncertain times. Its practical fieldwork encourages keen attention to local vulnerabilities at a crucial time in the HIV/AIDS experience.

You can gain confidence in HIV health promotion and harm reduction practice through the study-plan-do pattern of the transformational health model. The process anchors your practice to the situation at hand. Continuous evaluation keeps you on track by informing you about how well your efforts are working while they are underway. You can make improvements to your projects and programs by implementing what you learn from evaluating the individual, interpersonal, cultural and structural influences on the HIV/AIDS situation.

The goal is to create the supportive conditions in the local environment necessary to sustain HIV prevention and extend life for those living with HIV/AIDS. The future of the transformational health model is in evaluating the effects of community health promotion on local conditions of HIV vulnerability and, ultimately, on HIV transmission and illness.

USING THE *FIELD GUIDE*

The structure of the remainder of the *Field Guide* closely follows the transformational health model. There is a chapter in the text to cover each step of the study-plan-do process in detail, as well as a chapter for each of the practice environments—interpersonal, agency, community and societal.

TRANSFORMATIVE PROCESS

STUDY Chapter 3: Study – Listening to HIV Experience with Research Skills

Health promotion is a social development practice that relies on good knowledge of "where people are" before attempting to enable them to be somewhere else. You need to know the symptoms before you can make a diagnosis. Lead with listening. Listening should be instinctive.

When you are faced with an urgent situation requiring intervention or have to bring life to a decaying HIV/AIDS program, your first impulse should be to do research to provide a foundation for your strategy. How much research depends on the situation. Productive discussions, interviews and focus groups with the affected people will build up a picture of what they are experiencing.

Be systematic in the way you document your listening: this will set up a benchmark against which you can later evaluate improvements. Make notes. Use a tape recorder. Look back over your notes to identify common themes. Listening is research with the purpose of helping you create a strategy that will mobilize people to act on the HIV vulnerabilities in their environment.

Participation and collaboration in research can also be useful ways to mobilize an affected community by challenging people to know more about themselves. They can then choose and affirm the directions they need to take to increase control of their health.

PLAN Chapter 4: Plan – Focusing on HIV Strategy in Evaluation and Planning

The next phase of the transformational model is to evaluate what you've learned from the people that need to be reached. The goal of your analysis is to determine strategy. This also establishes a benchmark that describes "where the people are" according to individual, interpersonal, cultural and structural influences on the situation. You eventually return to the benchmark to evaluate health improvements. This amounts to assembling a picture that describes the HIV/AIDS situation, in terms of risk conditions or vulnerabilities and the strategy required to alter them.

As your knowledge of the HIV/AIDS situation develops through continuous active listening, a productive strategy will eventually emerge based on experience from the affected people themselves. To develop supportive conditions, you will need to think not only of the social situation, but also of your capacity and your agency's capacity to make a difference. Investigate and think through the logistics. Look for triggering devices that will mobilize people to act productively for HIV health.

DO Chapter 5: Do – Building Supportive Networks for HIV Health

Doing transformational health promotion creates the infrastructure of supportive people needed in the affected environment. Doing is all about linking people together so principles of health promotion can be applied—encouraging people to increase their control over the factors that influence their health. Your ongoing presence and monitoring of the situation assures a process that remains dedicated to health improvement. Monitoring identifies hidden barriers that may be working against the intended strategy so you can eliminate or fix potentially harmful practices as they become clear.

You keep working to develop the needed support and reduce the harms as you find them until you are ready to re-evaluate the situation.

THE PRACTICE ENVIRONMENTS

INTERPERSONAL Chapter 6: Inner Practice – Personal Transformation

Implementing HIV health promotion really must begin with you. Enabling others to increase control over their health requires good interpersonal skills, a facilitative approach and cultural competence. These skills develop over time and the learning process is full of insight and personal development opportunities.

AGENCY Chapter 7: Agency – Transformative AIDS Organizations

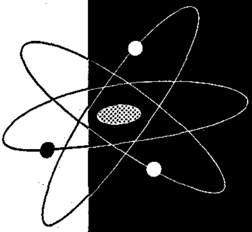
Community AIDS agencies are not only engaged in organizing community leaders to take appropriate action but they are also, in themselves, a practice environment in which to apply health promotion. The development of the *Field Guide* was based on this premise. Practice in this environment relates to staff and organizational development, planning and evaluation, and problems such as burnout and personal safety.

COMMUNITY Chapter 8: Community – Transforming the Social Environment for Community Health

Health promotion is a social development practice with a long history of work in communities. AIDS agencies are products of this same tradition. Community development may well turn out to be the most effective way for AIDS agencies to sustain primary HIV prevention—by improving conditions in the community environment.

SOCIETY Chapter 9: Society – Transformative Groups – Societal Change

Transformational health is a productive approach to HIV/AIDS advocacy. The study-plan-do cycle provides advocacy with accurate local information to influence policies that affect HIV health. In this way, the model enables practice within any environment.



PART TWO

METHOD

HIV HEALTH PROMOTION INITIATIVES REQUIRE A CLEAR UNDERSTANDING OF SPECIFIC INFLUENCES ON THE HEALTH OF THE PEOPLE THAT NEED TO BE REACHED. YOU CAN CREATE THIS FOUNDATION BY INTEGRATING RESEARCH ACTIVITIES INTO FRONTLINE AIDS WORK. THE STUDY-PLAN-DO METHOD BRINGS ACTIVE LISTENING AND DOCUMENTATION INTO THE PROCESS OF WORKING WITH PEOPLE CONFRONTING HIV SITUATIONS. THE MAIN IDEA IS TO KNOW WHERE PEOPLE ARE BEFORE GUIDING THEM SOMEWHERE ELSE. AS THEY BEGIN TO MOBILIZE, YOU CAN HELP PEOPLE USE STUDY-PLAN-DO AS THEIR OWN METHOD OF GAINING CONTROL OF THE CONDITIONS AFFECTING THEIR HEALTH. STUDY-PLAN-DO PROVIDES A WAY TO EXPLORE THE CONNECTIONS BETWEEN PEOPLE, THEIR ENVIRONMENT AND HIV IN ORDER TO GAIN KNOWLEDGE REQUIRED TO MAKE CHANGES THAT WOULD REDUCE VULNERABILITY. HEALTH PROMOTERS SOMETIMES REFER TO SUCH METHODS AS PARTICIPATORY ACTION RESEARCH, PROCESS EVALUATION OR TRANSFORMATIONAL LEARNING, BUT THE ESSENCE IS STUDY-PLAN-DO. ■

CHAPTER 3

STUDY

listening to HIV experience with research skills

Opening moves are always crucial in strategy. In health promotion and harm reduction, the critical entry point is through listening. People who may be vulnerable to HIV/AIDS must first be heard if others are to help make a difference to their lives. Listening places you in a position to address the "lived experience" influencing their situation. This chapter of the *Field Guide* presents practical strategies for using social research practices to help you listen to the experience of people for whom health promotion and harm reduction strategies are intended.

Everyone doing AIDS work is faced with making decisions about the content and delivery of programs, services and communications. As the HIV/AIDS epidemic has grown more complex, the need has grown to be more specific about addressing the particular health problems and underlying conditions of various groups. Differences in age, gender, sexuality, identity, race, class, region and culture influence the way people experience health and participate in health promotion activities and messages. Without a true understanding of the inner motivations, barriers and challenges faced by the people who need to be reached, we face a real danger of expending human and financial resources without having much impact or providing much benefit.

The way to maintain the relevance and impact of health promotion programs, services and communications is to keep in touch with the intended recipients in a systematic and meaningful way. Quite often the key ideas that would improve the impact or delivery of health promotion are already on the minds or in the experience of the intended recipients. They simply need to be heard. The orderly documentation of what they have to say can greatly influence strategy.

Integrating research into the delivery of health promotion and harm reduction efforts enhances effectiveness simply because of the close contact listening brings to the people for whom the efforts are intended. Ideally, everyone involved in the delivery of programs would be included in listening to recipients, participants or clients. Continuous documentation of this listening not only builds the evidence required to evaluate programs and services but ultimately may be used to define the strategy, content and delivery.

To date, research in the world of health and health care has been dominated by quantitative methods such as laboratory, clinical and epidemiological sciences. Quantitative research is useful in health promotion too; however, quantitative methods are not the most effective way to listen to the people who need to be reached.

Surveys, for instance, help in defining the size and growth rate of vulnerable groups, their demographic characteristics, the proportion experiencing one issue or another and the relationships among factors influencing their health. Surveys, however, provide little depth for understanding what the people are really like or what they really feel. Quantitative research, then, is no substitute for listening to what HIV experience is really like for the people who most need to be reached. This is a task for *qualitative* research.

WHY WE NEED QUALITATIVE RESEARCH

Qualitative approaches to health research are increasingly gaining attention because the methods are useful and accessible to many different players in community-based work. For example, professional researchers have taught qualitative research methods to individuals with low levels of literacy in harm reduction programs for injection drug users (IDUs). This enabled researchers to acquire accurate "inside" information on drug users' behaviour and HIV experience. The side benefit to these efforts is that the trained community "researchers" also become insider "health advocates" who can spot problems and correct them in the most practical way.

Qualitative research methods allow fieldworkers to get "up close and personal" with the people who need to be reached, exploring what they are thinking, what worries them, what turns them on or off, what words they use among themselves, whom they listen to, whom they trust and what they fear.

For all these reasons, qualitative methods of observation and listening have been the core of the *Taking Care of Each Other* project. Community participation, documented observation, focus groups, interviews and case stories have, in these ways, brought forward knowledge of the experience of working in community AIDS agencies, knowledge that has been instrumental in developing community HIV health promotion and harm reduction.

This chapter of the *Field Guide* presents the research functions of health promotion and harm reduction while illustrating how listening to recipients is both a practical and increasingly necessary feature of AIDS work.

The lead Case Story documents how eight personal interviews facilitated the setting up of support services for injection drug users in a reluctant community HIV/AIDS agency.

The Reflections section links listening to the transformational health model.

The second Case Story describes the research experience of creating a video for youth outreach.

Practical Fieldwork presents the fundamentals of systematic listening with social research skills.

- Why listen with research skills?
- Who should listen?
- Who should be heard?
- How can we listen effectively?
- How can we document our listening?

CASE STORY Street Drugs, HIV and Community Care in Montreal

Erin Harvey was co-ordinator of the Support for Injection Drug Users Project at AIDS Community Care Montreal (ACCM) from January to August 1994. This is her story of the role listening played in transforming the agency's approach to injection drug users.

INTERVIEWER (INT): *Give me an overview of the Injection Drug Users-Project you co-ordinated at ACCM.*

ERIN HARVEY (EH): There was a real lack of services for injection drug users [IDUs] and ACCM knew that something had to be done for this population.

It was hard to get services for them outside the agency, such as basic medical care. It was just as difficult to get them services, like buddies, within the agency.

Even having IDUs drop into the office was a challenge. Most of them felt very uncomfortable coming in. So it was clear something needed to be done to make it a more welcoming place for that population.

INT: *How did you identify the need for a service that wasn't being addressed by the agency?*

EH: I was case manager at the time. When drug users would be referred to us or look us up in the phone book, I'd meet with them and try to set them up with a buddy or pass them on to another member of the community for other services.

There was real resistance in the agency. Resistance is putting it mildly actually: people just refused to work with the drug population. Sometimes I would get really angry and think that this was just outright discrimination. At other times I would understand that they were scared.

INT: *How did the project unfold?*

EH: The first thing I did was a needs assessment in the IDU community. I went around to various drug rehab agencies looking for people who would agree to an interview. It was a bit of a problem because we had trouble finding people to come forward. I put up signs at the needle exchange and the local clinics and nobody called. Through word of mouth, though, I finally found people.

I did eight interviews. Those interviews were how we were able to say *this* is the problem.

The next step was to start putting together a workshop from what we learned. ACCM, at the time, had six teams of buddy volunteers. I did a workshop with each one of the buddy teams, the management team and the board. I wanted to make sure that everybody in the organization was on side.

One of the members would come with me to do the workshop and answer questions about drug use. This was really successful. There were still people who were not willing to work with that population and who didn't feel prepared, but by and large the majority did.

The needs assessment also showed that we needed to have a group, so all of the people I interviewed ended up forming this group. At the outset, it wasn't going to be a support group; it was going to be whatever they wanted it to be. But it turned out being a support group.

INT: *What kind of questions did you ask in the interview?*

EH: What services do you feel are missing? How do you feel about being a person with HIV? How do you feel about being a drug user? Where do you get your support? Those kinds of things.

I really tried to get a picture of how they identified themselves and how this related to other people and what they thought of other people. A lot of them felt like they were less deserving of services because AIDS was their own fault. They were "drug users," "losers." My aim was really to find out how service provision, or the lack of services, affected them.

INT: *One of the strategies that came out as a result of the qualitative research was organizing workshops. What were the priorities you had in developing the workshops?*

EH: The priority was to help workshop participants to be able to see drug users in a new light. I connected it to the gay community trying to get the rest of society to regard gay men, especially those who were becoming HIV-positive, as human beings.

I made some parallels there. It was helpful to show how the gay community rallied around the AIDS crisis in order to fight stigma. And yet, we were stigmatizing drug users.

The most important thing was to change people's attitudes so they could be more compassionate and loving and caring about other human beings—no matter what their situation—and to see that drug use might be bad and might cause somebody to do things considered bad, but that the drug user isn't bad.

INT: *Were people's prejudices and perceptions of the drug-using community your biggest barriers in trying to carry out this project?*
EH: No doubt about it. They were the biggest barriers, because people don't understand drug addiction.

INT: *How prevalent were these attitudes in the leadership at ACCM?*
EH: Very prevalent. I happened to be on the board at that time, and it was a real struggle. There were people who had been with the organization since its inception, and ACCM was seen as a place for people who behaved in certain ways and reached out "in the right way" to get help.

I think a lot of people thought that the drug-using community should take care of their own, that it wasn't "our" responsibility.

INT: *How did it change?*
EH: The workshop helped a lot; and I think that certain members on the board and in management, whether they liked it or not, knew it was something that we couldn't avoid. IDUs were a growing and vulnerable population, and it was something we had to address. So the workshop sort of tied it all up.

INT: *How did you develop the trust of the drug-using community?*
EH: Trust emerged as a major issue in the needs assessment. Respondents felt unable to trust and unable to be trusted; they felt that nobody would ever trust them.

So I decided that I was going to trust them from the beginning. The interview itself went anywhere from an hour and a half to three and a half hours, so even in the interview process trust was being built. They began to believe that we cared about them and genuinely wanted to help.

Then I decided I was going to have the group at my apartment, and I gave the members my home phone number. I thought this could be a big disaster or it could be a big success, one or the other. I think it was a big success. There were a couple of phone calls at 3 o'clock in the morning, but it certainly didn't affect my life in any significant way.

I have to tell you that the first night they came I was thinking, "Should I put some things away?" But I decided I wouldn't do it. I was going to trust them. I never had a problem.

People working with drug users prejudge that they will do anything for money. I'm not saying it doesn't happen. I know it does.

I also know that for the eight participants the relationship they were building with each other, and with me as their facilitator, was too valuable to jeopardize.

Can it be generalized to the larger community? It's harder when you're serving a bigger population to build really personal relationships and trust. Yet I still think it's important to at least begin with trust as opposed to beginning with mistrust, which is what most people do with drug users.

INT: *Was there any other kind of work done on building self-esteem or exploring self-empowerment within the community?*

EH: The group ended up as a peer support group, and included counseling on what addiction is about. Addiction is very often about self-esteem.

All but one of the eight people were trying to stay clean, but it wasn't a requirement for the group. It was interesting to see the group process work, and for the group members to end up helping each other.

INT: *What resulted from the workshop at ACCM in terms of attitudinal change, service provision, policies, things like that?*

EH: A policy was developed as a result of the project. Drug users are now accepted as members any time they reach out for help; they cannot be refused because they are drug users. I think the biggest change was attitude.

And among the support group participants, every person who wanted a buddy could now get one, and they did. Not all eight people wanted them, but I think four or five had buddies.

INT: *Do you think the project is going to have long-term benefits in the drug-using community and, if so, what would they be?*

EH: Well, I'm hoping. Certainly, the project benefited the eight people I was dealing with. One has since died, but I know his last months were much better. He had a buddy; he was part of the group; and he hadn't really had any support before that. I know that the project had a profound impact on him.

INT: *Were there any surprises along the way?*
EH: I guess the biggest surprise was that rehabilitation and service agencies that were set up for drug users—not necessarily for those with HIV—were not terribly interested in the project. They were happy to put up a poster and leave pamphlets lying around, but they generally weren't taking a pro-active role.

INT: *They didn't see HIV as an issue for their clients?*
EH: No. Which to me was like, "How could you not!?" I really don't want to generalize, and I can't speak for all, but the four or five agencies I made contact with had no strong interest in making formal partnerships with AIDS organizations.

INT: *Would you say there was a particular ingredient or event in the project that made it work?*
EH: I think having drug users involved at the beginning was probably the most important ingredient. They really *defined their own needs* and they defined how those needs had to be met. I think that the project was very empowering for the group of people involved. It couldn't have been done without them.

INT: *What kind of lessons did you learn through the project in Montreal that you would bring to other cities with a large drug community?*
EH: I think the experience has helped me to understand addiction and the reasons people become addicted, and to see people as individuals but also in the larger context of community.

Some people, for whatever reason, find living in this world unsatisfactory, and it's more satisfactory when they're high. I think this says a lot about the world we're living in. Our society is not working for a lot of people.

INT: *Did you look into any of the predisposing conditions for addiction or HIV, like childhood sexual or physical abuse?*
EH: Sexual abuse occurred in probably 80% of the cases I worked on.

I can give you one example of a lesbian couple I was counseling: one had HIV, one did not, and they had both been sexually abused. They had absolutely horrible life stories. They were in their mid to late twenties, but were really functioning at the age level of 14 or 15 in relation to the world around them.

It went through my mind several times that I didn't really know what I was counseling them for. To get off drugs? The society we live in is not prepared to accept them, even if they're drug free. And they don't even have the skills to work at McDonald's.

I think the most important thing that came from the project was that my compassion increased. I've become more compassionate and less judgmental. I hope other people have as well. We're certainly not in a position, as service providers, to ever judge another person. *We don't know their stories.*

REFLECTIONS Transformative Listening

Listening laid the groundwork for a more supportive community-care environment for these HIV-positive drug users. In spite of the apparent risks, Erin had to step outside the agency frame, as well as her own, in order to understand the people she needed to reach: that tactic changed the culture of the agency. The interviews were key to the process. Telling the real stories of the lives of IDUs during the workshop triggered the natural compassion of the support workers. From there, HIV health promotion could continue to develop in the most appropriate way for that population.

One of the main ways health promotion differs from other forms of HIV/AIDS activism is in the manner in which research practices influence the strategy to be taken. As shown in Chapter 1, the Precede-Proceed model (study everything before you do anything) demonstrates a practical approach to health promotion planning based on various forms of research. This Reflections section provides the focus of that research: listening to HIV experience.

Community responses during the first decade of AIDS were driven, largely out of necessity, by crisis. People sometimes skipped over strategically important steps without even realizing it. Few thought of checking out prevention education messages with their intended audiences to see if people would respond as expected. Much of the work was created on "gut instinct" alone. Research was only rarely used, if at all, and most often remained in the hands of professionals and academics.

Although many projects and message campaigns continue to be guided by the instincts of individual organizers, AIDS agencies have long encountered problems with this approach. Message campaigns and prevention programs are created all too often with little noticeable effect. "Stop AIDS" sends an ambiguous message. "Don't be a fucking idiot. Wear a condom." was a slogan intended to reach young men, but only insulted them. "Don't worry if your man doesn't have a condom. Take a deep breath and tell him to go get one." was intended to reach women, but has been widely dismissed as unrealistic, if not dangerous, for women in abusive relationships.

Experience drawn from a growing number of support and education initiatives—some of them case stories in the *Field Guide*—show the potential of a more integrated and informed way to operate. Experience has shown, for instance, that listening to a small sample of the target population before designing a program tends to produce a truer fit with the inner motivations of the intended audience.

Participation in community-based research is also a critical method of health empowerment. People of every background love data. Everyone is eager to discover the inside details of how other people really think and feel. These are strong motivations for people to participate in research. The process of learning *how* to know things about health is one of the features of research for health promotion that most enables people to increase control over and improve their health.

Normally, community health research is the role of professionals such as epidemiologists. Early in the AIDS experience, for instance, epidemiologists took to the streets, bars and bath houses doing "shoe leather" research to track down how the alarming new illness, so-called Gay-Related Immune Deficiency, was spreading. Determining that the new epidemic was sexually transmitted required dogged investigation. Once the routes of transmission were discovered, AIDS could be more effectively identified as a condition acquired not by virtue of one's social identity, but through particular behaviours.

To have adequate impact in today's circumstances, community AIDS agencies need to proceed in similarly dogged ways with appropriate methods. Research is needed, for instance, to move HIV prevention strategies beyond condoms to address the influence of social relations in safer sex. The closeness of community AIDS organizations to vulnerable populations suggests a powerful label for this approach: "ground-zero epidemiology." So what kind of research would be the most appropriate for community-based AIDS organizations that may not be able to acquire the sophisticated skills of trained epidemiologists?

ETHNOGRAPHY IN COMMUNITY HEALTH

The method of listening explored in background studies for the *Taking Care of Each Other* project and the *Field Guide* has already proven to be worthwhile in advancing health promotion strategy. Although they are forms of qualitative research, the methods are more technically a form of ethnography. Ethnography embraces research methods that originate in sociology and anthropology. The practices emphasize immersion in a culture, society or institutional environment such as a hospital, an AIDS agency or an HIV-affected community.

Community-health ethnography is well within the grasp of many agencies involved in AIDS work, both large and small. The procedures for gathering information and interpreting HIV experience are based on formal disciplines with rich intellectual depth, but it is not necessary to know the underlying research theory to do the work and learn from it. Depending on the work at hand there may be little need to research as extensively as is described here. Good listening and keeping a journal may be all that is required to participate and perform a role within a community project or program.

A core insight for all research aspects of community HIV health promotion is the recognition that *health is an experience, not a behaviour.* To influence the social determinants of HIV/AIDS, we need research that explores the lived experience of health for the people we need to reach. Community-health ethnography uncovers this territory when we set up situations in various ways to listen to the lived experience of people for whom HIV health promotion is intended.

This approach to research is helping participants at the Pacific AIDS Resource Centre (PARC) learn more about the health needs of people living with HIV/AIDS, youth barriers to safer sex, staff experience in the AIDS workplace, satisfaction with support services, the challenge of eating well and living with HIV/AIDS, and many other details as they emerge. The studies from PARC and others from across Canada reported as case stories in the *Field Guide*, add significantly to our knowledge of how to handle an expanded health promotion focus on HIV vulnerabilities.

Recently, health promotion theorists have been interested in "participatory research" for all of the above reasons. As an "enabling" process and as a method of developing more knowledge about promoting health, broad participation in active listening can affect every facet of a community agency's work. The *Field Guide* is a good testament. The transformational health model is the product of the kind of research experiences presented here.

LISTENING TO SOCIAL EXPERIENCE

The transformative aim of health promotion is to reframe accepted, yet harmful, patterns of social life that are increasingly recognized as root causes of illness. But before any reframing can begin, harmful patterns of social behaviour need to be identified in everyday experience. Listening for those patterns with the purpose of raising them for further attention is one of the practical uses of research for health promotion.

Some models of health education are based on the rationale that, if given adequate information, people will adjust their attitudes and behaviour to achieve health, or at least to protect themselves from deadly microbes. Nothing is wrong with this logic; yet there seem to be few explanations when healthy behaviour is not universally adopted. The only recourse for health practitioners, based on traditional logic, is to do more of the same: more campaigning, more messages, more pamphlets and more condoms. The transformative model moves back to the field to listen, learn from and mobilize the people considered to be vulnerable or in other ways affected by HIV/AIDS.

Community HIV experience has indicated for some time that people do not adjust their sexual behaviour as easily as previously believed. This was explained as "relapse"—when initial panic fades, the explanation holds, people return to previous risk-taking behaviour patterns. However, health research has begun to suggest other reasons why people remain vulnerable to HIV. Vulnerability often has more to do with social-environmental factors such as stigma, poverty, discrimination, sexism and racism than with individual behaviour. Similar social-environmental patterns have been noted with smoking. People are more apt to start smoking when others in the environment smoke—at home or at work. It is also more difficult to stop smoking when others continue, even if nicotine replacement is used.

This knowledge has profound implications for current and future HIV prevention and support initiatives. Now that we know homophobia causes HIV/AIDS, poverty causes HIV/AIDS and family violence causes HIV/AIDS, how do we transform HIV prevention?

We are only beginning to understand systemic social patterns, such as homophobia, family violence and early childhood abuse, as forms of HIV vulnerability that affect both transmission and illness progression. The range of research possibilities opened up by a social analysis of HIV/AIDS has hardly been touched.

Much has been learned from community AIDS work about the beneficial effects of social support, community participation, activism and advocacy. AIDS organizations now need to apply their considerable experience to circumstances in society that perpetuate HIV vulnerability.

LISTENING TO HIV VULNERABILITY

Gay men are a focal example of the role that marginal status plays in vulnerability to HIV. Homosexual men continue to be widely acceptable targets of bigotry. Associating HIV prevention with gay sex, even this far along in our experience of the epidemic, causes many people to feel justified in denying HIV education programs in schools in the misguided belief that it promotes homosexuality. Gay teens, already at risk from their sex practices and their inferior status as youth, are made more vulnerable by those with the power to determine the information they can and cannot have.

Persistent homophobia and its links to AIDS make people affected by HIV feel that their lives are socially unworthy. Research in San Francisco has documented the significant role that low self-worth plays among gay youth who do not adopt safer sex practices. Further, when young men become infected with HIV, negative environments reinforce their already damaged psychological resources so they don't take advantage of opportunities for self-help. The quality and length of people's lives are clearly at stake in such environments.

Epidemiological research on young gay men in Vancouver, known as the Vanguard Study, found a strong association between experiences of coercive or nonconsensual sex and continuing risk behaviour. The data seems to be saying that rough social environments discourage people from establishing personal control. The study also brought attention to the intensified vulnerability of young gay men with a history of sexual abuse in childhood.

The long-term effects of growing up in stigmatized circumstances may also damage the development of the social skills necessary for community co-operation. No one would deny the effectiveness of community responses to HIV/AIDS during the first decade. But experience in the second decade suggests possibilities for disorder and calamity within community AIDS agencies.

Listening to local communities and target groups may well be the most strategic way to uncover and expose the societal conditions that foster HIV transmission and illness instead of health. The challenge is to listen carefully and to know what to listen for. An examination of societal relationships and HIV vulnerability on a global scale inspired the model of inquiry linking health with human rights at the Harvard School of Public Health.

The central point in the development of effective listening is the distinction between behaviour and experience. Health is an experience, not a behaviour. Research better suited to the study of HIV experience will help develop our understanding of how social situations and conditions influence health. These inquiries should proceed in ways that affirm and support the experience of those affected: this is the true meaning of listening.

LISTENING FOR THE STORY

Research worth the effort *tells the story of an affected group*. When the story is retold, people adjust their values and sensibilities. The focus of the emerging story is what gives the listening direction.

- Who is in the story?
- Where are they?
- What are they doing?
- When are they doing it?
- Why are they doing it?

There are many ways to achieve the kind of listening that can address these basic questions. The case story that follows tells how one group listened by using a video camera and discovered they had gathered significant qualitative research findings along the way.

CASE STORY *You, Me & Reality*—YouthCo Listens to Youth

This is a story of "accidental research" that turned up significant findings for HIV prevention and harm reduction.

It all started with YouthCo, a collective of young AIDS activists in Vancouver who are doing prevention outreach for people in their teens and early twenties. During their first year of existence, they came to the conclusion that most of the existing HIV/AIDS information materials were not reaching a youth audience. Many of the group felt that video would be more appealing.

Being young themselves, the YouthCo members knew of serious issues for HIV prevention. Still they wondered why so many young people were having problems with the basics of safer sex and condoms. The problem did not seem to be knowledge. It was about actually putting safer sex into practice.

Through a special nonprofit community initiative, members of the YouthCo board met with Karen Schell, a young video maker who seemed to fit the task immediately. The group had a few concrete ideas about what they wanted in the video. They knew they wanted the young people and their stories to be real—no narration, just the voices of experience. The audience would hear about young people's experience with sex and HIV directly from the participants.

YouthCo was able to recruit a few participants from a youth services bureau. They found the rest by "snowballing" (each recruit finds someone else to bring in). The original videotape was gathered in one long focus group session. Once the discussion got started, the camera simply picked up the conversation. Each participant then provided a personal interview, going in depth from material raised in the focus group. Altogether, Karen shot four hours of tape.

Everyone knew they were on to some very important material and insights from the taping sessions, even before the editing had begun. Karen felt overwhelmed and, at the same time, personally challenged by what she had seen. She transcribed all four hours of material herself and developed lists of issues raised by the participants in the taping. For Karen, the big concern was how to take this large amount of powerful material and turn it into a 12-minute show.

RESEARCH REVEALED

Once the material was on paper, the data looked so strong that one of the YouthCo organizers got in touch with Dr. Steffanie Strathdee, epidemiologist at the British Columbia Centre for Excellence in HIV/AIDS. She was one of the first to recognize that YouthCo members had actually performed a worthy piece of qualitative research while creating their video. With that realization, the move was on to bring in a young researcher who could translate all the stages of creating the video into the terms of qualitative research. That job fell to Erin Harvey (her earlier work in Montreal is profiled in the lead case story of this chapter).

With so many creative minds at work on the project, the value of the video began to clarify and take shape. Karen conceived of the title *You, Me & Reality*, based on her analysis of the transcripts. What she saw in the editing room was that issues of self-esteem and communication interfere with youth practising what they already know.

Once Erin got to work, she was able to take the themes even further and explore how they interfere. She took the further step of showing the video to another group of young people and taping their focus group discussion afterward. What she found was that self-esteem is involved in the basic comfort level that youth have with sex and talking about sex in the first place: "If young people are not comfortable talking about sex, they will also find it difficult to negotiate safer sex."

USING THE FINDINGS

The findings from the YouthCo video project are significant, considering that a small group of activists went into the project with something more practical in mind. They have been able to express a critical reality that many people would find familiar in their own experience, yet the problem is so much more acute in the presence of HIV. The suppression of open discussion of sexuality in families and schools creates a major social barrier for HIV prevention among young people who are exploring their sexuality more than their parents and teachers would like to admit.

With this insight, YouthCo now realizes the importance of setting up a supportive environment for free and open discussion of sexual issues with the young people they see. Anyone interested in using the video for youth HIV prevention and harm reduction work must keep in mind the importance of such scene-setting.

YOUTH VULNERABILITIES

This inventory of social-environmental risk factors was compiled during production of *You, Me & Reality.*

INDIVIDUAL

"You don't know about sex, so you don't know what to do sexually, so you don't prepare."

- Many young people lack sexual knowledge, experience and/or confidence.
- They have little opportunity to talk objectively about sexual feelings.
- Loneliness and isolation intensify feelings of vulnerability.

INTERPERSONAL

"Choice depends on peer pressure and your susceptibility to it. There is less choice in a herd mentality."

- Most young people have little experience with sexual communication.
- Self-esteem depends on conformity, which can lead to susceptibility to coercion.
- The more comfortable people are with sex, the more confident they are with ensuring their sexual safety, and vice versa.

CULTURAL

"You should be able to talk about sex without it being either X-rated or clinical—there should be an in-between, which could be just, you know, normal."

- Conflicting cultural values about sex are everywhere in the environment.

- Sex is perverse; sex is pleasure; sex is meaningless; everything is sex.
- Open and honest discussion of sexuality is tough going or discouraged.

STRUCTURAL

"I have all the knowledge I need but I still don't use condoms, and we just don't even talk about it."

- Condoms are expensive.
- Buying condoms in stores is embarrassing.
- Safer sex is institutionally unsupported even in popular culture like movies.

LESSONS FOR HIV HEALTH PROMOTION FOR YOUTH

- Use educational materials that are immediately accessible; e.g., video, Internet.
- Actively engage youth in generating their own discussion.
- Maintain an easy stance in facilitating sexual discussion.
- Encourage co-operative, challenging, action-oriented learning.
- Create a supportive, comfortable environment, affirming ideas and experience.
- Promote learning by discovery and discussion rather than by pushing safety.

PRACTICAL FIELDWORK Developing a Research Skill Base

Most of the people who worked on the YouthCo project had little idea they were engaged in serious work until they showed a rough cut of their video to the epidemiologist. They understood the power of video, however, not only to document what people are saying but also to stimulate further debate. Video's ability to communicate street experience without written words is its real strength. The technical side of video can be daunting but also a source of enjoyable learning without classrooms. For audiences more attuned to research and data, Erin's work helped to draw out the significance of the video. That too was an important contribution toward understanding the complex dynamics of youth sexuality and the social environment.

Although health promotion makes use of research methods to collect data and listen to those in need, research, in itself, is not health promotion. Occasionally research can be useful in encouraging community participation in health promotion. More often, though, listening should be integrated into the delivery of health promotion in such a way that information gathering is continuously going on in the background.

In support programs, for example, health promotion is aimed at maintaining a supportive environment for people living with HIV/AIDS. However, keeping up to date on the experience of people receiving those services assists with vital decisions that could affect the way programs are delivered. For instance, listening to people on both sides of a buddy program led to a decision to close out a community service, considered near-sacred, in favour of case management and care teams. See the Case Story "Introducing Care Teams at AIDS Vancouver" in Chapter 4: Plan—Focusing on HIV Strategy in Evaluation and Planning.

WHY LISTEN?

These are a few of the decision points typical of program and service delivery in community AIDS agencies where listening to participants or potential recipients could provide a more effective outcome.

STRATEGY DEVELOPMENT: Listening for health issues and surrounding conditions expressed by the people that need to be reached before developing or redesigning HIV/AIDS-related community services, programming or messages.

NEEDS ASSESSMENT: Listening to gain specific information about a group's HIV prevention and support needs that would assist in making decisions about suitable service, program or communication delivery.

PILOT: Listening to sample audience reactions to trial messages, programs or service components before full implementation—to confirm content or contribute to adjustments.

MONITORING: Listening to participants and volunteers to keep in touch with ongoing "grass-roots" reactions to implemented programs, to learn from recipients, to keep abreast of new developments in the situation, to make refinements and adjustments to program content and delivery.

EVALUATION: Listening to a diversity of participants and stakeholders to determine the outcome of prevention projects or support programs, whether they reached the intended groups, how well the intended groups responded and what the effects of the program were.

PLANNING: Listening to participants and volunteers to sum up the effects of recent efforts on a community HIV situation in order to reconsider or adjust future programs, services or communications.

WHO SHOULD LISTEN?

Research is often seen as a separate activity that places extra demands on everyone involved in the delivery of health promotion services and programs. On the other hand, effective health promotion is almost impossible without paying attention to the reactions of the people who benefit. The question arises as to who should actually be doing the listening and the compiling of what is heard.

PROGRAM MANAGER: The person in charge of a program gets personally involved in systematic listening to pull together "lived experience" information that would help to make service, program or advocacy decisions.

TEAM: Listening may be co-ordinated among a group of fieldworkers with the intent of assessing a community HIV/AIDS situation; e.g., a team of outreach workers compiles observations and notes from talking with visitors to a needle exchange or public sex scene.

CONTRACTOR: The AIDS agency contracts with a freelance research specialist to conduct interviews, focus groups or survey research. The specialist reports back with findings and recommendations that would give direction to service, program, communication or advocacy decisions.

COMMUNITY DEVELOPMENT: An AIDS agency may use participatory research as a development vehicle to stimulate a community-wide "listening to each other" dialogue, aimed at enhancing support from the local community for HIV prevention, harm reduction or health improvement. See the Case Story "Rural Nova Scotia Outreach Experience" in Chapter 2: Transformational Health—Practical HIV Fieldwork for an example.

INSTITUTIONAL PARTNERSHIPS: An AIDS agency may negotiate with professional researchers from a university or research institute to conduct listening within the community, especially when sophisticated research tools and techniques would provide reliable data for the purposes of advocacy.

WHO SHOULD BE HEARD?

As HIV continues to increase in the population, prevention remains the best possible strategy for community AIDS agency programs fighting infection or illness. Vulnerable groups are known and described in the literature but this does not necessarily equate to knowledge that would assist program delivery. The composition of groups and the mood of communities are constantly changing, which makes listening all the more important. The following are some of the known HIV "target" groups that need to be heard. Race, class and regional interpretations further define the field.

YOUNG GAY MEN: New young men come out each year who have not been exposed to prevention messages and programs of previous years. To keep pace with emerging trends and culture, HIV programmers need to listen to young gay men on their own terms.

YOUTH: Teens are having sex earlier than ever and they are experiencing skyrocketing rates of sexually transmitted disease. HIV/AIDS programmers need to listen for the social influences and pressures teens experience in their sexuality as a way to inform prevention strategies. See the Case Story "*You, Me & Reality*—YouthCo Listens to Youth" earlier in this chapter.

WOMEN: Male-to-female transmission of HIV is considered much more likely than female to male. Issues of gender, culture and power relations pose serious challenges and barriers to health promotion activities. HIV prevention strategies need to be influenced by the experience of women in HIV-vulnerable situations, such as partners of injection drug users. See the Case Story "Women and HIV in Edmonton's Women's Shelters" in Chapter 5: Do—Building Supportive Networks for HIV Health.

MAINSTREAM GAY MEN: Group counseling and peer support continue to be effective in HIV prevention for mainstream gay men. But sustaining safer sex and condom use continues to pose a challenge for community-based HIV prevention efforts. Programmers need to listen to the ever-changing dynamics gay men experience in a culture under siege by HIV. See the Case Story "Rural Nova Scotia Outreach Experience" in Chapter 2: Transformational Health—Practical HIV Fieldwork.

MEN HAVING SEX WITH MEN: Often termed "hard to reach," men who have sex with men (MSM) but do not identify themselves as gay continue to pose a challenge for community-based HIV prevention. HIV-test counseling has revealed that denial is a major barrier to condoms and safer sex. Still, very little is known about social barriers experienced by MSM and how to overcome them. See the Case Story "Rural Nova Scotia Outreach Experience" in Chapter 2: Transformational Health—Practical HIV Fieldwork.

PEOPLE WITH HIV: People who know they are infected with HIV can take early preventive measures, such as enhanced nutrition, to significantly extend and maintain their health. Programs for asymptomatic people living with HIV are still underdeveloped. Community programmers need to listen to the inner motivations and worries of people with HIV to build strategies for early intervention. See the Case Story "Introducing Care Teams at AIDS Vancouver" in Chapter 4: Plan—Focusing on HIV Strategy in Evaluation and Planning.

TRANSGENDERED PEOPLE: Transgendered people do not fall within commonly acceptable sex roles, and so they experience inordinate discrimination, abuse and denial of social privilege. Living under these conditions is a potent source of HIV vulnerability. Transgendered people may have difficulty with employment, their self-esteem shattered by the abuse they receive. HIV health promoters must listen to the inner experience of transgendered people to fully appreciate the need and their potential to mobilize social transformation.

INJECTION DRUG USERS: Local drug scenes are unique cultures that influence the behaviour of members. HIV prevention and harm reduction programmers need to listen for developments that influence the risk of transmission. See the lead case story in this chapter, "Street Drugs, HIV and Community Care in Montreal."

HETEROSEXUAL MEN: The most likely place to reach heterosexual men with HIV/AIDS information is in the workplace. Listening on this front could open up new strategies to combat HIV/AIDS stigma and homophobia. See the Case Story "Breaking into the Corporate Workplace" in Chapter 9: Society—Transformative Groups—Societal Change.

HOW CAN WE LISTEN EFFECTIVELY?

Listening to HIV experience with research skills is a potent way to enhance the effectiveness of AIDS agencies, not only in the delivery of programs and services, but also in advocacy with governments. The following techniques are commonly used in qualitative research to express what people are experiencing in their own words and stories.

OPEN-ENDED DISCUSSION

Prearranged conversations with people both in a problem situation and surrounding it may be enough to gain true impressions of "what's going on," especially when troubleshooting a program delivery problem or just starting out in strategy development. Simple point-form notes in a journal are an accepted way to gather material from such sessions.

DIALOGUE

Dialogue is an advanced form of conversation that differs from open-ended discussion in the intention of the participants to develop a new appreciation of issues. Dialogue requires a shared willingness to leave opening positions behind in the effort to explore advancing ideas and new possibilities. These sessions are most productive with opinion leaders and professionals. Because they are unpredictable and sometimes ground-breaking, they should be recorded on audiotape.

INTERVIEWS

Interviews involve face-to-face listening to informants who have been selected for their position within a problem situation. Although interviews are sometimes organized by a schedule of questions, they may be completely open-ended, drifting to wherever the informant wishes to go. Interviews differ from discussion and dialogue in that the informant does most of the talking. Notes are sometimes enough to record this form of listening but audiotape is better for detecting the subtlety of social effects in HIV experience.

PARTICIPANT OBSERVATION

This form of listening originates in sociological research. It involves deep immersion in a scene or event with the intention of recording details of behaviour and the real words of participants, possibly over a period of time until the situation is well understood.

The practice is to be both a participant and an observer at the same time, wherever your fieldwork takes you. You end up learning about yourself as much as you do about other people. The technique forces you to pay extraordinary attention to ordinary details. Participant/observer technique is useful in settings where there is an established, ongoing environment that you want to understand, such as hospitals, clinic waiting rooms, meetings, the street, bars, cafés.

Practice deep listening, and try to suspend or ignore your "automatic" thoughts, feelings and expressions while in the setting. Keep your attention focused, but don't stare. Take careful note of your surroundings, and build your visual memory of the setting and the people.

Immerse yourself in the scene as if you were an ordinary participant. Speak to anyone as you would normally, but concentrate on listening to remember "real words" and statements of others.

Leave the setting when you feel saturated with the experience. As soon as possible, find a quiet place to describe your experience in writing in a notebook or portable computer. Replay a mental movie of the experience, and try to quote any statements in "exact words." Describe remarkable situations you observed, and make notes about the mood, the tone and atmosphere of the setting.

Add to your notes until you have enough material to tell the story.

FOCUS GROUPS

This is a form of arranged discussion with a small group of people representing the experience of a larger group. Focus groups are a very worthwhile and underutilized method of systematic listening in community health settings. The "group" effect stimulates the sharing of ideas and experiences, which participants find supportive and energizing.

Here are a few points to consider in leading a focus group:

- Invite five to eight people for a one-hour discussion and let them know that you wish to tape it. Some people may appreciate a reward for their contribution such as a light meal or token honorarium.
- Prepare a few questions (four or five) in advance that will open up the issue you are exploring. Try to make the questions provocative. Don't bore the participants, but don't be too aggressive either!
- Do some scene-setting and icebreaking by way of introduction. Keep the pace moving and include everyone in the discussion.

- Stay neutral—neither praise nor dispute the claims people make. Defer any questions that are put to you; your aim is to hear from the group. Encourage participants to address each other.
- Thank the participants. Assure them that their contributions will remain anonymous. Have each sign a consent form stating that they agree to allow the taped material to be used for research. Distribute honoraria.
- Provide the participants with any summarized feedback or reports that result from your record of the group session.

SURVEYS

Surveys are often the first thing people think about as a method of doing research. No wonder—polling is more than common in these times. The ability of polls to accurately predict voting patterns and other trends, however, is based on sophisticated sampling, large sample sizes, well-structured questionnaires and powerful statistical tools normally unavailable to community AIDS agencies.

As suggested earlier, much of the listening required for health promotion is closer to the people and less expensive than survey research. The pressure to produce quantifiable data and "measurable" results, however, makes surveys attractive, especially for evaluation. Surveys are also a way to listen to a larger sample of people than interviews and focus groups.

Questionnaires can be a form of "outreach" listening to people who may be difficult to hear in an HIV environment because they are ill, wish anonymity or are otherwise unavailable to participate face-to-face. Surveys provide insight into the proportion of people who have specific attitudes or experiences that could be addressed by programs, services or communications. Good survey data is often useful in advocacy. Questionnaires, however, are difficult to construct and you may require computer skills to interpret them. Community programmers would be well advised to seek experienced assistance and sufficient budget rather than to try doing surveys in house, especially if accountability is required.

There are occasions, however, when a simple one-page questionnaire can provide a quick read on attitudes, perceptions, level of satisfaction and intentions in the community, which could help in planning health promotion.

The following pointers—lessons from hard-won experience—may help in setting up a community survey as a form of "remote listening" for the AIDS agency.

Know what you want to know from the survey. Most questionnaires poll opinions or attitudes, which can help to show how people think and feel about an issue. Aim for a sample of at least 100 respondents. In most cases, community-based sampling will not be random. This weakens the ability of the survey to predict that the sample's answers would be true for the whole population. Your aim is to listen to the community's "lived experience," not to calculate the rate of HIV transmission.

You can sample HIV/AIDS-affected groups by using one of the following methods:

- Quota sampling: Get the required sample all in one demographic category, such as gay men 18-24, and eliminate all others.
- Convenience sampling: Go to where the people are—on the street, in bar or café—and poll anyone available.

Think ahead to coding, analyzing and interpreting the results while constructing the questionnaire. The more questions, the more work. Coding survey forms into a computer can be tedious and time intensive.

Good questions require good writing skills. Keep the number of questions low—think 10. Keep them simple—one point only. The use of "and" in a question should be considered carefully.

Use close-ended questions, single-answer multiple choice. "Check those that apply" questions are difficult to code and interpret.

Scaled questions are useful to gauge opinion or levels of satisfaction, but keep the scale down to three or five points. For example: "often/sometimes/never," or "strongly agree/agree/neutral/disagree/strongly disagree."

Open-ended, qualitative, or "fill in" questions are difficult to interpret. In a small survey, however, they often yield surprising results, and sometimes offer a means for people to communicate with the authors of the questionnaire.

Demographic data is absolutely *required* to analyze answers to questions. Typical questions include age, income, education, type of employment, postal code, length of residence and type of residence. In surveys that are meant to be anonymous, you may want to reassure respondents that this information will not be used to identify them.

Pretest the questionnaire with individuals from the group you are aiming at in the survey before using it. Troubleshoot ambiguous questions and unexpected responses.

Once the survey forms are returned, you can use graph paper to get a quick read on how people responded. Code one question at a time. Go through the whole stack of completed surveys and mark cells corresponding to the response categories in the question. See the example chart with this section. Once you have gone through the whole stack, you will see a bar graph that indicates the strength of response over the range of categories in the question.

Coding a Survey Question: Sample Format

How often do you use the Internet for treatment information?

Never	X	X	X									
Sometimes	X	X	X	X	X	X	X					
Often	X	X	X	X	X	X						

The use of a statistical software package to code responses is highly recommended. The coding is tedious, but once the data is entered the software will help you cross-tabulate responses to detect differences in the way people answered according to their age, where they live and so on. The software also produces accurate graphs that can be used to report the data in written and oral presentations.

HOW DO WE DOCUMENT OUR LISTENING?

The formal literature of qualitative research presents detailed descriptions of various disciplined ways to collect and interpret field data that are the products of listening.

The position of the *Field Guide* is that people's "real words" are a valid and reliable basis for interpreting community health experience—one reason that many of the case stories in the guide have been told in interview form. When real words are brought into a text, as they were in the *Taking Care of Each Other* monograph, they are subject to the varied interpretations of readers. Those differences in interpretation are expected as a natural consequence of reporting.

Working with real words suggests a certain rigour is required when listening in the field. Some of the methods suggested in this chapter require only a notebook or portable computer to keep a running journal of your listening. When using methods such as participant observation, it is important to remember and record real words in your journal before they are forgotten. In other circumstances, such as interviews and focus groups, audio or videotape should be used. A small cassette audio recorder is by far the least expensive and least time-consuming method for collecting qualitative data.

Tape makes it possible to have an electronic record of real words. Word processing software makes it possible to move the words around once they have been transcribed. Audiotape, a portable computer and word processing software are the ideal instruments for qualitative research. With an Internet address, you can distribute findings anywhere in the world in a matter of seconds. You can also use the Internet for listening through newsgroups, bulletin boards and e-mail. The process of sorting words to analyze the products of listening is described below.

An effective strategy for reporting the products of listening, from the *Field Guide's* perspective, is to keep real words up front where others who need to understand an issue can see them for themselves. Often the most powerful statements of health experience come from the people who need to be reached. Those statements need to break through to the people with the power to make a difference to the situation.

TRANSCRIPTION

Make a word-for-word transcription of audiotapes on a word processor. Using electronic files makes later analysis and editing much easier. You may be able to hire someone to do this work for you. There are people who do this professionally for meetings and court hearings.

SELECTIVE TRANSCRIPTION

Listen to the tapes and transcribe only the most effective statements that express key points. This is a useful technique for processing audiotapes of meetings or conversations.

THEME ANALYSIS

Read through all notes and transcriptions to determine common references, problems or experiences. List the themes that emerge from the texts. Often these themes are expressed by the participants themselves. Think of the themes as headings or categories.

- Try to keep the number of categories to four or five.
- Match a variety of coloured highlighter pens to the categories.
- Reread the material a second time and highlight statements that best illustrate the themes with appropriate colours.
- Rearrange the material using word processing software to cut and paste statements of exact words into theme categories.
- Review the material and sum up the themes in your own words.
- Create a report using exact words to illustrate your interpretation.
- Distribute your findings widely through your advocacy network.

A NOTE ON EDITING

In fieldwork, dynamics between the listener and the speaker involve both in making up the spoken text of an interview or focus group. The listener, for instance, chooses whom to listen to and the speaker uses the opportunity to decide what to say. These are only some of the hidden layers involved in interpreting "lived experience." In dealing with spoken text, it is often necessary to delete and reposition real words to have them make sense on the page. This procedure has been applied to the interviews in the *Field Guide*. The intention is to remain true to real words during the editing process, causing as little distortion as possible. In this way, editing is as much part of the analysis and interpretation of the products of listening as themes and categories are.

COMMUNITY HEALTH ETHNOGRAPHY

Ethnography is an immersion form of research that aims to understand a total culture. Ethnography uses participant observation and other listening techniques described in this chapter in a co-ordinated team effort to gain an understanding of the mind-set and inner workings of an HIV/AIDS situation or vulnerable group. Many types of situations common to urban AIDS agencies would make ethnography useful (e.g., street youth, raves, drug scenes, needle exchanges, public sex environments, women's shelters, gay neighbourhoods, AIDS agencies).

Entry etiquette is crucial when entering a new scene. Obtaining relaxed acceptance is the first order of business. The HIV prevention or health agenda may well continue to remain in the background throughout your research.

Observe everyday experience and living conditions. Use participant observation, informal interviews and spontaneous focus groups to collect material. Look for ways to engage people in telling their own stories. Offering a video camera for this purpose works well in some settings, but may be considered intrusive in others. Always ask permission first.

Collect enough material to get a feel for the circumstances and sentiments of the people. Avoid the urge to collect huge amounts of data that would be difficult to interpret. Transcribe the diaries, audiotapes or videos you've collected into a word processing format and follow the theme analysis and interpretive procedures described earlier in this chapter.
Distribute the product of your work liberally through the appropriate advocacy network!

PARTICIPATORY RESEARCH

Community development is often cited as the core of health promotion. HIV experience has shown how true this is by the example of community-based AIDS agencies themselves. Community agencies have proven their worth and their resiliency in spite of devastating loss.

Yet community development remains a little-used strategy for some of the work AIDS agencies could be doing to manage the HIV/AIDS situation in their core communities. Participatory research offers rich potential for facilitating community development. The intended outcome is a more supportive environment for HIV prevention.

Uncovering the roots of HIV vulnerability is a key role for participatory research: organizing people and groups to learn about themselves while they contribute to greater understanding of what may be getting in the way of HIV prevention. See both case stories in Chapter 2: Transformational Health—Practical HIV Fieldwork.

Focus on the health of the community environment rather than safer sex behaviour when framing the goal of the project. Everyone will know that HIV prevention, support and care is the underpinning when they realize the project is sponsored by the community AIDS agency.

You may want to explore some of the following features of the community environment with members of the community:

- key community health issues
- relationship between the state of the community environment and HIV status
- satisfaction with community-based AIDS agencies
- experience and satisfaction with the health, social service and other government infrastructure
- satisfaction with the community environment, neighbourhood, services, clubs and businesses
- desire for change to the existing community, both specific and general
- visions of the ideal community
- specific suggestions for development

Look for ways to involve existing community groups in contributions to a community-wide effort, either by performing an organizing role or enlisting participants.

Consider many different ways to gather material, such as a combination of interviews, focus groups and a survey. Think through to the end of the project when all the material this produces must be organized, analyzed and interpreted. Resist the temptation to do all the work yourself even when you feel it could go better that way. Plan for the most effective use of agency staff and volunteers and organize a special project team of staff and volunteers. The "snowball" process may be useful to recruit wide participation. One participant brings in two friends, and they each bring in two friends, and so on.

Just in case, you need to know this in advance: facilitating a community study to completion usually requires great diligence and patient effort on the part of the leader—and that makes it worth doing.

QUANTITATIVE OPTIONS

Without a doubt, numbers are essential to understanding the HIV experience and are a required element in budgeting and funding AIDS work. The easiest way for AIDS agencies to get data is by accessing professional networks and partnerships. A few tips from experience follow.

SECONDARY SOURCES

Consult secondary sources of research data such as unpublished epidemiological reports, market trend research and consumer studies.

- Review the published research literature for unrelated studies of the same group or an HIV/AIDS-related study of the same group in another location.
- Watch the newsstand for loosely related coverage in magazines—often a cheap source of expensive data.
- Compare patterns found in the literature to the local situation.

RESEARCH PROFESSIONALS

Use research professionals whenever possible.

- Consult researchers who have completed research in other regions—by phone or e-mail.
- Consider hiring an experienced freelance researcher. Ask to see previous reports. Check references.
- Consult with a research institution such as a university.
- Contract a market research firm to conduct the entire survey (expensive) or include a few pertinent questions on a larger survey (reasonable in cost).

CHAPTER 4

PLAN

focusing on HIV strategy in evaluation and planning

A strategy for health promotion that develops out of field knowledge is the real treasure to be gained from listening to people who need to be reached for HIV health promotion. Strategy is focus: knowing how, when and where to apply health promotion efforts. Evaluation increases confidence about how those efforts are actually working. Planning organizes the pieces of the work needed to carry out the strategy.

A good example of the place of strategy in HIV health promotion is the "corporate breakfast." After years of cold calls to a seeming wall of denial, nothing moved on the HIV/AIDS agenda for Vancouver's workplaces. Applying a well-conceived strategy turned the situation around and brought together 100 Vancouver business professionals to talk about HIV/AIDS in the workplace. It took only a few weeks of listening to the right people to come up with the breakfast strategy. It took days to plan it and months of work to carry it out. But the strategy, the breakfast, was the thing that worked. See the Case Story "Breaking into the Corporate Workplace" in Chapter 9: Society—Transformative Groups—Societal Change.

Without strategy, a plan would be empty—just a schedule for business as usual. Strategic planning, on the other hand, is pro-active and change oriented—a blueprint for transformation. The only way to really know what to do about an HIV situation is to study the risk conditions thoroughly, so strategy develops from the creative impulse that uses what you know to tell you what to do. Most of the time, that impulse comes out of what people have been telling you all along. Much of the work you have to do from there is organizing people to meet face-to-face, to mobilize on their own path of learning and to take control of the health issues raised by HIV/AIDS in their environment.

As shown in Chapter 1, health by itself can be a useful concept in strategy for managing HIV/AIDS in communities. "Health" is a more inclusive and comprehensive approach to HIV prevention, for instance, than "condoms and safer sex" or "food, shelter, medicine." Health brings the individual, interpersonal, cultural and structural circumstances of an HIV situation into the planning frame, along with the threats, obstacles, opportunities and challenges that a strategy must address. Health is the mission of today and a vision of tomorrow.

From a health point of view, the more supportive the environment, the more effective HIV prevention, support, treatment and care will be. Health promotion planning must focus on the ways and means to build support, to build consciousness of HIV/AIDS realities in the community and to mobilize people to act. The enabling feature of health promotion makes the people within an HIV situation responsible for carrying the strategy forward. That sense of responsibility has to be nurtured, of course, but first it has to be put in place.

This chapter is about using your experience of listening in the field to make sense of what you must do to mobilize people for HIV health promotion. Chapter 5: Do—Building Supportive Networks for HIV Health will describe how to create social networks or a supportive infrastructure of partnerships, collaboration and networking.

The lead **Case Story** in this chapter is about how Black CAP (Coalition for AIDS Prevention) uses a well-attended annual festival as the centrepiece of its strategy to bring HIV/AIDS and the social issues surrounding HIV/AIDS into the consciousness of black communities and their neighbours.

Reflections shows how the strategic planning of community AIDS agencies may be used to manage the HIV situation in a productive way.

The second **Case Story** tells of dramatic change in support services, moving from buddy programs to care teams.

Practical Fieldwork provides tried-and-true methods to move from experience in the field to evaluate strategy in planning HIV health promotion.

CASE STORY Black CAP's Festival Outreach in Toronto

Juanita Smith co-ordinates Caribana outreach at Black CAP (Coalition for AIDS Prevention) in Toronto. Her story shows how planning, evaluation and a bit of strategic community wisdom can become an agency's most effective HIV strategy.

INTERVIEWER (INT): *What is Caribana about? Why did Black CAP get involved?*

JUANITA (JS): Well, Caribana is the largest event in the black community here in Toronto. It started in 1967 (Canada's centennial). It was a way for the Caribbean communities, quite small at that time, to share some Caribbean flavour with Torontonians.

Caribana takes place every year: a two-week festival which climaxes on the first long weekend of August with a major parade in Toronto—over a million people see the parade all over the world. So within that context, Black CAP presents its Caribana outreach. It is the largest single event of the agency. We have been doing this for the past six years, sponsored by the Toronto Department of Public Health.

INT: *So the Caribana event sounds like it's meant as a way of celebrating the Caribbean experience and sharing cultural difference with the rest of Toronto.*

JS: Yes. I'm not so sure if that's how it has evolved. Frankly, it's just the biggest street party in Canada.

It's a nice hot summer event. Caribana does have political undertones, but most people just really go out to have a ball.

INT: *What were some of the issues that Black CAP wanted to address by becoming involved with Caribana and how did that then take place?*

JS: We wanted to make use of the event: the high profile, the numbers of people attending, the party atmosphere, the social connections. We wanted to use that to profile: a) AIDS in black communities; b) Black CAP's services; and c) additional resources in southern Ontario related to HIV and AIDS. We also wanted to use it as a springboard to launch many of our other events during the year, even to recruit volunteers to the agency.

INT: *How difficult was it for Black CAP to get involved with Caribana? Was there any kind of resistance on the part of the organizers?*
JS: Not really. The organizer of Caribana is the Caribbean Cultural Committee. We approached them at a time when an awful lot of denial about HIV existed in the community. There still is in certain pockets. So we approached the committee from that perspective: the need to publicize the agency, the need to educate the black community and the need for Caribana to get on board.

INT: *What do you think some of the barriers are to recognizing that HIV is an issue in the Caribbean community in Toronto?*
JS: I think, like in many communities, ethnocultural and not, there is a level of AIDS phobia. Also the earlier media reports linked HIV and homosexuality. Folks in our community thought it was a gay, white, male disease.

So that sort of fueled the denial because, at the same time, there was certainly a lack of acknowledgement that homosexuality existed in the community. So it was sort of double denial that occurred. Another one was the myth surrounding the African origin of HIV and AIDS—some of the myths that were stirring around in the early eighties.

INT: *Could you elaborate on that a little bit?*
JS: Like the misinformation around GRID [Gay-Related Immune Deficiency] in the early eighties, there were reports that HIV originated in Africa. We knew, like everyone else, that it is sexually transmitted in one of the most efficient ways. It was a time when there was talk of HIV coming originally from green monkeys. So we thought, "What are they trying to say we were doing with green monkeys?" For a people who have come out of a historical context where our sexuality has been racialized, it sort of put gasoline to the flames of denial.

INT: *When you initially went into Caribana, did you have a particular strategy in mind in terms of addressing some of the denial in the community and trying to break down some of those barriers?*
JS: We did. In looking at the event, we clearly didn't want to intrude—sort of beat the parade boards over their heads with our message. We wanted a kind of subtle integration of HIV information into the parade. We also recognized the way in which folks receive difficult information.

If it's tough or difficult, they don't want to listen so it's very important to make it fun.

We also thought that this would sort of remove the sting from the issue. We thought that to deploy volunteers on the route, to have them dress as if they're ready to party, would build on the spirit of the event.

So that was a kind of broad overall strategy. The other piece was a recognition that, in order to address HIV and AIDS successfully in black communities, it's important to integrate HIV with other social community concerns. There were specific things that we did to ensure that we reached those goals.

The strategy was to recruit about 50 volunteers—a minimum—to identify pertinent resources in southern Ontario and make that information available at the parade, recognizing that Caribana participants come from throughout the province and even throughout the country.

We then designed a condom wallet. One side is clear plastic and the other has Black CAP's information printed on it, a condom slipped in one side and four business cards. We also provided our volunteers with T-shirts with the phrase "Ask me about rubber wear" on the front and the Black CAP logo at the back.

We include other ASOs [AIDS service organizations] and resources from southern Ontario. We request a $50 honorarium from the other ASOs to undercut the costs of the festival. We staff an information table at the parade site. It's used for providing more condoms to volunteers and also for patrons of the parade.

We provide training on the specifics of street outreach to these volunteers. We usually enjoy excellent media coverage around the event. That serves to welcome the volunteers on the parade route. The volunteers are also involved in stuffing the condoms and the pieces of information in the wallets.

We found in the past couple of years that probably 50% are not on our regular volunteer pool, sort of one-event volunteers. That usually serves to link them into doing additional volunteer work. It provides them with education on HIV and the impact of HIV in black communities so they then go back to their different areas in the community and spread the word.

On the morning of the event, the 50 volunteers, all dressed in their T-shirts, come down to the office to pick up their bag with condoms. Each bag in the past has contained about 200 to 250 wallets. Needless to say, they cause quite a stir taking public transit to the parade. So there's education going on all the way to the route. Once they are on the route, they normally team off. We encourage this because, particularly for first time volunteers, it can be quite intimidating talking sex talk in public.

Once they're on the parade route, they mingle with the parade. What we found is folks are looking out for us as the years go by. People would say, "Oh my gosh, I was looking out for you guys this year!" That is clearly because of the *consistency* of the method and the message.

It takes, I would say, about 45 minutes for each volunteer to distribute all 250 condom wallets. The festival does not allow lengthy engagement with patrons. But because of the nature of the wallet, it allows folks to put it in a pocket or take the cards out, put them in a wallet to be used at a later date. They can use the wallet for other things, for their driver's license or what have you. And our information is on there. We usually attach our banner to a float, so again, you have potentially a million people seeing the message.

In 1993, we conducted a survey. That was tough to do. The volunteers solicited information from folks on the route. They asked specific questions. About 89% of the people that responded said that they wanted to see us continue the outreach, and 94% said they would share the information with a friend.

We always conduct *focus groups* with the volunteers following the event to provide us with feedback in terms of participation, how it was for them, but also to get sort of a pulse on what the community was saying as they were disseminating the information.

INT: *What kind of information do you usually get from the focus groups in terms of community feedback?*

JS: We're seen in the black community as being on the cutting edge of addressing social issues. So in a way they're not surprised that we will try a creative way to address a serious issue. They like the fact that we're able to deploy a huge amount of volunteers. That flies in the face of what many folks feel: volunteering is not a big thing in black communities. We also are well received because of the intergenerational aspect of the volunteers when they do the outreach. Also the diversity of the pool: men, women, gays, lesbians, everyone having a ball. So they admire the way we do things.

The other piece is they like the method in which we present the information. It is not intrusive. I would say, in talking to folks when they call us for workshop requests or other services, that most of the folks mention Caribana was the first place they recognized Black CAP or heard about HIV and AIDS in black communities.

INT: *Are there any other questions that come up in the focus groups? I'm thinking specifically of the information you get from the volunteers, their own experience.*
JS: Volunteers in the past have told us what we need to do. In the first three years, we used plastic bags (for the wallets). Feedback told us that they needed a knapsack or something like that. We were able to provide them with a knapsack with a Black CAP logo on it. That was used as a fundraiser as well. We asked them whether or not they felt prepared to answer a lot of the questions. How did they feel around people asking them issues around their sexuality, or whether or not they were HIV-positive? What were some of the gaps? Were they available for other activities? It provides feedback for us to structure and shape the next year's event.

INT: *Do the volunteers feel prepared when they go out there? Do they have a good comfort level around the various kinds of questions they get from the community?*
JS: They do, they do. The kinds of questions they get are in the training. The training is done by volunteers who have been a part of the event for a couple of years. It's a peer model. Some questions come up consistently every single year. "Why do you need a black response to HIV? Isn't that reverse discrimination?" One of the other ones is, "I had no idea that HIV was a concern in black communities." Or, "Oh, there's a black agency doing this work? Who are you? What do you do? How are you funded?" That sort of thing. And then, "What is going on in the Caribbean?" There's always that link back.

INT: *How do you deal with a question about why you need a black event for HIV/AIDS? What are some of the training components that the volunteers go through?*
JS: They do a kind of "AIDS 101," if you will, to prepare them with the factual pieces. We also tell them exactly why Black CAP is at Caribana, why

this is an essential initiative of Black CAP. We provide them with a history of Black CAP and Caribana, some of the positive pieces, some of the challenges. We also always have seasoned Caribana volunteers, well positioned in the training sessions. We also do an overview—quite an extensive overview of Black CAP and the way we do our work in the community. We also do the "do's" and don't's" of the street outreach.

Some of the things we talk about are how to or not to engage people with controversial questions; how not to try to bluff one's way through an issue. You don't have to know all the answers, that sort of thing. To spot the questions a mile away when folks really want to beat up on you, like the Bible-thumping folk. You know, "Oh my gawd, you're promoting sex." How to spot it a mile away, what to say, how to engage or not. We do a role play.

In order to *break through* some of the denial that exists in the community, it is important to *know the culture* and the day-to-day realities of the population that they're reaching out to.

INT: *I wanted to look a bit more at what you talked about in terms of the politics of Caribana and how your outreach works with that.*
JS: One of the strategies that we have always used at Black CAP has been to go to where the community is at. Black communities here in Toronto are not defined by specific geographic boundaries. And so we recognize that in order to cross that barrier and others, we had to meet the community on their own turf. Caribana is only one such event that we do each year—we do a number of others. We staff information tables on an ongoing basis at different community events so it's part of that.

Why link with social issues? I would say a lot of the infrastructure in black communities looks at addressing social issues. If you are going to meet the community with your act, it is necessary to work within the infrastructure. A lot of the things that we address go hand in hand with social issues, be it homophobia in the black community, sexism, safer sex negotiation, health promotion strategies.

INT: *I'm wondering too, whether or not you work with other organizations, non-AIDS organizations, in the black community in Toronto in looking at these issues?*
JS: Oh yes. Let me sort of highlight it again—we talked about the infrastructure. A lot of the existing infrastructure is dealing with socio-political

issues, economic issues. I don't know if I told you that Black CAP's approach has always been a holistic approach—mind, body, spirit—looking at all things that impact on our health.

Having said that, one of the ways to ensure that the message gets through is to link in with folks who are already linking into the community. So we're linked to agencies that provide services to youth. We are aware of black teachers, and sometimes not black teachers, in the school system and at the school boards. We provide them with resources to address HIV in their classrooms.

INT: *It sounds then like a lot of the work you do is advocacy with other organizations in the community.*
JS: Yes. It's difficult for the community to "unlink" us from the jobs that we do. It is not unusual to see us at a demonstration or something like that that has nothing to do with HIV and AIDS. Not necessarily as an agency, but as individuals. When we speak at these spaces, the community automatically links us back to the agency.

INT: *How crucial do you think that social analysis is, on an agency-wide basis, to your effectiveness as an HIV/AIDS agency?*
JS: It's a huge piece. We try to encourage it in the way we do our things, even the way we conduct our staff meetings, the link here at the agency. We discuss issues openly. We don't always necessarily have to agree with each other but we're allowed to state our point of view. That's really important for a population struggling with discrimination in other areas. It's important to allow each other to speak.

So the agency sort of developed our political analysis. Specifically, we do an analysis into immigration patterns. We do an analysis into the historical context of black people's lives. An analysis into poverty issues, sexuality, homophobia. I don't think we could have addressed HIV effectively or even made the inroads we have made had we not been willing, as an agency, to tackle the tough issues that are swept under the rug in other spaces in the community.

When we are in those spaces, we don't put up with homophobia. We talk. We challenge things. We move discussions to a new level. Because you have to do it when you're dealing with HIV. We also try to form links. A lot of people are aware of discrimination around race, so we try to create links between race, AIDS phobia, sexism, homophobia and so on.

INT: *I'm wondering how the work in Caribana has led to other changes in the agency or other longer term benefits for the agency's work in the black community in Toronto.*
JS: I would say it allows us to communicate Black CAP's needs to a large portion of the community. We have seen a steady increase in the number of individuals wanting to volunteer. We've realized because of the success of the parade that we would like to extend our outreach to other activities associated with the festival. We realized that it's better for the volunteer to co-ordinate Caribana because so much of it involves volunteer activities.

INT: *You're talking about AIDS organizations in the Caribbean?*
JS: I guess, all in all, it's just a kind of confirmation for us at Black CAP that to integrate HIV and AIDS info with other community issues is an effective method of addressing HIV in black communities—a confirmation.

The possibilities are endless. Once you've decided on a strategy, it's so creative. For example, a number of black women will be launching a lounge wear collection, and they've asked us to do a workshop at the launch. Again, that's sort of going to where the community is at.

We are seeing a number of individuals who are accessing our materials and who are talking to us to glean strategies on how to address this issue within their own setting: be it their classroom, their own living room or their summer barbecue. So we have taken the information out to the community. Now the community is coming to get the information from us and take it to do the work themselves. To address these shifts, we are structuring our resources differently.

We don't do workshops any more where we would come in and talk to 30 people to get this information out. Now we're talking to two people so that they can go back and share it with 30 people that we will never meet. That has meant more time.

We have also had to train a pool of about 15 volunteer peer educators. They're the ones that do about 90% of the workshops, allowing myself to do those other kinds of consulting, if you will, with individuals in agencies out there, so they can address the issue in their own setting.

INT: *What would you say you've learned from Caribana?*

JS: Collaborative initiatives have the potential for success—Caribana is collaboration all the way. And the other piece is that—when information is hard to swallow in a community, it's important to make it fun and interactive.

INT: *Have there been any surprises or unexpected results from your work in the community?*
JS: When we look back at the beginning, the surprise is that it has continued to be successful, that the outreach continues to grow along with the festival.

Another surprise is just the enthusiasm of the volunteers. A lot of them, [it's their] first time doing work in this way, first time being introduced to the issues in this way, and it's just their enthusiasm. They greet the folks on the street with a particular kind of enthusiasm.

INT: *Anything else you think might be helpful for other people doing similar kinds of community development work?*
JS: I don't know if I have said it enough: *involve* the communities, *understand* the needs of the community. The medium is the message, right? Particularly for ethnocultural communities—link it to a festival. Just make it fun. Because you may not be able to get a word in edgewise, in some communities at least, in any other way.

REFLECTIONS Managing the Community's HIV Situation

The fascination of Black CAP's story is in the use of the festival as a strategy to develop community support for HIV health. Using existing structures is an important way to build health promotion initiatives, but the festival has a flamboyant attitude that gives this initiative its real connection with the community. The serious side, however, is the listening going on at many levels—especially in focus group evaluations with the condom distributors. They too are listening as they filter through the crowds. Study-plan-do is the underlying current that has sustained Black CAP's Caribana strategy through the years.

Health promotion moves through cycles. An initiative may go through several cycles of study-plan-do as follows:

- Listen to HIV experience.
- Plan further studies.
- Do interviews, focus groups; scan experience.
- Focus a strategy and plan a pilot.
- Do the pilot.
- Evaluate the pilot and adjust the program.
- Launch the initiative.
- Monitor its impact.
- Plan formal evaluation.
- Do evaluative research.
- Analyze the findings.
- Report the findings.
- Plan distribution of the findings.

Experience suggests that moving through these cycles is equivalent to an organization's learning process. The process takes on a life of its own and progresses even though people come and go in the agency. Learning to increase control over and improve health may take months or years. Yet, in the meantime, the learning experience shapes transformations in people, groups and whole communities.

Collecting strategic information is an important first step. Quite often, however, listening has been overlooked in favour of gut instinct alone, assumed knowledge or, understandably, the urgency to get on with action—a "do-do-do" mode. In many instances, preliminary evaluation has been considered an obstacle to progress or a waste of time and money that could be spent on direct action. Such unchallenged assumptions have been known to produce ineffective, poorly targeted and potentially dangerous initiatives. Informed planning, based on real listening and a clear focus, makes a significant difference.

Most community agencies have embarrassing examples of local projects that may have caused more damage than good. One well-intentioned campaign, for example, meant to raise awareness of how same-sex partners relax their vigilance over safer sex, painted such a grim picture of deceit within male couples that the opportunity to provide supportive strategies was entirely missed. The unintended message was: "Don't trust intimacy." So much for inspiring increased control over health.

WHOLE-COMMUNITY PLANNING

Planning HIV health for a vulnerable community must involve more than programming for a single issue or group. The *whole community* must be taken into account. The capacity of an agency to carry out its plan also needs serious consideration.

This form of whole-community planning is best done collectively, involving as many people responsible for an agency's programs as possible. The work becomes an engagement in learning from each other about the whole situation in order to create the best possible plan of action for the community, its groups and the agency itself.

The fund of information held by outreach and intake workers from their everyday listening experiences, as well as their specific studies, is a good starting point. In addition, a few key pieces of research are strategically important.

One of the main elements in developing a local profile is gathering epidemiological knowledge: the numbers of new infections, the newly AIDS-diagnosed and deaths. Due to uneven access to anonymous HIV tests and test-result information, this information is not always easy to obtain. If no official records of HIV test results have been compiled, community information may well be the best way to keep strategically informed.

AIDS Vancouver's support program, Project Sustain, has developed a client records system to keep track of the vital statistics of people who come in for support services. The system keeps the agency in touch with changes in the gender, age, sexual history, drug use, living situations and financial circumstances of the people who come in for services. Such a records system can provide opportunities for observing new phenomena such as unexpected side effects from drugs or the increase in sexual abuse survivors among new clients. The agency also learns a great deal of street-level knowledge about the epidemic from its clients. Detailed records-keeping provides a powerful source of intelligence for use in an agency's planning.

Strategic partnerships are also valuable. Agencies at the Pacific AIDS Resource Centre (PARC), for example, maintain close links with epidemiologists at the British Columbia Centre for Excellence on HIV/AIDS. The epidemiologists track various kinds of data to produce estimates of the region's HIV-infected population.

Through calculations and joint surveys with the membership of the British Columbia Persons With AIDS Society (BCPWA), for example, AIDS Vancouver was able to develop various epidemiological profiles of its core community. Key studies were inspired by BCPWA members themselves. With the help of staff at the Centre for Excellence, survey ideas were turned into useful research initiatives.

AIDS Vancouver has learned when to expect increased demand for community care and hospital services through a survey of BCPWA's membership. From these findings, the agency was able to determine when people thought they may have been infected and when they tested positive. That information made it possible to predict when worsening symptoms will be experienced by increasing numbers of people—thus increasing the service demands on the agency. These predictions are further confirmed by tracking new clients coming to AIDS Vancouver for support services. This knowledge, troubling though it is, has increased the agency's confidence in its ability to plan for the future needs of its community.

Assembling information for planning primary prevention has proven to be more daunting. Epidemiological information can help to identify vulnerable groups, such as female partners of injection drug users and homeless or jobless youth. Other forms of research, such as recent community surveys, are also helpful.

Experience shows that community outreach workers can plan more effectively if they have better local information about the social-environmental conditions that set up risk and vulnerability. This—planning more research—has become a subject of its own in AIDS Vancouver's strategic planning.

HEALTH GAP/HEALTH STRATEGY GRID PLANNING

A comprehensive view of health promotion for an entire community, in terms of prevention and support, is the basis for development of an HIV health strategy.

AIDS Vancouver has found that broad participation is essential when assembling information on gaps and priorities. People with day-to-day contact in frontline work are the closest source of information. Each participant contributes data on contact or intake frequency and the results of any recent surveys. Few people in a multiservice organization have a comprehensive grasp of everything their agency is involved in. Planning is an occasion to bring everyone together for an overview and assessment of the "big picture."

An effective means to approach agency planning is to lay out a grid that can accommodate every program and activity of the organization. Each program or project leader reports on the year's activities, identifies gaps and indicates priorities for initiatives over the next year. See the Practical Fieldwork section later in this chapter for guidelines.

Reporting also helps to inform everyone about the coverage the organization is providing to its community. This level of activity focuses a large amount of information into a very small field. In fact, AIDS Vancouver has found it useful to arrange the information on one page for an at-a-glance summary of the agency's overall effort. From this viewpoint, a critical perspective begins to emerge.

Participants in the planning process begin to see that the gaps each program leader reports on can be reinterpreted as health risks and vulnerabilities in the community, for which specific types of health strategies can be planned.

While going through the experience, participants in AIDS Vancouver's strategic planning process realized that their sense of the organization's capacity had transformed. Previous perceptions had focused on merely coping as the agency struggled to meet the ever-increasing demands of HIV/AIDS with little recognition or support from the community. With the completion of the strategic plan and a health strategy for the whole community as a guiding force, participants' attitudes changed. The agency, they realized, did indeed have the capacity to manage HIV/AIDS in the surrounding community.

Health promotion planning will not necessarily create a miraculous change within an AIDS agency. But it can promote a change in thinking that also changes the capacity of the organization. It can help an agency to understand how best to change and challenge itself and, in doing so, to realize a preferred future for the health of the community and surrounding society. With its potential for transformation, health promotion planning becomes an important and powerful tool for addressing the fast-changing challenges of AIDS work.

CASE STORY Introducing Care Teams at AIDS Vancouver

Increased understanding of HIV/AIDS illness has made it possible for people to live longer with relatively good quality of life in contrast to the early years of the AIDS epidemic. In the meantime, community organizations have had to adjust to new realities. People living longer with HIV have longer term needs. Their marginalization and isolation can be so severe that they have no social support network. The strategy is to create one.

Jennifer Karakul was in the process of concluding a project with Support Services at AIDS Vancouver—a contract that had run overtime several years—when she stopped to reflect on the transformation since she began her work.

"A lot has happened. A lot has changed. When we started to really look at the way things were done in the past, the way things have changed for our clients and conditions in the community at large, we started to change our approach.

"I think, in general, we had been stuck in the past and we'd continued to respond in the same way because it was comfortable. It's hard to make change; it's hard for the clients, hard for the staff and hard for the volunteers. And yet change was obviously necessary.

"The buddy program was set up years ago in response to people who were dying much quicker than they do now. We didn't want to see people dying alone so 'buddies' were assigned to help people through the process.

"The buddy 'assignment' lasted six to eight months or maybe as long as a year. We didn't have the prophylactics, medications and treatments for opportunistic infections that we have now. So the buddy program was a response from the community to ensure that people had someone with them to help them through wills and other preparations for death.

"When we looked back at the program, we realized that some of our volunteers had been assigned to the same person for two, three and even five years.

These were volunteers who had signed on for a one year commitment, four hours a week. Some of them were burning out or feeling guilty. It was a 'how can I possibly stop doing this now that I've known this person for two and a half years' sort of thing. We thought this obviously isn't right. So we started to investigate other ways we could do this work.

"The first idea was that we could develop the existing support network around the client and his or her family and friends. A volunteer would come in and co-ordinate all the existing possibilities. The client would have as much or as little support as was wanted.

"This was fine, in principle, but we had a problem of consistency. In emergencies, staff had to be assigned to cover for volunteers. But the other more telling reality was that the people coming in for support had no existing social support network themselves: no friends, no family, no support.

"So that's when we looked at a model from a Texas church group called the Care Team Model. Care teams are prefabricated support networks made up of volunteers who can supply all the various needs that a client may have over and above those supplied by Home Care—they're a way to cover gaps in existing community services.

"Care teams allow volunteers to support each other, overcoming the problem of isolation that many buddies experienced. Care teams also afford accountability; there is a process they go through to manage all types of situations. And care teams provide a flexible structure. As more service is required, the care team is already in place to move more members in.

"So we thought this is where we need to go. We wanted to get out of last-minute calls from buddies, burned out after five 12-hour days in a row. It wasn't healthy for the client, the volunteer or for us because it always put us in an emergency panic with no other resources to draw from.

"We thought we could use care teams for the 'not very well' to the 'very ill' client. But this meant we would need to take a completely different approach to people who are well. We had people who were out there dying alone, yet we had this buddy program tied up with people who were well.

So when someone called who was desperately ill, we had no one to send. People died before we were able to get someone there. That's not what we wanted. We wanted to be able to respond.

"Now we have three care teams in place and more on the way. We figure each team can take on two or three clients. If we need more people we can just pull them in from one of the teams that isn't as active."

Care teams in place, Jennifer also saw a new need to maintain good relations by announcing the change in the organization and community. Some long-time volunteers felt more committed to the existing buddy program than to the new concept of community support. Program changes brought unexpected resistance and anger from some volunteers. On balance, though, the new idea brought refreshing change.

"The whole manner in which we train volunteers has changed. The training is geared to provide volunteers with the skills they need to work with people who aren't well, to the point where they are dying. We'd been sending buddies out expecting them to cope with the whole course of the illness on their own."

PRACTICAL FIELDWORK Planning for HIV Health Promotion

Refocusing a support strategy as emotionally loaded as buddy programs is a delicate feat. Listening with empathy to people involved in the program and taking into account real change in treatment and life expectancy brought forward the realization that change was necessary, but how? Finding an effective approach required more listening and some trial-and-error experience to move into a new strategy. Clearly, it had to work as well for the client as it did for the agency for the sake of everyone's health.

The ultimate goal of health planning is to increase the agency's capacity to manage the HIV situation in the community. The development of capacity does not necessarily imply an increase of staff or financial resources, although that may be a conclusion reached within the agency. Capacity is also a matter of focus and best use of available resources. The crucial insight to gain from well-researched planning is how the agency can move from coping with HIV/AIDS as it presents itself in the community to having a clearer sense of how, where and when to intervene.

Planning draws on the experience of the past and present to orient future efforts and resources. This section deals with some inevitable questions that must be answered in order to see the HIV situation in the community for what it is, before embarking on trying to make a difference or adjusting efforts already under way. The procedures described here could be used to work through a strategy for a single project or a spectrum of activities across an agency's entire program.

EVALUATING STRATEGY

There is a close connection between planning and evaluation. The Precede-Proceed approach to planning for health promotion described in Chapter 1, for instance, uses evaluative research extensively. It aims to "diagnose" quality of life, epidemiological status, behavioural and environmental conditions, people's current health-related knowledge, beliefs and skills, as well as an organization's capacity to affect the health circumstances of the population. Once a program is under way, evaluative research is applied again to monitor and measure its impact.

The kind of evaluation you may be engaged in corresponds to how far HIV/AIDS program activities have developed on a particular project. There are several different types of evaluation:

FORMATIVE EVALUATION: applies to the beginnings of a project or strategy and uses needs-assessment activities such as pre-existing data, surveys, interviews and focus groups to generate material for strategic planning.

PROCESS EVALUATION: refers to pilot testing and ongoing monitoring activities using participant observation, feedback forms, client profiles, focus groups and other forms of listening to bring forward material for adjustments in planning and programming.

OUTCOME EVALUATION: considers the results at the end of a project and is obtained through attendance records, feedback forms, surveys, focus groups and other forms of listening or full-scale external research to compare previous community HIV/AIDS-related health status to the current one.

Granting agencies are increasingly insisting that an evaluation component be built into fundable projects. For this reason alone, it is important to know that evaluation is simply a type of research, although a specialized form. Evaluation is usually done to help make decisions about whether to add, drop or adjust a program. The skills and methods of listening to HIV experience may be all that is necessary to bring forward the evidence required to make those decisions.

In some cases, however, an external evaluation would be useful to provide an independent opinion of whether a program or the whole agency's effort is working as intended. Such an evaluation could be necessary in a crisis situation where transmission rates appear to be rising out of control, or would be desirable to measure the quality and length of life changes in an HIV-positive population. These external evaluations would be best conducted in partnership with an institution.

KNOWING THE COMMUNITY'S HIV SITUATION

Even while a community agency is engaged in listening to HIV experience on various fronts, the sense of progress is often elusive. A few core planning-focus questions can help to make sense of what is happening:

- Whom have we been listening to?
- What have we learned about the people/the agency?
- What are the HIV risk conditions?
- What are the HIV health gaps?
- What does our information tell us we need to do?
- Whom do we need to reach?
- How will we approach them?
- How will we know we're having an impact?

WHOM HAVE WE BEEN LISTENING TO?

Answering this question faithfully may be more instructive than it first appears. It is quite possible in AIDS work to expend effort trying to break into a situation, all the while talking to the wrong people. The development of an "HIV/AIDS in the workplace" project was held back for two years while the organizers worked in vain to interest corporate executives. Once they were recognized as an inappropriate choice of target, the right one became clear. Approaching managers in charge of personnel—the people who would be responsible for handling an employee problem with HIV/AIDS—produced a remarkable turn around. See the Case Story "Breaking into the Corporate Workplace" in Chapter 9: Society—Transformative Groups—Societal Change.

WHAT HAVE WE LEARNED?

A simple question like this one can break through a baffling array of unconnected data. There are times when it may seem justifiable to present great quantities of data to support a proposal, but planning requires clear thinking about what the data means. Answering this question requires a leap from the data to an interpretation. You can make that interpretation when you have the evidence to back it up. Approaching problems from a learning point of view is also a productive way to move beyond blame and recrimination when projects have not worked out as expected.

... ABOUT THE PEOPLE WE NEED TO REACH?

Listening to HIV experience from the people that need to be reached will inevitably say much about who they really are. This information may not be obvious on the surface but it may be underlying what they say. The more you learn about the obstacles, fears and motivations of the people that need to be reached, the better chance you have of mobilizing their participation.

... ABOUT OURSELVES AS AN AGENCY?

Listening should also expose perceptions among people about the agency you represent and the work it is doing. This can sometimes be uncomfortable, especially when an unfavourable image persists, as it often does, in vulnerable communities. By definition, HIV-vulnerable communities endure many kinds of systemic dysfunction such as discrimination and homophobia, which comes through in the way people behave toward any institution, even their own.

In health promotion, as in politics, perception is reality. As such, the image the agency has in the community can deeply affect the impact of its efforts. An agency may seem to be "too uptown" for one group of people that need to be reached and too "low down" for another. Since these conflicting perceptions pose an obvious dilemma, tailoring the image to each group may be a serious issue that needs to be taken up in planning.

WHAT ARE THE HIV RISK CONDITIONS?

Answers to this question may seem obvious when strategies for some of the main vulnerable groups, such as men having sex with men, are under consideration. But looking carefully at the social environment may suggest deeper answers, such as a history of abuse in partners of injection drug users.

One way to extend the interpretation of a group's risk conditions is to list these conditions as an inventory. The YouthCo AIDS group developed an inventory of barriers to safer sex that young people talked about in the video that YouthCo made on the subject. (See the Case Story "*You, Me & Reality*—YouthCo Listens to Youth" in Chapter 3: Study—Listening to

HIV Experience with Research Skills.) The inventory listed risk conditions as diverse as lack of open discussion of sexuality in the home or school, little experience with sexual communication and having enough money to buy condoms.

WHAT ARE THE HIV HEALTH GAPS?

Health gaps may be anything that suggests the possibility of unmet needs or untreated risk conditions or lack of a supportive infrastructure for health promotion. Health gaps are sometimes identified by those in need through comments such as "If we only had . . ." or "What we really need is . . . " Or they may be identified through formal surveys and collective responses.

WHAT DOES OUR INFORMATION TELL US WE NEED TO DO?

This question links the data with strategy and frames the argument for a particular approach to a problem. The strategy that feels right is likely the best one to pursue—using, of course, listening skills to maintain the best possible advantage for the initiative.

In planning to intervene to fill a health gap, the agency's capacity must be taken into account. Financial resources, staffing, available time and other priorities of the agency's mission need to be considered. If resources can be focused into a strategy, identified "health gaps" may well transform into "opportunities" to mobilize the group that needs to be reached.

WHOM DO WE NEED TO REACH?

The health promotion perspective recognizes the need for a supportive infrastructure to create a supportive environment for HIV prevention and harm reduction efforts. This means that it is necessary to plan not only for the direct recipients of an initiative but for those in the surrounding environment as well—individuals and groups that have the power to build a supportive environment. In one case, for example, women's shelter directors needed a specific approach in order to establish an HIV/AIDS program for their clients. Even then, the shelter staff needed a separate activity to prepare them for HIV/AIDS programming. Those activities helped to prepare the approach to the clients themselves. See the Case Story "Women and HIV in Edmonton's Women's Shelters" in Chapter 5: Do—Building Supportive Networks for HIV Health.

HOW WILL WE APPROACH THEM?

This often-overlooked question could make or break an initiative. In any new setting, cultural awareness can be used to understand and apply the appropriate social etiquette to make an approach. In prison outreach, it was important to recognize what to wear on different occasions, depending on who was being addressed. The inmates would mock a suit but wearing one was necessary to gain the respect of prison officials. See the Case Story "Transformations in Prison HIV Strategy" in Chapter 6: Interpersonal—Inner Practice—Personal Transformation.

HOW WILL WE KNOW WE'RE HAVING AN IMPACT?

This should be a precautionary question, not one left to the end. If your program encourages the kind of listening described in Chapter 3: Study—Listening to HIV Experience with Research Skills, you are already well on the way to collecting material that would indicate what kind of impact a project is having.

If an external independent evaluation is desirable, it would be best to plan for professional involvement.

GRID PLANNING

A simple grid is a powerful tool of analysis for planning a single project, a program or a whole agency's activities. The trick is to reduce your answers

Outreach Planning Grid

TARGET GROUP	HEALTH GAPS/RISKS	HEALTH PROMOTION STRATEGY
Marginalized women in the Downtown East Side district	Access to HIV/AIDS education/support Marginalization by • low literacy • alcohol and drug issues • sex trade work • racial discrimination • poverty High concentration of risk activities in neighbourhood environment	Drop-in at women's centres Workshops Developing print resources Developing one-on-one talk resources Networking with women's agencies regarding health issues (food, violence, shelter)

to the planning questions above to a few telling words so everyone can see as much of the plan as possible on one page. The above example is from a 1996 annual planning event of agencies involved in women's outreach.

WHOLE-AGENCY PLANNING

Experience has shown that the process described here brings a high degree of clarity to managing HIV situations within the community, even where community AIDS agencies are trying to reach and support several vulnerable groups. This adds to the complexity of planning, but the procedures described in this chapter will accommodate several program activities.

Going through an exercise to consider each activity as part of the whole is an excellent opportunity for staff, volunteers and board members to participate in strategic planning for the agency. The experience brings a high level of focus to what the agency is doing, the unaddressed issues and the capacity of the agency to handle particular situations. This kind of assessment and planning not only inspires more confidence but also greater capacity to manage the community's HIV situation.

Capacity increases by having better control over the factors affecting the health of the community, being able to identify them and creating strategies to deal with them. From year to year, some needs may continue to go unmet. When they are, the agency can readdress the situation with direct programming or advocacy with powers that can make something happen. The following process enables an agency to conduct an annual planning exercise on its own initiative, with or without the support of an external facilitator. Many adaptations are possible. Experience with self-organized planning will provide many insights that would help mold the exercise to the best advantage of the group.

PREPARATION

Announce the meeting about a month ahead to allow time to draft year-end reports. The reports should describe the year's activities, including participation statistics and trends. Use the planning focus questions to frame the reports.

ROUND 1: WHERE WE ARE NOW A respected staff member, a manager or a board member facilitates the meeting. Have each person or team responsible for a program activity present an oral report to the whole group. Encourage feedback and suggestions. Use a flip chart to record key information that comes forward in the reports:

- targets (people we have reached)
- activities (what has been done)
- risk conditions (HIV risk behaviours, poverty, discrimination, abuse, drugs, homophobia, fatalism, etc.)

After everyone has had an opportunity to report, return to a consideration of the agency as a whole using a SWOT (strength-weakness-opportunity-threats) analysis:

- Strength (where the agency is doing well)
- Weakness (pitfalls and disappointments; unfulfilled goals or promises)

SAMPLE SWOT ANALYSIS

STRENGTH

- Breadth of experience
- Volunteer/staff unity
- Committed board
- Community profile
- Physical space
- Talented leadership
- Cheap, effective quality
- Research capacity
- Unique health role
- Desired services
- Community infrastructure
- Collaboration/ partnerships
- Shared philosophy
- Training capacity
- Creativity
- Flexiblity
- Professional credibility
- Practical response

WEAKNESS

- Past history/conflicts
- Funding: self-reliance, competition, uncertainty
- Negative profile: AIDS Inc., bureaucratic, HIV industry
- Humble about own success
- Diversity image
- Over-extended programs
- Burnout potential

OPPORTUNITY

- Political change
- Health board restructuring
- Support network and alliances
- Impending election
- Conference exposure
- Media relations
- Health system partners
- Health promotion planning
- Case management
- Client tracking data base
- Dynamic reputation

THREATS

- Overwhelming demand
- Unstable epidemic
- Political shift right
- Uptown profile
- Impending election
- Unreliable funding
- Health policy shift
- Unstable political climate
- Agency burnout
- Social service policy shifts
- Health board restructuring
- Broadening epidemic
- Activist groups
- Losing steam
- Good news/dashed hopes

- Opportunity (where potential benefits are in the environment)
- Threat (what in the environment might hold the agency back or create undesirable situations)

As the sample shows, a SWOT analysis can bring social conditions into focus for community health planning, simply by taking inventory of the environment.

Encourage brainstorming from the group. Complete each category, one at a time, using the flip chart to record the group's suggestions. Tape the flip chart sheets to a wall in sequence, if the room allows.

Encourage reflections on the day's work from the group.

Appoint someone to convert material from the flip charts into a word processing format and distribute the record of the meeting to participants. Draw the meeting to a close.

ROUND 2: WHAT WE NEED TO DO Allow about a week for processing the information from Round 1, if this is convenient. Some groups may wish to conduct the entire exercise over two days or a weekend retreat.

Briefly review materials generated from the first meeting.

Facilitate a second round of oral presentations in which each activity leader or team will consider strategy for the year ahead:

- priority targets (the people we need to reach)
- HIV health gaps (untreated risk conditions, support needs, infrastructure development, advocacy)
- strategy (intended action for the year ahead)

Review the day's proceedings with the whole group participating. Take the group through a priority analysis of the agency's efforts and group them according to categories such as "urgent," "maintain," "watch", "drop." Encourage brainstorming and use a flip chart to record responses.

Convert the day's proceedings to a word processing format and distribute. Aside from the clarity to be achieved from summarizing and looking back on a year's work and addressing strategy for the year ahead, the material generated from these sessions may be used directly in grant preparation, budgeting, advocacy and fundraising initiatives.

Experience has shown that planning exercises can be adjusted from year to year to take advantage of learning within the agency. In the second year, for example, Round 1 could begin with an evaluation or assessment of the previous year's strategy. Take the inventory of target groups and have the whole group work together to assign a grade indicating how well the agency did in reaching or supporting the intended people.

TARGET INVENTORY

The *Field Guide's* perspective encourages whole-system thinking about well-known public health concepts such as target groups and risks. The systemic point of view positions the people we need to reach as those at risk and those in the surrounding environment. These include people in a

TARGET GROUPS

OUTREACH

Out gay men
HIV + gay men
MSM (non-identifying gay men)
Young gay men
Asian gay men
Asian MSM
HIV + Asian men
Women
- in recovery
- First Nations
- low literacy
- partners of IDUs

TRAINING

Social workers
Home care workers
Community service organizations
Recovery staff
Hospice staff
Nursing students
Medical, pharmacy, dental students
Prison staff
Personnel directors
Youth workers
ASO staff
Volunteer organizations
Business and labour leaders

COMMUNITY

Media reps
Health colleagues
Political groups
Bureaucrats
Politicians

TARGET GAPS

Straight bar crowd
Men in recovery
Immigrant groups
Municipal employees
Street youth
Injection drug users
Counselors/therapists
Teachers
Physicians
Health-care professionals
Transgendered individuals
Sex trade workers
Mixed-HIV status couples

position to make policy changes, provide support and whose attitudes we need to change to make the social environment more supportive for prevention, health promotion and harm reduction efforts.

WHOLE-AGENCY HIV HEALTH STRATEGY

Seeing all the health promotion initiatives of an agency in one frame provides the base for evaluating the comprehensiveness of the HIV health

WHOLE-AGENCY HIV HEALTH STRATEGY

	PRIORITIES	GAPS/VULNERABILITIES	PROPOSED STRATEGY
PREVENTION OUTREACH	HIV-vulnerable communities	risk conditions persist HIV+ health conditions	face-to-face contact community health plan
MEN	gay HIV+ gay young gay gay Asian MSM	HIV+ health education ethnocultural outreach men in relationships mixed-status couples street youth	outreach visibility community recognition HIV+ health program gay youth project
WOMEN	in poverty First Nations IDU partners	transition centres workforce shortage network maintenance	neighbourhood project literacy sensitivity health workshops training of volunteers
PRISON	gay, HIV+, MSM	HIV+ health	workshops, one-on-one
DEAF	young gay	isolation, discrimination	training of interpreters
COMMUNITY CARE	HIV+ men/women 90% disadvantaged 30% multidiagnosis	insufficient funds, food, shelter, psycho-social support	support services practical help programs food bank
INTAKE	304 new 116 deceased	insufficient staff privacy in waiting room	meet expected increase relief staff
CARE TEAMS	2,000 client hours	poverty/isolation	more team-leader contact
FOOD BANK	288 users	quality/quantity of food hygiene	new donor campaign stock expansion
EMERGENCY FUNDS	$6,000/month draw	high demand	new funding sources
COUNSELING/THERAPY	55 hours/month	excessive demand	inclusion of HIV+ partners
MEDICAL EQUIPMENT	122 users	affordability of equipment	storage/repairs
HOSPITAL VISITATION	57 clients	isolation	volunteer training
PET PALS	HIV+ owners	absences	training of SPCA volunteers

strategy for the whole community. It can also point out problems and gaps in the agency's strategy. The example on these pages charts the strategy of an agency of about 25 employees who are struggling to keep up with demands for HIV-positive support services in an area of high rent and high unemployment.

WHOLE-AGENCY HIV HEALTH STRATEGY

	PRIORITIES	GAPS/VULNERABILITIES	PROPOSED STRATEGY
INFORMATION SERVICES	community, schools HIV+ men/women employers/employees	beliefs & misperceptions stigma/discrimination	information, resources message management
LIBRARY	980 registered borrowers	information demands	on-line network
HELPLINE	15 calls/day	message consistency	supervisor training
PRINT RESOURCES	500 bulk requests	inventory demands	message review
COMMUNITY RELATIONS & DEVELOPMENT	schools, institutions government community organizations	HIV stigma heterosexism	extension of network of supportive individuals, groups, organizations
WORKPLACE	employers/employees	secrecy, isolation	creation of visibly supportive environments
CONSULTING/LOBBYING	health professions/ government	consistency of support	provision of information/influence
COMMUNICATIONS	media/society	denial, stigma	provision of information/influence
TRAINING	health workers social services AIDS workers	outdated messages and resources–print, video demand for training	resource development message promotion training of trainers
ADMINISTRATION	people in AIDS work agency staff	self-reliant sustainability	plan, manage, develop funds, consult, lobby
VOLUNTEER RESOURCES	community members	consistent message	training/updating
FUND DEVELOPMENT	donors	insufficient sources	reprogramming
HEALTH PLANNING	HIV-vulnerable	workforce knowledge	in-service education
BOARD	community leaders	community image	communication strategy

CHAPTER 5

DO

building supportive networks for HIV health

Doing HIV health promotion requires a mix of inner confidence and interpersonal and facilitative skills, as well as education, advocacy and community development tactics. The approach to practice is often developmental, using the realities of HIV risk conditions in the social environment as a starting point. The examples of HIV outreach cited in the *Field Guide*, for instance, have approached the field as community development with an HIV focus rather than as basic prevention with direct appeals for condoms, clean needles and safer sex. Much of what occupies HIV health promoters in the field is setting up networks of supportive people to develop their own more basic HIV initiatives such as prevention, harm reduction and support for people living with HIV/AIDS.

Since AIDS work inevitably unearths the social issues at the roots of HIV vulnerability, the development approach prepares people for the tougher ground of issues such as sexism and homophobia while they are organizing support for HIV/AIDS basics. Eventually people's deepening inquiries lead to the connections between persistent HIV and systemic issues such as sexism and homophobia. That process increases their understanding of what to do and how to approach the issues in their own environment.

The focus of this chapter is on the action phase of the transformative model—actually doing HIV health promotion in the field. As you will see in the Case Story, Reflections and Practical Fieldwork sections that follow, health promotion makes liberal use of social development tactics to create supportive environments by building the infrastructure to take on HIV prevention, harm reduction, support and care. Reaching the people who need to be reached often provokes encounters with social barriers such as sexism, AIDS stigma and homophobia. Getting around them is a matter of bringing people's best practices into action.

This chapter shows how to use social and community development tactics for HIV health promotion, while working productively on HIV vulnerability and risk conditions to prevent both infection and undue illness. The desired result is a supportive environment that makes HIV prevention possible in all its dimensions. In other words, sustaining HIV prevention and health has to seem worth the effort to the affected people. Some of the desired effects of supportive infrastructure are as follows:

- HIV prevention messages get through to where they need to go.
- The supportive environment makes sustaining preventive practices seem worth the effort.
- Snowball effects engage more and more people in HIV health promotion.
- People learn to recognize and avoid harmful or discriminatory social practices.
- People living with HIV/AIDS are encouraged to participate in changing social environments to make them more supportive.
- People rise to higher purposes such as taking care of each other.
- Affected communities work together toward a common goal.

The lead **Case Story** shows how dealing with the social aspects of HIV/AIDS offers, in many cases, a more appropriate starting point than basic AIDS prevention. Seeing HIV prevention in the context of family violence pointed out the vulnerability of women and forced open the doors of women's shelters, institutions already in place to support them. HIV prevention then became another layer of action.

Reflections discusses how social environments regulate HIV/AIDS behaviour and health, and proposes a social model of HIV prevention to work with while creating a supportive infrastructure.

The second **Case Story** is about building supportive networks in AIDS care environments: in this case as a nursing AIDS elective.

Practical Fieldwork gives you the basic ingredients for creating, developing and enabling the supportive networks needed to manage HIV/AIDS in affected and vulnerable communities.

CASE STORY Women and HIV in Edmonton's Women's Shelters

Nancy McPherson is a Community Health Developer with the Capital Health Authority, Public Health Services, in Edmonton. She co-ordinated a project on Women and HIV in Edmonton from September 1991 until April 1994.

INTERVIEWER (INT): *You were co-ordinator of a Women and HIV Project at the Edmonton Board of Health. Could you give us an overview of that project and what it was trying to do?*

NANCY McPHERSON (NM): We were trying to initiate some HIV prevention and support for [HIV-]positive women in women's shelters and transition houses within Edmonton and the surrounding area. We began by recognizing that the public health department needed to take some strong action in HIV prevention with a focus on women.

Where to start? There obviously weren't the resources or the connections available to address women in general in Edmonton—we finally clicked into a link between a higher risk of HIV infection and domestic violence. So we started to look at women in abusive relationships.

This became our linkage with the shelters: there were women in abusive relationships staying there. The chipping away of women's self-esteem over time by virtue of being in abusive relationships puts them at high risk for HIV. So AIDS seemed a natural fit with the work that women's shelters and transition homes do: they deal with not only physical, psychological and emotional abuse, but also with sexual abuse.

The shelters also look at physical safety and communication. Lots of work is done around self-esteem. Once they leave the shelter or transition home, women are able to look at their own health and take action on it.

We could see the natural fit between HIV and the work the shelters did. But when we got the project up and running, our challenge was that front-line shelter workers couldn't see the fit.

INT: *Between violence in the home and HIV?*

NM: Exactly. Over time, we've compartmentalized our themes, our topics and our work into small boxes. Often what I would hear is: "Look, what does this have to do with me? My area of expertise is domestic violence and now you're bringing me HIV. I don't know anything about that." They just didn't see how interconnected the topics were.

INT: *How were you able to break through?*

NM: We recognized that the Board of Health had absolutely no legitimacy or any real connection with women's shelters. So we established a three-way partnership that involved the provincial co-ordinator of the Alberta Council of Women's Shelters (which has the mandate to influence shelters throughout the province) and the director of Edmonton Women's Shelter (which is certainly the biggest shelter in the area and serves the largest number of women and children per year).

But we didn't start adding on everybody who had a vested interest, or everyone we thought politically ought to be at the table. We kept it small and manageable.

We had a rough plan in mind in terms of what we wanted to see come out of the project, but we recognized, right at the outset, that these were only possible strategies and that it was really something that was going to have to unfold.

First, we took the plan to the shelter directors. We thought if we didn't have buy-in at this level, we were dead in the water. It was a much harder sell than I thought it was going to be. It was a very thin line, I found, to challenge a shelter's work enough to open [the directors'] eyes to an HIV project without offending them by implying that everything they'd been doing, to this stage, wasn't good enough.

Also, the directors, at that point, were feeling really overwhelmed by the work they already had, and this was an indication of what was to come from the frontline workers as well: "We've got enough on our plates; please don't bring us HIV to deal with." As if my presence was going to "bring them HIV"!

It took a while to work through the fact that HIV is coming, with or without the project. It sounds so incredibly naive and simplistic, but that's certainly where the thinking was at the time.

The directors were also feeling strained financially, and before they could even think about the project, they needed a guarantee that this wasn't going to cost them any money. I couldn't give that guarantee because I knew, in terms of staff time, it would cost them. So if I started by saying, "Well yes, in fact it is going to cost you," the door closed.

I would say the real breakthrough for us was when we spent a full day just looking at the work of shelters and how to weave in the topic of HIV. The breakthrough exercise, which was very simple, was using case scenarios of probable HIV situations that shelters either had or were going to face.

I broke the group of women up and had them work in smaller groups with some key questions:

- How would your shelters deal with an HIV situation today?
- How would you like your shelter to deal with this situation?
- What needs to happen internally to make that happen?

One director was brave enough to report back to the larger group that "our shelter would deal with an HIV situation very poorly; there is nothing internally that could support us in dealing with HIV right now."

Once that started, there was the freedom for others to say the same thing. Also, I think looking at the trend of what is actually happening with women was important—not just rates of infection but also looking at what the HIV and abuse experience is for women, and why women are becoming infected. That's when the shift happened.

INT: *By looking at the social environment?*

NM: Yes, and hearing it from a woman's perspective and not from the director of a shelter. Prior to that, the feeling was: "Tell them to use a condom if that's what's needed." It was the critical social analysis that had been missing.

We then went through a similar process with the frontline workers—developing understanding about what the HIV link with their work was. But something happened there; something was missing. I had a very clear picture of what work in a shelter was all about. I had done a lot of volunteer work in a shelter years before. The part that was missing—that I was counting on being in place and, in fact, wasn't—was knowledge of sexuality.

I had wanted to start directly on HIV with the staff. But it wasn't working. Finally they came to me and said, "Look, you want us to start at a place that's not possible for us. You want us to talk about HIV but we have trouble talking about sex. We've never looked at sexuality before."

Given the amount of sexual abuse that residents had experienced, I was astounded that sex and sexuality were not part and parcel of the general orientation for shelter staff.

It never occurred to me that, in fact, they typically approach abuse from a *physical* perspective. They work on spiritual, psychological and emotional levels of abuse, but, with our society the way it is, everyone keeps clear of the sexual aspect.

We needed to stop where we were and look at organizing talking circles and sexuality workshops—starting, in other words, at an earlier point. Not only did this require more time than we had budgeted for, it involved more time than even the women realized they'd needed.

INT: *I would assume that these shelters and transition homes operate using a feminist analysis.*
NM: Absolutely. Feminist analysis is certainly what kept the issue moving forward. The women who were grounded in a feminist analysis moved very quickly. The difficulty was that I was quite naive and assumed that *all* workers in the shelters and transition homes would operate on that premise. What I didn't realize was that this was not the case for probably half of the staff.

INT: *What came out of the project?*
NM: Our sole focus was to try to raise the awareness, understanding and knowledge of the staff so they could deal with these issues internally. Then they could look at how to be supportive to positive women and their children when they arrived in the shelter.

What was interesting was involving the staff *and* the residents who were in at the time in the development of the resources they wanted. The value of the resource production, I discovered, was not in the final product but in the process of creating it.

The staff and residents became really angry about the kinds of messages and resources that were out there; existing HIV materials in the shelters didn't relate to their experience. For example, there was a poster with a very attractive, unbeaten woman on it who said, "You don't have to worry if your partner doesn't have a condom. Just take a deep breath and tell him to go get one!" A battered woman would respond with, "What a crock! I can't tell him anything!" Women at the shelters decided to create their own resources.

The other breakthrough was change to HIV policy within the organizations. The typical scenario was that there wasn't any policy. The shelters that were progressive enough to have an HIV policy in place had policies that were quite dated and inappropriate. One of them, for example, was titled, "How to manage the AIDS carrier."

So we created an HIV policy that would work for a shelter. This was a great step forward. I would be really naive to say that every shelter has incorporated the new policy as written, but at least it's a guideline, a model of what they need to work toward. Some shelters adopted it right away. Other shelters could only take parts of it.

INT: *How has the project dealt with the culture of domestic violence within the context of HIV?*

NM: One of the things that I've come to realize is that AIDS education has become very myopic about condoms. They're all we promote, and their use is the outcome we're looking for.

What this project did instead—while never losing sight of the value of a condom—was to focus on the value of the power women hold. We focused on whatever incremental level of power women may have; this was the starting point, and it was all grounded in self-esteem.

The issue we faced was that if it's taken 35 years to chip away at a woman's self-esteem, then we're not going to be able to piece it all back together in a four-hour workshop.

We looked at other issues too, but the classic one was where women place their sexual experience. For women, it's intimacy. For men, it's release. So what can we act on?

A lot of the women started to use vaginal spermicides. This is a harm reduction strategy that lots of AIDS educators will challenge me on: spermicide isn't good enough.

But we don't provide any false reassurances for women. I wouldn't do that, even in a situation where a woman holds a lot of power. For many of these women, it is the first time they have taken any real control. It's a starting point.

A number of women over the course of the project went back to their relationships a number of times, so it was interesting to hear their feedback. They took a perverse pleasure in knowing that they had vaginas full of spermicide without their partners' knowledge. It was the equivalent of declaring, "Yes, I've got control, and you don't even know it."

INT: *Do you think this project has led to any other changes or longer term benefits outside the community you were directly trying to access?*

NM: I think it did initially, but I think we lost some of it over time; we consulted with a variety of agencies in the city that served women but were not necessarily related directly to the area of domestic violence. While the project was unfolding, there was something to focus on, and it was a reminder, a tap on the shoulder, to say, "Don't let this one get shelved." Unfortunately, once the action phase of the project was over, things started to slide, so I wouldn't say there has been a long-term impact.

INT: *Except in the community you were directly trying to access.*
NM: Exactly. Now, what I have done is taken a lot of the learning from this project and implemented it in other projects.

INT: *What did you learn from doing the project that you didn't know before, and what advice would you have for others doing similar projects?*
NM: It was that piece about where I wanted to start. We had to start with sexuality, much earlier than HIV, and this was really surprising to me. It made me realize how anal-retentive society is around sexuality, and what the implications are for the clients as a result.

We are in worse shape than I realized. It doesn't seem like we're getting on with our agenda or getting on with our business, whatever that is. I think addressing sexuality is critical to moving the HIV issue forward.

INT: *Are you aware of how many of the organizations that you dealt with have HIV policies?*
NM: Every shelter has either a portion or the entire policy in place right now. Unfortunately I can't give you numbers, but more shelters have experienced HIV-positive women arriving. All I know is what I've been hearing about experiences from women in the community, and the experience has been positive.

INT: *There have been funding cutbacks in Alberta recently, and I wonder what kind of impact the political and economic environment had on the work you were trying to do.*
NM: I would say that initially it had a really negative impact because at that time the shelters were all quite worried about their funding. There were lots of rumours about what was to come, so nobody wanted to rock the boat. A number of shelters didn't want to state publicly that they were on board with the HIV project, in case it had funding implications.

INT: *HIV was viewed as a kind of peripheral issue?*
NM: Right. Certainly, what's happened over time is that shelter staff are more aggressive than ever in terms of being committed to HIV, and it's almost an "in spite of you" attitude toward the province.

INT: *Anything else you thought was really significant about the project?*
NM: I think one of the things that I would like to be really clear on is that we felt it was critical to involve the women who were actually going to be affected by the project all the way along.

UPDATE

News of Nancy's work reached the Pacific AIDS Resource Centre and helped a shelter project in Vancouver to leap ahead by using lessons learned in Edmonton. The Vancouver project's organizers held an information lunch for recovery and shelter workers and invited Nancy to give the keynote address.

REFLECTIONS People Supporting People

Recognizing the link between higher risk of HIV infection and domestic violence was the igniting spark of the project in Edmonton. But the real work began as a resolute process of building support from within the relevant agencies where previously little recognition of the issue existed. That meant a deliberate-but-respectful approach toward building partnerships among agencies and supportive relationships among professional players. Establishing a supportive climate at the top created the conditions necessary for practical health promotion with the vulnerable group.

The emphasis on a supportive environment in health promotion has sometimes appeared to be too indirect to people working in community-based AIDS agencies. The prevention bottom line, after all, has to be condoms, safer sex, clean needles and access to testing. For people living with HIV/AIDS, the crucial needs are food, shelter and medicine. Why invest so much limited time and energy into creating a supportive environment when results are so difficult to achieve and often not measurable?

That social environments influence HIV vulnerability is a troubling concept. More immediate explanations are easier to accept. Our culture still holds individuals accountable for many of their health problems despite growing awareness of environmental factors such as stress, poverty and pollution. Now as we continue to see people failing to practise HIV prevention measures, an old public health question arises: Why do people continue to put themselves at risk for exposure to HIV?

The question, although justified in certain respects, is steeped in a view of life restricted to accounting for specific acts. The people who commit unsafe behaviours are seen to be out of control in some measure, possibly because of drugs or alcohol. The focus remains on the individual; the dual impact of a persistent virus and social circumstance escapes attention.

THE SOCIAL VIEWPOINT

A social view of health presents a more dynamic range of possibilities. Even the simplest social analysis suggests that it takes two people to transmit HIV. As such, the dynamics *between* people become involved. In order to understand how people continue to be exposed to HIV, therefore, social conditions and environments have to be brought into view. Listening to people who are vulnerable because of circumstances, such as discrimination and family violence, has shown HIV infection to be one of many possible results of damaged self-worth. The opportunity for health and extended life after infection is held back by the same conditions, unless there is some form of supportive or enabling intervention.

If a social perspective had been taken to its logical conclusion in the early days of the epidemic, primary prevention for HIV/AIDS might have emphasized social relations that set up conditions for risk behaviour, rather than a multitude of different ways to say, "Wear a condom." The social approach would have opened up issues of sexual communication, coercion, abuse, intimidation and so on as the context of explanations for unsafe behaviour.

The fact that HIV is sexually transmissible makes harmful social dynamics all the more important to understand, account for and do something about as part of HIV health promotion. The societal environment, however, is so fraught with moral conflict about sexual expression that this approach is unlikely to occur without serious attention to building a supportive infrastructure. In the meantime, moral conflict around sex will continue to affect the way HIV-vulnerable people see themselves, their interactions with others and, ultimately, their health.

SUPPORTIVE AND SURROUNDING ENVIRONMENTS

From a transformative perspective, creating supportive environments for people who are vulnerable to either HIV infection or illness is important, but so is building support in the surrounding environment. Research on the determinants of health shows why.

People with limited control over their own decisions experience poorer health in general, and HIV/AIDS is just one of the serious threats. The way this lack of control affects people can be seen in the health of the systematically marginalized: people living in ghettos, youth on the street, sex trade workers, drug users, urban natives. Their HIV vulnerability is not simple coincidence.

Groups in society on the receiving end of stigma and discrimination are more vulnerable to illness than those who enjoy status and power. Sadly, this suggests that, without some more comprehensive intervention than simple behavioural prevention, if one source of illness, such as HIV, could be eliminated from vulnerable communities, others may take its place.

This understanding strikes at the core of knowledge about HIV vulnerability among women, ethnocultural communities, gay men and, increasingly, injection drug users. If HIV health strategies fail to go beyond the distribution of safer sex and injection messages, HIV/AIDS will continue to be a dominant health issue among marginalized communities.

A SUPPORTIVE ENVIRONMENT WITHIN AN AIDS AGENCY

Experience with efforts to improve environments that surround individuals suggests that positive results can be far from immediate but they do inch forward a step at a time. Work at the Pacific AIDS Resource Centre (PARC) aptly demonstrates this. PARC has an analysis of supportive environments and has tried to create a supportive setting for members, volunteers, staff and clients alike. Nevertheless, there are times when it is difficult to recognize tangible accomplishments as the HIV/AIDS outlook in the community worsens.

Even so, there has been change. A vibrant workforce of staff and volunteers has developed. People living with HIV/AIDS know they have a place to go. If all else fails, they have access to food, shelter and medicine. Many participants have outlived all expectations. Meanwhile, PARC continues to be a beacon of support for sustaining prevention for everyone else who remains uninfected.

One of the clearest ways the strength of community support has been expressed is in the physical environment of the PARC building itself. In the midst of theoretical and practical efforts to approach HIV health promotion from a supportive environment perspective, the centre underwent a stem-to-stern renovation. The architect, an HIV-positive man and an active participant in the Persons With AIDS Society, deftly translated supportive environment into the building's design. That strategy has transformed a "sow's ear" of an old downtown office building into a "silk purse" of an HIV/AIDS agency.

The centre's main floor was made to resemble a street scene instead of an institution. Called PARC Avenue, the street-like setting is home to a library, a grocery, a clothing outlet and a school.

The centre's traditional food bank was reworked into the AIDS Vancouver Grocery, a no-charge food store. Instead of a grab bag, clients now choose their preferred foods from the shelves.

PARC's library fills the main corner of the building. With careful attention to lighting and atmosphere, the library has become an inviting centre for learning and a real symbol of the agency's main purpose.

An upstairs lounge was redesigned and furnished to resemble a café. Called Café Positif, the lounge is more socially supportive than a clinic-style waiting room or a catchall for hand-me-down furnishings.

Attention to the building environment has also ushered the centre through productive new doorways in the health system. For example, the story of PARC's participation in the design and evaluation of an AIDS elective for student nurses at the University of British Columbia is told in the case story that follows this section. An important component in the course is a visit to PARC, providing an opportunity for students to meet people living and working with HIV/AIDS. In this way, PARC and its clients, volunteers and staff have been given an opportunity to influence, to some degree, future health-care environments for HIV/AIDS in the region.

PARC also established a regular venue for HIV-positive gay men and their friends to meet. Called "Living Proof," the group has become a supportive alternative to the stigma and isolation that seropositive men sometimes experience in the larger gay community.

SUPPORTIVE ENVIRONMENT AND PREVENTION

An opinion leader from the gay neighbourhood in the vicinity of PARC, a practising psychologist, once offered an opinion of the influence of the local environment on HIV prevention for young men coming out. "When a young gay man arrives, with great trepidation, at the door of the Gay and Lesbian Centre looking for support and finds himself in a seedy building smelling of pee, he takes that on. He believes this is what his life has come down to and what he deserves. That affects how much drive he has to protect himself in the scene he is coming into."

A frequent response to discussion of the need for an environmental approach to prevention—even within community-based AIDS organizations—is that having an influence at a social level is simply not possible. Such broad-based work, it is argued, will get in the way of more concrete efforts to get people at risk to wear condoms and practice safer sex.

Creating a supportive environment does not, however, suggest taking on society or even an urban community as a whole. It is a slow process of building a supportive infrastructure. The most important element is the network of supportive people. Setting up supportive conditions in immediate situations and circumstances like the local gay neighbourhood, AIDS hospital and HIV test facilities is more realistic and achievable than taking on society. The "ripple" effect will eventually influence the larger community.

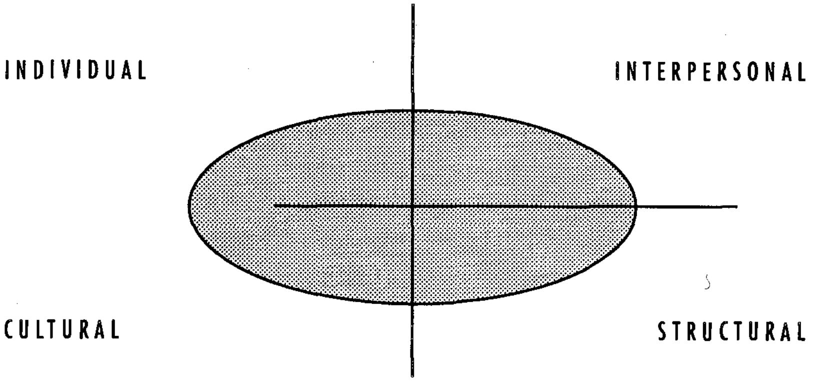
SUPPORTIVE PREVENTION I

HIV health strategy is by no means an escape from behavioural approaches to prevention and risk reduction, such as safer sex, the promotion of condoms and clean needles. Health promotion is an overlay that seeks to influence the methods by which prevention is presented and conducted.

As new generations reach sexual maturity without an immunization program on the horizon, the need to advance environmental approaches to HIV prevention is becoming all the more obvious. Fortunately, the HIV/AIDS research field is broadening to include sociological explanations for vulnerability. The social-environmental understanding of HIV prevention suggests approaches to safer sex and clean needles that show great potential for taking health promotion programming in the direction it needs to go.

As the influence of social environments becomes more prominent in prevention thinking, it makes sense to expand the model of prevention beyond risk behaviour to include the social risks where some of the significant barriers to prevention exist. Addressing each point in the vulnerability analysis guides a more complete analysis of HIV risks and thus the development of supportive prevention strategies.

HIV VULNERABILITIES



INDIVIDUAL Consider the inner mind as influenced by societal realities.

INTERPERSONAL Consider the possibility of dysfunctional social relations influenced by dysfunctional societal environments.

CULTURAL Consider the influence of social bonds, value conflicts, stigma and discrimination toward gender, race and sexual orientation.

STRUCTURAL Consider the influence of money, and the lack of it, and the protection of law or lack of it.

While exploring youth barriers to safer sex through the *Field Guide's* research network, a key social barrier to youth practising safer sex was uncovered. (See the Case Story "*You, Me & Reality*—YouthCo Listens to Youth" in Chapter 3: Study—Listening to HIV Experience with Research Skills.) The varied comfort level that young people feel about frank discussion of sex is actually an impediment to safer sex. For cultural reasons, teens lack confidence in themselves, lack the language to communicate between each other and lack support from the social environment during their sexual awakening. A sex-conflicted society and silence on the issue at home have created a dangerous mix in an HIV-endemic world.

In the video documentary on the subject, *You, Me & Reality*, young people clearly recognized their vulnerability. The youth-produced video emphasized the irony of pushing condom-based risk reduction in an unsupportive social environment: "If we can't talk comfortably with each other about sex, how can we ever get to safer sex?" The underlying question is: Where and how do young people learn to negotiate safer sex if their elders are unprepared? The rates of sexually transmitted diseases and teen pregnancies suggest that society fails to help them with the answer.

The four aspects of the vulnerability analysis bring the social-environmental message home. HIV prevention, to be effective, must now address a wide range of issues that include social realities and barriers such as inhibited talk about sex. For young people, though, it is not only a question of having enough confidence to try condoms but having enough money to afford them. The structural point of the social focus indicates another way in which youth are vulnerable and another issue to be addressed.

Considering all the aspects of the vulnerability analysis keeps all the potential social risks in view. Listening to the people affected and creating an infrastructure to support initiatives to deal with these issues will lead the way to the future of HIV prevention.

SUPPORTIVE PREVENTION II

The lessons that HIV-affected communities are learning about long-term survival suggest that HIV/AIDS programming has an important role to play in the education of people living with HIV and in developing the infrastructure for social support.

Research has shown, for example, that attention to nutrition immediately following an HIV diagnosis can extend life and improve overall health and the length of the symptom-free period. This knowledge has sparked an urgent need to design prevention education for people in the earliest possible stages after infection.

However, many people's lives fall apart after diagnosis. Job loss leads to poverty, which means lack of money for food. Various strategies for building a supportive infrastructure have been tried:

- in Montreal: A collective kitchen where large quantities of food are cooked in an industrial kitchen by the participants themselves, to be divided later and taken home
- in Vancouver: The Grocery, a complete store where all the items are available off the shelves at no charge
- in Vancouver: Loving Spoonful, a meals-on-wheels program for people sick with AIDS

Beyond the concrete approach, two environmental goals for HIV prevention arise:

- Reframe the way in which people living with HIV/AIDS view themselves and their circumstances by enabling supportive social conditions.
- Limit the damaging effects of hostile social conditions by building an infrastructure that supports the health of people living with HIV/AIDS.

Community agencies have already developed some capacities. A social-environmental perspective helps to emphasize the importance of social supports for health and survival. In relations between community AIDS agencies, care facilities and providers, work on supportive networks can play a significant role in the health and quality of life of people living with HIV/AIDS. Collaborating more closely with professional communities is the way to bring health-promoting strategies to their attention.

Employers also need to develop more supportive strategies for HIV/AIDS in the workplace. AIDS Vancouver developed a simple but effective poster to promote the issue in a variety of workplace settings: "We care about AIDS. We care about you." See the Case Story "Breaking into the Corporate Workplace" in Chapter 9: Society—Transformative Groups—Societal Change.

SUPPORTIVE AIDS WORKPLACES

Community AIDS organizations are themselves social environments in which supportive conditions play an important role in the health of their volunteers, employees and the people who seek their assistance.

PARC has established a forum called PARC Rounds to bring forward reflections on working in the local HIV/AIDS environment. The format is a simple discussion circle that chooses a new focus every other week. The stresses of work, ethnocultural relations, gender issues, personal safety and a variety of other matters are discussed. The forum invites and supports honest and uncensored discussion about the work environment and workplace issues. It seems to help. See the Case Story "PARC Rounds: Reflection in Practice" in Chapter 7: Agency—Transformative AIDS Organizations.

CASE STORY Building Networks for Supportive Health-Care Settings

This case story shows how extensively partnership and collaboration can build a supportive infrastructure for HIV health promotion in health-care settings.

Sooner or later, people living with HIV/AIDS are bound to encounter the health-care system, usually in the form of a nurse. Irene Goldstone, Director of Professional Education and Care Evaluation at the British Columbia Centre for Excellence in HIV/AIDS, recognized the importance of that encounter—that it could have a crucial impact on the future health of the AIDS patient. Something had to be done about that: the preparation needed was undergraduate training.

The first point of collaboration was with Anne Wyness, a long-time ally and professor of nursing at the University of British Columbia. That connection cemented a partnership between the UBC School of Nursing and the centre that gave birth to a senior-year elective, HIV/AIDS: The Challenge of Caring.

Anne and Irene knew that nursing students needed more than universal precautions and a clinical explanation of HIV/AIDS to apply health promotion principles to the care and treatment of AIDS patients. The elective's design would have to bring nurses into their own encounter with the depth and complexity of the social issues surrounding HIV/AIDS. One of the clear ways to do that was to have each nursing student get to know someone living with HIV/AIDS. Another was to bring resource persons into the program who had direct experience working with HIV/AIDS.

Working on long, cultivated relationships in the community network, Irene went to the Pacific AIDS Resource Centre for help in developing some crucial elements of the nursing elective. The British Columbia Persons With AIDS Society helped by organizing volunteers to pair up with nursing students for an interview and follow-up visits. Positive Women's Network provided experience on women's symptoms, treatment and care issues. And AIDS Vancouver provided true grit in the form of spokespersons from "Man to Man," the HIV prevention program for gay baths and park scenes and from Project Sustain, the frontline support program for people impoverished by AIDS.

The combined effect of Anne's experience with teaching nurses and Irene's close connection to the community, research and hospital resources developed into an inspired course program. The nursing students would go through several off-campus encounters with the realities of HIV/AIDS. One of the first encounters would be with Jackie Barnett, a seasoned street nurse, whose HIV experience was based on the mean streets of Vancouver's downtown east side. She would set the tone of the course with straight talk on sex, the sex trade scene and sexuality in general.

The course was just getting underway when Anne and Irene realized that they needed to get an evaluation component in place. Again, the community network put them in touch with Terry Trussler, just as the National Health Promotion Project (NHPP) was getting started. One of the goals in the NHPP plan was to explore a partnership venture in health promotion with a professional association. The nursing elective at UBC was a perfect fit for the intent of the project. The NHPP contribution to the nursing AIDS elective would be to set up the research protocol for the course evaluation. So this set in place yet another partnership and collaboration.

The evaluation would be based on the principle of "listening to experience." Two focus groups would be brought together. Discussion would be guided by questions that brought reflection to the experience of the program: what it was like to learn in that way.

The core questions were

- What did you feel most challenged by in your experience with this course?
- Did you experience any surprises or breakthroughs?
- What would you say were your significant learning moments in the course?
- If you were going to teach this course next term, what would you change?
- Do you think this experience will affect the future of your career?

In addition, each student would be called for a telephone interview six months after the course. Terry would moderate and tape the discussion while Anne and Irene acted as listeners or nonparticipant observers. The tapes would be transcribed for later analysis.

The course came to completion and by all accounts had gone well—the first focus group was spellbinding. There was a strained moment of silence at the beginning, as if the students had expected different questions. Then the real story broke open in an unexpected way. The nursing students began to speak not only of their increased knowledge from the course, but of its impact on their lives: the course had been a "life changing experience." It had brought on serious encounters with the attitudes of colleagues, family, friends and dorm mates. Getting to know someone HIV-positive transformed their personal values and beliefs. Being taught by a gay AIDS professional reversed their assumptions about homosexuals. Indeed, the course had been the "best event" in their nursing education.

Several repetitions of the course and evaluations later produced convincing additional data, even accounting for variations in the students' experiences. The collaboration between Anne, Irene and Terry has now moved into reporting the experience to other education programs. This has brought news of the course, the inspired program, the student experience and the evaluation methodology into several professional conferences. That exposure has already had ripple effects. One is the involvement of the nursing AIDS collaboration in a new senior elective on AIDS planned for UBC, combining disciplines of medicine, pharmacy, dentistry, social work and, of course, nursing.

PRACTICAL FIELDWORK The Who and How of Social Development

The partnerships between the community agency, the university and research centre, as well as the professional collaborations, make the story of the nursing AIDS elective a unique example of how HIV health promotion can transform the health-care system by establishing an infrastructure of supportive people. The early contact between nursing students and people living with HIV is the ultimate source of lasting change because the experience itself was so transformative. The system-wide ripple effect of the evaluation adds another layer toward building a more supportive health-care system by peer-to-peer contact in the professions.

Creating a supportive environment for HIV health promotion will call on all your skills, practices and experience working with other people. The demands of breaking through social barriers and individual resistance may well challenge your practical capacities to the limit, but experience has shown that consistent effort builds momentum. Your listening skills and inner practice will tell you where to begin and what you need to accomplish. Following the suggestions below will set up the foundation for a supportive infrastructure to build and grow. From there, you can work with the raw material of the situation as developments unfold.

SOCIAL BUILDING SKILLS

EXISTING STRUCTURES

Most situations where AIDS work needs to be done already have existing groups, agencies and organizations surrounding them. Experience with community health promotion has shown repeatedly that work with existing groups moves the agenda forward faster than setting up new ones. It is easy to see why. The capacity of community AIDS agencies to do basic HIV prevention reaches a limit at some point. If no work is being done to build the capacity of existing organizations to perform this role from within, the pressure on community agencies grows out of control. People's expectations are frustrated. By working with existing organizations, such as women's shelters, schools, corporations and professional groups, you can build the infrastructure to accept responsibility for basic HIV prevention and usually much more.

PREDISPOSED INDIVIDUALS

The key to getting the building process started is to look within settings for individuals who already have responsibility for decisions related to HIV prevention or handling HIV situations. With women's shelters in the case story earlier in this chapter, it was the shelter directors who needed to be consulted first. In the case of the AIDS in the workplace project, reported in the case story in Chapter 9, it was the directors of personnel. While it is true that health promotion is often called a bottom-up process, often the person who opens the way is someone at the top.

FACE-TO-FACE CONTACT

Experience has shown that people change their attitudes and behaviour more easily in face-to-face situations than through media-driven message campaigns. In health promotion thinking, the media are used to set up the right conditions for real work, which is usually face-to-face. When setting up infrastructure, it is useful to know this rule of thumb because it can give you ideas about which way to move as your work develops. With the AIDS in the workplace case story in Chapter 9, the face-to-face idea was to bring a group of personnel directors together for the first time at a business breakfast where they could hear about the corporate HIV experience of a respected business leader.

PEER-TO-PEER EDUCATION

AIDS agencies have long understood the value of peer education. The case story in Chapter 6 shows how opinion leaders among prison inmates were brought into the role of HIV educators. The peer model also works in many other settings where HIV health promotion needs to be done. "Peer-to-peer" applies to provider groups such as nurses, social workers and physicians, as well as to many other groups of people in organizations, community and society.

SOCIAL WAYS AND MEANS

The people who need to be reached by HIV health promotion include those in HIV risk conditions, as well as those who have the power to do something about HIV vulnerabilities, wherever they are. Obviously the field for HIV health promotion is more extensive than basic HIV prevention because it includes advocacy in government, institutions and industry. While AIDS stigma, sexism and homophobia continue to present barriers, HIV health promotion has already built a considerable infrastructure of support. Many would say, however, that the work has only just begun and there are justifiable worries about how to sustain it.

PARTNERSHIPS

The idea of partnership is borrowed from business but easily applies to setting up infrastructure for health promotion. Partnerships draw together skills and resources that would not be otherwise available. The drawing card for the creation of a partnership is that both parties gain from the engagement, though perhaps in slightly different ways. Partnerships have been useful in relations between community AIDS agencies and government, research institutes and business.

SPONSORS

Sponsorship is a form of advertising that allows corporations and other businesses to attach their names to products for a fee. Sponsors have a similar role in fundraising for community AIDS work, but they have the added value of contributing to supportive infrastructure. The public display of an array of corporate logos attached to advertising for various community HIV initiatives plays a symbolic but important role in communicating that a supportive environment is developing.

COLLABORATIONS

Where partnerships bring together agencies and organizations, collaborations involve people more directly in working together. In the complicated world of HIV/AIDS, collaborations are needed to bring people with different skills together to work on issues too complex for one person working alone. Collaborations have been useful in HIV/AIDS research, bringing together scientists, epidemiologists and community leaders on issues that would have been otherwise unrecognized.

OPINION LEADERS

The use of opinion leaders to build support is borrowed from politics. Early prevention initiatives sought out and used the most popular men in the bars to do safer sex education. Similarly, people who have influence in a neighbourhood or community could be very useful in developing a supportive infrastructure for HIV health promotion. Often these people are already on boards of various groups or they may be regular faces in the community press.

POLITICAL LEADERS

Cultivating political support has always been an important feature of the HIV/AIDS drama. Yet, in spite of all indications that the epidemic is increasing, political positions appear to have hardened against it. Although, "in your face" activism may be necessary at times to move the political agenda, eventually the real work will require a more direct and collaborative approach.

BUSINESS LEADERS

Experience from the AIDS in the workplace project case story in Chapter 9 has shown that business leaders are a needed element in the infrastructure for HIV health promotion. For one thing, the workplace continues to be the most accessible way to reach mainstream society for HIV prevention. Experience with that suggests that tackling HIV/AIDS fear, sexism and homophobia is a necessity. Business leaders who have witnessed how HIV/AIDS can shatter productivity at the office are most predisposed and ready to work with peers. The appearance of major banks and corporations in the infrastructure is more than a symbol of support.

SUPPORTIVE FRAMEWORKS

POLICY

Unintended discriminatory effects of policies can often lead to devastating consequences for people living with HIV/AIDS. The introduction of a three-month residency requirement for social assistance in British Columbia, for instance, had a direct impact on service demands at the largest AIDS agency in the province, AIDS Vancouver. Supportive policy has long been regarded as one of the main tracks of the HIV/AIDS effort worldwide, yet the advocacy work is far from over.

Building a supportive environment for HIV health promotion requires a legal framework based on human rights principles and community initiative to make changes where necessary. Community AIDS agencies are well positioned to keep vigilant over policies that do more harm than good. Attention is required not only to the policies of government but to institutional policies as well.

GOVERNANCE

As the community AIDS infrastructure in Canada has grown, governance has become increasingly complicated by issues of representation along gender, HIV status, racial and regional lines. Even so, setting up and adjusting the way in which community agencies organize themselves is a critical layer of work on the infrastructure for HIV health promotion. As one community worker put it, "If AIDS agencies can't set up supportive structures, how can we expect other organizations to do it?"

RESOURCES

Building a supportive infrastructure for HIV health promotion requires both human and financial resources—if you can't fund it you can't do it. Seasoned fund developers recognize that funding is built on good relationships. In effect, fund development and health promotion are the same thing. Building a supportive infrastructure for HIV health promotion is also the foundation for sponsorships, endorsements and donations.

SUPPORTIVE ACTION

STRATEGY

The emphasis on strategy in the transformational health model comes from hard-won experience doing HIV health promotion in the field. In the art of war, strategy imposes the time, place and conditions of combat on the enemy. Where HIV/AIDS is the only real enemy, strategy is about setting a supportive infrastructure in place by defining the time, place and conditions in such a way that people will be eager to participate. Strategy is a product of good listening.

In the AIDS in the workplace case story in Chapter 9, the working strategy was defined in advance: to reach the people closest to making decisions about employees with HIV and bring them together, face-to-face, over breakfast. Carrying out all the parts of the strategy created lots of work, but the momentum from the breakfast eventually built to a provincial and then national business and labour coalition on HIV/AIDS.

PROJECTS

In many ways, the HIV situation is so large and complicated that it would be completely overwhelming if it were not for the small and discrete pieces of work people are doing to chip away at the problem. Setting up projects with realistic, achievable objectives and an end in sight is one way to gain commitment from people. When people can see that their efforts will have a desirable outcome by a certain date, they are more willing to put forth the effort required to get the work done. In a world full of competition for time, well-defined projects are necessary devices for getting things done.

PROCESS

In the lead case story of this chapter, the narrator reflects on work that clients at the women's shelters did to create prevention material closer to their own experience. In the end, she realizes that the true worth of the effort was not the products themselves but the process the people went through in creating them. The observation is true in much of health promotion work, especially where the effects are sometimes not measurable. By listening, practising and supporting people through their own processes of discovery, the aim of creating a supportive infrastructure for HIV health is achieved.

PART THREE

PRACTICE

Practice in health promotion is all about personal and professional conduct. Health promotion begins within yourself with self-empowerment, increasing control of conditions affecting your own health. Practising health promotion, however, is fundamentally interpersonal: taking care of others by enabling their health. As an organizational practice, health promotion can increase the capacity of community-based AIDS agencies to manage local HIV conditions by emphasizing strong method and "best practice." In the same way, health promotion can help communities overcome HIV vulnerabilities by opening up ways to improve the social and physical environment. Ultimately, health promotion encourages societal change by the force of a many-layered mix of people working to alter the root social conditions underlying HIV vulnerabilities—issues such as heterosexism, discrimination and poverty. In recognizing the health impact of social and cultural conditions, it is useful to match various ways of doing health promotion to a practice environment: interpersonal, organizational, community or societal. You can confidently handle any HIV health initiative by working through study-plan-do and best practice for the environment. ■

CHAPTER 6

INTERPERSONAL

inner practice—personal transformation

The focus of this chapter and those that follow is on applying the transformational health model to the practice environments typically encountered in community AIDS work. The model represents these as nested spheres symbolizing their interconnected impact on health.

The first and primary practice environment is interpersonal—between people. Supportive practice is everything in taking care of each other. Nowhere is this truer than in face-to-face encounters with other people—clients, colleagues, volunteers, community participants.

The reality is that interpersonal transformations can only take effect when they begin from within the individual. Inner practice is, therefore, the foundation for applying transformational health to every practice environment. In this way, taking care of each other is as much a personal path of transformation as it is a social one.

This chapter describes several practices of health promotion that are essential in using the transformational health model in any environment. These practices provide the reality and the ground of your work with the people you encounter in any setting. Because much of your work as an agent of transformation depends on relationships, the practices described here will help to keep you on track and focused in the most productive way for the health of the situation.

The **Case Story** in this chapter is about developing an HIV prevention and harm reduction program in prison. The success of this venture truly depended on a keen sense of interpersonal practice.

Reflections describes several features of health promotion and social learning practices essential to transformational health.

In **Practical Fieldwork**, the focus is on journals, diaries and case notes as sources of data from the field and personal transformation.

CASE STORY Transformations in Prison HIV Strategy

Gregg Brown has been involved in prison outreach with AIDS Vancouver for two years. His story is about creating a supportive environment for HIV health in an unlikely place. His social analysis, stance and attitude in circumstances where society cares least suggests that HIV health strategy can work anywhere.

INTERVIEWER (INT): *To begin with, tell me what the situation was. What motivated you to get going and how did you break in?*

GREGG BROWN (GB): I read an article in *Angles* newspaper about an inmate who was serving a life sentence in one of the local federal institutions. He was trying to promote education around HIV and AIDS to other inmates, and was having a very difficult time doing this.

There didn't seem to be anybody actively working with the correctional system to give inmates access to HIV education and support as we have on the outside. My basic philosophy is that inmates are people, regardless of the crimes they've committed. They have the right to the same health care and support services and access to appropriate education to keep themselves from getting a terminal illness.

I found that life expectancy was a lot less for inmates because they don't have the same access to nutrition and support groups and peer support as we do on the outside. So this was my motivation going into it.

I initially started doing some very generic "AIDS 101" workshops that weren't really geared toward inmates—or in any way toward correctional facilities. They didn't work very effectively.

So I had to really look at how we could educate inmates most effectively. Talk to them at their own level, using language they understand. Don't come from a clinical health-care model or from within the correctional system because they won't listen to people from the correctional system. I looked at the best size of group and, because of the "con code" in the jails, at the best way to make safe environments for asking questions.

We had to do a very primitive needs assessment when it came to actually trying out different types of workshops and educational models to find out which ones worked the best.

INT: *How did you do the needs assessment?*
GB: I went around to a number of different jails and talked to inmates who were infected with HIV or who'd been affected by it, who'd had friends die of it, or who'd maybe just come in off the street and been around the downtown east side to use the needle exchange program. I also talked to health-care professionals in the jails, assessing what their actual knowledge base of HIV and AIDS was, and talked to the security staff.

INT: *What did you find?*
GB: Well, I found that within the correctional system, as on the outside, many health-care professionals have little knowledge of HIV and AIDS. They had little knowledge of the psycho-social issues, the economic issues and the support services people need.

The inmates tended to have a better education because of their street knowledge. It's not a good idea to share needles. The general consensus was they wanted to isolate those who had HIV, to put them into segregation. They used to post names up on the walls in the jails of people who were HIV-positive.

INT: *Are the people that you're meeting getting infected in prison or have they been infected before incarceration?*
GB: Within the provincial jail system, because there's a high turnover—two years less a day is the maximum sentence, and many sentences are three months, 30 days and so on—the infection is probably occurring on the outside and coming in. Within the federal system—because sentences are two years and over—we are finding that the majority of HIV infection is happening within the jails.

INT: *By what means do you suspect that they're getting infected in the federal prisons?*
GB: Sharing needles. In one of the institutions I work with, a population of 450 inmates probably has six rigs going around. From what we know from talking to the inmates, 60% to 70% are injection drug users or will inject at one time or another while they're in jail. So it vibrates through that population. Bleach has just recently been allowed into the federal system by the Solicitor General, so we're working on a project right now to have it available in all the federal facilities. But up until a month ago, you

had to steal bleach from the laundry or from the kitchen, so people did not have access to it.

INT: *What was your contact with prison officials like?*
GB: It's been very positive, because I haven't gone in from an activist point of view. I've gone in more from an education point of view, looking at it from the perspective of helping both the inmates and the institution, not just helping the inmates.

One thing I've learned from the system is that there is a real intermingling of societies: you've got the cons at one end and the security at the other end, and there's a real barrier down the middle. The cons don't like to listen to the jail people, and the jail people don't like to listen to the cons, so they needed to be shown what the benefits would be for everyone.

I was able to work with the jails and get them to realize the more people they have with HIV infection, the more stress it's going to be on the staff. It was the same working with the cons. They're very bonded in the sense that they don't want their "brothers" to catch it as well. So I was really working with both, not just the inmates.

INT: *So after the assessment, what did you do?*
GB: After trying different types of workshops, we went for a more structured approach. There was a group out at Matsqui penitentiary called Prisoners of HIV, which is a group of concerned inmates. I started attending their meetings on a regular basis to try to talk one-on-one and develop some trust so I could hear the real dirt.

Going into an institution as a stranger, an outsider, you're not going to hear anything. They don't trust you; they don't trust anybody. So you have to develop trust, and that took three to four months. Once I'd really got the inside track as to what was going on, it was easier to find out where in the institution we needed to educate. At Matsqui, we initially worked with the pre-release program, which is a series of programs for inmates who are about to be released into society. We started doing small workshops combined with presentations.

The language was street level, with no clinical terms whatsoever. We focused on how to clean needles and how to use bleach correctly; the institution never taught this because they don't acknowledge that there is drug use. In fact, there are better drugs in jail than on the street.

The workshops worked really well. After doing them for a couple of months, I trained a couple of the inmates to do the induction program, because I realized I just couldn't keep going out there six times a month. And the inmates will listen to other inmates. They'll listen to me before they'll listen to Correctional Services, but they'll listen to another inmate before they'll listen to me.

The inmates I trained are working really well. There are two inmates, with one staff member, who actually do the induction program. It's geared to those who are coming into the institution: you're not going to have access to bleach (until a month ago), so this is what you need to do to clean your needle. If you have to use a can of Coke to rinse out the blood, it's not going to kill the HIV, but at least it will get rid of whatever blood's in there—this sort of thing. Again, we gear it towards how to live without catching HIV in jail and, if you are HIV-positive, what you need to do to avoid transmitting it to anyone else.

INT: *Some people have been calling your approach "harm reduction"—do the best that you can to manage the situation.*
GB: And in jail you have to, because you don't have access to bleach and if you're not allowed to shoot up, you're not going to use bleach and water three times, 30 seconds apart, with a guard breathing down your neck—it's just not going to happen. You're probably going to flush water and flush beach once really quickly and shoot it out, which is better than nothing. So we really do talk about harm reduction. It's very difficult in jail to eliminate or minimize the risk.

INT: *What did you learn about prison culture from the people you were in contact with?*
GB: The culture's so divided—it's very much the "con code," and then there's the ethics of the security people, and the ethics of the frontline staff who are nonsecurity, such as the hobby workers. The staff are much more likely to listen to one of their own talk about HIV and AIDS. They'll listen to me or to a nurse, but they're certainly not going to listen to anybody off the street: they don't trust them.

The biggest priority in doing work in the jail system is developing trust between the community organization and the jail, because they are doing the best they can within the confines that they're given. So you work at changing those confines and those policies.

They also want to know that you're not going to bring needles in for the inmates. I'd love to bring in clean needles for every inmate who uses, but I can't. I'd risk my security clearance, I would be barred from jails and any work that I could do wouldn't go on. I've learned about the divisiveness between staff and inmates. You have to almost sell the program to the security people and the inmates.

The guards and security people and staff are really concerned about fights and blood spills, and what to do if somebody who's HIV-positive threatens them: he's going to bite or he has a rig filled with blood. Whereas the inmates are really concerned about sharing needles if this guy's HIV-positive.

INT: *You skipped really lightly over the "train the trainers" work. What went on there?*
GB: It was a difficult process. It really began with identifying a couple of the inmates who had some pull with the other inmates. There's a real hierarchy with the cons themselves—there are "heavies" and "wimps"—and we needed some guys who were well respected, who weren't stoolies and who weren't going to rat on the guys using drugs. They needed to be really trusted within the prison system.

INT: *So the prison staff were aware that you were trying to find these cons? They were in on this?*
GB: We had their support to do it. We got three inmates who were entrusted to do workshops. They watched me do a couple with other inmates in the pre-release program. They helped me out and then we did a "train the trainer" workshop with other inmates who'd already taken the HIV training and knew what was going on. They were able to ask questions to find out what the trainers' knowledge level was.

We really focused on injection drug use and didn't talk about anal sex between men. In jail, there are guys who are jailhouse gay, but they don't identify as gay. Condoms are available in both federal and provincial institutions, but in some institutions you have to go to health care and say, "Can I have a condom, please?"

Other institutions have them in the living units where they are accessible, and still other health-care units have them where you can just walk in and grab some out of a bowl. The problem with the condoms, though, is they can be used for suitcasing drugs around the jail, which spreads hepatitis B and C. So they're afraid to use condoms or go to health care and get some because security might see them grab condoms and assume they're getting it to suitcase drugs. There are so many things they have to watch out for. But during the workshops we do talk about condom use.

INT: *Are you still doing workshops?*
GB: In the federal system, a lot of the programs are set up and running. Right now we're attempting to provide some form of support. On AIDS awareness days, we'll maybe do a short presentation to 150 people and have volunteers go around and chat individually with family members. We've been doing workshops in the actual living units because that's the safest environment for people who are there for the short term.

INT: *What do you think gets them into the workshop?*
GB: Sometimes it's mandatory, depending on the institution. I prefer that they're not, because usually mental blocks go up as soon as they're forced to go. People usually come because they're interested. They don't want to give it to their girlfriends or their wives and children. In a federal jail setting, they're really concerned about themselves and their fellow inmates; they don't want to pass it around among themselves.

INT: *You started out with the concept that these are people too, and they need education. But what do you feel about these people?*
GB: I don't know a lot about what their crimes are; it's not very good policy to ask, so I don't. I've developed a relationship with some over the years, and I know what their crimes are. One of the inmates I work closely with is doing a life sentence for murder. It really comes down to a humanitarian thing for me.

INT: *It speaks to human rights, too. There are certain inviolable principles that influence how we treat people, no matter what the situation. Here's a situation where we have people who are vulnerable but they still have rights.*
GB: I think that's really important because inmates within the jail setting are numbered, coded and not necessarily treated with the same courtesy and dignity that we're used to on the outside. Part of rehabilitation, as far as I'm concerned—and this ties into health issues and self-esteem—is that the inmates are feeling lousy about who they are. They don't give a shit if they use a clean rig or not.

But if they're greeted with a handshake and made to feel like a decent person, they are more likely to care about their own life, and in turn, are more likely to care about society. They may reoffend and they may not, but—and this is where we come in—hopefully they will not spread HIV to someone else or catch it themselves. It's been said that a society is measured on how it treats its offenders and criminals, and it's really true. How do we treat our people? Are we enabling them to get better? Do we care?

INT: *I've heard other people talk about nothing but barriers in this sort of work. You've certainly met barriers, but you've also overcome them. What do you think happened? Is it professionalism?*
GB: I think it's professionalism, and I think it's not taking a visibly activist approach. I think there's a need for activists, but I also think that, certainly within the jail setting, you have to be very careful. You have to walk a political line, and the biggest thing I've learned is how to walk that line and respect the different dynamics between different levels of the institutions, whether it's at the inmate level or the staff level.

You have to walk that line without treading on any toes and know how to push to get what you want. You can't go in with big placards, attracting lots of negative media attention, and expect to get anywhere.

We've been able to go really subtly through the system, get things done and then advertise what we've done so it's positive for both inmates and institutions. If I write letters to the press saying we need needle exchanges and they're not giving them to us and they're terrible people, I won't get anywhere; I'll just alienate people. The needle exchange is very valuable for an institution because it helps reduce the rate of HIV infection. This costs the taxpayers less money, and inmates are happier.

INT: *Is it necessary to find people predisposed to what you want to do?*
GB: Absolutely. You need to find people who are predisposed to help you. At each institution I go into there's one staff member—it could be a security person, a health-care person or a case management officer—who I can liaise with. They can tell me that the warden's in a good mood and now's the time to talk to him about doing that big AIDS information workshop. Or that it wouldn't be a good idea to talk to him on this date, because that inmate's been put into segregation for using drugs. You need that inside person.

INT: *It strikes me that the institutions are learning as well. Have they themselves suggested that they've seen something happen because of your work?*
GB: Absolutely. One reason we feel that Matsqui was chosen for the bleach pilot project was that the HIV education level the staff and the inmates achieved is so high compared to other institutions. At Fraser, a lot of HIV tests are requested after we go in and do a workshop. Matsqui is the same; the inmate group there is active in advocating HIV testing. Inmates can go and ask questions of other inmates about HIV and AIDS. It's that *trust level* again; they'll listen to peers.

INT: *We've been talking about preventing infection, but what about another kind of prevention—after they're released—what have you been doing around that?*
GB: The biggest component of my prison outreach over the last six months has been making support services more accessible to [former inmates] on release.

We look at education and support on a continuum. I don't go in and start support groups, but I give them the information to do that. I usually bring application forms from PWA [Persons With AIDS] and support services, and maybe some housing subsidy information and have them fill out the forms if they need them. I try to arrange for PWA peer counselors to come in if they need to talk to a peer counselor.

I look at it from a support perspective: get people hooked up to services. I talk to the intake workers at AIDS Vancouver because people getting out of jail are often dealing with very different needs than people who are walking in off the street. They may have been incarcerated for five years and have no idea where the welfare office is in their area. So we really look at it on the basis of practical support and access to peer support if they need it.

INT: *What would you say was the major contribution to the success of this project?*
GB: The ability to talk to the inmates on their own level and to gain their trust and be human. I'd say that's been the biggest success.

INT: *One of the things that I've been more worried about with a lot that has been done in the name of community AIDS work all over the country is that people have not taken the time to absorb the situation. They've gone in, they* *want to do the pat thing, and when it doesn't work they recoil from it and say, "Oh God, there's a wall of denial there."*

GB: Absolutely. My biggest concern with community AIDS work, from talking to people in different parts of the country who do prison work and other types of AIDS work, is that there are people developing policies on a national or community level who are directing programs and developing different types of support or education initiatives who have no idea who they're providing the service for.

They have no idea what it's like to be in jail. I need to be out there doing community service work around people with HIV, so I don't forget why I'm here. This is my biggest concern: people who are not doing the groundwork or working with the people they're providing service for. Things change so quickly in AIDS work, and you have to be on top of it.

INT: *Any final things to say?*

GB: Well, something that's been really important for my professional development is the presence of community AIDS groups at conferences, to be part of working groups, committees, networks, and so on.

Whether it's attending a Canadian Nursing and AIDS Care Conference, going to the BC AIDS Conference or working with a steering committee, it's invaluable for my own professional development and invaluable to the work that I do. I'm able to take what I learn and bring it back to the steering committee level or workshop level. I really find that this is where I get my support. Developing this dialogue creates support, but it's also networking with other people who do your work, who know what your gripes are and what your successes are. I think that's really important.

REFLECTIONS Reflection, Learning and Cultural Competence

The successful penetration of an otherwise-hostile environment recounted in the story of prison outreach depended entirely on tact and excellent interpersonal skills. Real cultural competence was required to establish credibility on both sides of the prison security line. But the lasting value of all that work was in enabling the inmates to carry on the HIV intervention themselves. That required trust and a clear recognition that their empowerment was ultimately necessary for HIV health in the circumstances.

The inner experience of practising health promotion needs specific attention in the *Field Guide* because there is more at stake than applying a few skills and techniques. As suggested earlier, the way you think about health has an impact on what you do and the outcomes you can expect from AIDS work. In the same way, your personal stance and conduct play critical roles in the success of your AIDS work—at every turn.

This chapter addresses a few of the key terms that have come to be associated with the practice of health promotion. The ideas are by no means free of controversy. But as you will see, the force of these ideas is in the guidance they can give as you come face-to-face with the challenges of day-to-day experience in AIDS work.

The following concepts are explored in this section:
- reflection
- empathy
- enablement
- empowerment
- stance
- supportiveness
- learning
- group work
- cultural competence

REFLECTION

The practice of health promotion has been described as a continuous process of moving between action and reflection. Reflection is the mental activity of going back over experience to recover thoughts and feelings, particularly after a difficult encounter or even an unexpected breakthrough. By taking time to look back at your own actions, you often come to new interpretations and realizations. This, in essence, is learning from everyday experience.

Opportunities for reflection are a built-in feature of the transformational health model. Gathering material from discussions, interviews and focus groups, for example, helps to establish not only where other people are but where you are at the same time. By listening to your own voice in a taped interview, for example, you often think of better questions to ask. You can use your reflections in subsequent interviews to improve the quality of the discussion. Often the result is that you get better material from other people because you made improvements in yourself.

Similar experiences occur in many day-to-day aspects of community AIDS work, such as outreach in distressed neighbourhoods, demanding intake situations, counseling of angry clients, handling of manipulative news media and troublesome advocacy with by-the-book bureaucrats. The challenge of difficult experiences is that they demand the peak of your abilities. When you reflect on the experience, you may not like everything that happened, but you have the opportunity to approach things in a new way on another occasion. If you provide yourself with too few occasions to reflect, you are in danger of constantly repeating your weakest or least effective strategies.

While the *Field Guide* was developing, people working in the agencies at the Pacific AIDS Resource Centre (PARC) were invited to participate in an experimental forum called PARC Rounds. The main point of the rounds was to bring reflection into the life of the whole agency as a group process rather than just a personal one. It took time for people to get used to the idea of bringing their real thoughts and feelings into a public discussion. Once the process got started, however, people actually began to look forward to the occasions and to demand more from them.

Another place where reflection plays an important role in agency life is in strategic planning. The process of pulling together a full year's worth of data from programs forces critical reflection on the state of the agency's capacity to manage the HIV situation. Often these reflections are the source of important insights about what to do and where to go next with health promotion strategies.

EMPATHY

Empathy is the experience of seeing the world from the perspective of others. Of course, it is impossible to truly know another person's experience. Yet, the source of much of the world's insensitivity is the failure to even try.

Day-to-day life in AIDS work often calls for empathy. The many and varied positions that people come from are often difficult to cope with all at once, especially when they may be in conflict with your own. Empathy helps you to listen and learn more about what others may be experiencing, without introducing your own views. You end up knowing more about "where people are" without prejudging them. That provides better opportunities to do the right thing at the right time.

ENABLEMENT

Enablement is one of key guiding ideas of health promotion practice highlighted in the Ottawa Charter for Health Promotion. (See Chapter 1: Health Promotion and the Language of Practice for more information on the Ottawa Charter.) The idea is crucial because "enabling people to increase control over and to improve their health" is far-from-usual practice in most health settings. It is much more common in our culture to defer to the authority of professionals to make decisions about health, including everything from medications to exercise and diet. Also, many professionals would rather resort to the safe and expected than take the time to enable the patient to take control of his or her own health.

In community AIDS practice, "enabling" means relinquishing the impulse to use power and authority to be in control. It is especially relevant in working with people living with HIV. Enablement allows their voices to be heard. Some of this involves careful listening. Even more, enabling is about encouraging people to make decisions for themselves in circumstances where they may feel the virus has ripped control away from them.

Many community AIDS work situations call for an enabling approach to stimulate health-enhancing community participation. Treatment information programs, for example, provide one important means by which people living with HIV may increase control over their own health: they learn how to delve into the background literature on medications prescribed by their doctors. Some have come to be greater authorities on the current medications than their own physicians are.

Enablement may well be easiest to master as a form of encouragement. Many people are so used to power and authority hanging over them that they have little experience with taking things on for themselves or even as part of a team. On the other hand, other people are so habituated to power over others that wielding it is the only way they know. This can be a source of great conflict in an AIDS agency environment where people living with HIV are demanding control. The results can threaten the capacity of an agency to reach the people who need to be reached. The answer seems to be for practitioners to step aside at such moments to encourage the energy of other participants to come forward.

EMPOWERMENT

Often, an HIV diagnosis shatters people's feelings of confidence to manage their health. This is why the experience of personal control is so central to health promotion. There is good research evidence to show that self-confidence is an important factor in recovering health. Another line of research has shown that people who experience power in their social circumstances enjoy greater health.

Empowerment is the enabling experience felt from within. To feel empowered develops from inner security or a sense of self-confidence. It is not really possible to empower someone else. All AIDS workers practising health promotion must themselves feel empowered if they are to get results with others.

From a practice point of view, the empowerment of individuals, groups and communities is a desired health goal. But the form empowerment takes can be a little unpredictable. It can, in fact, be a test: to encourage empowerment but to allow it to take unexpected forms without interference.

STANCE

Suspending judgment, avoiding knee-jerk reactions, being receptive to new experience—all are part of the detached stance required to practice health promotion effectively in AIDS work. Describing how to achieve such a stance is a little difficult because this stance requires an unusual separation of the self from ordinary, everyday circumstances.

One of the case stories in the *Field Guide* tells how a group of HIV outreach workers came to a realization about their stance in the field. Through experience, they discovered that to interact with men who have sex with men in public environments, they would need to suspend many of the frames of reference they understood to be common among gay men. (See the Case Story "MSM Outreach in Ottawa" in Chapter 8: Community—Transforming the Social Environment for Community Health.)

Effectively, this meant dropping gay symbols from their clothes and suspending personal negative attitudes about the sex practices of the men they encountered. They came to understand that a consciously open stance was necessary in order to engage this vulnerable group. The nonjudgmental stance the outreach workers adopted was repeatedly confirmed by their success at communicating with the people they needed to reach in the field.

SUPPORTIVENESS

Beyond achieving a detached stance, there is another equally important practice in health promotion. While it is not always possible to be completely clear of human faults, the AIDS worker needs to adopt a supportive posture. In other words, you need to overcome the desire to withdraw supportiveness when participants in the community are angry, acting on the offensive or appearing to attack you.

By continuing to be supportive in such circumstances, you are more likely to learn what is behind the surface gestures of those who are angry. When you act defensively or use the "grapevine" to vent your difficulties with individuals, you only worsen the situation. It may help to know that anger is often a signal that empowerment is about to occur. People often use the energy of their anger to rise to the occasion that, in the end, increases their control over the factors affecting their health.

LEARNING

Transformation is just another way of describing the process of learning from everyday life experience. Recovering health provides the motivation for individuals, targeted groups and communities to try different attitudes and approaches to living. This kind of learning can be far more important than learning that results from traditional education in an AIDS service environment.

The *Field Guide* emphasizes continuous listening and analysis of vulnerable social environments, which are central to the kind of learning processes that allow communities to improve control of their health. These processes affect individuals, groups and whole communities, often taking on a life of their own.

Thus, it is equally possible to think of your field experience having a transformative affect on you, as much as on the others you work with. You are in the flow as much as you are stimulating it for the others you work with. The learning stance allows you to fulfill your true potential.

Many people who have retired from AIDS work have spoken about the effect that the experience had on all aspects of their lives, and how this was a source of both intense wonder and fear. Virtually everyone recognizes that in spite of the intensity and overwhelming nature of the experience, AIDS work is a great source of personal growth. These observations only serve to underline the transformational effects of taking care of each other.

GROUP WORK

While references to community seem central to health promotion, experience has shown that small groups are the real practice setting. Both outreach and intake usually focus on individual encounters, but the small group is actually where social development begins. The formation of a group—the human bonding, the sense of identity that develops—is, for many, their first experience of community.

Obviously, facilitating small groups is an essential component of practising health promotion, from mobilizing volunteers to providing support to conducting research. Facilitation styles range from nondirective to highly interventionist. Experience has shown that the facilitation style that enables people to increase control over their health tends toward the nondirective. Enabling means doing more listening than pressing your own agenda forward.

While the level of intervention most often depends on the composition of the group and the personalities, experience and vulnerabilities of the members, people are most responsive when the framework is open to any contribution the group members wish to make. And while the discussion may seem chaotic at times, *openness* is what makes the experience interesting and exciting to the participants.

CULTURAL COMPETENCE

The impact of the social environment on HIV health raises important questions about the role of culture and cultural difference in health promotion. Getting to know people as individuals is certainly a valuable approach, but it serves no one to pretend that culture is insignificant. To proceed by ignoring cultural difference only invites feelings of frustration. Many of the suggestions in this chapter are helpful in cross-cultural relations; however, there are deeper issues to consider.

Culture describes shared beliefs, values and ways of being that saturate everyday experience. From this perspective, culture may refer to the living patterns and characteristics of an ethnic group, members of a religion, an area of a city, a corporation, a political party or, as the case story in this chapter shows, a prison community. Cultural differences of all kinds can set up communication barriers, discrimination and conflict that greatly affect HIV health promotion efforts. For example, we have learned from Asian men that their social status in their culture places them at risk in sexual situations by making it difficult for them to carry through on their intentions for safer sex. Learning to recognize the role of culture in social relations is therefore an important feature of inner practice.

Cultural competence is about bridging cultural difference—allowing people to communicate respectfully and productively. Beyond a simple willingness to know other cultures, however, cultural competence requires a realistic appreciation of the influence of your own value system. Culture affects your perceptions, your responses and, therefore, all the ways you relate socially.

Cultural competence grows with awareness, respect for diversity and experience. It helps to know more about the cultural values of the people you are working with, which comes from developing personal alliances. A well-facilitated workshop can also provide a safe and enlightening way to discover cultural assumptions that may otherwise go unrecognized. Showing that you are there to learn can create a more open environment that encourages others to participate. When you allow yourself to learn from, rather than influence, other people, barriers can drop and authentic human relations can begin.

PRACTICAL FIELDWORK Keeping on Track with a Journal

Keeping a journal or diary is a useful method of inner development, not only for health promotion but for life in general. In the study-plan-do process, however, a journal is particularly useful for keeping field notes to document listening of various kinds—including participant observation, conversations, meetings and interviews.

Journal-keeping is open to many different forms of writing and ways of keeping notes together. Here are a few pointers.

WHAT TO WRITE

There may be times that you want to write as if you were writing a letter—to express your innermost thoughts. But this way of keeping a journal could get in your way because of the effort and time required to record your reflections regularly. More often a few quick notes jotted down to express some key thoughts or moments of insight are all that is necessary. You may wish to write down the flow of events or important bits of conversation in a meeting. You might include the content of significant dreams. The important thing is to leave traces of the day in a record so that you can look back from time to time.

WHAT TO WRITE IN

Some people like loose-leaf binders and others prefer hardbound notebooks. The advantage of a small notebook is that you can take it into the field everywhere you go. Notebook computers are portable, but they can be obtrusive in a meeting or in the field. Computers have the advantage, however, of allowing you to work with the text easily.

WHEN TO LOOK BACK

Simply writing things down in a journal has almost magical effects in the workings of inner consciousness, but there may be times when you need to look back over your writing to see where you've been. You can use your journal to do a theme analysis as described in Chapter 3 in Practical Fieldwork. Think of your journal as a source of data.

CHAPTER 7

AGENCY

transformative AIDS organizations

During the development of the *Field Guide*, many participants pointed out that the working environment of community AIDS agencies would benefit from health promotion practice. A distinct feeling existed that so much passionate work went into the community that little energy was left for the agency. This was recognized as a potential health risk for depression and burnout in agency staff. A serious question arose: if we can't build a supportive environment within the agency, then what are we doing in the community?

The focus of this chapter is on applying study-plan-do within AIDS agencies as a process of organizational change and development. It is certainly worth considering whether the practices promoted by an agency are its actual practice. Another vital question comes to mind: How do we know we aren't creating or perpetuating the risk conditions we are trying to avoid?

Certainly, such questions about the working environment of AIDS agencies have arisen from experience around the seroconversion of community AIDS workers. When a knowledgeable and self-confident community AIDS worker gets infected with HIV, friends and colleagues begin to wonder about their own vulnerability. Is HIV prevention purely a matter of personal responsibility or does the environment play a role?

HIV is an infectious agent and prevention only reduces the risk. The risk from the environment is in the way the environment sets up individual behaviour. In the AIDS agency workplace, where disability, illness, poverty and death are commonplace, stress is a fact of life. The effects of this kind of stress on intimate behaviour vary. Unquestionably, the health of community AIDS workers is a constant issue. HIV infection is only one of the risks.

The **Case Story** in this chapter tells about a project that was implemented during the production of the *Field Guide* to encourage reflection on the state of AIDS work and the practice of health promotion.

Reflections presents some additional ideas about the inner life of an AIDS agency.

Practical Fieldwork focuses on practical ways for people in AIDS work to bring group reflection and other opportunities for self-development into the experience.

CASE STORY PARC Rounds: Reflection in Practice

Although people in AIDS work often talk about the experience, the content is rarely about theory, method and practice. This is a dialogue between Terry Trussler, research consultant and project leader, and Rodney Kort, project co-ordinator, reflecting on an experiment to introduce such a discussion into the everyday life of the three AIDS agencies that comprise the Pacific AIDS Resource Centre (PARC): AIDS Vancouver, the British Columbia Persons With AIDS Society, and the Positive Women's Network.

TERRY TRUSSLER (TT): *When we designed the project, a number of things were tossed around before getting going. We knew there had to be some kind of attention paid to practice issues—not simply based on what was happening day-to-day, but underlying principles about how to operate. That area had just not been in the discussion. We looked at various ways we might have some kind of discussion circle in which we would raise issues, one at a time, and bring some reflection into the experience of AIDS work.*

Video seemed to be the way to go. There was a strong call, at that time, to video just about everything we were doing so we could go back to it. We were thinking about how to obtain data from the real life of the agency as it was happening. Video has a lot of inherent problems, though. You simply can't videotape everything. You'd have mountains of tape—very difficult to process.

One of the first things that you had to do was look at how to implement this idea. So what did you face?

RODNEY KORT (RK): Co-ordinating PARC Rounds was one of the most challenging aspects of my job. I thought it was a really interesting way to go about getting information and reflecting it back to the participants. Of course, implementing it turned out to be a lot more challenging than I had anticipated.

Some students from the film school were interested in the project and really enthusiastic. I managed to get equipment that was fairly reasonably priced and so on. But I hadn't worked in a community AIDS organization before. It was a fairly steep learning curve, in terms of understanding what some of the issues were, and just getting a grasp of the environment at PARC: what was going on between the organizations, between the individuals; what the morale was like; what kind of experiences people were having in various areas.

When we first started videotaping, there was a lot of interest in the rounds. People were keen to go to that kind of a forum, to try and look at what was going on in the organizations, to try and work together on some kind of solution.

But, once the process started, participants did not feel comfortable with video cameras and a crew there. We went from three cameras, sound equipment, lights and the whole Oprah Winfrey Show, down to one camera for the next couple of sessions. And then we did away with video entirely.

I think this is one of those areas where you have to respect the wishes and the experience of the people—however much it means—sort of shift your own operating system. That really gained us a lot of credibility in the organizations. It was a process of ongoing consultation and adaptation to the working environment.

TT: *My take on that was that we had to model our own process. If we wanted other people to adopt health promotion as a model, we had to be listening, we had to be practising.*

RK: Absolutely. PARC Rounds was meant to be participatory health promotion research. So if we wanted the buy-in, if we wanted to demonstrate the kind of model we were working with, we really had to be responsive to the concerns that people raised.

Rounds changed quite significantly from the beginning to what they looked like toward the end of the year. The video was one aspect. The other was that, originally we had invited people from other local AIDS organizations to participate as well. This was a real problem for some PARC participants. They felt they were having to be guarded in what they were saying—community-based AIDS work is such an intensely political arena.

This was really brought out in the rounds on cultural competence. There were several representatives from other ethnocultural and aboriginal AIDS organizations at the meeting. Rather than discussing how cultural competence worked or could work in health promotion, it became agency bashing.

The session was valuable in that it pointed out what some of the issues were. But it didn't really get down to core operating principles—just an exercise in agency jostling and jurisdiction. So that really pointed out that we needed to restrict the discussions to the organizations at PARC—another change in strategy that really helped people to buy in.

There was always a debate going on. Individuals and organizations come with their own agendas, their own concerns, their own issues. Some of them are the same and some of them are not. Or it may be an issue with the process or methodology of what we were doing. I acted as a mediator all the way through—something I wasn't really prepared for, but I came to understand it as part of my role.

So whether it was a staff or management issue or a safety concern, or even in terms of trying to communicate to government and the funders the importance or the value of the work, I acted as a mediator in a lot of different ways.

TT: *How did you do that? Did people access you or did you have to stir the pot a little? Did you actually go and talk to people to provoke some discussion on these issues, or did people see you as the person they needed to talk to?*
RK: Originally I really had to make an effort to go out and talk to people. That was part of the groundwork of talking and listening to what people had to say. I did a lot of my own rounds, in a way, to get a sense of what people's experiences were and what they were saying. As I became better known and as the rounds became better known and achieved a higher profile in the organization, people would come to me.

TT: *Can you remember some of the issues they came to you with?*
RK: People were coming to me and saying, "I don't feel comfortable criticizing something in my own organization because there's somebody from this other organization who can use that as ammunition with funders or with management." There were other ones, particularly among the women, who didn't feel comfortable speaking out. I think when people saw that I did listen, that I was responsive to what they had to say, it really helped in terms of the credibility of the process.

TT: *It seems to me there was another significant shift where most of the impetus for new topics was coming from the group. Then there was the formation of a steering group to get that going.*
RK: Certainly as the rounds progressed, there was no need for me to come up with topics. The question was how to decide among the topics. I think

the steering committee was really key, making sure that all the PARC organizations had a stake in what was going on in the rounds.

They were people who understood the value of rounds, understood what we were trying to do in terms of looking at practice principles and health promotion issues at PARC. They could then help drive the process as well. That again evolved out of being responsive to the environment in which we were working.

TT: *What was going on as you saw those things?*
RK: It was a very new kind of experience in new work for me, a steep learning curve, a really fascinating way to look at what was going on, right at the heart of AIDS work. That's where we were and PARC was really an ideal place in which to try out something like this.

We have three different organizations with different mandates, different kinds of operating philosophies, different directions, trying to work collaboratively to make sure that people living with HIV and AIDS are at the centre and stay at the centre of the equation. I sometimes, especially toward the beginning, didn't feel qualified to contribute.

I was doing a lot of listening, just on my own, information gathering, getting a really strong sense of what was going on and how that related to the work. In the development of my own perspective on health promotion and AIDS work, rounds was really a formative kind of experience to go through.

There were certainly times where I was uncomfortable, where I wasn't sure sometimes what my role should be. There were times when I wanted to jump in and participate and wasn't sure whether that would be appropriate or not.

TT: *Eventually, we got it down to tape recording and transcription, and I wonder how people responded to that. It seemed to me that even toward the end, there was still a lot of anxiety over what was in those transcriptions and what we were doing with them and what this research was all about.*
RK: I think there's always a certain level of apprehension when there's a tape recorder present and people are talking about the kind of fundamental, contested, controversial and potentially divisive issues that came up in the rounds.

But I think they also understood that there had to be some compromise as well, because this did have to be part of our research. We were there for a reason and we wanted not only to provoke this kind of analysis at PARC but also to use that experience in developing a health promotion framework for the entire country.

There was an understanding that this was part of a broader analysis, a broader research effort and a broader attempt to develop a model for health promotion in community-based AIDS work. The answer was in feeding that information back to participants and coming up with a report with an analysis of the transcripts. People at PARC really liked the report. They could see what the end result was.

TT: *I want to get to the report but I want to comment on the tape recorder. I felt that we had to model our intentions, so we wanted to show just how systematic we could be. We weren't going to arrive there sometimes with the tape recorder and sometimes not. We had to be consistent. We had to make sure that we were practising and that those transcriptions were done. We had to have a plan and I wanted to be able to show everyone, eventually, that this was all going to come into what we were writing about health promotion.*

RK: One of the first issues that we dealt with was essentially: What's it like to work in this environment and what are some of the issues that just come from day-to-day life working in the environment? Then we got to more topical things like cultural competency. And then as things swirled around for a while, we started to look at the PARC Rounds—like, what is this? There was one session in which we actually got to that and then there was another one in which we were having to account for the project itself and what we were trying to accomplish.

TT: *What were some of the most interesting points for you?*

RK: I wanted to get a sense of what people thought of rounds, basically do a kind of assessment. What came out was reassuring, because a lot of people were saying that this is a really important forum; that people really want to contribute to it; that they want to use this as a way of looking at their own practice.

And then some really practical results came of it: restarting the safety committee; starting up the frontline workers' working group; starting a diversity working group. There were some really concrete results coming out of rounds.

One of the rounds topics that inspired the most controversy was on gender. That came out of looking at safety issues in doing the work, not only physical safety but safety around speaking up during rounds itself and so on. That was really difficult, because I was acting as mediator, and there was a group of women who really wanted to deal with some issues around gender. There were problems around ownership of AIDS. The women felt gay men were resisting sharing the disease. I also had to deal with the interests of some of the other participants, who did not particularly want to see this as an issue.

TT: *Was there also pressure to bring in another facilitator?*
RK: Yes and, specifically, a woman. Rounds divided up into a women's session and a men's session. Not everyone liked the fact that we divided up. That kind of division was regarded with some apprehension.

I attended the women's session, and it was probably the most difficult for me. I didn't participate, but the women were quite happy to have me there because I had built up a relationship of trust with them. They didn't hesitate to speak out fairly strongly in my presence. But it was also difficult in that I recognized there were some really fundamental problems at work in that environment around gender, but also around sexual culture, around the mandates and the way the different organizations operated.

I think there are a lot of unacknowledged—sometimes acknowledged—tensions between women and gay men working in AIDS. Gay men feel that the agenda is being focused on women and children, that gay men's needs are not being reflected in programming and public policy to the extent that the epidemiology of the disease warrants. Women on the other hand feel that gay men don't want to share their place in terms of dealing with the disease.

TT: *And don't acknowledge women's vulnerability?*
RK: Gay men acknowledge that women are vulnerable, but they feel it pales in comparison to how they see themselves as vulnerable. The women feel a lot of anger directed at them. That is a result of gay men's frustration with being marginalized, with being stigmatized in the HIV environment, as well as in the broad social environment.

The women said that a lot of the men in the building resented the amount of resources that they had, and the space they had to work, when their numbers were comparatively quite small. So the women felt a certain amount of underlying hostility. But there was also acknowledgement that there were men who were allies, that there were men who did make a space for them at the table, so to speak.

TT: *I moderated the men's session and opened up with the opportunity to talk about anything, about what it's like to be male and working in HIV. We had a few comments on that for about five minutes. But the rest of the hour and a half was on conflict with the women. It told me that men were certainly aware of it.*

RK: Part of the reason we have a diversity working group now is because of some of the stuff that came out of the gender rounds. A group formed to look at PARC policies on diversity issues: around gender, serostatus, sexual orientation, sexual harassment, ethnocultural issues, racism in the workplace.

In reflecting on PARC Rounds, it astonishes me that there has been so little work done in looking at what's going on in community AIDS organizations. There's so little analysis and research on what's happening at ground zero of the epidemic.

TT: *Well, of course that's why we were doing all this.*

RK: It's difficult working to establish a level of trust and collegiality in order to make participants feel comfortable enough to speak on these issues. That took a long time. I can't imagine this happening with an academic or an outside researcher coming in and turning on a tape recorder and saying, "Talk." I just don't think that would happen. You really need to establish yourself in the community organization for that to come out of the work.

TT: *An outsider may seem to be a solution. That's why we have consultants. But I feel that people have more resources to do things like this on their own than they realize. They have to stay with the process to prove that to themselves. In the end, we had to suspend rounds because of other demands of our project. But now I see that people realize there's a vacuum.*

RK: I've heard that from a number of other staff members who recognize rounds as the only forum that exists at PARC, and the only forum, as far as I know, of its kind in the country, where people from different organizations can come together and look at core practice issues in AIDS work: how they do their work, how they develop their programs and planning, what kind of thinking goes into outreach.

TT: *Let's talk about writing the report. What was it like for you to have to deal with all the material. How did you cope with that?*

RK: It was really overwhelming to have to sift through all those transcriptions. But it was also really fascinating to go through all of that, to be reminded of what went on and to realize some common themes. Some significant issues came up time and time again. It then became a process of drawing those issues out of this mass of information and material. The themes seemed to surface fairly naturally.

What I did was model *Taking Care of Each Other* and *More Reflections* [publications produced during the development of the *Field Guide*] in terms of presenting the process, the methodology, the rationale, then the analysis and people's own voices. Having people's own experience speak through the report was really key. I think that is a much more powerful way of presenting that kind of information than the standard professional style of report with one or two quotes sprinkled around.

TT: *So what were some of the main points you drew from that?*

RK: One of the biggest ones was communication. I actually broke down communication in the report into three different areas: internal communication or organizational communication; interorganizational communication; and external communication. There were problems within organizations, a lack of perspective on what other departments are doing.

Even more significantly, external communication seemed a big community development issue: how we communicate what we do—and how effectively—to the community and the population that we're serving.

People kept saying we don't tell people enough of what we do. We don't communicate our success. We don't let the community know how much work actually goes on here and how many people we are actually helping. There has been a real turnaround since then, in how AIDS Vancouver and the other organizations now present themselves.

REFLECTIONS Learning Organizations

Life in an AIDS agency is certainly not all dark, but sometimes it can be difficult to see the light. This is what makes practice dialogue so necessary. The opportunity to reflect and record the experience is an important coping device that can also transform the climate of the workplace. In the case of PARC Rounds, good faith was established between rounds participants and organizers through the audiotapes and transcriptions. The rounds dialogue created its own supportive momentum, but the transcripts held the promise that importance would be attached to what was being said.

The cultural evolution of AIDS agencies is a unique and fascinating story. Unlike most other health-related, community-based organizations, AIDS organizations developed autonomously in each community, avoiding the corporate format of a head office with branches. AIDS organizations function much differently than the Red Cross does, for example.

Independent evolution has allowed the development of community agencies that are unique expressions of the communities from which they have emerged. This has also allowed AIDS agencies to link together and learn from virtually any other AIDS service or self-help organization in the world with relatively few bureaucratic impediments.

Such loosely defined structures have their own challenges, however. Relationships can be tenuous. And politics, conditioned by societal values around HIV, can affect relations among people in the agency, between the agency and the community, and between the agency and society at large.

A BRIDGE BETWEEN WORLDS

The bridging role of a community AIDS agency is clearly expressed through its advocacy work. The view that the root causes of HIV transmission and disease progression are societal—including gender and racial discrimination and homophobia—has raised the possibility that fighting HIV by altering behaviour in particular risk groups is insufficient to manage the epidemic.

In view of the social determinants of HIV health, AIDS agencies need to work beyond their traditional core communities to be strategically effective. They must cast wider nets to improve the quality of care and treatment of those infected and better protect HIV-vulnerable groups.

The transformational health model represents the AIDS agency within its core community, but also emerging from it to forge its own place in society. This representation aptly expresses the evolution, purpose and role of AIDS organizations as bridges between worlds.

Community-based organizations are expressions of the health aspirations of the core communities from which they emerge. The influence of AIDS organizations on society, in turn, is determined by the collective action, skill and power of whoever turns up from the community. As such, AIDS agencies represent the health leadership of the community coming forward. The complement of staff, volunteers and board comprises community members who, for various reasons, social affinities and individual expertise, have come together to accept responsibility for the management of HIV in their community.

Even with the strong interaction of community members and participants, however, the relationship between an agency and its core community can be tenuous, due in part to the social complexity of AIDS issues. Links between AIDS agencies and their communities can be fraught with controversy. People are rarely indifferent when it comes to HIV.

STEERING CHANGE—UNDERGOING TRANSFORMATION

Experience at the Pacific AIDS Resource Centre indicates that health promotion is as important to the inner life and culture of a community AIDS organization as it is a strategy for wider community action. The collective effect of people engaged in health promotion activities can have a profound impact on a community organization itself.

Not surprisingly, collective efforts are also unpredictable, and our challenge is to develop ways of working that are flexible enough to embrace unexpected change. The patterns of life in an organization need attention;

the work environment itself needs health promotion; and an organization needs to consider its own strategy for transformation.

Without an organizational learning strategy, the inner life of a community AIDS agency can be chaotic. One experience observed in rounds was that individuals and their programs were, to some degree, isolated and alienated from each other. Although fuzzy communication can be apparent at many levels of an agency, it is often most apparent between the traditional education and support departments of an AIDS agency.

At AIDS Vancouver, the staff of the two departments sometimes had little knowledge of what their peers were doing. There was, indeed, deep suspicion and mistrust underlying this gap in organizational understanding. People doing support work felt that the educators were focused too exclusively on distributing condoms. People in education looked at the existence of the support department as the all-too-obvious failure of education.

The solution was to create a program steering group drawn from the staff of both departments. Members of the new group began to establish common ground. Prevention, they recognized, is as much an issue for people living with HIV as for those who are uninfected. They also recognized that education was an important component in improving health conditions for people with HIV. The steering group's insights have begun to influence programming in both departments. Staff now work together on overall organizational planning with a view to orchestrating health promotion strategy for the whole organization and its surrounding community. Interdepartmental prevention and support outreach was one result.

PARC Rounds was another organizational learning strategy in the same vein. Teaching hospitals have a long and formal tradition of "medical rounds," an essential learning experience for new physicians that provides direct exposure and dialogue with groups of doctors and interns. "Grand rounds" are even more formal occasions in which researching health professionals present work in progress. The PARC Rounds, by contrast, are informal—sometimes even a little chaotic—yet they provide a valuable forum in which participants can discuss the challenges and frustrations of work in an AIDS agency. (The case story in this chapter describes the development of PARC Rounds.)

Creating innovative opportunities for communication, at all levels of an agency—no matter how surprising the results—is worth the effort because it is the true basis of a responsive and healthy agency.

PRACTICAL FIELDWORK How to Run Rounds

The use of rounds—the practice discussion described in this chapter's case story—is a worthwhile experience for any AIDS agency. You can have a mix of volunteers, staff, participants and board members. You can play with the format in different ways. PARC Rounds started out in the style of a TV talk show and ended up as a sacred circle. Food and sometimes a little wine help to get talk flowing. Here are a few tips.

SCHEDULING

One of the first pitfalls is around finding a point in the day when people are available for reflection and inward-looking discussion—a serious barrier in getting PARC Rounds started. The timing needs to be researched and negotiated. It gets easier as the event becomes established.

FACILITATION

The PARC Rounds facilitators were felt to be insiders by the people who attended. There were stress points in the evolution, however, where it was necessary to seek an unbiased (i.e., outside) moderator for the next session. This was done through word-of-mouth connections.

TOPICS

Generating topics is another early issue. PARC Rounds started out taking direct aim at the controversial issues going on in the life of the agencies. That got some people out just to see what would happen.

DOCUMENTATION

PARC Rounds started out with video and ended up with audiotape and transcription. In the end, the video was missed by many who would have liked a visual presentation of the inner workings of an agency rather than a written report.

REPORTING

Recording and transcription were essential to the real impact of rounds on the PARC community. Transcription allowed a serious theme analysis to take shape from which a final report was written and presented orally at a rounds session. If the time and energy of the co-ordinator or participants make it possible, reports from each session could be prepared and circulated for ongoing feedback and discussion.

CHAPTER 8

COMMUNITY

transforming the social environment for community health

The focus of this chapter is on the application of the transformational health model within vulnerable communities. Because most community AIDS agencies are creations of HIV-affected communities, they are usually considered by public health and other government planners to be living examples of the successful evolution of health promotion through community development—from a public health perspective. Community agencies that organize their HIV prevention and support activities in tune with these health-policy assumptions are often unconscious of their origins. The idea of using community development as a way to improve quality of life in the environment of their own communities has somehow been lost.

There are two fundamental concerns in HIV-affected communities: keeping HIV infection rates low and enhancing the conditions for optimum quality and length of life for people living with HIV. Community AIDS agencies have had most of their success in creating effective and appropriate ways to handle these issues by keeping HIV-prevention messages current in affected communities and supporting people living with HIV.

So far, most community prevention programs have been simple, practical and direct in providing the following:

Information and other related services
- information campaigns—events, posters, pamphlets
- presentations in schools, institutions and workplaces
- distribution of safer sex packs containing free condoms, lube and information
- outreach in public sex scenes and women's shelters

Direct support
- intake and referral services
- free food and clothing
- needle exchange
- library services and treatment information
- crisis counseling
- medication allowances
- emergency assistance funds
- housing assistance
- individual advocacy
- home care and pet care
- care teams and hospital visiting

Most of what community AIDS agencies have learned about health promotion has come from work directly on and around these activities. Interestingly, most community development work has also focused on organizing volunteers, leadership and fundraising for these activities. Health promotion has provided the underlying theme of enabling the participation of the affected community and especially enabling people living with HIV to take a leading role.

Although many who have been part of this history would admit that most of the action has been do-do-do, study-plan-do has been there all along. Before study-plan-do had a name, transformational health was happening in the form of innovations for HIV health promotion. Indeed, the case stories in the *Field Guide* are the reports of those breakthrough experiences. The transformational health model is the end product of sifting through those stories and many other experiences. The result is an expression for a way of working to ensure that HIV health promotion keeps advancing, along with our understanding of the epidemic.

Currently, few AIDS agencies have moved beyond the frame of the HIV vulnerabilities of their mandated communities, although the impetus is certainly on the horizon. This impetus will come from changes in medications and treatment that will increase emphasis on what to do about people recovering from illness and returning to work.

Health promotion theories described in Chapter 1: Health Promotion and the Language of Practice clearly point toward embracing whole-health approaches to community vulnerabilities such as HIV. Population health research, for example, raises the possibility that, even if HIV prevention were completely successful, something else could come along to replace it if underlying community vulnerabilities are not addressed.

The implications point the way to further innovations in HIV health promotion at the community level. Transformational health will be a useful and timely method of moving forward with these innovations. Addressing the roots of HIV vulnerabilities in HIV-affected communities will undoubtedly uncover related health issues, among them the social determinants of the situation. The study-plan-do approach will not only help to uncover those issues but will point the way to productive and worthwhile ventures to improve health in HIV-vulnerable communities. We have only to put into practice what we already know.

The Case **Story** in this chapter relates the intricacies of community relations that may be encountered in making HIV health promotion a reality.

Reflections focuses on underlying and systemic issues at the roots of the continuing vulnerability of HIV-affected communities.

Practical Fieldwork provides a simple and practical community venture to support people living with HIV in HIV-vulnerable communities—and have fun doing it.

CASE STORY MSM Outreach in Ottawa

People don't lie. It just isn't possible for them to tell the truth.
—MIKE GRAYDON

Mike Graydon's story is about the importance of taking a receptive, nonjudgmental stance in HIV fieldwork. His story illustrates the transformative potential of health strategy both in a frontline HIV-risk environment and behind the scenes, raising community support.

When Mike Graydon began his outreach work at the AIDS Committee of Ottawa (ACO) in 1990, he already knew that some of the problems most prevention programs were facing were their own self-created barriers around gay identity issues.

"Right off the bat we were looking at gay and bisexual men who don't identify—a much broader view of the men who have sex with men (MSM) problem." He attributes the support he got from his agency and the ACO board to continuous dialogue. "I was constantly talking about this stuff and that helped put out a lot of fires, fast."

This is Mike's story of how an AIDS agency's response to a universal urban phenomenon—men having sex with men in public parks—ended up influencing the social value systems working among several disparate groups, including the park board, two police authorities, the park maintenance crews, organized gay community leaders, the local AIDS agency and the HIV-vulnerable group, men who have sex with men.

Mike attributes his understanding about MSM outreach (for both himself and the agency) to his work in bath houses when he initiated his Bath Buddies Program. "It was a fairly passive program that we ran for two years. We would visit the bath. They would give us the same room every time and we put up signs. We'd sit on the edge of a bed and people would just drop by. We did not have especially good relations with the guys who ran the baths. They were receptive, but they weren't willing to do a lot."

Efforts to improve the program always met with obstacles. An office in the baths would have permitted discussions in a less charged atmosphere, but bath owners were either unresponsive or had to cope with too many other demands. Plans for an office in a bath with on-site HIV testing were discussed for a long time, but there was no action.

What Mike and ACO learned from the experience, however, was invaluable. How do we choose and train volunteers to take on the role of HIV educators in public sex environment outreach, for example? "All the volunteers have been from the bath population—either they currently use the baths or have at one time. But they are totally cool with them. We think the fact that they're drawn from the population makes them really credible. One week you see them having a good time, the next week they're educating people."

From his experience, Mike also learned how to talk to men about HIV in a public sex environment. Pat "safer sex" messages were eventually transformed into "harm reduction" chats. This signaled acceptance of realities. "We tell them: if you get sucked take a piss. And even if you just go to some guy's room and play with him for a minute, wash your hands."

Mike and his group began to recognize that they also needed to take women's health into account as well. They knew that many of the men they encountered at the baths were returning home to women. So in their talks, they included the possible impact that sexually transmitted diseases (STDs) might have on relations with women.

When Mike was challenged to address the National Capital Commission (NCC), which manages local federal parkland, on complaints they had received about sex in the bushes at Remic Rapids Park, he knew he could take on the problem directly, and with his agency's full backing. He used the complaint as an opportunity to teach the park authority, the Ottawa police and the RCMP (federal police) about public sex.

"What I taught them was that park sex is part of our culture. We react differently to men's sex in bushes because it's a homophobic culture. It can mean life and death if you bust these guys. One is sure to die because he'll kill himself. You can't erase this; you can't eradicate park sex either, so don't even try. If you do, you will just scare the men to some other place that may not be as safe."

The clincher that brought the outreach program into being was an offer the park authority and the police found hard to refuse. "We could use this as an area to do really good AIDS education for a group of men that we don't have any contact with," Mike urged. The NCC board responded unexpectedly well to his suggestion.

A central issue, it seemed, was garbage—all the spent condoms left untidily in the park. One of the city councilors who was quite livid about it was heard to ask, "Why can't they take their condoms home, goddammit?" Mike retorted, "Would you put a shit-covered condom in your pocket?" His frank tactic worked, and Mike received the consent of the Ottawa police, the RCMP and the NCC to do AIDS outreach at Remic Rapids.

The next problem was finding volunteers. Unexpectedly, Mike met with negative reactions in the gay and lesbian community. "I was talking very publicly about outreach in parks, and they wanted to shut them down—as if I could shut down the parks!

"Their view was that irresponsibility brought us AIDS; by becoming responsible, AIDS would go away. The community pushed hard to stop park outreach, but I just said no. They argued that men in the parks were not from the gay community. I would reply that undoubtedly this is true, but no one else will advocate for them, so I will." The community remained divided, but did not interfere any further.

Work began with urgent practicalities. The NCC put garbage cans near the site, but these weren't being used. The commission felt it had done its job. NCC staff argued that their maintenance men had only high school education and were terrified of "fags" and AIDS. Mike offered training for the parks crews to explain to them that they could not get AIDS from picking up the garbage. They need not be afraid of AIDS—unless they were having sex in the park.

The biggest issue Mike faced was finding volunteers. Potential volunteers faced the "what will my friends think?" problem. "There was one guy who really wanted to volunteer," says Mike, "but I had to sit down with his partner and work through all the partner's fears about how his social circle would be harmed by the other's outreach in the park. If you do the baths or the parks here, you are really looked down on, even though a sizable slice of those who look down on it do it!"

"So after two years of searching, we finally set out with four volunteers. A pair went out every week. We didn't collect any data. It was just a matter of: Can we be here? Will they talk to us or run away? How will it work?"

What the volunteers found immediately was that they should not wear similar-looking jeans, T-shirts and jackets as gay men often do. It was confused, they discovered, with an undercover police uniform. They also found that their apparel should not bear any identifiably gay icon, such as a pink triangle, because it could be seen as offering the threat of a tirade on their lack of sexual liberation.

The volunteers carried condoms and lube, and approached people in a friendly way with "Hi, how are you doing." "We would just chat," says Mike. "We'd remind them to put their condoms in the garbage cans—and by the way here's a condom. We'd throw in a sexual safety message or a harm reduction tip just like at the baths. We were overwhelmingly well received; just three guys bolted and didn't talk to us. That left 83 who were willing."

"The second year was easier because, by that time, the volunteers and the project were known. Guys were much more willing to talk. The volunteers were building trust."

Mike added a basic research component, "just a little tick-off form the volunteers could fill out after they talked to the men regarding frequency of visits to the park, age, if they have sex with women, whether she knows, whether the contact seemed nervous, whether there was alcohol on his breath and so on."

Mike also saw the need to set a basic ground rule for the volunteers: no sex while on duty.

In reflecting on why park outreach may have worked out even when there was resistance from the gay and lesbian community, Mike attributes it to good dialogue within the AIDS agency. "We look at root causes—a racist, heterosexist culture—and we address those issues. We always approach the AIDS issue within a social change framework. This has always prepared the ground ahead of time for whatever we do."

Mike noted that they did not have a specific plan in taking on Remic Rapids Park. "But we certainly have a way of thinking. My thinking is about access to information. Who has greatest or least access? Those with least access are the guys in the park. At ACO, we decided to go after the guys in locales where there was the least access, and to get to them in a sexually charged environment where they are about to initiate sex. This was a smarter way to go, we felt, because people so easily compartmentalize their sexual experience."

Mike was able to identify the breakthrough with MSM outreach at Remic Rapids. "I would say that a big part of it was my ability to talk about public sex. And what's behind that is the analytical framework we have at ACO. We put park sex in a cultural framework—an oppressive culture, which denies sexual choices and options. Some guys may like to do it outdoors but most have few other options. "

"I think this analysis fits in with a larger analysis that ACO has, right from the board and volunteers to staff. We approach issues in a social change framework, not just in terms of delivery of services. We also work on ourselves; we challenge each other on sexism and racism, etc. Ideas may get thoroughly trashed, but unlike other places, it isn't personalized."

ACO's experience with MSM outreach can be transferable to other cities. "If you're prepared to do a lot of education within the agency first—this is where the line gets drawn. Are you going to be a social service deliverer or a social change activist? Because only when you take the social change tack, will you get this level of success. You'll get other people to buy in. Does the NCC ally themselves with us publicly? No. But I have letters of support from them. "

"The benefit of our program," Mike concludes, "is that we've been kind to people—respectful of what they do and where they do it. We've been their advocates. We've provided something for those people that has never happened before—five minutes of kindness. I think that's raised the profile of the agency a great deal in terms of tackling tough issues. It's enabled us to go from saying, four years ago, 'This is how we think it is' to 'This is the way we know it is.' "

REFLECTIONS HIV Vulnerability and Communities

The story of MSM outreach in an Ottawa park shows the importance to HIV health promotion of the advance preparation of the layers of the societal and community environment surrounding a vulnerable population. Although many successful encounters occurred in the field, the contacts with government, police and community officials were equally necessary to support HIV health in this situation. Beyond that, the field workers' conduct in the field and the adjustments in behaviour that they had to make were an important part of using HIV health promotion as an intervention in HIV risk conditions.

One of the significant lessons of the HIV experience must surely be the contribution of community organizing as a first line of defence against an unexpected epidemic and its repercussions. Before much was known about the illnesses showing up in their community, Vancouver gay men took on responsibility for protecting the public blood supply. Following the prompting of their doctors, who apparently suspected a blood-borne pathogen, volunteers put up hand-lettered signs in baths and bars advising gay men against blood donation—several years before HIV was actually identified.

As information that the pathogen was sexually transmitted became available, some of those same community organizers formed AIDS Vancouver. The new agency took on prevention not only in the gay community but for the whole city. Then, as HIV was identified and information about the specific vulnerabilities of other groups such as women and ethnocultural groups became known, the agency's response was to hire the appropriate leadership, even when funds were already thinly spread. AIDS Vancouver sponsored the development of several communities in this way, focusing on women, Latin Americans, African-Americans, Asians and South Asians. Each group eventually developed its own community AIDS agencies.

The enabling principle—that people from diverse communities know best how to mobilize their own forces—helped to spawn groups all over Canada to manage the specific HIV prevention and support needs of women and ethnocultural and First Nations communities. The co-ordinated community effort became an effective frontline effort against HIV, especially in contrast to worse scenarios experienced elsewhere. Nevertheless, community development in response to HIV is far from over.

The AIDS epidemic has lasted long enough to converge with the arrival of a new generation of young people who will, inevitably, find themselves vulnerable for the same reasons that the first generation was. Although much has changed to make sexual health information more available, social barriers still persist. The barriers against people practising what they already know originate in their socialized discomfort and moral confusion over sexuality and sexual orientation. Even now that sexual orientation has been added to the human rights code of Canada, homophobic and racist socialization poses a continuing systemic threat.

SOCIETAL CAUSES, COMMUNITY VULNERABILITY

The Pacific AIDS Resource Centre (PARC) has uncovered a phenomenon among HIV-positive gay men that offers an important insight into HIV vulnerability. Anecdotal reports suggest that many seropositive gay men have experienced abuse as children. They have been subject to scorn and violence within their families, targeted by bullies in their neighbourhoods, and they have been the victims of early sexual abuse.

Determining the full extent of the damage is difficult, but early interpretations of the data suggest that as many as 30% of HIV-positive gay men have histories of some form of abuse; more detailed prevalence studies are underway. A research design to determine if a relationship exists between childhood abuse and HIV risk behaviour in adulthood has already been developed. An interpretation of HIV vulnerability that uses the social environment can help in probing and understanding why people fail to practise what they already know as effective preventive behaviour.

The social stigma that a majority of gay men experience from the time they are young boys can be a constant assault on their dignity. Taunts, labeling and violence are all part of the pattern. Although everyone responds to environmental challenges differently, the long-term effects of homophobia and discrimination mire personal histories in painful memories, damage self-esteem, destroy the confidence to deal with difficult situations and interfere with abilities to sustain productive and healthy relationships. The adaptive patterns that can result are familiar: over-compensation, extreme worries about self-image and a diminished sense of personal control.

Dealing with the damage caused by an abusive environment is a significant theme in community HIV prevention. Experience has already shown that isolation contributes to HIV vulnerability: affected people need to know they are not alone. There is no better place to begin relieving the problem of isolation than in enhancing community development efforts within the communities from which many AIDS organizations developed in the first place.

One of the primary reasons that community AIDS agencies must take charge of this task is demographic change. Over the next few years, communities across Canada will experience a rise in the proportion of young people in the general population. New generations of gay youth may be no less vulnerable to HIV than those infected in the first wave in the early and mid-1980s. The same societal conditions persist. Clearly, we need to address social vulnerability as an HIV risk condition.

Social vulnerability must also be seen as a precipitating factor in HIV illness—poverty being one of the most obvious aspects. Urban AIDS organizations witness abject poverty every day among people whose HIV status has sent them "from the penthouse to the outhouse." A young architect living with HIV made the point clear at an AIDS walk rally: "It is a simple fact: People living with HIV/AIDS have inadequate incomes, cannot find adequate housing and cannot afford to feed themselves adequately."

The popular image of gentrified "A-List" gays is a simple stereotype that disguises an uncomfortable reality in an otherwise healthy society. Homophobia, AIDS stigma and discrimination marginalize people, narrow their potential and eventually render them ill.

Since the origins of community AIDS work go well beyond urban gay populations, HIV-affected communities need to uncover similar vulnerabilities in their own circumstances and experience.

AN OPPORTUNITY FOR RENEWAL

Questions have arisen concerning the focus of larger AIDS organizations, which bore much of the early effort and costs of primary prevention for the general public. Although there was often a sense of noble purpose in spite of social resistance, there were unintended effects of "general public" prevention programming. People in communities from which the largest AIDS agencies arose in the first place began to express a sense of disconnection and alienation.

Anger and disaffection are common in AIDS work. But there are also signs that the ravages of AIDS and time have weakened the bonds that motivated early community responses to AIDS. The development of HIV health promotion with a social-environmental interpretation of HIV vulnerability is an occasion to re-examine those bonds. The wider purpose of creating positive health environments in the wake of primary HIV prevention offers a renewed strategy.

There is also a need for periodically taking the pulse in the core HIV-affected communities. It can be dangerous to assume that the AIDS agency is in touch with its community because the staff, board and volunteers are largely made up of core community members.

People belong to more than one community at a time. Which community is the primary source of identification? This is an important question for AIDS groups addressing a mix of gender, sexuality, serostatus and ethnocultural backgrounds, all of which serve to define HIV health realities.

Experience in community AIDS work has demonstrated that access to the larger community is impossible without access to its subgroups. Although people may identify with a "community," their everyday experiences are often more closely linked to those of people they consider to be most like themselves. As such, group affinities must be seen as a strategic vehicle for community transformation.

The force of people's voluntary associations will continue to be a predominant source of strength in the face of the AIDS epidemic. The transformational effects of people working together are multifaceted and direct—on community participants themselves, on the communities they represent and on those they target in their advocacy work.

It is noteworthy that many of the larger community AIDS organizations in Europe and North America grew out of pre-existing gay communities that were already organizing around human rights issues. The seriousness of AIDS resulted in the emergence of organizations totally devoted to the new health crisis, sometimes superseding all other community action.

We have come full circle. Our insights about the societal causes of HIV and AIDS lead back to efforts that deal with human rights abuses expressed as HIV vulnerability. Clearly, the preferred future is to convert what we learn from community AIDS work into strategies for more supportive societal environments. This is as much a group's task as it is a community's—group after group, wave after wave.

PRACTICAL FIELDWORK Sponsoring "Living Proof"

Here is an outline for a sponsored event explicitly designed to enhance community support for people living with HIV. "Living Proof" was created by AIDS Vancouver to explore casual and enjoyable ways to reduce isolation and segregation of HIV-positive gay men. The main idea of the event, which is purely recreational (with a point), could be modified to suit any group or community.

The event itself is simply a barbecue, pub night or cocktail party. It's the organizing around the event that gives it its significance and importance as a way to improve HIV health conditions and show visible support for HIV health.

Like most community events, Living Proof began with a small working group to figure out logistics and carry the ball through all the important stages, such as getting ads into the community newspaper on time. The composition of the working group should be a good mix of people with differing serostatus, staff and volunteers depending on the community.

The two main jobs for the group are arranging the time and place and publicizing the event. AIDS Vancouver co-sponsored the first Living Proof with British Columbia Persons With AIDS Society (BCPWA) and several other local agencies.

In the beginning, there was some research around expected numbers and an appropriate venue. An easy and welcoming atmosphere was desirable and realistic for low-cost entertainment. Eventually, the manager of a popular disco offered to run a barbecue and pub night a few hours before regular opening hours on a midsummer night.

The advance publicity is almost as important as the event itself. The organizing group writes a press release to highlight the issue of isolation, the importance of positive social contact and the problem of serostatus segregation in the community. If all goes well, the press release gets a story on these themes into the neighbourhood or community newspaper. The working group needs to be ready to be interviewed on the subject, to speak from experience and explain the general goal of Living Proof—a community-sponsored occasion to express support for people living with HIV and their friends. Vancouver's Living Proof got a front-page story in the local gay and lesbian community newspaper.

The group also needs to look after advertising. Vancouver's Living Proof had a rave card designed to pass out in neighbourhood cafés and bars. The same photo and copy were used for a small ad in the community press.

The event itself is a party with a community flavour—door prizes and greetings from the community leaders. The working group needs to work on sponsors for the prizes in advance, of course.

One final piece of business is evaluation. Vancouver's Living Proof had a five-question survey printed on a postcard. The questions were written to take the pulse of the community on the issue, as well as to probe whether it would be worthwhile to run the event again.

After the event, the working group pulls together a report on the project, which may help future work. Vancouver's Living Proof got high marks from those in attendance and the community in general. People who were unavailable for the first occasion were looking forward to the next.

CHAPTER 9

SOCIETY

transformative groups—societal change

This chapter applies transformational health to HIV conditions surrounding, but external to, HIV-affected communities. HIV experience has shown that breaking into society's organizations and institutions for HIV health promotion and advocacy continues to be daunting, even this far along in the epidemic. Most groups outside affected communities do not recognize their HIV vulnerability until a situation arises where someone gets infected or has to leave work because of the onset of symptoms. Such cases have opened the door to the corporate world, as you will see in this chapter's case story.

Gaining access to groups in society is more about HIV stigma, sexism and homophobia than about HIV itself. These issues are sometimes cited as the "problem" getting in the way of basic HIV prevention. Experience from the field has shown that dealing with these barriers may well be the most appropriate starting point for mobilizing supportive approaches that coincidentally decrease HIV vulnerability. The typical places where this has to occur are those that, in some way, converge with vulnerable groups and communities—schools, universities, corporations, hospitals, government services and health professions.

Applying transformational health to these situations is the same as applying it anywhere else. The process is study-plan-do from within, and the intent is to develop the whole environment so that it is more conducive to HIV health.

The **Case Story** in this chapter shows how a well-framed strategy, thorough planning and dogged pursuit can break through seemingly impenetrable walls of social denial.

Reflections points out some societal forces underlying HIV vulnerability and how to work with them.

Practical Fieldwork outlines a project to bring professional groups into HIV health promotion.

CASE STORY Breaking into the Corporate Workplace

This is a story about health promotion fieldwork on the corporate front line. It is not about basic HIV prevention in the workplace but about the familiar barriers of shame, stigma and homophobia that keep HIV education out of the workplace. Terrah Keener was hired to turn around a failing initiative at AIDS Vancouver. Here, in her own words, is how she did it.

INTERVIEWER (INT): *What did the workplace project look like when you got to AIDS Vancouver?*

TERRAH KEENER (TK): When I took over the program, there was really not much in place or going on. We did an interview with the outgoing co-ordinator. He identified barriers and reasons why they weren't getting anywhere with the corporations. Apparently, corporate people didn't want to talk to him, or they didn't want to deal with the issue.

His attitude was that corporations were all wrong and doing horrible things to their employees. I think his position contributed to them not wanting to talk to us. It sounded like he was just after them to implement AIDS employment policies without really talking about what policy meant and what they could do for their organization.

I would say his attitude was also the general attitude in this agency. The workplace project was the least favourite project here. It wasn't seen as very important. Who would want to deal with business when they're just seen as capitalists chewing people up? So there was major "attitude" going on here around business.

When I took over the program, I did a mini-assessment of AIDS workplace programs going on in North America—called all the major AIDS service organizations in the US and Canada over a couple of days. I wanted to see what other approaches were being taken, because I didn't think going in on the offensive was very productive. I wanted to find out what was really going on.

I quickly turned my own attitude around with those calls. The corporation was not always the bad guy.

I found out that there are lots of businesses that want to do the right thing. They may even have done the wrong thing in the past, but a lot of it was totally out of ignorance and not out of malice. There were, of course, organizations that were firing people. But you just found a variety of attitudes out there in the business world, and they weren't all horrendous.

As I called around, I found that there was nothing going on in Canada really. People got money to do some workplace initiatives. That's what produced the *Act Now* material. It's about HIV in the workplace for employers and employees: how it's transmitted, what you have to worry about, having an AIDS policy. Very basic.

Pretty useless, I thought. It's rare that an employer has the time to read through a manual like that and then, after reading it, to really have the skills to implement anything. And that was the objective. But they still have no understanding of the issues. They may know transmission. But they still won't have any idea around stigma, which is the main issue in the workplace. It's not really HIV; it's homophobia. It's everything else that comes along with HIV.

So after talking to lots of people in the States, I found a lot more going on. There was more of a focus on education, looking at the workplace as the final frontier for AIDS education. Here's a huge captive audience that for all intents and purposes had never really been tapped.

We've been working in the gay community, which has been great. But there's always this discussion: How do we get to the heterosexuals? Well, one way to get to a big portion of the population is to get them at work. Granted, you're still only getting working individuals, but you're covering a lot more people than you would if you tried to just stand on the street or whatever. In the workplace, there appeared to be a huge opportunity to do some really good, interactive type of work.

So I started looking at the Boston model and I got in touch with an organization called The National Leadership Coalition on AIDS, which is an umbrella organization out of Washington, DC, that tries to co-ordinate all workplace initiatives. They have a board, which includes CEOs from major corporations around the country. And major labour representatives. They are working at quite a high policy level and they do a lot of lobbying of the government. They also work with corporations all over the country and probably all over the world by now.

They try to encourage organizations to have ongoing educational programs, as well as AIDS policies. It's a great resource centre. They have a library. As an organization, you can call up and say, "I'm calling from Iowa or wherever, business of about 75 people. We're having this and this going on. We don't know what to do." Either they'll try to help, or they'll say: "We have a member who's in the next city down from you. Why don't you give them a call?" They were hooking geographic areas together. There's a lot of mentoring going on. It was through them that I was able to come up with a keynote speaker for what I wanted to do.

I wanted to bring local businesses together on this issue. We needed to get business people into one room, to start them talking about some of the AIDS issues facing the workplace. I also thought a peer education model was the key. So I hit on the idea of getting it all going over a business breakfast meeting. I'd heard breakfast meetings were growing in popularity among professionals.

I just knew from listening to the ineffective projects that they were "AIDS organizations trying to tell business what to do"—not an effective strategy. Business has a tendency to look at non-profits as not very expert. So what I had to do was to get business to talk with business.

Through the Leadership Coalition on AIDS and Northwest AIDS Foundation, I hooked up with US West, a corporation of about 50,000 employees that has done extensive work around HIV. The vice president in charge of personnel was willing to come up to Vancouver and talk about why US West felt it was important to educate their employees about AIDS. He came from a very compassionate, humanist side and the crowd loved him—they were just spellbound.

INT: *How did you get business people in Vancouver to come to the breakfast? How did you generate interest in actually coming together in that way?*

TK: I developed a database using the Vancouver Book of Lists. We had no database; we had nothing. I took the top 50 companies in BC and then the top industries and hotels. I just went through categories like that putting together a database of about 500.

Then we did a two-part mailing, specifically to personnel managers. The first contained a covering letter that introduced AIDS Vancouver and the services we had to offer, a note from our own Director of Personnel and a reprint of an article from the *Harvard Business Review* called "How to Manage AIDS." It's quite a good article written by a personnel manager about his experience of having two employees with HIV. He's quite honest about the damage that happened. He's honest about how he dealt with it, what he did right and what he did wrong. It's very easy to read. You get caught up in the story.

The second mailing was an invitation to the breakfast printed on a very attractive card appealing to professionals. Three weeks after the invitation went out, I got on the phone and called everybody. That's the only way to do it. You find out that invitations got lost or went to the wrong person. I got 100 people there out of a little under 500. It is an incredible return considering that we started from nothing and a history of bad attitude.

INT: *When did you start the project and when did the breakfast happen?*
TK: The breakfast happened the first week of October during AIDS Awareness Week. The first mailing went out before the summer; the second in July. I came in on March 1st. That was not a lot of time to do this for AIDS Awareness Week. I spent September on the phone. The phoning took forever.

INT: *Did you use volunteers?*
TK: That was really hard because you had to be able to talk about the issue—you couldn't just have a volunteer going "Hi, I'm calling to follow up about..." You had to do a real sell job, talk about the issues. And they'd have questions. There was only one volunteer who really had the knowledge to do that phoning. He probably called about 150 and I did the rest. It was grueling, but it paid off. You still have to do that grunt work, making personal contact and answering lots of questions.

INT: *What kinds of questions did you get?*
TK: Well, they really think it is a problem: "Tell me, what's going on? Is it illegal to fire someone?" Or, "I really want to go—tell me how I can convince my boss to let me go." Very few negative responses; the occasional "Not an issue here"—click! Mostly it was "Oh, thank god you called, I've been looking for information." Mind you, human resource people are much more open to this sort of thing.

I wanted to try to get rid of as many barriers as possible. One was cost, so the agency paid for it all. It just made good business sense. Breakfasts really aren't that expensive. They are popular because people don't have to get release time to go. We would have them out by quarter to nine.

INT: *Do you think the breakfast was key in being able to implement the AIDS in the workplace program?*
TK: Yes, it really was the trigger. But professionals do want to know about issues that can affect their business. They want to know about new trends; they want to be prepared. They want to consult with their peers. We targeted human resource managers to try and get people in decision-making positions that related to HIV. Some of them couldn't come, but they'd send someone on their staff, and that was fine.

INT: *So what developed out of the breakfast meeting?*
TK: From there, we developed a business coalition. I knew I wanted this coalition, so I tried to plant the seeds in people who sounded really interested. I had also been working with some businesses directly. I was already trying to cultivate people who I thought might be key or who were showing a really keen interest. And so by the following February, I'd developed a core of about 20 people who'd expressed interest, and I invited them to the first coalition meeting.

We've probably got about five of those original members. Some of them still call me and say, "Sorry I haven't been to a meeting in eight months, but I'm still interested." We send them minutes of the meetings. Thus was born the business coalition.

INT: *Do you know if it had results in the companies that you contacted? Have there been changes in policy?*
TK: It's so hard to track. Unless they're getting in touch with me, I have no idea. But we just did a survey that we're still trying to figure out. One of the questions asks whether an AIDS policy is in place. Out of a sample of 330 organizations, 23% said yes, 77% said no.

What's really interesting—actually quite frightening—is that 14% have had more than one HIV/AIDS situation in their workplace. Out of that 14%, a very low percentage had a policy on HIV.

INT: *So most of the people who are dealing with HIV don't have a policy?*
TK: The survey totally supported everything we've always thought: that there still aren't a lot of AIDS policies out there, still not a lot of education out there. There are a lot of organizations that have had an HIV/AIDS situation but they don't know it. It's really hard to get to that. How do we

find that out? We know a lot of employees don't come forward and say, "I'm going off on disability because I have HIV." They say, "I'm going on disability because I have cancer." Or they'll just quit so they don't report it to their workplace.

INT: *So the 14% is actually probably quite low.*
TK: Very low. The survey has set a precedent in Canada. We got a market research firm to design it for us and do it all pro bono—$11,000 worth of work, free. We're putting together our own executive summary to highlight some of the findings. We hope to launch that with a press conference. I believe this is only one of three surveys in North America—definitely the most recent. The last one was probably done in 1990 in the States.

Next year, we want to hold two forums: one in the fall, one in the spring. They will be coalition-sponsored. And one may be held for managers and another on policy. We participate in lots of conferences now. We get calls to come and present on policy development specifically. We'll continue doing conferences with different professional associations. We want to continue the tradition of a breakfast to bring people together and update them.

INT: *Do you see the potential for the initiative to go forward on a national level?*
TK: Absolutely. This has been so key in helping with policy decisions at a government level. I think it's really important that we have some allies in business. And they say they could do major lobbying if they knew our issues.

I personally think it's one of the more important committees for this agency, because of the partnership that could develop. They can do a lot for us: fundraising, visibility, governmental work. These are relationships that could go on and on forever.

INT: *That seems like a really long-term effect as a result of the initiative. Are there any others that you can identify?*
TK: Well, this is a problem no one wanted. People have no patience. When the coalition first started, I said this will have a huge impact on fundraising, but it's not going to have an impact next week or in six months or maybe even in a year. You have to let these things grow and progress and that's been the hardest thing.

In HIV, everyone wants an immediate Band-Aid, and I say, no, this is an investment. And if we can hook it up nationally, that would be great. So this is not short-term, it's all long-term. We're going to get long-term residuals from it.

INT: *So what did you learn from your experience on the project that you can take away?*
TK: I learned a lot about how to deal with the business community and that we need to stop looking at them as our enemy. I really enjoyed the people I worked with on that—not that I wouldn't enjoy them; but the corporate culture, which we look at as so alien from us—it's not. I'd sit around and chat with these people, and we talk about the same dramas that are going on in their workplace that go on here. There are so many similarities. People are trying to make a living and get through their lives.

INT: *Do you think there are a lot of barriers at other AIDS organizations to doing the kind of work that you did?*
TK: Absolutely, because business is seen as the enemy. Or business is so foreign that there's no way we can speak to them. When people here go to the breakfasts, they don't even know how to interact. Even I approached it too politely. We were treating them like they were gods or something. It was very weird.

So I think we need to be looking at them more as colleagues. They're not from another planet. It's true, when they do come to this office, they stick out. But it's a different uniform basically.

If a non-profit walks into a business and says, "We're not conforming to you," there's alienation right away. When I would go there, I would put on my suit. I would still talk the way I talk, and say what I wanted. But you have to set that up.

INT: *Do you think there were barriers from their viewpoint too?*
TK: Sure, they had to understand what a non-profit was about. The human resource people understand non-profits a lot better, because they do a lot of charity work. They rely on agencies for other social issues that they deal with. But you have to educate executive staff about a community group's expertise.

I was not surprised about that. They've just never heard of us. They didn't hate us; they just didn't know we existed. When you sit there and outline your services, they're going, "Wow! Really?" They didn't have a clue about the scope of the work.

INT: *What do you identify as the key ingredient in the success of the project that you were working on?*
TK: Having some very powerful people—or at least people from companies that carry a lot of weight. But those people inevitably become your spokespersons. The Royal Bank knows that. We know that when Royal Bank's name is attached to something, it gets noticed. And they're willing to do that.

INT: *As you say, a lot of work hasn't been done in the business community. What kind of advice would you give to someone else doing similar kinds of work?*
TK: Get the business community together. Find your leaders who want to do this type of work. And I think you do need to do a survey or some kind of needs assessment of your community. That's key. It's like anything else, we need to be able to substantiate our claim. And people love to be surveyed.

INT: *So the coalition, in a lot of ways, acts as a bridge between the community-based organizations and the business community?*
TK: Oh yes. In fact, that's one of our mandates—to work in collaboration with local AIDS organizations.

INT: *So you see a lot of progress being made in the future?*
TK: Absolutely. And they want it too. It's been very interesting. I enjoy my work a lot—they're a neat group of people. I've had a good time and I've learned a lot.

REFLECTIONS Groups, Groups, Groups

Building societal support for HIV health has never been easy, but the story of the corporate breakfast reveals that success is possible when the approach and the strategy fit the situation. Terrah's scan of workplace HIV projects across North America in only a few days illustrates the importance of the study-plan-do aspects of this project. She was able to break down the apparent walls of denial in the corporate hierarchy by sorting out who was most predisposed to support HIV policies in the workplace. Enabling the personnel managers to take on further development of the corporate contribution to HIV health promotion was the next significant step. That involved another stage of study-plan-do.

Focusing on the social causes of AIDS sometimes triggers feelings of vertigo, as if there is no firm ground in sight. Hard-won rules for living in an HIV-endemic world still apply, but safer sex, clean needles and condoms no longer seem to be enough to manage the epidemic. HIV health promotion may need to challenge society's most entrenched forces in order to make headway. Issues of race, gender and sexual orientation are looming larger on a politically charged AIDS landscape where HIV is not easily seen in social-environmental terms.

If stigma, discrimination and oppression set up conditions for HIV transmission and illness, then what kind of AIDS work should we be doing? A few important details about society may help you to get your bearings. To do anything about the social causes of HIV, we have to apply what we know about the social determinants of health to the HIV situation.

TAKEN-FOR-GRANTED CONDITIONS OF LIFE

People living in abusive and discriminatory conditions often consider their lives to be normal or at least commonplace. We are all vulnerable to this reality in one way or another. To get along, people silence their feelings of oppression even though more critical reflection on everyday social relations would reveal all sorts of problems.

People are often less aware of bad social habits than personal ones. Anyone can see the potential danger of second-hand cigarette smoke, but it is more difficult to see a personal communication style that may well turn out to be offensive or damaging to others. Yet, to understand the ways in which people negotiate interpersonal status and power is to know the roots of HIV vulnerability.

Discriminatory and abusive power relations between men and women, men and men, women and women, or adults and children can set up conditions for HIV transmission. As experience from women's shelters has shown, being on the receiving end of abuse not only damages self-esteem but also encourages dysfunctional life patterns and habits. Gay men experience a similar phenomenon through the many guises of homophobia. Under such conditions, people find it difficult to be in control of their health.

So what do we do about it? It makes sense to look for and expose harmful, dysfunctional social conditions and show how they relate to HIV. But we really have to take our work a step further. To be transformative, we need to establish supportive strategies to create environments more conducive to health. As described in previous chapters, this is a task of building supportive networks.

A GROUP-BY-GROUP PROCESS

"Society" is too vast a landscape to navigate alone. Social transformation can, however, be managed—by working with groups. Enabling people to increase control over and improve their health would therefore be a group-by-group, wave-after-wave process.

Shared-but-unexamined beliefs about acceptable conduct, regardless of their moral, political or aesthetic foundations, create deeply felt affinities that shape much of our participation in society's groups—in politics, religion, even sports. Humanity is linked together in this way, group by group. But identification with groups also forms the basis for discrimination against others, and herein lies the cause of a good deal of social damage. Homophobia and HIV vulnerability are just two manifestations. Hate and violence come from the same mold.

Nevertheless, working with groups is the key that unlocks the potential for social transformation as a by-product of HIV health promotion. Experience from AIDS fieldwork shows that transformative effects occur when people are brought together in group environments that support them, despite their individual fears about HIV. Societal transformation is the ripple that starts with small-group transformations and spreads outward.

Society is not static. One of the more interesting theories of contemporary life is that we are witnessing an explosion of groups forming out of different kinds of social affinity. Earlier interpretations of society and culture based on class divisions, such as "labour/management" and "blue collar/white collar," have given way to a wider and potentially more valuable pattern. Studies of public opinion indicate that the kinds of popular music people listen to, for example, may define a vast network of significant cultures within society that cross class, ethnic and racial boundaries—think of the different lifestyles of people who listen to "country" or "rap."

Music is only one aspect of such diversity; many more are evident in fashion, art, religion and sexuality. Yet belief in a dominant society with all the gender assumptions it represents continues to prevail in spite of alternative arguments.

GROUP STRATEGY IS TRANSFORMATIONAL STRATEGY

What does this belief in a dominant society and its web of groups linked by various affinities mean for HIV health promotion? First, it means that society is anything but a monolith. It is, instead, the generalized expression of interrelated cultures and groups. Although certain groups may appear to agree on the existence of a primal order or a core set of values, each person's sense of what those values are can be very different.

A second realization is that subcultures and groups all have a shaky hold on their memberships. Forces that hold people together can vary without their sensing it in each other. This is strategic knowledge for health promotion. Without an understanding of a society composed of evolving and diverse cultures and groups, the project of HIV health promotion would be overwhelming and hopeless.

The reality is that people are influenced by more than one culture or group. Unfortunately, AIDS workers often experience such multiple memberships as multiple oppression. The disadvantaged of society are marginalized so well that they may be confined to several dysfunctional cultures at once. Frontline AIDS workers often see this as a web of health issues and vulnerabilities describing a single person. An "adolescent male survivor of sexual abuse, street-involved, drug user, mentally challenged, sex worker having sex with other men" serves as a poignant example.

The more advantaged in a society are also affected by multiple group affinities. It is possible, therefore, to find people predisposed to change within the ranks of traditionally conservative social groups. In the health-care system, for example, medical professionals are sometimes regarded as bastions of conservatism. Yet we also find physicians willing to be in the HIV vanguard.

FINDING AND ENABLING THOSE WHO WILL HELP

In practical terms, the first real step of societal transformation is searching out predisposed people—those who already see the need but have no support to develop a serious initiative. The next step is to bring the predisposed individuals together into a supportive group where experience can be shared.

Field experience suggests that finding predisposed individuals is a creative and challenging task for a community AIDS organizer who must draw people out by setting up expectations.

In this chapter's case story, human resource managers in the corporate community were, in a sense, waiting for more support from AIDS agencies. Because human resource managers are responsible for employees who disclose their HIV-serostatus (or who begin to experience symptoms of HIV disease), they were already predisposed to hearing more about how to handle workplace HIV issues.

The responsive AIDS worker set out to change the human resource managers' stereotyped image of community AIDS work. The managers were presented with a professional image. They were offered realistic opportunities to learn about HIV during a short information session. The breakfast format suited their busy schedules in a voluntary time slot. The AIDS organization even took care of the meal bill.

LINKING PEOPLE FACE-TO-FACE

Nothing is more exciting than linking people with a common cause who have been previously alienated by circumstance. This can be an important moment and is certainly a critical step in the transformative process. The challenge for an HIV health promoter is to shift a group's potential into real empowerment. Creating supportive conditions is part of the group's learning process and, ultimately, the group's responsibility.

PRACTICAL FIELDWORK Planning a Corporate Breakfast

As the case story shows, bringing local businesses together to provide support and direction on dealing with HIV/AIDS in the workplace is a good idea that can only get easier to implement as time goes on. In Canada, corporate leadership is provided by the Workplace AIDS Coalition. You can look to this group for advice and support in working with your local business community.

The corporate breakfast is a useful way to highlight the business focus of HIV/AIDS on World AIDS Day or another similar occasion. Here are some of the main organizing points for the breakfast:

- Obtain lists of employers in the city or region from the library or city hall.
- Address mailings to the manager in charge of personnel by name.
- In the first mailing, include a reprint of a business story about AIDS, other helpful material and a covering letter.
- In the second mailing, send the invitation to the breakfast. It must look professional.
- Choose a speaker who is accepted as a leader by the business community. The Workplace AIDS Coalition can help you find someone.
- Use a downtown hotel for the venue.
- Link the event to an occasion such as World AIDS Day.
- Schedule the breakfast from 7:00 to 8:30 a.m.

Use the occasion to form a local division of the Workplace AIDS Coalition and to link people into other, wider initiatives.

EPILOGUE

Uncertainty has been and continues to be one of the confounding realities of HIV and AIDS. Promising new treatments capable of slowing down the progression of HIV illness are on the horizon. For some people involved in the trials, the reversals have been more dramatic than anything to date. Yet, little is known of the long-term effects of new medications. More troubling is their high cost and thus their lack of affordability for both individuals and the public health system. These are emerging issues for HIV health promotion: advocacy within the health system to ensure access to treatment and efforts to enable people on the rebound to recover meaningful lives and careers.

Some of the uncertainties that lie ahead are clearly economic, such as stable public funding. Shifting health policy may pose problems for community-based AIDS agencies that continue to require government funds to operate. But these in themselves are advocacy challenges for which transformational health, with its firm grounding in evidence from the field, will become a useful and increasingly strategic tool.

As governments everywhere attempt to contain costs, the language of social policy has gradually become one of economics. Social programs, once seen as necessary "expenditures" to maintain civil society, are now seen as economic "losses." The essential contribution health makes to a thriving economy must now be justified as "investment," and decisions about where to invest must be based on "evidence." From where, one might ask, will this evidence come? In all likelihood, health systems will need to rely on information from frontline community agencies exploring and evaluating the best and often cheapest practice in managing HIV in their communities.

So much remains possible, both to reduce the threat of HIV and to alter underlying conditions of vulnerability, through community-based efforts. Now that a community-based infrastructure has been created worldwide, the potential to develop even further is on the horizon. Social transformation is both the challenge and the motivation. But it can happen only by building within community agencies the capacity to manage local HIV situations. To get there means playing a serious role in knowledge gathering on the local scene by monitoring the upstream, midstream and downstream realities of HIV health.

What transformational health will bring to the policy table is the *evidence of real HIV experience* in vulnerable populations. Enhancing the capacities of AIDS agencies to listen, document and analyze the experience of HIV in their communities will at the same time build their capacities to present the evidence required for appropriate policy. Everyone working in community AIDS work can participate by increasing their own study-plan-do skills. This will be an exciting development to watch and evaluate in the coming years.

Even so, the advocacy challenges that lie ahead are only one element of the future of transformational health. The more immediate and visible transformations will be those that appear in communities, agencies and the people who take on the challenge of a systematic approach to HIV health promotion. That horizon is already visible in the work of many of those who contributed to the *Field Guide* by

- the depth of their effects on policy in the health system;
- the forging of alliances with health-care professionals;
- the creation of corporate partnerships and sponsors;
- the designing of social-environmental approaches to HIV prevention;
- the alignment of community support services to meet the challenges of changing HIV conditions.

The future promises so much more as experience with the model grows and contributes to the expanding dialogue on best practice in community AIDS work.

That dialogue has already extended around the world. At the Community Forum of the XIth International Conference on AIDS held in Vancouver in 1996, 500 delegates from five global regions met to confer on important issues for the development of community-based AIDS agencies. One of the main themes was the integration of social research and evaluation into the frontline programs and practices of community-based agencies.

The following statements were recorded during two full days of meeting together and working through a resolution-building process, not unlike a long series of focus groups.

"Research is a learning process where knowledge is created by all actors involved: researchers, community, funders and government."

"The knowledge of social research is essential for successful HIV health promotion programs."

"The focus of social research is the dynamic relationship between behaviour and social environment and not individual behaviour alone."

"Building the capacity of community organizations to do social research increases their general capacities as community agencies."

"Governments should recognize that quality research makes quality health policy."

"Community organizations should integrate social research into their program activities."

"Special attention should be given to developing knowledge surrounding secondary prevention (midstream health promotion) for people living with HIV/AIDS."

"Communities should continue to validate their research by documenting, reporting and disseminating their findings through their own publications and audiovisual materials."

The forum experience made it clear that a growing number of agencies around the world appreciate community AIDS work as a formal practice and are actively engaged in developing their organizations using social research to master the process. In addition, these "researching" community organizations want to network internationally to develop the field, to consult on design and methodology, to access this knowledge and to formally publish the results of community-based study-plan-do experiences.

These developments are arriving at a crucial time in the history of HIV/AIDS in the world. Not only is the experience of connection and common purpose developing as never before, but so is consensus about the focus and methods of community-based AIDS work. In this way, transformational health, with its emphasis on method, practice and social environment—study-plan-do and the practice environments—arrives on the scene in good time.

The future, in this respect at least, offers some certainty. The dialogue created as community agencies everywhere pick up the challenge of study-plan-do in their field practice will be transformative on a global scale. And the richest experience of all will be being there, doing it.

REFERENCES

Allers, C., et al. "HIV Vulnerability and the Adult Survivor of Childhood Sexual Abuse." *Child Abuse and Neglect*, vol. 15 (1993).

Andreason, A. *Marketing Social Change.* San Francisco: Jossey-Bass, 1995.

Bailey, K. *Methods of Social Research.* New York: Free Press, 1978.

Bandura, A. "Perceived Self-efficacy in the Exercise of Control Over AIDS Infection." *Evaluation and Program Planning*, vol. 13 (1990).

Bernstein, N. "Teen Sex Wars: Learning to Love." *Mother Jones*, February 1995.

British Columbia's Women's Hospital and Health Society. "The Challenges Ahead for Women's Health." Vancouver: British Columbia's Women's Hospital and Health Society, 1995.

Brodkey, H. "Dying: An Update." *The New Yorker*, February 7, 1994.

Bull, C. and J. Gallagher. "AIDS Education, Why It's Not Working: The Lost Generation." *The Advocate*, May 31, 1994.

Bunton, R., S. Nettleton and R. Bùrrows, eds. *The Sociology of Health Promotion: Critical Analyses of Consumption, Lifestyle and Risk.* London: Routledge, 1995.

Center for AIDS Prevention Studies. "Are Informal Caregivers Important in AIDS Care?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1996.

——. "Can Clinicians Help with HIV Prevention?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Can HIV Prevention Make a Difference for Men Who Have Sex With Men?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Can Theory Help in HIV Prevention?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Do Condoms Work?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Does HIV Prevention Work?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Does Needle Exchange Work?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Does Sex Education Work?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "Is HIV Prevention a Good Investment?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center For AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "What Are Adolescents' HIV Prevention Needs?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "What Are Inmates' Prevention Needs?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center For AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "What Are Women's HIV Prevention Needs?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "What Are Young Gay Men's Prevention Needs?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

——. "What Is HIV Testing's Role in HIV Prevention?" *HIV Prevention: Looking Back, Looking Ahead.* San Francisco: Center for AIDS Prevention Studies, University of California, San Francisco, and Harvard AIDS Institute, 1995.

Centre for Health Promotion. *Health Promotion Knowledge Development Study.* Toronto: Centre for Health Promotion, University of Toronto, 1993.

Choi, K. and T. Coates. "Prevention of HIV Infection." *Current Science* 8 no. 10 (1994).

Community Research Initiative of Toronto. "A Workbook for Community-based Research." Toronto: Community Research Initiative of Toronto, 1996.

Csikszentmihalyi, M. *Flow: The Psychology of Optimal Experience.* New York: Harper and Row, 1990.

Darroch, V. and R. Silvers. *Interpretive Human Studies: An Introduction to Phenomenological Research.* Washington DC: University Press of America, 1982.

Darroch-Lozowski, V. "Body: The Attainable Border of Semiotics." Paper presented at the Semiotics as a Bridge Between the Humanities and the Sciences Conference, Toronto, November 1995.

Dobie, K. "Teen Sex Wars: Hellbent on Redemption." *Mother Jones,* February 1995.

Drucker, P. "The Age of Social Transformation." *The Atlantic Monthly,* November 1994.

Evans, R. and G. Stoddart. "Producing Health, Consuming Health Care." Population Health Working Papers. Toronto: Canadian Institute for Advanced Research, 1990.

Evans, R., M. Barer and T. Marmor, eds. *Why Are Some People Healthy and Others Not?* New York: Aldine De Gruyter, 1994.

Evans, T. Review of *Why Are Some People Healthy and Others Not,* by R. Evans, M. Barer and T. Marmor, eds. *Health and Human Rights* 1 no. 2 (1995).

Federal, Provincial, Territorial Advisory Committee on Population Health. *Strategies for Population Health: Investing in the Health of Canadians.* Ottawa: Supply and Services Canada, 1994.

——. *Report on the Health of Canadians.* Ottawa: Supply and Services Canada, 1996.

Foucault, M. *Power/Knowledge: Selected Interviews and Other Writings 1972-1977.* New York: Pantheon, 1980.

Freire, P. *Pedagogy of the Oppressed.* New York: Seabury, 1970.

Gay and Lesbian Medical Association. *The Silent Crisis: Ongoing HIV Infections Among Gay Men, Bisexuals and Lesbians at Risk.* San Francisco: Gay and Lesbian Medical Association, 1995.

Glaser, B. and A. Strauss. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago: Aldine, 1967.

Goldstone, I. "Palliative Care for HIV Disease: The Desirable vs The Possible." *Journal of Palliative Care* 11 no. 2 (1995).

Goldstone, I., et al. "Patterns of Care in Advanced HIV Disease at a Tertiary Treatment Centre." *AIDS Care* 7 no. 1 (1995).

Green, L. and M. Kreuter. *Health Promotion Planning: An Educational and Environmental Approach.* Mountainview CA: Mayfield, 1991.

Green, L., et al. *Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada.* Vancouver: The Royal Society of Canada, 1995.

Greenfield, T. and P. Ribbins. *Greenfield on Educational Administration: Towards a Humane Science.* London: Routledge, 1994.

Gubrium, J. and J. Holstein. *Constructing the Life Course.* New York: General Hall, 1994.

——. "Interpretive Strategies for Qualitative Evaluation in Health Care." Paper presented at the 2nd International Conference on AIDS Home and Community Care, Montreal, 1995.

Hamilton, N. and T. Bhatti. "Population Health Promotion: An Integrated Model of Population Health and Health Promotion." Ottawa: Health Promotion Development Division, Health Canada, 1996.

Hancock, T. "Health, Human Development and the Community Ecosystem." *Health Promotion International* 8 no. 1 (1993).

Harvey, E. "Qualitative Research Investigating an

Outbreak of HIV Among Drug Users in Vancouver." Paper presented at the 9th Annual British Columbia HIV/AIDS Conference, Vancouver, 1995.

—. *You, Me & Reality: Youth Negotiating the Barriers to Safer Sex.* Vancouver: YouthCo AIDS Society, 1996.

Health and Welfare Canada. *Achieving Health for All: A Framework for Health Promotion.* Ottawa: Supply and Services, 1986.

Health Canada. "Government Response to the 8th Report of the Standing Committee on Health, A Study of the National AIDS Strategy: Report of the Sub-Committee on HIV/AIDS." Ottawa: HIV/AIDS Policy, Coordination and Programs Division, Health Canada, 1996.

Hogg, R., et al. "Impact of HIV Infection and AIDS on Death Rates in British Columbia and Canada." *Canadian Medical Association Journal* 150 no. 5 (1994).

Holstein, J. and J. Gubrium. "The Active Interview." In *Qualitative Research Methods Series.* Thousand Oaks CA: Sage, 1995.

Hopcke, R. *A Guided Tour of the Collected Works of C. G. Jung.* Boston: Shambhala, 1992.

Huber, J. and B. Schneider. *The Social Context of AIDS.* Newbury Park CA: Sage, 1992.

Isensee, R. "Dynamics in Gay Relationships." *Christopher Street*, vol. 136 (1994).

Jacobs, J. *Systems of Survival.* New York: Vintage Press, 1992.

Johnson, J. *Doing Field Research.* New York: Free Press, 1975.

Jung, C. *Psychology and Alchemy.* Princeton: Princeton University Press, 1968.

Ka'opua, L. *Training for Cultural Competence in the HIV Epidemic.* Honolulu: AIDS Education Project, University of Hawaii, 1992.

—. "Cultural Competence: A Challenge for Us All." Paper presented at the 9th Annual British Columbia HIV/AIDS Conference, Vancouver, 1995.

Kassirer, J. "The Next Transformation in the Delivery of Health Care." *The New England Journal of Medicine*, January 5, 1995.

Kinsman, G. "Managing AIDS Organizing: 'Consultation,' 'Partnership,' and the National AIDS Strategy." In *Organizing Dissent: Contemporary Social Movements in Theory and Practice*, edited by W. Carol. Victoria: Garamond, 1992.

Kirby, D. "Teen Sex Wars: Sex Miseducation." *Mother Jones*, February 1995.

Koesell, T., et al. "Selected Methodological Issues in Evaluating Community-based Health Promotion and Disease Prevention Programs." *Annual Review: Public Health*, vol. 13 (1992).

Kohak, E. *Idea and Experience.* Chicago: University of Chicago, 1978.

Kotler, P. and E. Roberto. *Social Marketing: Strategies for Changing Public Behavior.* New York: Free Press, 1989.

Kuhn, T. *The Structure of Scientific Revolutions.* Chicago: University of Chicago Press, 1970.

Labonté, R. "Community Development as a Professional and Organizational Practice." Paper presented at the 2nd Canadian Conference on Health Promotion Research, Vancouver, 1993.

—. "Health Promotion and Empowerment: Reflections on Professional Practice." *Health Education Quarterly* 21 no. 2 (1994).

—. *Health Promotion and Empowerment: Practice Frameworks.* Toronto: Centre for Health Promotion, University of Toronto, 1994.

Laing, R. *The Politics of Experience and The Bird of Paradise.* Harmondsworth: Penguin, 1967.

Luckmann, T., ed. *Phenomenology and Sociology*, New York: Penguin, 1978.

Mann, J. "AIDS in 1994: The Personal and Global Challenge of Renewal." Paper presented at the Xth International Conference on AIDS, Yokohama, 1994.

—. "The Next Step: AIDS, Communities and Human Rights." Paper presented at the 2nd International Conference on AIDS Home and Community Care, Montreal, 1995.

Mann, J., et al. "Health and Human Rights." *Health and Human Rights* 1 no. 1 (1994).

Manrell, T. "Care Teams: Going the Distance." *Volunteer Voice*, March 1996.

Marchand, R. and T. Trussler. "Participatory Research, Empowerment and Community Transformation." Paper presented at the 2nd International Conference on AIDS Home and Community Care, Montreal, 1995.

McKinlay, J. "The Promotion of Health Through Planned Sociopolitical Change: Challenges for Research and Policy." *Social Science Medicine* 36 no. 2 (1993).

McKnight, J. "Regenerating Community." *Social Policy*, Winter 1987.

Medical Research Council of Canada. *Investing in Canada's Health: A Strategic Plan for the Medical Research Council.* Ottawa: Supply and Services Canada, 1992.

Merson, M. "Returning Home: Reflections on the USA's Response to the HIV/AIDS Epidemic." *The Lancet,* vol. 347 (1996).

Mezirow, J., et al. *Fostering Critical Reflection in Adulthood: A Guide to Transformative and Emancipatory Learning.* San Francisco: Jossey-Bass, 1991.

Miller, R. and I. Miller. The Modern Alchemist: *A Guide to Personal Transformation.* Grand Rapids: Phanes, 1994.

Morris, M. *An Excursion into Creative Sociology.* New York: Columbia, 1977.

Mustard, F. and J. Frank. *The Determinants of Health.* Toronto: Canadian Institute for Advanced Research, 1991.

Myers, T., et al. *The Canadian Survey of Gay and Bisexual Men and HIV Infection: Men's Survey.* Ottawa: Canadian AIDS Society, 1993.

——. *First Nations AIDS and Healthy Lifestyles Survey.* Toronto: First Nations Steering Committee, 1993.

National Advisory Board on Science and Technology. *Healthy Wealthy and Wise: A Framework for an Integrated Federal Science and Technology Strategy.* Ottawa: National Advisory Board on Science and Technology, 1995.

National Minority AIDS Council. *Action Handbook for Boards.* Washington DC: Support Center for National Minority AIDS Council, 1995.

National Planning Forum For HIV/AIDS Research. *A Position Statement on the Essential Requirements of HIV/AIDS Research in Canada.* Ottawa: Health Canada, 1996.

Nutbeam, D. and V. Blakely. "The Concept of Health Promotion and AIDS Prevention. A Comprehensive and Integrated Basis for Action in the 1990s." *Health Promotion International* 5 no. 3 (1990).

Office of Health Promotion. "Our New Understanding of Health." Victoria: BC Ministry of Health, 1993.

Office of the Provincial Health Officer. "Health Goals for British Columbia: Identifying Priorities for a Healthy Population." Victoria: Province of British Columbia, 1995.

Patton, M. *Qualitative Evaluation Methods.* Beverly Hills: Sage, 1980.

Power, R. "Drug Use and AIDS: Macro and Micro Perspectives." Paper presented at the 9th Annual British Columbia HIV/AIDS Conference, Vancouver, 1995.

Prairie Region Health Promotion Research Centre. *Sharing Knowledge from Health Promotion Practice: Workshop Orientation Manual.* Saskatoon: Prairie Region Health Promotion Research Centre, 1994.

Project Access. "Final Report: Activities and Evaluation." Montreal: Project Access, 1996.

Putnam, R. "Bowling Alone: America's Declining Social Capital." *Journal of Democracy* 6 no.1 (1995).

Rhodes, T. "Researching Risk Behaviour: The Role of Qualitative Research." Paper presented at the 5th Annual Conference of the Canadian HIV/AIDS Research Association, Winnipeg, 1995.

Rhodes, T. and R. Hartnoll. *AIDS, Drugs and Prevention: Perspectives on Individual and Community Action.* London: Routledge, 1996.

Riley, D. "Harm Reduction: Policies and Practices." Paper presented at the 9th Annual British Columbia HIV/AIDS Conference, Vancouver, 1995.

Rotello, G. "Our Little Secret." *The Advocate,* April 15, 1996.

Schilder, A. *Canadian HIV Research and Its Leadership.* Ottawa: National Planning Forum for HIV/AIDS Research, 1996.

Schrag, C. *Experience and Being.* New York: Northwestern University Press, 1969.

Schutz, A. *The Phenomenology of the Social World.* New York: Northwestern University Press, 1967.

Sékaly, R. and D. Roy. "To Stifle HIV/AIDS Research Now Is to Imperil Society Today and Tomorrow." Montreal: Clinical Research Institute of Montreal, 1996.

Senge, P., et al. *The Fifth Discipline Fieldbook: Strategies and Tools for Building a Learning Organization.* New York: Doubleday, 1994.

Shilts R. *And the Band Played On: Politics, People and the AIDS Epidemic.* New York: St. Martin's Press, 1987.

Stachenko, S. "National Opportunities for Health Promotion: The Canadian Experience." *Health Promotion International* (1994).

Stoddart, G. and S. Birch. "Promoting Healthy Behaviours: The Importance of Economic Analysis in Policy Formulation for AIDS Prevention." Population Health Working Papers. Toronto: Canadian Institute for Advanced Research, 1990.

Strathdee, S. and M. Schecter. "The Epidemiology of HIV/AIDS in Canada: 1995." *Practical Allergy and Immunology* 10 no. 15 (1995).

Strub, S. "Fifty for the Future." *POZ*, February 1996.

Toubia, N. "From Health or Human Rights to Health and Human Rights: Where Do We Go From Here?" *Health and Human Rights* 1 no. 2 (1995).

Trotter, B., ed. and the New York People With Aids Coalition. "AIDS and the Transgender Community." *Newsline*, April 1996.

Trussler, T. "How Can We Be Sure We Aren't Creating the Risk Conditions We're Trying to Avoid?" Paper presented at the Canadian Public Health Association Conference, Edmonton, 1994.

——. "Revisioning AIDS Work." Paper presented at the Xth International Conference on AIDS, Yokohama, 1994.

——. "A Transformational Model of HIV Health Promotion." Paper presented at the 9th Annual British Columbia HIV/AIDS Conference, Vancouver, 1995.

——. "Methodological Foundations for a Participatory Model of Research in HIV Health Promotion." Paper presented at the 5th Annual Conference of the Canadian HIV/AIDS Research Association, Winnipeg, 1995.

——. "The Case for Participatory Evaluation in HIV Health Promotion." Paper presented at the 2nd International Conference on AIDS Home and Community Care, Montreal, 1995.

Trussler, T. and R. Marchand. *Taking Care of Each Other: Health Promotion in Community-based AIDS Work.* Vancouver: AIDS Vancouver, 1993.

——. *More Reflections on Taking Care of Each Other: Health Promotion in Community-based AIDS Work.* Vancouver: AIDS Vancouver, 1994.

Trussler, T., A. Wyness and I. Goldstone. "Community AIDS Work's Crossing into Nursing Education: A Case Story." Paper presented at the Crisis in the Human Services Conference, Cambridge, UK, 1996.

United Nations. *Strategic Plan 1996–2000.* New York: Joint United Nations Programme on HIV/AIDS, 1995.

Van Manen, M. *Researching Lived Experience: Human Science for an Action-Sensitive Pedagogy.* London: Althouse, 1994.

Veiel, H. "Childhood Abuse and HIV Infection in Homosexual Men: Review of the Literature." Vancouver: British Columbia Centre for Excellence in HIV/AIDS, 1995.

Ventura, M. "Dissed, Mythed and Totally Pissed: A Generation at Risk–The Age of Endarkenment." *Utne* Reader, July 1994.

Walinsky, A. "The Crisis of Public Order." *Atlantic Monthly*, July 1995.

Wallerstein, N. "Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs." *American Journal of Health Promotion* 6 no. 3 (1992).

Weir, J. "The Death of Safe Sex." *Details*, October 1995.

Whitehead, B. "The Failure of Sex Education." *The Atlantic Monthly*, October 1994.

Wilber, K. *A Brief History of Everything.* Boston: Shambhala, 1996.

Women's Research Centre. *Keeping On Track: An Evaluation Guide for Community Groups.* Vancouver: Women's Research Centre, 1990.

Wong, C. "Paradigms Lost: Examining the Impact of a Shift from Health Promotion to Population Health on HIV/AIDS Policy and Programs in Canada." Ottawa: The Canadian AIDS Society, 1996.

World Health Organization. *Ottawa Charter for Health Promotion.* Paper presented at the 1st International Conference on Health Promotion, Ottawa, 1986.

Wyness, A., et al. "Preparing to Care: Report on the Evaluation of an Undergraduate HIV/AIDS Elective: The Challenge of Caring." Vancouver: British Columbia Centre for Excellence in HIV/AIDS, 1996.

Zaner, R. *The Way of Phenomenology: Criticism as a Philosophical Discipline.* New, York: Bobbs-Merrill, 1970.

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WHAT IS HEALTH PROMOTION FOR COMMUNITY AIDS WORK?

HOW DOES HEALTH PROMOTION INFLUENCE SOCIAL ENVIRONMENTAL CAUSES OF HIV & AIDS?

HOW CAN COMMUNITY AIDS AGENCIES INCREASE THEIR CAPACITIES TO MANAGE THEIR LOCAL HIV SITUATION?

The *Field Guide* presents health promotion for populations affected by HIV and AIDS based on actual experience in community work from across Canada. Drawing on field studies, case stories, and a critical overview of health theory, the *Field Guide* assembles a practical model of HIV health promotion useful for everyone interested in community health work.

Three years in the making, the *Field Guide* is a product of a participatory research and development initiative known as the National Health Promotion Project — a creative collaboration between AIDS Vancouver, its partners in the Pacific AIDS Resource Centre, Health Canada and the member agencies of the Canadian AIDS Society.

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