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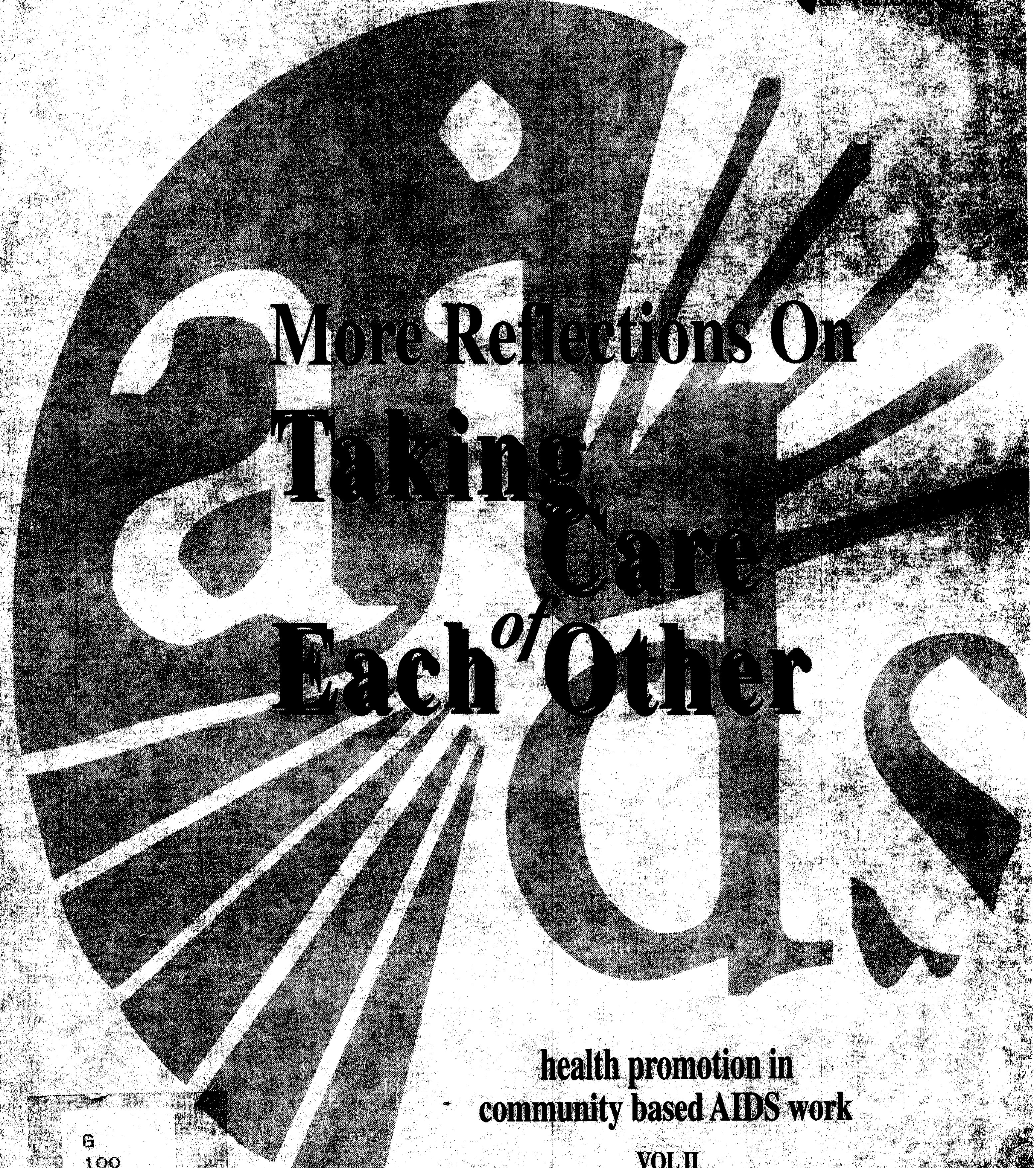

More Reflections On Taking Care of Each Other

health promotion in community based AIDS work

VOL II

Phillip

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Taking Care of Each Other

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This project was funded by the AIDS Education and Prevention Unit and the AIDS Care and Treatment Unit of Health Canada as an initiative of the National AIDS Strategy.

CANADIAN CATALOGUING IN PUBLICATION DATA

Trussler, Terry.
More reflections on taking care of each other

Includes bibliographical references.
ISBN 1-895922-03-8

1. AIDS (Disease) – Prevention. 2. Health promotion.
3. Community health services. I. Marchand, Richard, 1950-
II. AIDS Vancouver. III. Title.
RA644.A25T74 1994 362.1'969792 C94-910849-9

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Foreword

This is the report of a follow-up inquiry after *Taking Care Of Each Other: health promotion in community based AIDS work.* We were invited to take another look at health promotion, to explore how we would address HIV/AIDS prevention and its social context. Given the circumstances of the time, a period of profound self-questioning in AIDS work, this was a much needed experience.

The state of doubt we uncovered was not so surprising considering disappointing news on the scientific front and reports of a "second wave" of infection among young Americans. Even so, we found that, by surfacing the issues in the minds of those we spoke with, there were valuable lessons to be learned about what to do and where to go next.

The text of those we spoke with describes the experience of these times in a spirit of uncompromising truth. It is our feeling that there is little to be gained from restraint, given the atmosphere. Apparently, we are in the midst of a transition in AIDS work; early optimism about eliminating HIV is being replaced by steely determination to get on with the enormous challenge of survival in spite of it.

So this is the character and purpose of what follows. We are encouraged to have found, even in these depressing circumstances, hints of a renewed vision that will undoubtedly reshape AIDS work.

Vancouver,
August, 1994

Please Note
Certain passages within this document convey impressions of medical or scientific knowledge about HIV and AIDS in the speaker's own words and experience. Readers should keep in mind that such statements appear in the text to illustrate variances of belief and opinion among people involved in AIDS work on crucial issues of prevention, transmission, testing and illness progression. These are not to be taken as scientific arguments. Please refer to established guidelines of Health Canada and/or the Canadian AIDS Society for clarification.

Acknowledgements

We wrote *Taking Care of Each Other* as a starting point for a general dialogue on the practice and ethics of health promotion in community AIDS work. What happened exceeded all of our expectations. Discussions swept through the network of AIDS workers, health professionals, researchers and policy advisors across Canada, each voice adding new dimensions to the evolving consciousness of AIDS work.

Several people played key roles in moving from discussion to, *More Reflections* the sequel. Heidi Lieplold, of Health Canada's AIDS Education and Prevention Unit, challenged us to extend our analysis into prevention and the social environment. That turned out to be a formidable excursion with more travails and insights than we imagined. Bob Shearer, of the AIDS Care and Treatment Unit, offered us much needed support and encouragement along the way. None of the analysis would have been possible, of course, without those who offered us their experience of AIDS work: Gwen Bird, Claudia Brabazon, Moffat Clarke, Bill Coleman, Lesli Gaynor, Terrah Keener, Henry Koo, Ken Morrison and David Richardson. Thank you all.

The disciplines of research, writing and reflection behind *Taking Care of Each Other* owe their origins to a remarkable life-long dialogue with Vivian Darroch-Lozowski and Ron Silvers, dear friends and mentors to the way of inquiry. We were delighted to confer with Steffanie Strathdee on epidemiological issues. Erik Ages gave the text careful treatment with his even handed editing skills. And Michèle Lonsdale Smith has once again brought the text to a new level of clarity with her graphic treatment.

As with every descriptive inquiry, we recognize that the people who have contributed to this work are a selective sample which is not truly representative of the whole field of AIDS work. While the scope of a study like this is inherently limited by its scale, our intent is to encourage everyone concerned to join in the evolving dialogue on the nature of AIDS work.

Rick Marchand, PhD
Terry Trussler, EdD

Introduction

We'll live in the moment, and if we get HIV and start to get sick, we'll just kill ourselves.

When we undertook *Taking Care of Each Other*, our purpose was limited to outlining some precepts, informed by health promotion theory, that could be used to guide the development of community AIDS work. To get discussion going, we distributed copies of *Taking Care* through the national network of community organizations represented by the Canadian AIDS Society. We did not anticipate the overwhelming response that followed. The most promising feedback we have heard so far is that *Taking Care of Each Other* is finding a place in strategic planning for several community organizations across Canada.

The attention gained by *Taking Care of Each Other* also fostered interest in further research on a specific question, the inspiration behind this current text. Our new inquiry began with what seemed, at first, to be a simple enough question:

What would health promotion mean for HIV/AIDS prevention?

We were expressly asked to consider the impact and effects of the social environment on HIV/AIDS prevention. At the time, we had only inklings of how people in AIDS work might reflect their experiences with these issues. What we uncovered was somewhat unexpected.

To break into the front-line experience of prevention and its social environment, we approached eight AIDS workers, all leading voices in the field, for in-depth interviews following the same process as described in *Taking Care of Each Other*. Their material, *in italic text,* was extracted verbatim from transcripts of the interviews. Each worker was selected for his or her particular experience and perspective related to the questions we were asking. Over and above the interviews, we engaged in eight months of consultation, both within AIDS Vancouver and among many partners and advisors. We also consulted several outstanding articles from recent literature that helped to guide our analysis.

Everyone who participated in the interviews found the experience at least slightly discomforting. Little wonder, because the subject of HIV/AIDS prevention, especially the assumptions and methods, has never received so much intense questioning as during the time of this inquiry. We hope that our findings and analysis offer a worthwhile contribution to the ongoing discussion. Because we encouraged some very direct "truth telling" in our questions, the reader may find some of the material as "emotionally wrenching" as some of the participants found it. Although there has been no conscious effort to provoke, the material from the interviews is full of conflict, contrast and paradox.

The inquiry followed a similar process to *Taking Care of Each Other*. We posed a few consistent questions as a framework for otherwise free ranging interviews. The core questions were as follows:

- What worries you most about the current scene around HIV/AIDS?
- What is your sense of where we seem to be with prevention? Have we learned anything?
- What attitudes toward HIV/AIDS out there surprise you?
- What is your experience of the current climate of sexuality?
- What about the impact of community organizations?
- How would you do things differently?

Particularly well-formed or significant statements from each interview were extracted and assembled for analysis. The procedure was somewhat more extensive than the earlier work, owing to the complexity of the issues. This will become immediately apparent in the blocks of one-line statements that appear at the beginning and end of each chapter under the headings: *observations, theories and strategies*. Each one-line statement was taken from the interviews verbatim, or near verbatim, and assembled in a data base where they were coded and distributed into categories. This process created such a high relief picture of the collective subtext under discussion that it would have been remiss to exclude at least a sample of that material in the text.[1]

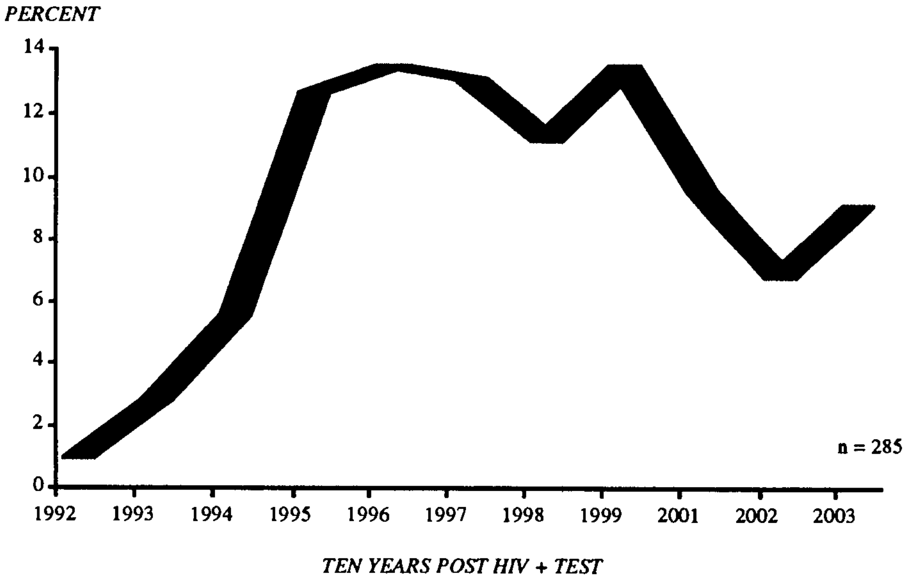
Although we were unaware of any particular pattern we were attempting to uncover in the analysis, we discovered, as each person dealt with the questions, that attention continuously shifted through three levels of understanding: observations, theories, and strategies. Such a finding is not at all unrelated to prevention and the influence of the social environment. Our contention is that everyone operates from their own common-sense theories about the world; these theories frame people's experience, their observations and strategies of existence.

In the age of AIDS, *how* people observe, theorize and operationalize their social existence is a crucial life issue affecting both the potential for HIV transmission and the quality of life for those living with HIV. In an overheated setting like AIDS work, people's observations, theories and strategies are continuously scripting collective reality, and with it the whole progress of AIDS work. Yet the "script" is rarely addressed explicitly. It takes the process of recording and transcribing to expose what is operative even to the speakers themselves. Here lies the significance of the research-consultation process in planning and strategy for the future of community AIDS work.

What you will see in *More Reflections* is a limited portrayal of the AIDS experience that a few people shared while dealing with difficult, unresolved social issues exposed by the epidemic. This material is very much situated in time: the winter of 1994. There is no better way to describe the character of that period than as a time of uncertainty. The air of disappointment following the release of scientific findings in June of 1993 at the 9th International Conference on AIDS in Berlin seems to have pervaded the whole field. At the same time, disturbing information about the impact and efficacy of prevention efforts has raised serious doubts about what to do next.

Meanwhile, the incidence of HIV infection continues to rise and the number of AIDS cases in Canada is expected to double in the next three years.[2] As if to make matters worse, community AIDS organizations all over North America are facing financial struggles, shortfalls and cutbacks. In partnership with the BC Centre For Excellence In HIV/AIDS and members of the Pacific AIDS Resource Centre, we have been able to assemble a picture of the current epidemiological situation as we know it:

Years of Need[3]



This line "the wave" represents a projection, ten years from the time of HIV positive tests, of a significant sample of BC PWA membership (1100). Ten years has been widely cited in research literature, such as the Vancouver Lymphadenopathy Study, as the median number of years from infection to the onset of AIDS symptoms. While theory of onset is still controversial, this representation is capable of assisting in planning community services.

Obviously, the looming specter of a rising wave of people entering the symptomatic phase of HIV has enormous implications for community AIDS work. The question about what to do is most pressing. The material contained in this volume is not intended to provide an answer; rather, it aims to describe where people are now in preparation for a renewal of strategy. Accomplishing that, we believe, will be nothing short of reinventing AIDS work.

---

[1] The style of inquiry explored in *Taking Care Of Each Other* finds its foundations in interpretive sociology which has a literature and tradition of its own, quite separate and distinct from social science. Some starting points for background reading:

Bogden, R. Taylor, S. *Introduction to Qualitative Research Methods.* NY, Wiley & Sons, 1975.

Darroch, V. Silvers, J. *Interpretive Human Studies, An Introduction to Phenomenological Research.* Washington DC, University Press of America, 1982.

Glaser, B. Strauss, A. *The Discovery of Grounded Theory: strategies for qualitative research.* Chicago: Aldine 1967.

[2] Letter from Steffanie Strathdee, Program Manager, BC Centre for Excellence in HIV/AIDS to Arn Schilder, Chairman BC persons With AIDS Society, October 19, 1993.

We have obtained estimates of HIV-infected persons in BC from a variety of sources: 1. seroprevalence studies from the 'general' population, 2. back-calculations using incidence rates from years past, and 3. provincial HIV testing results. All three methods have their drawbacks, but each is a way of validating the estimates obtained from the others.

Number of AIDS cases in Canada reported as of July 1993: 8,232
Believed number of AIDS cases (delays, underreporting): 12,000
Estimated number of HIV+ gay/bi men in Canada: 22,500
Estimated number of HIV+ women in Canada: 3,000
Number of AIDS cases reported in BC as of June 1993: 1,518
Estimated number of HIV infected in BC: 7,100

also cited in:
Strathdee, S. Schecter, M. Hogg, R. O'Shaughnessy, M. Current Trends in HIV/AIDS epidemiology in British Columbia. *BC Med J;* 1994,V36 N2.

[3] Schilder, A. de Haan, L. Hogg, R. Goldstone, I. Le, A. Craib, K. *Patterns of migration for persons with HIV/AIDS.* Vancouver PWA, British Columbia Centre for Excellence in HIV/AIDS, 1993.

In B.C., like other provinces in Canada, HIV/AIDS treatment and care is mainly available in large urban centres; p 2.

Social Environment

I have gotten to a place where I accept the world as absurd.

In the first decade, community organizations forced AIDS into public consciousness by raising the alarm about the possibility of a deadly infection in our midst. When, for instance, the gay community in Vancouver became aware of the potential danger to the blood supply, volunteers put up signs in bars and baths warning patrons against donating blood, even before the cause of the new illness was understood. Measures like these, followed by *safer sex* campaigns, must have saved countless lives. Even so, such efforts seem to have awakened society to a world of unexamined social issues.

Seeing the health impact of the social environment has never been very difficult for anyone sensitive to the AIDS experience. Although, in theory, everyone is equally vulnerable to HIV infection, we have always understood, viscerally at least, that the people who get AIDS somehow represent, in one way or another, the margins of social order. And those who do not normally think of themselves as marginal soon do if HIV antibodies are discovered in their blood.

Certainly, the behavioural view of HIV/AIDS provides a more neutral explanation: the risk of infection is increased with known risk activities. A decade of safer sex and clean needle campaigns leapt into being on the foundation of this assumption. We can only presume that all the scattered but intense prevention initiatives provided the critical information people needed to avert massive rates of infection.

We should not forget, though, that the behavioural idea was a leap from GRID (gay-related immune deficiency), the provisional name given to AIDS early in the epidemic. In those times, anti-infection campaigns targeted known risk *groups*. It took considerable pressure from gay communities to rename the illness and shift attention to *activities*. Developments in HIV theory supported the behavioural view so completely that the concept of risk activities was easily established, with the exception of a persistent faction of the "politically incorrect" who insisted that AIDS was a "gay disease."

Meanwhile, we have only just begun to grapple with current information about new infections. Although the evidence we have is confounded by the uneven availability of HIV testing, the lack of confirmable HIV statistics and the weak state of HIV knowledge, new infections seem to have remained a "gay" phenomenon, with the exception of rising rates among heterosexual women. In light of the epidemiological picture, many AIDS workers have begun to wonder whether AIDS may really be a "gay disease" after all.

This experience, combined with global findings on the social determinants of health, builds up a profound synthesis on the relationship between the social environment and AIDS. It is a complex subject, and one which necessitates the expansion of our discussion of health promotion to actually address the substance of this growing awareness. If we accept world-wide epidemiological data which tell us that social status, irrespective of financial means, is as much of a health factor as smoking or exercise, no wonder that abused women, gay men, and drug users get AIDS.[1]

This new wave of thinking does not necessarily negate what we already know about the behavioural and viral causes of AIDS. But connecting this knowledge with social determinants explains why AIDS has become the primary health concern of gay people, even though it is not exclusively a gay disease. Moreover, the very real evidence that HIV does not discriminate or exclude anyone only serves to strengthen the socioenvironmental view that illness may well be a manifestation of social conditions exercised through such forces as rank, esteem, power and authority.[2]

We have already begun to embrace the notion of "supportive environments" in AIDS work, based on our intuitive experience that such conditions promote health. We have also noticed a strong association between commonplace social reactions to AIDS and homophobia. These experiences, and many more specific observations which will be presented in this document, open up channels of action for AIDS work which are far more comprehensive than earlier behavioural or virus-based education and health promotion efforts.

In the following segments we will encounter three contexts of the social environment: society, core community and organization. We found, as our interviewees spoke from their experience about the state of prevention, that their appreciation of the situation continuously shifted in reference to these three contexts. If we accept that the influence of social context is inescapable, it follows that the way we must address AIDS beyond risk **behaviour** is to act on the risk **conditions** which find expression in social forces found in each context.

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[1] Mustard, F. J., Frank, J. *The Determinants of Health.* Canadian Institute for Advanced Research, 1991.

Whatever is "going around," people in lower social positions tend to get more of it, and to die earlier — *even after adjustments for the effects of specific and individual behaviour* or environmental hazards; p14.

It also raises the possibility that disease-specific policy responses — through health care, public health programs or otherwise — may not reach deeply enough to have much effect. Even if one "disease" is "cured" by such responses, another could well take its place; p14.

Specific links to HIV/AIDS are an interpretation of this text.

[2] *ibid.*

The above, and other similar research, leads to the 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; p15.

Society

The most disheartening thing I hear is: "What do these AIDS people want?"

OBSERVATIONS

- *In terms of all the social problems that AIDS has expressed, nothing has been solved.*
- *Heterosexual men have all the power in our society and they are the least involved.*
- *I'm really amazed at the lack of concern for the people who've become infected and died.*
- *It scares me that we don't have the support of the wider culture.*
- *Canada spends pathetically on research and development.*
- *Of all schools of social work in the country, only a few have HIV in their curriculum.*
- *There is still a belief that AIDS is a white man's disease.*
- *The Asian medical community doesn't want to deal with the AIDS issue.*
- *Now we are seeing people die in droves and nothing much changes, it's just disregarded.*

So far, AIDS has become "household" knowledge because of the perceived threat, media attention and community efforts to raise awareness through devices like The Quilt, AIDS Walks and the Red Ribbon. Gradually, a noticeable shift of sympathies has occurred, presumably as more and more people have become affected in one way or another. Even so, AIDS stigma remains entrenched in society, affecting everything from the scattered acceptance of safer sex among heterosexual men to the adequacy of community fundraising. Objections raised in Parliament to the attendance of foreign HIV positive delegates to the 1996 International Conference in Vancouver only confirms that the state of social acceptance is far from desirable.

Although phobic reaction, degrading attitudes and negligence are still commonplace, we have scarcely encountered the way in which these conditions, all socially exercised, influence the health of AIDS affected communities as well as society in general.[1] Little wonder, because dealing with HIV infection and living with HIV have been overwhelming if not exhausting experiences.

Nevertheless, it is becoming clearer that stigma presents a serious challenge to the health of HIV/AIDS affected communities and so to their health promotion. To answer these challenges, we have to overcome deeply entrenched beliefs and taboos which are upheld and promulgated by governments, corporations, churches, schools and families — all of which impinge on the health of AIDS affected people, and ultimately everyone.[2]

Here is how our interviewees described the state of HIV/AIDS in society.

> *I wonder what's going to happen to the kind of place where we live, the society we live in? I don't see fewer and fewer people affected. I see more and more. I see more and more people becoming infected. So I become concerned about how this is changing the way people live their lives.*

In one sense, AIDS has become so commonplace that it is glossed over...

> *My concern is that AIDS used to jar people into consciousness. When we started seeing people on television die from AIDS, when we started hearing about condoms or cleaning needles, it meant something. But now that we are seeing people die in droves and nothing much changes around us, it's just disregarded.*

The impact is never felt, so it seems, until AIDS is personal.

> *A human resources manager had been getting anonymous phone calls, always from men who have HIV and didn't know what to do about it. Then she got a call from a woman who was totally wrecked on the phone. She said, "I have HIV. I found out when I lost my child. My child had HIV. I feel fine, but I'm an emotional wreck and I don't know what to do." The manager couldn't get her to leave her name, and doesn't know where she is. She just hung up. The woman who received the call said she never felt so helpless in her life. Ever. That, for her, was the turning point.*

What seems to be underlying almost everything about the social response to AIDS, even beyond the dictates of religion, are deeply rooted, dark misgivings about sexual drive.

> *We live in a culture that instills neurosis about sexuality.*
>
> *Because we are so up-tight about sex, can't talk about sex, we can't experience sex freely and openly. Our culture teaches us that. It's all hidden, dirty, bad, naughty. It's not that it's a fun and exciting form of sharing that's fulfilling, or rewarding. Those aren't the ways that sex is really talked about in our society. I think sex is the central issue.*

> *Buddhism doesn't talk about or negate homosexuality; Christianity does so, and openly.*
>
> *Going to Catholic school, I was torn about being gay, knowing it was unacceptable.*
>
> *It worries me that heterosexuals still find it difficult to speak about sex openly; it makes them so vulnerable.*

The paradox of a society that so freely exploits the allure of sex, but which is also deeply constrained about its avenues of expression, suggests fertile ground for a venture into health promotion. Yet, some see a less direct approach.

> *Our general strategy is to get AIDS accepted as a health issue, a less threatening approach than bringing in all the taboos, like drugs and homosexuality.*

Even if we believe that confronting homophobia and sexual values in general would create a healthier environment for all, time might be our greatest foe.

> *We could spend a lot of time, energy and money trying to get the infrastructure in place so that social change can move forward, so that a more healthy environment gets created for people. But the benefits of that approach are decades down the road.*

THEORIES

- *In the social realm, AIDS causes nothing directly itself but is the author of causes.*
- *Unless you've been directly affected, you don't really feel the need for AIDS education.*
- *As people become more saturated with AIDS, they become immune to others' suffering.*
- *The search for a magic bullet to deal with HIV fails to deal with most of the problems.*
- *For things to change, AIDS has to be perceived as everyone's concern.*
- *Our culture is erotiphobic; as a culture, we're sexually unsophisticated.*
- *Not being able to talk about their sexual problems is what leads people into trouble.*

STRATEGIES

- *Accepted as a health issue, AIDS is less threatening than drugs and homosexuality.*
- *The access point may be sex. What we are really after is social change.*
- *We have to get to see that sex is just another human behaviour that people engage in.*
- *We have to take sexuality out of the closet; nobody else will, except us fags and dykes.*

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[1] Mustard, F. J., Frank, J. *The Determinants of Health.* Canadian Institute for Advanced Research, 1991.

Although the exact pathways and biological mechanisms are not yet completely clear, there is growing laboratory and clinical evidence that emotions and mental function working through the nervous system impact on host defense mechanisms and directly affect well being; p21.

[2] *ibid.*

It follows that the determinants of health are not just a problem of some poor, deprived minority whose situation can be deplored and ignored by the rest of us. De te fabula narratur, we are all (or most of us) affected, and this in turn implies that the effects of such factors may be quantitatively very significant for the overall health status of modern populations. *The issues involved are not trivial, second or third order effects*; p13.

Core Community

We have incredible health problems across the board; then we sort of added HIV on.

OBSERVATIONS

- *I was more optimistic about the gay community within Canadian culture prior to AIDS.*
- *62% said more good than bad has been done to the gay community as a result of AIDS.*
- *For many, the whole idea of gay liberation means sex whenever they want it. I disagree.*
- *I see this juxtaposition in the gay community between sex and death.*
- *We've seen strength where we thought there was no strength.*
- *Generally speaking, we are seeing a schism between positive and negative people.*
- *Viral apartheid: people are becoming more selective as the epidemic progresses.*
- *Positives want to develop both sexual and life relationships with other positive people.*
- *Historically, we have never given ourselves any sort of recognition.*

Most HIV/AIDS prevention and support programs in Canada have arisen from self initiating community groups. As time went on through the first decade, new groups developed as specific needs were recognized in response to issues of culture or language. Ethnocultural, aboriginal and other culturally specific AIDS groups proliferated in this way. In another trend, AIDS groups developed regionally to support local or rural populations outside of the major urban centres. Some groups got their start within major AIDS service organizations (ASOs), and others developed from their own separate initiatives. All start-ups were seen to be ways of strengthening the overall prevention effort by extending the reach in the most effective, community-inspired way. Few foresaw the long range problem of continuous funding for such expansion.

Perhaps this situation developed from the way in which HIV/AIDS prevention was theorized as a problem of information which could be made appropriate for a specific community by members of that community. This being done, the work could end. Now, as we awaken to the idea that HIV/AIDS transmission may be as much a problem of social conditions as of specific risk behaviour, the long range consequences are inescapable. Even if a cure for AIDS can be found, risk conditions may persist that could eventually lead to other illnesses.

The oldest ASOs, AIDS Vancouver among them, arose from gay communities early in the epidemic. The experience of isolation and inattention was a set-up for an organizational response that went in all directions to raise awareness of the HIV threat to society as much as to the specific communities from which they originated. Gay men became a "target population" of those organizational efforts with their own specific message.[1] As the epidemic progressed, major ASOs have become quite skilled at tailoring messages for specific groups, such as schools and workplaces. The unforeseen consequence, however, has been a kind of institutionalization of AIDS work that has distanced community organizations from their original constituent communities.

As HIV theory developed, few could predict that HIV/AIDS would remain such a predominantly gay phenomenon.[2] Although the true extent of seroconversion continues to be difficult to assess due to the uneven state of HIV testing and reporting, the overwhelming majority of those who are HIV positive, and those who are at risk, are apparently gay.[3] Even so, at least one critic has pointed out a general trend toward the "de-gaying of AIDS," citing funding statistics from across the industrialized world.[4]

Among the many ironies of the situation, AIDS organizations are often seen from the outside as largely gay organizations. This became abundantly clear through a recent, spurious episode in the Vancouver press when an avowed heterosexual man complained of being sexually harassed by other men while accepting support services from the British Columbia Persons With AIDS Society. The obvious homophobia of his "they tried to convert me" statement was not even addressed in the press report.

These circumstances, along with research information about the state of gay sexuality from the *Men's Survey* (1993) and a variety of observations under general discussion, raise a mountain of new questions about the state of core communities that originated AIDS organizations as we know them.[5]

Certainly, the state of gay communities was a preoccupation of everyone we spoke with.

The positive effects of community development are recognized…

> *As gay men, we have learned that the world our families promised us is not real. We've learned that there's an essential feeling of longing that many, and I would say all gay men feel, and lesbians as well. As they are coming to terms with who they are, many gay people feel this spirit of longing; it becomes central to their existence, and can be a very strong asset in the face of adversity. We've made small inroads on capitalizing on and exploiting that strength. That is the bright spark in all of this.*

But the persistent health problem may not even have originated with HIV.

> *We have incredible health problems across the board. And then we sort of added HIV on. Well, the addition of HIV is not a simple one. It's also a reflection of where we are as community, and as individuals in a community....*
>
> *As a community, we've got a generalized, depleted immune system. And all the search around a magic bullet to deal with HIV is not dealing with most of the problems we need to deal with.*

Some already see fatalism creeping in.

> *People who think they're likely to become infected may make certain choices and decide, ultimately, that they don't care whether or not they become infected. They may start seeing their lives as simply playing out for twenty or thirty years.*
>
> *I see this juxtaposition in the gay community between sex and death. I was in Montreal recently, and I walked into all the bars, where mirrors invited you to see the urinals on the ceiling; there were photos of naked guys with hardons, and there were table dancers. In the midst of all this, there was a pamphlet on the bar about "dealing with your own death."*

Educators are already seeing the limitations of "safer sex" information...

> *It's quite clear to me that in terms of the gay community we need a more vivid understanding of what sexual dynamics are all about — the subjective as opposed to the objective realities of sex. I think we're also realizing that sex doesn't take place in a vacuum. People with real, whole lives engage in sexual activity. What is the relationship of our sex lives to the rest of our lives?*

...and that social realities provide a potent backdrop for vulnerability to transmission and progression.[6]

> *Everything is stacked up against gay men. You have a culture which disapproves of us. We have individual self esteem and body image issues that develop as a result of internalized homophobia, and so on. And our culture is erotiphobic; it doesn't want to talk about sex, particularly between gay men. The gay community mirrors this to some extent.*
>
> *As gay men, a lot of us want acceptance too much; so we conform, thinking we will fit in with it all. When the message is that you're bad, and you're wrong, and you're evil, there's an unconscious response to comply. This means getting infected, being sick, and suffering, and dying. That's the message society gives, and I think a lot of men take it in.*

What to do about the circumstance of the gay position in society as it relates to risk conditions for HIV transmission and AIDS is almost too overwhelming to contemplate, given continual episodes of anti-gay violence in the streets and verbal attacks by fundamentalist church leaders. Optimistic observers would point to the social change which has already happened as a result of AIDS. Yet, it is clear to everyone that real change may take lifetimes.

> *There are two basic social recognition forms. One is money. The other is space. But none of this is tied up to the work we do around community development. Historically, we've never given ourselves any sort of recognition.*

In the meantime, the way out may involve a renewed approach to community development that may feature HIV or AIDS, but in a more general approach to community health. We need to secure a positive social environment by co-creating a supportive community. The most obvious issues to work on: the apparent HIV positive/negative split, same-sex partners, supportive community centres, disaffected gay youth and so on...

> *A lot of gay Asians are not out to their families. This says a lot about their sexuality.*
>
> *If we can't change society, we can change the way we in the gay community see, and talk about, sex. This would be a more obtainable goal, and won't be as threatening to everybody else.*

THEORIES

- *As gay men, we want acceptance too much, so we conform, thinking we will fit in.*
- *In a time of so much dying, the gay community has developed its consciousness.*
- *I used to think our culture's control of gay people was unwitting and unintentional.*
- *It's not about money, but about public acknowledgment that the gay community exists.*
- *Gay community is similar to what it must be like to live in a war zone for your entire life.*
- *Their shame is the feeling they have tattooed on their forehead: "I get fucked in the ass."*
- *Society disapproves of us; individual self-esteem and body image issues result.*
- *We have a closeting of our sexuality as result of what is happening.*
- *People who think they're likely to become infected may decide that they don't care.*

STRATEGIES

- *A rule about dealing with Asian cultures: first make them feel good about being gay.*
- *If we can't change society, we can change the way we in the gay community see sex.*
- *We need smaller community groups that seem more informal.*

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[1] Odets, W. *AIDS Education and Prevention: Why it has gone almost completely wrong and some things we can do about it.* Paper delivered at National Gay and Lesbian Health Conference, Houston July 23, 1993.

Our model for prevention since the early days of the epidemic has remained unchanged and it is worth briefly outlining it. It is a public health model that espouses information and education as the foundation of behaviour change, and for those not persuaded by good sense alone into behaving differently, the power of social compliance. Most people will comply with peer norms, regardless of what they make of information, and education can create"community standards of behaviour." While this public health approach is not worthless, it is also not brimming with psychological insight regarding the most complex and subtle of human behaviours, sexuality. Nor does it address the complexity of feelings, conscious and unconscious, which must inevitably occur during life in an epidemic; p5.

[2] Mustard, F. J., Frank, J. *The Determinants of Health.* Canadian Institute for Advanced Research, 1991.

...much of the potentially remedial burden of ill health in modern society is not restricted to the most marginalized and disadvantaged segments of society. As with many other situations in the health of populations, a good deal of this burden arises from the large numbers of persons who are only somewhat deprived in their personal and material lives, as opposed to the much smaller number of persons who are relatively severely affected; p39.

[3] Odets, W. *AIDS Education and Prevention: Why it has gone almost completely wrong and some things we can do about it.* Paper delivered at National Gay and Lesbian Health Conference, Houston July 23, 1993.

A shocking measure of the social realities with which we now live is revealed in a simple figure that no-one dares to utter out loud: Today the average life expectancy of a San Francisco gay man between the ages of 16 and 24 is somewhere in the *mid-thirties.* About 40 years short of what we have been enculturated to expect: 45% of the normal male lifespan in the U.S.; p2.

[4] Horton, M. *Homosexually active men and the evolving global epidemic of HIV.* Paper delivered at the 9th International Conference on AIDS; Berlin, June 1993.

[5] Odets, W. AIDS Education and Prevention: *Why it has gone almost completely wrong and some things we can do about it.* Paper delivered at National Gay and Lesbian Health Conference, Houston July 23, 1993.

Our AIDS prevention work has not always been completely wrong. But in 1993 there are historical, medical, social and psychological issues that have converged to make the responsibilities, task and approach of AIDS education a completely new one... At best, AIDS education has entered a period of profound relapse, and that we cannot correct by repeating what we have done or doing that more stridently; p1.

[6] Hogg, R. Strathdee, S. Craib, K. O'Shaughnessy, M. Montaner, J. Schecter, M. Lower socioeconomic status and shorter survival following HIV infection. *Lancet* 1994. (in press)

Organization

What other kind of work has people who have such a level of dedication and talent?

OBSERVATIONS

- *We've had to organize rapidly and always with this sense of urgency.*
- *I spend a vast majority of my time not talking about AIDS at all, but about the context.*
- *Real gender issues are going on in this building, fueled by over-crowding and over-work.*
- *You get accused of making your career off AIDS. So we bow a bit to PWA pressures.*
- *The difference between the volunteers at AIDS Vancouver and PWA is immense.*
- *We still can't get this sense of support and security out to the people we are trying to serve.*
- *I have to think of health promotion as my work in a context of health promotion.*

From early beginnings until now, community AIDS work has been ruled by crisis. Simply keeping up to the problems of prevention and support, in all their complexity, has been an overwhelming experience, demanding such full attention to the developing situation that little energy has remained to examine community organizations themselves. Nevertheless, emerging circumstances are already forcing attention on organizational dynamics.[1]

When circumstances change, strategy must change — an obvious set-up for organizational change. People understand this intuitively, but it is not particularly easy to let go of established patterns. Efforts to improve an organization get derailed by efforts to defend it. But real change is not necessarily about the power structure. The critical changes are about the way people are dealt with in everyday situations, and that is the real change of power.

With uncertainties exploding on many different fronts — disappointing scientific and clinical findings, worrying evidence from evaluative research on prevention as well as financial and leadership struggles — the need to realign AIDS work has never been more apparent. Yet, in the scramble to keep up with all the incoming information, few have recognized that fundamental change in community organizations is already under way.

What all the changes will look like is still to be determined, but there are good reasons to welcome the opportunity to make a significant difference in the way community organizations do their work. As the emerging approach to prevention increasingly focuses on risk conditions rather than risk behaviour, attention to the social dynamics involved cannot help but include the working environments of community AIDS organizations. Given mounting case loads, the burnout of personnel, financial shortfalls and so on, the question arises about how supportive working environments in community AIDS organizations actually are.[2] Although there are no statistics, the alarming number of AIDS workers who have seroconverted during their employment is highly suggestive, yet rarely discussed. Undoubtedly, attention to the social conditions in which risk behaviour arises will bring organizational dynamics into discussion.[3] The organization is, after all, a social environment, and needs health promotion as much as any community. Perhaps the best way to treat an AIDS organization, then, is as a community of co-workers.

When asked to reflect on the state of AIDS, our interviewees consistently referred back to the state of community organizations.

The organizational problem is widely apparent.

> *This is not new, but one of the issues that's important is the way we are centralizing everything on HIV. It's a combination of waiting for the magic bullet, and, at the same time, of not dealing with some of the central issues.*
>
> *What worries me is the infighting, for lack of a better word: the inability of various organizations or individuals in organizations to work together. The turf war is what worries me, and what wears me out, and what will ultimately drive me away from this work. I think a lot of people feel it.*
>
> *I think we have come a long way through a period of just doing the work. But now we're catching up in terms of comprehension and theory. This is giving us an impression of where we are now and where we need to go. But all of this is almost too overwhelming for most people. People want to see the work in bite-sized chunks.*

A grasp of erroneous patterns is coming to light...

> *There's a basic, pervasive problem going on now about how we are in organizing on AIDS. The way we tend to deal with the way we run our organization is outward and then down instead of working from within toward the out.*
>
> *It's a huge mistake for us to say that because we deal with bureaucrats at different levels, or management of organizations, or directors, that these are the models that we should be taking and putting into place as our own. We have to be creating and recreating our models according to the work we need to be doing. But this is not what's happening.*
>
> *Part of me wants to say that we're at a crossroads, but I think we've had an understanding that what we are doing is ineffectual for quite some time. We really don't know what else to do.*

Entirely new ways of shaping AIDS work are already conscious...

> *You know how we have divided things up into treatment, advocacy and education prevention? It means that we have all these weird lines of work on singular functions that are way beyond the capacity of the people doing them to manage. You have people who gather information, put it together and diffuse it. These are all different kinds of jobs.*
>
> *I think the work should be redeveloped in terms of three departments. Community development, communications, and health promotion. So what you'd have is the health promotion department as an information gathering department. Communications would be an information diffusion machine. And community development would be what we do with it all in terms of an operational plan.*

The sense of what to do already exists...

> *I think we need to play up our advocacy role. As people become increasingly more saturated with AIDS in the world, they are becoming increasingly numb to the significance of the numbers, the facts and figures. We've become immune to suffering.*

But there is little real consensus.

> *I think community organizations have to narrow their focus and concentrate on doing a few things well. They have to back off the front-line work and use their know how and lobbying skills to go after the right targets. We need strategies with leverage.*

The "internal" issue of serostatus power is a fertile ground for reviewing everyone's experience of the organization's social environment.

> *Then there's all the stuff around how we deal with HIV in terms of organizational development — how we deal with it in terms of serostatus politics or identity politics. What we have are people and groups who have their own agenda. They're fighting; each wants to have some control over what they perceive to be the issues or resources that need attention.*
>
> *What we don't have is a sense of building alliances, and it's the most constructive thing we could be doing right now. But then, in a funny way, I can't say this, because I'm a white, privileged gay male who happens not to be infected. I have no credibility because I'm seen to be the high man on the totem.*
>
> *What's happening — as has already happened in the male community — is a split between HIV positives and negatives. Now it's starting to happen with women across the country. So we thought, before this starts happening here, let's get together and discuss the issues. A lot of it was that the HIV negative women were saying, "I feel that I always have to defer to a positive women, that I can't speak for them. Ever. And then I feel I shouldn't really be doing this work."*

While the serostatus issue can make AIDS work uncomfortable, there is also the possibility that what gets heard, in the effort to smooth things over, are the least empowered voices.

> *The positive women were saying, "We're tired of speaking." HIV negative women, on the other hand, were afraid to tread on the toes of positive women by saying something wrong, or (politically) incorrect, or by making assumptions. Meanwhile, the positive women, at least those at this meeting, were saying "we're very glad someone else is doing this work because we don't have the energy." Some say they have the energy some days, but other days they can't get out of bed.*

As the situation grows more complex, the demand for skills has grown, suggesting the possibility of professionalizing AIDS work.

> *We have to encourage educators who are starting out to make this a career for themselves. I know this is controversial. My rationale is that we need committed people. We don't need people who want to work in a community organization for a year or so by default. We need people with skills. We do have them, but we need to keep enticing people with skills.*

Some fear that professionalism would supplant the grass roots community focus even more.

> *The backlash is that you get accused of making your career off of AIDS. But we need people who are taking this very seriously and want a career in this; we need committed educators and support people. We don't look down at people who work in other health organizations and who are committed professionals, but it happens here. These things happen, so why not have people who are willing to study it and develop it? This is not going to happen if we only stick to community people.*
>
> *The problem is that we've created our own barriers. We've developed social and cultural barriers in what's now called the "AIDS culture."*

The limits to growth are already obvious, even though the ratio of people living with HIV is at least three times greater than those living with AIDS. With the fiscal situation of the nation in a state of doubt, there are fears that AIDS work will have to do so much more with even less.

> *I would love to come out with a harder line, like: "We are an AIDS service organization. We will provide this, this and this. And yes, we want community input. But we can't do everything. We cannot provide all the services that gay men and lesbians need to access around addiction, incest, violence and self esteem. These are issues that other organizations need to start dealing with. We have to work together, so quit hating us."*
>
> *We are so over-crowded. We can renovate as much as we want, but the building is not going to get bigger. And the reality is that the staff is going to get bigger. I think we need to start looking at that. We have to start looking at the impact of being on top of each other, and what that means. We are over-crowded. There's no private meeting space. What about putting people on flex time, making every other week a four day work week? There are, of course, real gender issues going on in this building, but they're fueled by over-crowding and over-work.*

Then there is a whole other side to doing AIDS work: the sense of having participated in something truly significant, affecting everyone's survival, in spite of all the constraints…

> *When I get out of bed each morning I ask myself where else, in what other kind of work could I be working along with people who have such a level of dedication and talent. I'm sure there are places, but I don't know where they are in our society.*

THEORIES

- *We tend to run our organizations outward and down instead of within toward the out.*
- *We cannot provide all the health services that gay men and lesbians need to access.*
- *Lines of work combine multiple functions, beyond the capacity of people to manage.*
- *People are so focused on their tasks that they don't frame their work within a larger sphere.*
- *We've developed social and cultural barriers in what's now called the "AIDS culture."*
- *Problems arise when people are unclear about differences and where they fit in.*
- *We have come a long way just doing the work; now we're catching up to theory.*

STRATEGIES

- *Community organizations have to focus and concentrate on doing a few things well.*
- *If we value ourselves and work together, we can effect powerful social change.*
- *We need people who are taking this very seriously and want a career in this.*
- *We have to encourage educators who are starting out to make this a career.*
- *We are going to have to get bigger, and the bigger we get, the more corporate we will look.*
- *We have to create and recreate our models according to the work we need to be doing.*
- *Three departments: community development, communications and health promotion.*

- *Exploring this could be great health promotion within our organization...*

  Laughing: we need to find a way to feel good with ourselves and those around us;

  Dreaming: to be able to say "there's where I want to be and these are the steps I will take";

  Sweating: once we're through laughing and dreaming,we set up to accomplish.

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[1] Mustard, F. Frank, J. *The Determinants of Health.* Canadian Institute for Advanced Research, 1991.

Indeed, a key part of the social environment is the *work environment*; p15.

[2] *ibid.*

Reviewing international research, the authors found that the lower the "decision latitude" at work, the higher the proportion of smokers. Examining the links between social class and chronic heart diseases on an international level, and considering the evidence from the Whitehall study, the researchers suggest that "above a threshold of poverty, position on the social hierarchy per se may be more important determinant of health and disease than material conditions"; p15.

[3] *ibid.*

The specific component of decision latitude that was measured — the worker's discretion over use of skills on the job — is an important part of the process of gaining control on the job sometimes referred to as empowerment: if the worker's skill is being utilized and developed, the worker is more likely to feel in control of many different situations that may arise; p16.

Prevention

I couldn't tell you about how to assist people to practice what they already know.

AIDS prevention is, by now, so commonly understood that safer sex has become a universal value of popular culture. Or has it? The information is simple enough and has never changed: avoid risk, use protection. And there has been plenty of experimentation adjusting the message to match the style or culture of target groups. Who would have thought, in the 1980s, that condoms would be advertised on television or sold in franchised shops? The massive effort to get AIDS prevention into mainstream consciousness appears, on the surface, to have been highly successful.

Yet, there is mounting evidence from research and field experience that the "information equals appropriate behaviour" assumptions built into AIDS prevention campaigns are either losing their edge or were never as effective as believed in the first place. We have learned from young gay men in communities like San Francisco, for example, that the sheer numbers of people ill and dying can produce a kind of collective fatalism; infection becomes regarded as inevitable, regardless of safer sex. So why bother?

Other experiences have raised even more uncertainties. From women, we have learned that the first-line defense of condoms is almost always in the man's control. From ethnocultural communities, we have learned that racial power imbalances are a set up for risk as the price of desire. From men who have sex with men, we have learned that their deep denial of same sex experience is an enormous hurdle to even hearing prevention information, let alone practising safer sex.

A rational explanation would suggest that the risk behaviour model is not at fault: there will always be non-compliance. And ultimately, we know that risk avoidance, or conscious use of protection, does reduce the risk of HIV transmission. So prevention knowledge will never really change as long as HIV remains a threat (which some believe will be eternity). Yet new perceptions of the situation could eventually change the way we think about and work with HIV prevention.

The developing logic involves a shift of thinking from behaviour which is individual to conditions which are social in origin. The predisposing influence of the social context is what makes the difference in the emerging perception. We already know that stressful living conditions, loss, isolation, discrimination and self-esteem are suspect in many forms of illness. What about HIV?

The question we know so little about concerns the *particular* kinds of social conditions that set up conditions for HIV risk. A recent study of young Australian gay men was able to show that starting off an evening in a "bad mood" increased the likelihood of unprotected sex.[1] What could put people in such a bad mood? Unemployment, financial distress, and interpersonal struggles are likely possibilities. However, because we would be missing the point to second guess the influences at work, we will, out of necessity, need to change our approach to HIV education in order to learn more about, and to have more impact on these situations.

Beyond HIV transmission, preventing HIV illness is another issue looming in the absence of a vaccine or cure. Because we have realized that the impact of social conditions, such as poverty and isolation, can mean unnecessarily rapid decline for people living with HIV, much collective energy has gone into support activities in community organizations. Even so, comprehensive prevention education has yet to be developed for people living with HIV. There is, however, growing recognition that its time has come.

In the everyday language of AIDS work, it is commonplace for people to think of HIV prevention in reference to transmission. For those living with HIV, prevention might also mean avoiding the risk of infecting others, or of re-infecting themselves with another strain of the virus. Even though quality of life for people living with HIV is very much in the consciousness of AIDS work, work in this area is more likely referred to as health promotion.

While conducting analysis of the interviews, it became clear that sensitivity to more expansive views of prevention is already developing. Paying close attention to the issues and to whom the interviewees were referring, the possibility of separating two categories of prevention — *Prevention 1* and *Prevention 2* — began to take hold. Prevention 1 describes the work of preventing HIV transmission; Prevention 2 describes the work of preventing HIV illness. A third category also appeared, as the interviewees referenced education and advocacy, that might apply to both forms of prevention and a range of supporting action that can best be described as *health strategy* or community health promotion.

Although this sketch of the territory is by no means complete — Prevention 1 and Prevention 2 are still only creatures of this analysis — its strategic value could be enormous. During a political confrontation between a coalition of BC AIDS groups and the provincial government, it became obvious to community leaders that ministry of health officials thought of HIV prevention in only the narrowest possible way: essentially, condom campaigns. The idea of secondary or tertiary prevention, or of education for people living with HIV, apparently had not even occurred to ministry officials. Yet the strategic importance to the health system of community inspired efforts to extend life or enhance the quality of life of people living with HIV could be substantial.

The following material, based on experience reflected in the interviews, examines three ways of addressing prevention in an inclusive HIV health promotion strategy.

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[1] Gold, R. Skinner, M. Desire for unprotected intercourse preceding its occurrence: The case of young gay men with an anonymous partner. *Int. J. STD & AIDS;* 1993.

Prevention 1

If you are sexually active, you can never really know that you are not HIV positive.

OBSERVATIONS

- *People are already saturated.*
- *People aren't actually behaving as our earlier model predicted they would.*
- *A lot of people become infected before they really realize what's happened.*
- *So many people who aren't infected think they should be cautious, but aren't.*
- *There's an inability to relate to HIV information personally, as receivers or dispensers.*
- *What we are doing is ineffectual, but we really don't know what else to do.*
- *People say they practice safer sex about eighty to eighty-five percent of the time.*
- *Loss of erection, and disruption of passion are the problems I hear of most frequently.*
- *Years ago people didn't practice birth control, even though they knew what would happen.*

- *To me, an ongoing desire for uninhibited sex is a purely human, healthy, natural trait.*
- *A group of men figure that same-sex sex isn't the same sort of thing as heterosexual sex.*
- *Bisexual guys have sex in the parks while their wives think they're in safe relationships.*
- *All the men they meet are married and they never meet the same guys, year after year.*
- *What would their wives say if they had condoms or lube around?*
- *Asian men feel the need to risk their safety to get acceptance from mainstream culture.*
- *Young gay men are thinking maybe it's not such a bad thing to become infected after-all.*

- *There should be prevention for lesbians, but they are the group least at risk.*
- *30 - 40% of women engaged in behaviours considered high risk for HIV transmission.*
- *Lesbians think if you've had a negative test together that you can do whatever you want.*
- *The other untrue belief is that lesbians don't have sex with men.*
- *We can't have penetrative intercourse without being bound up to the knees in latex.*
- *Women's bodies are not always in their control: condom use is a decision made by men.*

The state of uncertainty surrounding Prevention 1 (HIV transmission) could not have been described more effectively or directly than through the voices of experience participating in this inquiry. Even though HIV prevention information is perhaps more abundant and accessible than virtually any other threat to health, many people doing AIDS work are fearing the worst about the efficacy of current approaches. Although there is little epidemiological evidence to support such dark views so far, field experience is more telling. The traffic in public sex scenes continues, unabated; a new generation of young gay men are becoming sexually active: these are the realities of life in the long-run of the epidemic.

The really serious doubt is where to go from here, and by what means. It seems apparent to everyone that the problem is not about information.[1] From there, the views become sharply divided. One version sees the problem as non-compliance: slip-ups happen, and because HIV is in the world, non-judgmental community systems should be in place to support those who become infected. Another version recognizes the problem as circumstance: HIV makes ordinary life in a repressive society so impossible that a new pattern of runaway infection is bound to materialize out of hopelessness.

The emerging discussion of social risk conditions may save the day where earlier versions of HIV prevention have stalled. People working on the front lines have already intuited the social dimensions of HIV infection, because it has become increasingly obvious that those most vulnerable are living with multiple oppressions of discrimination, poverty, isolation, abuse, mental illness or drug dependency. Subtler forms of social risk conditions are only now being recognized, such as the inevitability belief in young gay men. The current situation, however, suggests that we do not know enough about the particular conditions of social context that make people vulnerable to risk behaviour and, ultimately, to infection.[2]

All of this indicates a rich field of opportunity for health promotion to address the impact of the social environment on sexual health. A renewed community development effort could be driven by the search for information and experience about the social conditions which impinge on the health of individuals and their communities. This strategy would open even more opportunities for new messages, new ways of targeting audiences and new approaches to prevention education.

It may be useful in planning for such a development to split Prevention 1 into two forms: a stream for young people who are presexual and a second stream for people who are already sexual. Each stream would focus on exposing risk conditions in the pervading social consciousness of target groups.

When our interviewees were asked about what worries them about current circumstance, this is what they had to say:

> *I think it's unfortunate that a lot of people still become infected before they really realize what's happened. And there's only one shot at this thing. We have no cure.*

Although injection drug use remains a serious HIV threat, sexual transmission is the preoccupation of most prevention educators because it involves everyone.

> *I think we've learned that sex takes place on all sorts of different levels. It may really be, when we strip away everything and bring it down to the bottom-line, that what sex may be about, essentially, is the exchange of bodily fluids: intimacy in its mechanics. But we've interrupted that, or the virus has.*

And on issues of sexuality, there are hotly conflicting views.

> *I really think there is something going wrong in the gay community when a thin latex shield can be seen as a barrier to intimacy.*

Information is already recognized as a non-issue in the prevention effort.

> *I know couples where one is positive, and the other negative; they can talk rationally and knowledgeably about safe sex and yet sometimes, when they have sex, they do unsafe things.*
>
> *The health belief model would predict that if you tell people that these are the risks of doing something, and these are the statistical chances of becoming ill as a result of such and such a behaviour, then the behaviour would cease. But we're finding that that's not the case. And I don't think gay people are different in this way than any other people.*

The shadow is the predisposing psychology of risk.

> *A fatalism has developed. With the changing information that says that maybe it's easier to get the virus, then what's the point? We're all going to get it. People who live in the big cities who've seen many of their friends die are saying, "What's the point? Why don't we just live in the moment, and if we get HIV and start to get sick we can just kill ourselves." This is one of the climates of sexuality that I hear about.*

Or perhaps sex, like life, is an inherent risk.[3]

> *There's some interesting recent research about sex drive, and the sex act being governed by a very primitive part of the brain which overrides everything else through the production of chemicals like endorphins during the sex, blocking rational or conscious thought. Which explains: "We were swept away with the passion of the moment."*

Then there is a question of focus:

> *Do we spend more time, energy and money on that huge group of men who don't attend gay venues but who do have sex with men? There is an obvious link to heterosexual women in this way. We've tackled the most needy groups, at least statistically, i.e., out gay men. We find all sorts of excuses about not reaching that harder-to-reach group, simply because we really don't know how to do it. Because we know that just providing them with information isn't going to have much impact on their behaviour.*
>
> *And if we have difficulty having an impact on behaviour in the out gay community, how are we going to be effective with a group of men who don't even figure that same-sex sex is the same sort of thing as heterosexual sex? They have dual compartments for them.*

The most vulnerable are the most difficult to reach.

> *I see a fair number of bisexual men, because test counseling is anonymous. It's one of the few places that people can come and talk about their bisexual behaviour. There are no records kept that could be subpoenaed, or end up anywhere. I never know the people I'm talking to. Whereas people can't go to their doctors or counselors because they are identified. Here's a population that I think is so at risk and yet so difficult to reach.*

> *I see many bisexual guys coming in who have sex in the parks while their wives think they're in safe, monogamous relationships. They have no idea that they're at any risk at all. Most of these guys will say they end up in the parks or baths without having consciously planned it. They just sort of ended up there, forgetting about condoms and their awareness of risk. It's usually a lot of guilt: just get it over with. They're afraid of discovery.*
>
> *And so it's like the message never relates to them. The most extreme case involves a man I talked to who is now dead. He got sick, and when the doctor asked him about sexual stuff, he said: "No that couldn't be it." The doctors finally got him to take a test and he was positive. But it was some time, even after that — though he continued to go to the parks — before it finally clicked in his head and he realized he had gotten sick from having sex with men. His denial had created such a split that it seemed that it was not even him in the park doing those things. He had four kids, and a wife, and all the stuff. You can imagine the fear that he must have felt about being positive, and his unconscious motivation to keep it out of his awareness.*

The extremes of the risk behaviour model are already suspect...

> *Sometimes, when I hear of some of these initiatives.... The one that really kills me was from Denmark, where volunteers actually go out to public sex places and help men put condoms on. Oh god! This was actually thought of as very innovative at a meeting I was attending, and I thought it was insane. That's just like going up to smokers, taking away their cigarettes, throwing them away, and then thinking you've cured them. What does that accomplish?*
>
> *There was another example from San Francisco, where they were planning to hire men who would go to certain bars and engage in (strictly) safe sex with other men there. So a man has safe sex with the demonstrator because that's all that he will do. What about the next guy?*

So what approach to take? Psychological?

> *To me, an ongoing desire for uninhibited sex is a purely human, healthy, natural trait. It's only a risk activity in the presence of HIV or some other microbe. I don't think the addictions model really works: to make an analogy between practising safer sex and abstaining from alcohol or drugs, for example. A very small percentage of people are addicted to sex, and for them it's a pathology. However, for the vast majority of people it's just human.*

> *So we have gay men shifting from the behaviour avoidance approach to a risk reduction approach. I see my job, at this point, as massaging that shift so that it's based on informed decision rather than a feeling of inefficacy: the feeling that it doesn't matter what I do here, I'm going to get infected and die. There will be a certain number of people who take that approach. We have to recognize that we will have to support them and recognize that that is just as valid a choice as that of someone who chooses to be celibate for the rest of his or her life as a result of HIV.*
>
> *I'd do what Walt Odets said at the National Gay and Lesbian Health Conference in Houston last July (93). I'd stop lying to people. I'd tell the truth. Nothing is more jarring than the truth. But it's hard for us to tell the truth: we don't really know how HIV is transmitted. We don't really know if, on its own, HIV is sufficient to cause AIDS in everybody.*

Or social? We've learned most of what we know about social risk conditions, so far, from ethnocultural communities and women.

> *We have identified a large population of gay Asians who are primarily attracted to Caucasians. Caucasians who are reciprocal in this attraction have an advantage. Because the Asians are not out to their families or, often, even their friends, they feel they need to secure the opportunity of having a sexual interaction with whatever it takes.*
>
> *We also know that, for women, risk is not a choice. People who are doing safer sex education have come to recognize that women's bodies are not always in their control and that condom use is a decision made by men and not by women. So, again, the prevention programs advocating that women don't go out without their condoms have been mis-targeted, although well intentioned.*
>
> *With women, the classic lesbian scenario would have two women come home and start to have sex. One woman then says to the other, in the midst of sex, "Have you had an HIV antibody test?" There's a belief that if you ask and the answer is negative, or that you've had a negative test together, you can do whatever you want.*
>
> *The other belief is that lesbians don't have sex with men. That's not true. In fact, sex with men is often unprotected and isn't talked about. There was a time when lesbians feared thăt they could give the virus to each other through oral sex, and so we needed to be geared up with latex. Now the belief is that we can get rid of the latex and we can start talking about other kinds of sex, such as sex with men.*

Perhaps the only way to move from the current state of HIV prevention is to get beyond information into a zone of experience where we can *exchange* information.

> *We need to look at ways of changing the sexual situation; we need to examine the emotional and psychological contexts in which sexual behaviour takes place. I don't think we have given this enough attention. I believe that members of the community who are most targeted in North America — gay white men — don't practise safer sex some of the time. Their intention is to practise safer sex all of the time. They certainly know they're supposed to. They are aware of the risks. They have seen their friends and lovers die. And yet this risk is still taken. Why?*

THEORIES

- *We don't really know how HIV is transmitted.*
- *We don't really know if, on its own, HIV is sufficient to cause AIDS in everybody.*
- *Sex chemicals like endorphins block rational or conscious thought.*
- *Strip away everything and sex may be about the exchange of bodily fluids.*
- *We should not carelessly and indiscriminately put foreign particles into our blood stream.*

- *Most at risk are young gay men; they're less sophisticated and newer to a lot of the issues.*
- *We aren't going to see society trying to protect gays in the schools.*
- *Gay men in relationships are at risk when latex is replaced by love.*
- *If bi-men are going to have condoms, then they have to admit that they have this interest.*
- *The priorities of Asian immigrants, like the Vietnamese, are not HIV and AIDS.*
- *Asians who see themselves as a marginalized immigrants are the ones at risk.*

STRATEGIES

- *Ask AIDS educators about how successful their own efforts are to practise safer sex.*
- *Address behaviour in the sexual situation: the emotional and psychological context.*
- *Anonymous counseling: one of the few places to talk about bisexual behaviour.*
- *Explore the values of sexuality in our society: the emotional issues around prevention.*
- *We need to get closer to understanding why people are taking risks.*
- *How strongly do people evaluate their intent to practise safer sex?*
- *Move from behaviour avoidance to risk reduction: informed decision rather than inefficacy.*
- *Research people who practice safer sex to find out why they do it.*
- *Simple: Use of a condom or latex barrier in sex will greatly reduce your chance of HIV.*
- *Spend on youth campaigns and ignore anyone over twenty five.*
- *Look for leverage: there's no way a community group can reach every school age child.*

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[1] Odets, W. *AIDS Education and Prevention: Why it has gone almost completely wrong and some things we can do about it.* paper delivered at National Gay and Lesbian Health Conference, Houston July 23, 1993.

Our education and prevention seem ever more firmly entrenched in the assumptions and approaches developed early in the epidemic when the losses were still few, the epidemic seemed a temporary aberration, and the natural fear and anxiety in gay men huddled over media reading about "gay cancer" provided powerful— usually irresistible—*internal* incentives to lay off sex for the time being—education or no education; p3.

[2] Ed. Reassessing Priorities: Identifying the Determinants of HIV Transmission. *Soc. Sci. Med*; V36 N5, 1993.

There may be many explanations for the neglect of the social context of HIV transmission: much research has been demand-led, funded by big agencies and drug companies concerned with individual behaviour not social change; the epidemiologists and biomedical scientists, rather than social scientists, have controlled the way in which the epidemic has been explored; the language of the response to HIV has been similarly biomedical; the inexperience of health researchers in stimulating or relating multisectoral activities; and finally, the inherent conservatism of most biomedical scientists and those that house and fund them; iii.

[3] Pringle, H. The way we woo. *Equinox*, Telemedia Inc, Camden East, December 1993, V6 N72.

At the New York State Psychiatric Institute in New York City, researcher Michael Liebowitz suggests that the powerful emotion of love is created by a tidal wave of certain naturally produced chemicals in the brain. And others have suggested that the taps for those chemicals might be directly controlled by our genes; p86.

... he now suggests that the sheer intoxication of love — the warm reckless euphoria that sweeps over us and *drives away all other thoughts* — may be caused by certain *chemical excitants* flooding into brain structures thought to control love and emotional *arousal;* p86.

Prevention 2

If you feel marginalized and put down, health is the best revenge.

OBSERVATIONS

- *There's a huge vacuum of information.*
- *Something is happening inside that they don't come out to seek treatment.*
- *They're not seeking any treatment or health care because they fear being outed.*
- *There's inadequate treatment for opportunistic infections or infection of the virus itself.*
- *There's no evidence that two positive people sharing the virus are going to die sooner.*
- *The big surprise is how quickly changes in people can take place.*

Early in the epidemic, community AIDS organizations advocated for the inclusion of those living with HIV in prevention efforts. Active participation in preventing transmission to others seemed one of the more obvious benefits — much more desirable than public health approaches advocating quarantine. And there were other prevention concerns. One was the possibility of secondary infection with another sexually transmitted disease that could dramatically worsen the condition of an immune compromised person. And there were fears that unprotected sex between HIV infected people might increase the "viral load," or transmit a different strain of the virus, increasing complications.

But people living with HIV had much broader, more urgent concerns that involved the totalizing problem of getting in control of life and health while experiencing the loss of immunity. The Vancouver Persons With AIDS Society formed on the strength of the collective drive for treatments and social solutions to this problem. It was not until AIDS Vancouver hired someone living with HIV that "Project Sustain," a support service approach to HIV health promotion, developed beyond the limited scope of prevention. In the two years since that time, health promotion for people living with HIV has come to mean much more than traditional treatments and support services.

The outline of a second tier of AIDS prevention education — Prevention 2 — is already forming, but has not been addressed specifically or strategically as such.[1] Treatment information projects opened the way into this territory out of a need for a first hand grasp of scientific, clinical, and pharmaceutical literature. Other efforts, focusing on such topics as nutrition and home care, are adding further dimensions.

One of the least addressed issues in this area is concerned with living HIV positive, asymptomatic and healthy. This is a "what about me" area for many active participants in community AIDS organizations. Some issues are addressed through library, counseling, financial assistance and voluntary participation. Otherwise, the field of opportunities to explore education and community development for healthy, positive living, including health consumerism, is wide open. At least two glossy magazines on the subject are now published in the US, suggesting that commercial potential is already being recognized.[2]

The influence of the social environment in determining risk conditions for HIV illness or progression should be a potent focus for the development of future projects.[3] The impact of discrimination, stress, loss and loneliness on health in general are already well documented. What to do about the psychological, social and practical problems of living well in spite of HIV stigma and shame is an area of specific need. A health promotion perspective would suggest that the most likely way to develop the area would be supporting self-inspired projects of HIV positive participants in community organizations.

Although we did not specifically ask about the prevention focus for people living with HIV, several of our interviewees referred to experience, concepts and issues that suggest it.

> *There is an absence of adequate treatment, either for opportunistic infections or infection of the virus itself. There's a lack of decent palliative care to alleviate the distress that people experience, both emotionally and physically, because of the absence of adequate therapies.... These things terrify me.*
>
> *The thing that I am really intrigued by, and that I don't see done well enough right now, is about how things have been divided up: therapies, treatment, information and support over here; prevention over there; and this big gulf in the middle. We absolutely need to bridge that. The notion that education is this continuing process, that prevention includes prevention for people who are positive, preventing them from becoming ill: it's a big gulf in a lot of people's minds. Here, I think, health promotion is the perfect answer.*

Of course, there are barriers …

> *The people who I see, when they initially test positive, tell me that they are not prepared to go to AIDS Vancouver or PWA. They say, "I just couldn't face that." "Maybe after I've dealt with this in six months or so, but it's too big a step for me right now." They need time to adjust to the whole idea. Walking into PWA or AIDS Vancouver, they feel labeled and identified. Because of all the guilt and fear, they don't want to advertise their newly discovered status. Most people do not want to access services within the first few months. They will use the phone line because they can be anonymous.*

The validity of the "re-infection" issue requires urgent clarification…

> *We don't really know whether two men who are HIV positive are going to make their situation worse if they have unprotected sex with each other. We don't know this, even though we tell people what to do.*
>
> *We talk about viral load theory and re-infection with the virus and yet when you try to find the studies, they don't say what the press has said they've said. There's absolutely no evidence to suggest that two positive people sharing the same strain of the virus are going to die sooner if they don't use latex in their sex lives than if they do. I think it's unconscionable for AIDS service organizations and others to demand that they do.*

Ironically, the development of HIV positive prevention has been seen as counterproductive to overall prevention strategy.

> *It's a double edged sword. We have the empowerment of PWAs on the one hand — documentaries about how people found meaning in life after they seroconverted — and on the other, negative men living in a time of chaos and fear. We wonder whether they are thinking that maybe it's not such a bad thing to become infected after-all, because their friends say that it's the best thing that ever happened to them.*

There are equally disturbing psychosocial health issues to consider.

> *Of course, there are other health implications in not using latex. But if they have that information and they choose not to, we need to be able to support those decisions. Again, we get into those existential questions, that even if it perhaps does shorten their lives for a year or two, or five, or whatever,*

> *maybe that's preferable to them: to have an uninhibited sex life for five years, rather than ten years of latex. These are questions that gay men are beginning to ask themselves, and they're answering them, without ever talking about it and without support.*
>
> *We have this contact who knows three members in our Asian community who epitomize the work that needs to be done. There are three guys who are HIV positive and gay but who are not out to their families. They are not seeking any treatment or health care because they fear being outed to their families. So they are choosing, instead, to die in isolation, even while they are with their families, in lieu of getting treatment. This is the kind of fear we are working with. Imagine doing this for so long and we still can't get this sense of support and security out to the people we are trying to serve?*

HIV testing is connected. Could it be that we still struggle with denial?

> *Was it right for them to have tests? Because they are not obviously doing anything better now. So they know they are positive. What now? Can they be responsible with their partners? They should be doing that anyway. Or their partners should be taking responsibility. They are now living their lives in turmoil because they know something is happening inside of them and they can't come out to seek treatment. I wouldn't be surprised if one of them is suicidal. So what's better? We are so quick to say "test!" when we think the answer is negative.*

AIDS libraries, even one-shelf satellites, could play an instrumental role as an attraction for independent or self-directed learning that may lead to other community activities.

> *People come looking for information, maybe having looked elsewhere, and maybe not expecting to find it. I'm talking about practical things: people whose doctors are giving them medication and they're experiencing side effects, or people who've received diagnoses and don't understand them, or relatives who've just discovered their HIV status and there's a huge vacuum of information so they end up here asking for information.*
>
> *I'm working with the treatment information project, trying to figure out where the role of the library ends and the treatment information project begins. There's a big difference between giving people information, and treatment counseling, which is what they do. Some people don't want to talk to a treatment counselor. They don't want the screen of someone else giving them information. They are more than happy if I point them in the direction of a few good books or journal articles; they want to sit down and look at an issue from several points of view and make up their own minds. They often don't want to tell anyone what they are looking for.*

The community development potential of educating people living with HIV to become well informed "health care consumers" has already been recognized. Creating the ways and means is the next step on the horizon.

> *I feel that one of the really satisfying things is seeing people discover they have options. Part of this happens informally. People come here and meet others and find out that those people have had similar side effects with what they've had prescribed, and they don't need to continue taking it because there are other options. People aren't often getting this kind of information from their doctors.*
>
> *The big surprise to me is how quickly changes (in people) can take place. For example, one of the volunteers, who started volunteering after I began working here, was brought in by his buddy. His buddy asked him if he wanted a library card (and he did) and whether he wanted to take a few things out. He had been volunteering elsewhere in the building and decided he didn't like it. He wouldn't meet my eyes, and was obviously very uncomfortable. Clearly, he was not very comfortable with much that was going on in his life. Now, inside of a year, he comes into the library to volunteer twice a week. He's completely changed. He's one of the people who has said to me that, since he started volunteering here, he is asking his doctor a lot more questions, and has a lot more understanding of what is going on. It has made a tremendous difference. The thing that surprises me is how fast it happened. I've seen it happen before my eyes.*

THEORIES

- *People have positive tests, but believe they are negative because they can't accept it.*
- *Because of guilt and fear, they don't want to advertise their newly discovered status.*
- *Will HIV positive men make their situation worse if they have unprotected sex?*
- *It may be preferable to have uninhibited sex for five years rather than ten years of latex.*
- *There's a big difference between giving people information and treatment counseling.*
- *It's no accident that access to AIDS information by the consumer has been privileged.*

STRATEGIES

- *People have to live their lives and we have to support them if they seroconvert.*
- *Providing consumer health information involves people taking control of health.*
- *Neighbourhood AIDS Watch.*

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[1] Labonte, R. *Health Promotion and Empowerment: Practice Frameworks.* Centre for Health Promotion University of Toronto, 1993.

The term tertiary prevention describes disease treatments which prevent a person from becoming more ill; or programs and actions aimed at physiological risk factors, preventing a serious disease from arising due to less than optimal physical functioning.... Secondary prevention describes programs or actions aimed at helping people change unhealthy behaviours. Primary prevention describes programs or actions aimed at helping people grow up with, or maintain, healthy behaviours; p4.

[2] *Plus Voice, The Magazine About Life & HIV.* Chicago. *POZ.* New York.

[3] Hogg, R. Strathdee, S. Craib, K. O'Shaughnessy, M. Montaner, J. Schecter, M. Lower socioeconomic status and shorter survival following HIV infection. *Lancet* 1994. (in press)

Health Strategy

If you can't argue the community development base of a new initiative then chuck-it.

OBSERVATIONS

- *Educators have become a self referential authority.*
- *They haven't become community organizers, they've become educators.*
- *There's no excuse, anymore, to be doing the information based stuff we've been doing.*
- *We have a discourse around community development but we don't have a viable activity.*
- *Gay men have incredible health problems across the board; then we sort of added HIV on.*
- *A situation has developed where people don't see HIV prevention as their responsibility.*
- *I couldn't tell you about how to assist people to practice what they already know.*
- *Divided up: treatment over here, prevention over there and this big gulf in the middle.*
- *One of the really satisfying things is seeing people discover they have options.*

As we have seen, observations and findings from an array of sources have raised serious questions about the informational approach to HIV. There are questions being raised about methods, assumptions and inherent social values. The uncertainty of these times has also brought about much critical reflection on the basic processes and conduct of AIDS work. Although many problems have become apparent, the solutions are not nearly as obvious. Even so, critical views do hold the makings of a revised strategy for community AIDS work.

Beyond HIV prevention, defining a health strategy for the social context of AIDS would provide an alternative vantage point from which to plan for action in affected communities and society in general. Seeing health as a strategy — superseding prevention — sets up a separate way of looking at things. Prevention is limited by specifics. Health strategy encompasses the social environment, making the raw ingredients of prevention actually possible because the whole situation, including the political, economic, social, cultural, institutional, organizational and community conditions, are brought into the process.[1]

The health promotion agenda for community AIDS work is already suggested by the discontinuity between what actually happens on the front lines and what we believe ought to happen. Two possible approaches could be undertaken simultaneously. One would be to muddle through, making small advances and changes wherever necessary. The other is to think and plan more comprehensively with a long range view of the total arrangement of conditions.[2] This enterprise should answer the question, "What relationships and partnerships will establish conditions where we can co-create a supportive environment?"

The seeds of change are already apparent within the critical views of people doing AIDS work...

> *The way we are doing things in our organizations has not caught up to any of the theory we have. We have a discourse around community development, but we don't have this as a viable activity, or at least it's minor in the scope of what's there.*
>
> *I'm not in the field anymore. But I don't think there is much excuse for us to be doing the sort of information based stuff that we've been doing anymore.*
>
> *AIDS educators have become a self referential authority. And what happens is that they haven't become community organizers, they've become educators. What we need to do is throw them out to the community. And the only education that would be done would be through the volunteers, who are the driving force behind the project.*
>
> *Most programs right now don't do enough outreach. We need to think of more creative approaches. I've heard of a store-front approach that would be great. I guess people have recognized that you don't just put out information and wait for people to come and get it. The information is only the base, the core product. A booklet is not going to help. Sorry.*

An example of an information-based project without a community strategy:

> *In —, they've been working on a booklet for young gay men for nearly a year and a half now. Yet there has been no or very little consultation with young gay men. There is no distribution plan. I keep saying that this is exactly what is going wrong. We should not be wasting our time doing this stuff if it isn't built in to some sort of community development process.*

Uncertainty has brought out sharply contrasting views about how to proceed...

> *I have a controversial view of prevention that I've thought long and hard about. We keep trying to repackage our material. But in prevention for anything, even as life threatening an issue as AIDS, there's not going to be one hundred percent compliance. There's not even going to be ninety percent.*
>
> *At some point, we have to stop being responsible for people who are making choices that we think are bad. First of all, we don't always know what went into those choices. We can talk all we want about latex, latex, latex. But that doesn't account for anyone's life.*

Nevertheless, a revised strategy is already forming in response to the situation.

> *To me it makes sense that HIV prevention follows a health promotion model, because we are just promoting good health. You make a choice. I think it's crucial that we educate children about this: hopefully, it will be ingrained as they grow up, providing for better choices about all health issues. Is this any different than people drinking, or smoking, or eating high fat foods? Or is it any different than people with high blood pressure who won't take their medication or follow a diet? Or people with high cholesterol or diabetes?*
>
> *Creating tools that can be used in conjunction with what people have or can have or should have is okay, but it only makes sense if there is a community development package that goes with it. I don't have any answers about how to do that.*

The way to get beyond uncertainty is through inquiry; not necessarily formal research, but co-investigative approaches involving authentic participation of groups and communities.

> *I'm big on evaluative research. There is a big gap out there. We need some action based research. If not recipes for how to do it, we need to develop different projects or organizations and try different things and record the process a lot more.*
>
> *I would like to see some research done with people who practice safer sex and find out why they do it. What is it that makes their behaviour sustainable? What are the factors contributing to non risk behaviour?*

The increasing complexity of the AIDS situation makes the "inquiring" stance all the more necessary for a health strategy.

> *One of the things that I find very exciting about the library is the carry-over into the bigger picture of consumer health information, which is what I see myself providing. As we've realized before, community based AIDS work has been health promotion, albeit without calling it that, for a long time. We see other disease groups doing what they clearly say is "after the AIDS model." The potential, here, is to take some of the lessons we've learned in order to talk about health in a new way.*

THEORIES

- *The people most at risk are the least valued in our society.*
- *In prevention for anything, even AIDS, there's not going to be 100% compliance.*
- *We're not reaching that harder-to-reach group simply because we really don't know how.*
- *Social determinants so profoundly affect us that prevention will look quite a bit different.*

STRATEGIES

- *We're wasting our time if our work isn't built in to some sort of community development.*
- *We used to say education is prevention: do we still believe it?*
- *Sexuality is by definition a social activity. We need a social analysis to take us further.*
- *Go into these communities and start at their level; make assessments.*
- *Psychology is useful, but leads to more problems than solutions; try social inquiries.*
- *More collective analysis or comparative system analysis that moves beyond sociology. Take different projects or organizations and try different things: record the process.*

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[1] Labonte, R. *Health Promotion and Empowerment: Practice Frameworks.* Centre for Health Promotion University of Toronto, 1993.

The first major implication of such an empowering health promotion practice lies in how we conceptualize health. While public health has long held to the positive, first half of the World Health Organization's famous definition, "a complete state of physical, mental, and social well being," health services, funding and practice remains focused on the second half of the definition, "the absence of disease or infirmity"; p15.

...people's experiences of health are more about their experiences of capacity and connectedness than about their experiences of disease or disability; or, as Miller defines health, it is "the increased becoming of what we are most deeply." Experiences of health are fluid, varying by age and gender, time and place. They are phenomenological experiences, constructed through social interaction with others and our shared repertoire of intersubjective meanings; p15-16.

[2] Kirp, D. After the Band Stopped Playing. *The Nation*; July 4, 1994.

...scientific setbacks force a refocusing on the human factor, on gaining mastery over the behaviours that spread AIDS. If nature, tamed, is not going to provide the solution, at least not for some time, then nurture—how we care for ourselves and one another—is where we must look again.

Synthesis

We need action based research; and if not recipes for how to do it,
then different projects or organizations trying different things and recording the process.

Seeing the collective consciousness of AIDS work pulled together in these chapters has an undeniable emotional impact despite the analytical frame in which the reflections are cast. Although so much has been accomplished, the enormous burden of the HIV/AIDS situation is still with us, and the scientific predicament makes it seem as if we have stalled in the middle of a vast, turbulent sea. *So what do we do now?*

Such times call for invention and energy, a critical occasion to check over the crew, the equipment and handling skills before we embark on another course. But what course should we take, given all we know from the high winds and waves of the last ten years? And another question comes crashing in: *How can we be sure we aren't creating the risk conditions we are trying to avoid?*

Take another look at the map, the three social contexts of AIDS work: society, the core community and the organization. As we observed earlier, all three of these settings are nested within one another, so their influence is inescapable for anyone doing AIDS work. But such influence is also reciprocal. Or, in other words, what happens in one context in some way affects the others. Reciprocity, as we all know by now, is a source of both danger and opportunity in this time of HIV and AIDS.

Because the social environment inescapably conditions quality of life for everyone, whether affected by the inherent risks of sexuality, or because of immune compromise, it seems more than likely that finding out more about these conditions and learning to gain a measure of control over them would be a very productive venture. What makes it so inviting for AIDS organizations, and their core communities, is that finding out about what social conditions, in particular, are *set-ups for risk or vulnerability* is within reach of most community participants. Such an inquiry does not require laboratory science, just good social process, which we've been calling community development, albeit with an explicit intent to investigate, to evaluate and to learn.

At least one observer of AIDS work has pointed out that we have come to understand the value of community development, but that where we lapse is actually doing it. While this criticism has its own backwash of irony, considering how far community AIDS work has come in a decade, the cold splash in the face is well worth paying closer attention to (if for nothing else than for a way to renegotiate the relationship between AIDS organizations and core communities). Without question, AIDS has brought on incalculable anger and dissent.

Little wonder that community AIDS organizations have found themselves targets in tricky relationships with the very communities they serve. The evolving question, though, is still: *What do we do now?*

The relevance of community development is that it applies in every context, not just as a means of interaction between community organizations and their core communities, but within AIDS organizations themselves and with society at large. A habit of thinking has evolved in AIDS work in which community development is seen as work with the core community or the constituent community exclusively. Such work has been limited to *providing* — providing condoms, providing education, providing support and so on — all very altruistic, but all one way. Receiving or exchanging information has been left to research specialists, and the problem, here, is the problem we are facing now. Community development, as a general strategy, could mean much more.[1]

One of the key issues with community development is knowing where to begin. How to keep it going is only a question after something happens. AIDS Vancouver has experienced both success and failure on this account. The "wall of denial" experience is a sure sign of impending collapse of an initiative. The worker fumbles on where or how to begin. An ambitious sounding plan of action becomes stifling inaction. Nothing happens, and either the community, the organization, or both are blamed.[2]

Success, on the other hand, starts with inquiries; not science, not even social science, really — just practical, thorough spade work.[3] When one new worker at AIDS Vancouver took over a failing workplace project, in which virtually nothing had happened in two years, she called every major ASO in North America to see what they were doing during her first two days on the job. This is research spadework (which, by the way, netted some very good ideas and some supportive relationships).

Practical field experience, and the writings of people who have been there have shown at least one dependable pattern underlying community development, no matter what the specific social context:[4] aim for a target group, institution or department; identify predisposed individuals; determine their needs, values and culture; bring them together, face-to-face; focus on and guide experience sharing; encourage leadership within the group; set-up collective learning as a mission; gather information; distribute findings and extend influence (by identifying and recruiting new, predisposed individuals).

Difficulty, at the beginning, seems to be about actually locating predisposed individuals within a target group. But within every seemingly monolithic wall of denial there is at least one caring person who sees beyond the standard rhetoric. When the archbishop of Toronto pleaded with parishioners to write letters to their MLAs against proposed Ontario same sex spousal rights legislation — a healthy social policy with supportive implications for AIDS prevention — leaders from an association of "concerned Catholics" voiced objection to the church hierarchy's Christian principles on national television. Although they are not always so easy to find, predisposed individuals, like concerned Catholics, exist in every context.[5]

With AIDS Vancouver's workplace project, the appropriate target group turned out to be human resources managers. Years of scheming about how to get CEOs interested in AIDS had produced almost nothing. Human resource managers, however, seemed predisposed because of their specific stake in handling employees with HIV and AIDS. By sheer coincidence, while researching links with health promotion professionals, the director of personnel of a major bank came forward with a crisis. That serendipitous contact opened the way to understanding how people who have such roles think and work — more research spadework. The experience convinced us of the strategy we were developing. We mailed out an article about employee experience with AIDS from *The Harvard Business Review* to the human resource managers of Vancouver's top 500 companies. For a second mailing, we sent a special invitation to a "networking" breakfast, featuring a guest speaker. And when it all came to pass, 100 of those invited showed up.

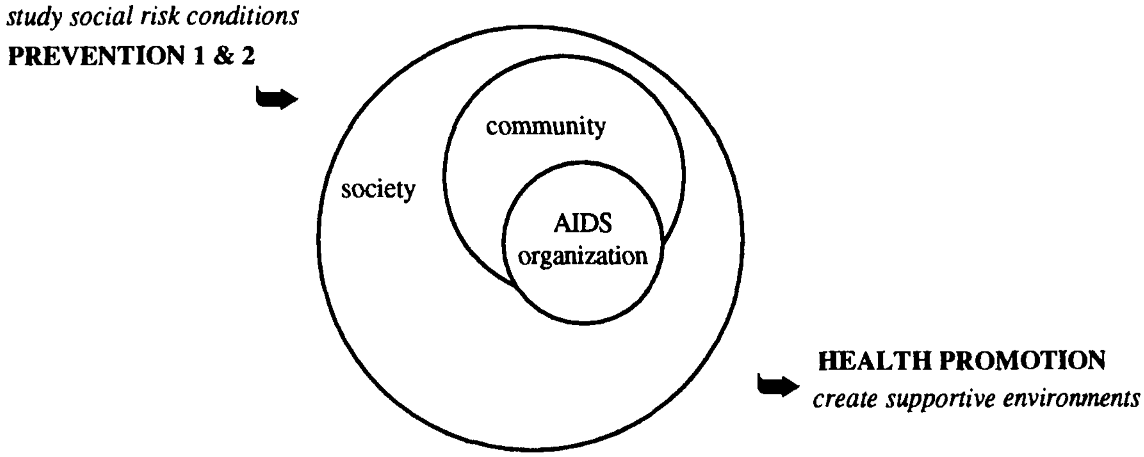
Keeping a community development project going presents another problem, but with the momentum of a face-to-face event and an interesting mission, the rewards of participation are their own motivation. In the case of a rural outreach project in Nova Scotia, it was encouraging the participants, gathered at a retreat, to research all the stores that sold gay porn magazines in their communities as a way to locate distribution points for safer sex information and announcements about support activities. With the workplace project at AIDS Vancouver, some of the breakfast participants, supported by a little follow-up and encouragement, formed a new group and named it the BC Business and Labour Coalition on AIDS. The first task they set for themselves was research on the financial impact of AIDS.

Future AIDS work could be about spinning out such mission oriented groups in the pursuit of community development in every social context touched by AIDS, according to needs and priorities identified by community organizations.[6] We need to get a grip on such strategies, now that we already know the basic terrain of HIV/AIDS. This is where developing knowledge of the social determinants of Prevention 1 and Prevention 2 provides a renewed basis for action, unlearning stigma and creating support in a universal health strategy for the age of AIDS.

As a general rule of thumb, reinventing AIDS work will be made possible by adopting an inquiry stance which depends far less on providing information — although basic information will always be necessary — in favour of experience sharing, value questioning, and knowledge gathering at every level of the social environment.

In *Taking Care of Each Other,* we presented a model to serve as a guide for reorienting AIDS work *within* community organizations for the practice of health promotion. Now we have arrived at a point where we can consider a strategic model for advancing HIV/AIDS prevention in a global strategy of health promotion, exploring risk conditions while co-creating supportive social environments.

Community Development Strategy for HIV/AIDS Prevention



The model represents the nested spheres of the social environment with AIDS service organizations (ASOs) or community based organizations (CBOs), bridging between core communities and society at large. Prevention 1 and Prevention 2 are the focal interests of a general strategy of health promotion in which the action is accomplished by exploring and investigating social conditions which may be set ups for risk and vulnerability to HIV and AIDS. The ultimate aim of the community development strategy is systemic, global participation in co-creating supportive social environments.

How can we be sure we aren't creating the risk conditions we are trying to avoid?

Obviously, this is a reflective-evaluative question for which there can be no answer without, of course, direct experience of the social environment for which it is intended.

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[1] Labonte, R. *Health Promotion and Empowerment: Practice Frameworks.* Centre for Health Promotion University of Toronto, 1993.

...two health promoters are developing heart-health community-based programs. One sees her clients in terms of cardiovascular disease outcomes. The other sees his clients in terms of their lived experiences. Outwardly, the programs may appear to be similar, at least initially. But in the former case, health never transcends its encasement by disease. In the latter case, heart health is merely one entry metaphor into the much richer, more complex experiences of people, which include their historic, gendered, class-based and cultural forms of oppression, expression or liberation; p35.

The difference lies in the professional's authentic commitment to hearing the experiences of people's lives, to understanding these experiences in the words people use to express them and to negotiating mutual actions to improve those situations people would like to alter; p35.

[2] *ibid.*

When workers do not feel esteemed in their jobs they tend to derogate, or victim-blame, the less powerful and community groups with whom they work. Where health promotion as empowerment is concerned, it is not "practice what you preach." It is, "if you do not practice, you cannot preach," full stop; p48.

[3] *ibid.*

An empowering health promotion practice holds that certain community processes (organization, mobilization, education) are necessary to enhance personal health and to create environments that are simultaneously more protective of health and more supporting of healthy personal behaviours. Not only does this require a reformulation of what success looks like; it also demands a different epistemology and methodology of research and evaluation; p37.

[4] Labonte, R. *Community Development as a Professional and Organizational practice: an action research project.* Paper presented at 2nd National Conference on Health Promotion Research; Vancouver March 1993.

[5] Labonte, R. *Health Promotion and Empowerment: Practice Frameworks.* Centre for Health Promotion University of Toronto, 1993.

Community development...has been pithily if cynically described as the point at which the organizationally powerless meet the socially powerless. Organizations that do not engender internal democratic participation tend to have poor, power-over relations with external groups and other organizations; p48.

[6] *ibid.*

"Community" is often presented as the engine of health promotion, the vehicle of empowennent. But it may be more accurate to say that the small group is the locus of change; p58.

We must be patient in this group-building, community creating task. It often takes between one and two years before the first "group" squiggle may form from the disconnected individual dots, group formation occurring when individuals self-identify as "group members;" p58.

Conclusions

It's a matter of a sense of pride, of community, and of caring about each other.

Can there be any doubt, from all the foregoing, of the need for a system of education for community AIDS workers? We have reached a time where even AIDS 101 requires revision to include activities which would expose and deal with the social context of prevention. And there is so much more to do in this work. We are advancing on many fronts, but we have no consensus of our theory and practice. Meanwhile, we have yet to develop a universal method of educating ourselves on how to proceed.[1]

Our way of working, throughout the field of community AIDS work, is about committee representation, business meetings, policy decisions, and project tracking — all very productive, but nowhere do we leave time for theory and practice. This absence, possibly more than any other factor, may account for the often dissonant and adversarial tone of some of our most basic discussions about what to do and where to go next. No wonder: we have yet to map what we understand to be adequate or desirable ways of functioning in AIDS work. And where our advocacy role with the agencies of society is concerned, consciousness of our theory and practice may well be the deciding factor for the future of AIDS work.

It seems unlikely that a crash course will do the trick, although we need to design one to introduce new workers to the situation. But our predicament is too diverse, too immense and too continuously changing to count on learning by crash course. We are much more likely to reach our full potential by instituting ongoing learning processes in which we are all continuously re-examining our principles and process in AIDS work.

The future of *Taking Care of Each Other* is already before us. We are ready to embark on a truly exciting learning venture as we turn to consider our theory and practice. We already know about some of the monsters we are bound to encounter along the way. But this path has a heart. And the mission before us is destined to define the humanity of the new millennium.

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[1] Odets, W. *AIDS Education and Prevention: Why it has gone almost completely wrong and some things we can do about it.* Paper delivered at National Gay and Lesbian Health Conference, Houston July 23, 1993.

In conclusion, it must become clear that education appropriate to 1984 is falling miserably short in 1993. This is because we do understand more than we did then; because the epidemic is not an aberration in our lives, but a permanent form of life; and because those who have lived through the epidemic are understandably no longer who they were before it started; p 23.

Appendix

Health promotion agenda at a glance

Society

- ☐ *locate how AIDS has changed society*
- ☐ *determine how AIDS is glossed over*
- ☐ *note what brings attention to AIDS*
- ☐ *relate sexism, hidden sexuality and social response to AIDS*
- ☐ *timetable a social change agenda*

Core Community

- ☐ *highlight the strengths of AIDS work*
- ☐ *open discussion on general health issues*
- ☐ *examine the roots of HIV fatalism*
- ☐ *create ways to process death experience*
- ☐ *research sexual dynamics of risk*
- ☐ *explore social causes of risk/vulnerability*
- ☐ *recognize AIDS work achievements*
- ☐ *promote community building objectives*

Organization

- ☐ *re-examine scope of health issues*
- ☐ *process experience of AIDS work*
- ☐ *forums: theory /practice in AIDS work*
- ☐ *reconsider: is what is preached, practised?*
- ☐ *re-examine organizational model*
- ☐ *pre-visualize criteria of effectiveness*
- ☐ *re-think or re-structure?*
- ☐ *advance advocacy role*
- ☐ *focus on efforts with leverage*
- ☐ *re-examine serostatus exclusion*
- ☐ *develop strategic skills or search for them*
- ☐ *map career paths in AIDS work*
- ☐ *examine unconscious barriers of AIDS culture*
- ☐ *relate funding to the spread of the work*
- ☐ *encourage solutions to work-space issues*
- ☐ *develop a system of AIDS work recognition*

Prevention 1

- ☐ *co-investigate sexual intent vs actual practice*
- ☐ *survey HIV fatalism experience*
- ☐ *study social influences of risk in outreach*
- ☐ *co-investigate unspoken risk experience*
- ☐ *explore unexamined social-sexual values*
- ☐ *research successful safer sex models*

Prevention 2

- ☐ *research social conditions of HIV distress*
- ☐ *reconsider categories of HIV knowledge*
- ☐ *review access issues for newly diagnosed*
- ☐ *update reinfection theory-knowledge*
- ☐ *investigate HIV+ glorification as risk*
- ☐ *co-investigate HIV+ sexuality*
- ☐ *review HIV test - health issues*
- ☐ *design HIV+ lifestyle health program*
- ☐ *extend library services as HIV+ support*

Health Strategy

- ☐ *re-evaluate community development strategy*
- ☐ *contextualize HIV info with social environment*
- ☐ *re-think, re-organize outreach strategy*
- ☐ *research audience groups on all info projects prior to writing/design*
- ☐ *review packaged info for inherent health strategy*
- ☐ *design community strategy into all initiatives*
- ☐ *undertake evaluation research, key issues*
- ☐ *investigate health consumerism options*