



# Taking Care of Each Other:

*health promotion in  
community based AIDS work*

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**Terry Trussler EdD  
Rick Marchand PhD**

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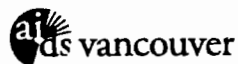
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# Foreword

This is the report of an inquiry which took place at the Pacific AIDS Resource Centre (PARC) during the first half of 1993. PARC is the home of three distinct AIDS organizations: Vancouver Persons with AIDS Society (PWA), the Positive Women's Network (PWN) and AIDS Vancouver (AV). Our research began with an exploration of what health promotion might mean in community AIDS work. To find out, we undertook an inventory of key concepts from the literature of health promotion and engaged several key informants — all working at PARC — in a round of interviews about current issues and conditions in their work.

What we found was that people, passionately committed to AIDS work, are practising health promotion without naming it as such. When we shared statements from the interviews and our interpretations with the education staff of AIDS Vancouver, we further discovered that bringing the practice of health promotion into AIDS work is the same thing as continuing to refine AIDS work as a faithful response to new perceptions of community needs. In the synthesis, we propose a model for refining AIDS work in that way: informed by health promotion research, theory and practice.

The report concludes with an outline of a specific, targeted action that the education staff of AV initiated as a result of the inquiry activities and discussions inspired by *Taking Care of Each Other*. We offer our readers this expression of our encounter with health promotion as an opportunity to consciously re-examine AIDS work on the way toward its transformation.

Vancouver,  
August 1, 1993

# Acknowledgements

There can be perhaps no experience more humbling in community AIDS work than to come face to face with the realization that nothing can happen without the community's co-operation. In pursuing this inquiry, thankfully, we experienced a passage more closely resembling a willed collaboration. That spirit of participation in new knowledge revealed, more than anything else, the inborn passion of doing community AIDS work.

We feel obliged to privilege Arn Schilder with a special thanks in this regard. In his characteristic vigilance, Arn saw the potential of health promotion early in the health policy game and within it the opportunity for community AIDS work. By his vigilance, it is really Arn who should be held accountable for bringing *Taking Care of Each Other* to this work. His view of the "bigger prize," spelled out so well in his interview, was another gift in the same spirit.

Through their collaboration we are also especially indebted to several others...

Beth Easton must have wondered if any man could rightly see the boundaries of gender power; nevertheless, she finely honed our attention to the gender issues in AIDS work. Howard Engel said, "health promotion is as health promotion does," and so defined the "food, shelter and medicine" approach to health promotion in AIDS work.

Mark Mees identified some key signs of positive change on the horizon.

Ron Parker broke the way clear for a real-life working experience of participatory research, and by his enthusiasm, showed the true potential of co-investigation as a form of community action in AIDS work.

Scott Robertson saw the connections between language, meaning and power, and within that, a vision of collaboration on the many social development themes extending from community AIDS work.

Mylo Riley focused our attention on the space women require to break the totalizing effects of gender domination.

Pam Weeks pointed out our pre-eminent need to fully recognize how far community AIDS work has already taken us.

A special word of thanks must go to Erik Ages and Sharon English for their committed proofing and editing of the text for printing. We would also like to thank the Canadian AIDS Society for its financial contribution to the printing costs and for assistance in distributing this study.

There were many others without whose contributions *Taking Care of Each Other* would not have been possible, especially the voices of the HIV positive community. We share their pride in seeing their contributions break through in the writing.

# Introduction

*Health promotion is as health promotion does.*

Our inquiry began exploring the question ...

*What could Health Promotion mean for community based AIDS work?*

This original question was less a problem of research than one of meaning. We were not too certain ourselves of any consensus about what health promotion was, what it was not, and what it might be.<sup>1</sup> That required some looking into. And we found, almost immediately, that meaning itself is an issue in health promotion. Health promotion means different things to different people and that meaning is at the heart of health promotion's potential, because the meanings we come to ascribe to health promotion will determine, to a large degree, how we do it.<sup>2</sup>

As in most research ventures, we turned to the literature. What we found did not make our situation any easier. Understanding health promotion requires seeing health from a variety of perspectives simultaneously, and tolerating a certain amount of ambiguity in doing so — a little like carrying on a discussion in several languages at once. And because health promotion is an evolving notion, it is also inconvenient to be too concrete.

Begin with this way of construing health promotion: action by people to meet their own, self-determined positive health goals, pursued through personal, group and community development in a context of supportive policies, resources and environments.<sup>3</sup> There appears to be so little to disagree with. But this one-sentence model of health promotion is loaded with ambiguities about what might be meant by such terms as “community,” “development,” or even “supportive.”

And the stew thickens the deeper you go. Empowerment, for example, is a threshold idea in health promotion, because there is a growing body of knowledge showing that unhealthiness is the product of the power imbalances and inequities in human life. So health promotion pits empowerment against inequity. And although empowerment is supposed to connote power sharing, the often heard injunction to “empower” others seems to imply that power grabbing is more like human nature.

Take community as another example of a health promotion concept. The outline of a community and how it may be perceived, by those who consider themselves members or otherwise, is intensely problematic. Although a term like “gay community” seems to be in easy correspondence with such obvious givens as the existence of a population of gay people living and being themselves in a neighbourhood locality of the city of Vancouver, their ability to function as a unified force is, as everyone knows, arguable. Diversity makes it that way. So what would this community's development look like?

But a critique based on the literature would not advance the cause of health promotion in AIDS work. This quickly became clear, because the literature is all so fresh and still developing. What was needed was something deeper and richer. Seeing this, we decided to probe what was actually happening in the experience of the people closest to AIDS work, in the vortex of it all, the community based organizations of Vancouver: Vancouver Persons with AIDS Society (PWA), the Vancouver Positive Women's Network (PWN) and AIDS Vancouver (AV), three separate but related organizations housed at the Pacific AIDS Resource Centre (PARC).

This was the first real shift in our thinking. To get at what health promotion means and might mean in AIDS work, our research problem moved from meaning to *doing*. Asking critical questions of those closest to doing the work of AIDS seemed a more productive and satisfying way of addressing what health promotion actually was in their experience. And so from this perspective, it appeared that what health promotion might be would follow far more realistically than anything we might have imagined.

To bring the notion home even more poignantly, we now recognize that what is and has been going on in the community based response to AIDS *is* health promotion, whether it has been named as such or not. The historical correspondence between the early community response to AIDS and the expansion of health promotion policy is as fortuitous as uncanny — an ancient community health practice, refined by the women's movement of the seventies<sup>4</sup> and taken up by gay men in peril during the eighties.<sup>5</sup> In this respect, the future of health promotion may well be shaped by community action against AIDS.

### *ABOUT THE RESEARCH*

True to the participatory values of health promotion, the research behind this report grew out of dialogue between Rick Marchand, who manages the Education Services Department at AIDS Vancouver and Terry Trussler, an independent consultant with experience in many agencies of the health system. Rick realized that, while health promotion was entering the vocabulary of AIDS work, there appeared to be only a surface appreciation of what the practice of health promotion, in its fullest sense, could be.

So we went to the literature and gathered concepts that appeared in various journal articles, verbatim, to establish a theoretical context. We recognized, however, that theory lacks sufficient power to change anything without the ground of real experience, so our next thought was to set up a means for various people working in Vancouver's community based organizations (CBOs) to contribute to the inquiry. We tinkered with some questions that we believed would bring to light some interesting reflections on their work. The interview format would ask critical questions: how their assumptions had been blown, what they felt about their effectiveness, what made them angry, and so on. We asked these questions of four men and three women, their sero-status similarly blended, all people who work in the various agencies associated with PARC. What they said forms the bulk of the text to follow.



Our analysis followed a simple procedure of taking exemplary statements and assembling them into categories of like kind. The next step was to write an analytical text, reflecting the literature, that set up and framed the meaning of the exemplary statements. A third analytical step points out the health promotion agenda raised by each statement.

During this work we also had a serendipitous opportunity to piggy-back with a national health promotion needs assessment. The national inquiry focused primarily on participants in Vancouver CBOs who are living with HIV. In pursuing this work, we formed a research partnership with a member of PWA who had little previous experience with research. Together, we processed several focus groups for the needs assessment, collected audio tapings, wrote transcripts and produced findings which were later sent on to Ottawa. Although only a small portion of that material is quoted in the text to follow, the experience had an indelible impact. Most of the pullout quotes under each heading in this text are from the voices of people who participated in the needs assessment.

It so happened that a major conference on health promotion, the 2nd National Health Promotion Research Conference, took place in Vancouver during the inquiry, and this provided a welcome opportunity to compare experiences. The conference was international in scope and featured presentations by both the Federal and Provincial Ministers of Health. Another conference of a more regional nature, which brought together people working with AIDS from all over British Columbia, was also very instructive. And, as well, simply participating in the life and occasions at PARC made the context for understanding health promotion in AIDS work all so real.

### *ABOUT THE TEXT*

The text to follow is similar to an audio documentary. The voice of narration appears in plain text and the voices of informants appear in italics. Each chapter is somewhat separate from the other, and it would be entirely possible to read them out of order. The point each statement makes about practice is summarized under a box heading entitled Health Promotion Agenda. The footnotes for each chapter include not only textual references, but also the concepts of their authors, verbatim, to add further depth of meaning. These can also be read as a separate, reflective text.

And finally...

Every project of this sort is limited in scope and this one is no exception. It was never our intention to take on explaining health promotion or AIDS work in all their complexities, but we have pulled together one particular view of the action which we hope will help to move things along. We are also aware of the imminent disclosure of many unintended biases in the way we have posed questions or in our selections and analyses of texts, but from this there can be no escape. We have, however, attempted to include a proportionate representation of voices speaking from various salient points of view, especially those representing gender and sero-status. There are many other views to be sure, so we encourage our readers to take up the critical challenge and extend the relevant knowledge.

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<sup>1</sup> Epp, J. *Achieving Health for All*. Ottawa, Supply and Services, 1987.

... a vision of health as a dimension of the quality of life; an articulation of the current and future health challenges confronting this country; an understanding of health promotion as a process of enabling people to increase control over their health... a commitment to dealing with the challenges of reducing inequities, extending the scope of prevention and helping people to cope with their circumstances. It means fostering public participation, strengthening community health services and coordinating healthy public policy. Moreover, it means creating environments conducive to health, in which people are better able to take care of themselves, and to offer each other support in solving and managing collective health problems; p12.

Policy Framework: reducing inequities, increasing prevention, enhancing coping. Mechanisms: self care, mutual aid, healthy environments. Implementation: fostering public participation, strengthening community health services, coordinating healthy public policy; p8.

<sup>2</sup> Poland, B. Learning to 'Walk our Talk': the Implications of Sociological Theory for Research Methodologies in Health Promotion. *CJPH Supplement 1*, March/April '92.

The emphasis in the new health promotion framework is clearly on comprehensivity and the integration of individual and social determinants of health.

... so the need to further our understanding of the social context and meanings people associate with health related events and behaviours; p33.

... meaning permeates and forms the basis of human thought and action, negotiated through interaction with others. The meanings we ascribe to phenomena therefore determine to a large degree our choice of available responses to them. Many of these meanings are shared to the extent of being totally taken for granted, imbedded in the culture, and institutionalized in rituals, habits and social structures which in turn influence individual socialization and behaviour; p33.

<sup>3</sup> Raeburn, J. Health Promotion Research with Heart: Keeping a People Perspective. *CJPH, Supplement 1*; March/April '92.

... where people feel in control of themselves their lives and their environment, have resources and control over those resources, have options and can exercise them, have knowledge and skills sufficient to make informed choices and take their own action, have decision making power in areas that matter, have clout, have a significant and meaningful role in the scheme of things; p22.

<sup>4</sup> Clarke, J. Feminist Methods in Health Promotion Research. *CJPH Supplement 1*; March/April 1992.

Health Promotion is actually the generic and the most ancient health policy known and pursued. At minimum, health promotion concerns the provision and acquisition of the necessities of life within a family or community of people.

Feminists recognize that men and women inhabit different social worlds: their social experiences are in many ways different from one another. There are health, illness and medical experiences that are unique to each sex.

... Out of these different experiences with their bodies arise different health vulnerabilities and opportunities and, naturally special foci for health promotion; p55.

<sup>5</sup> Pinder, L. Health Promotion and AIDS Prevention. *CJPH, Supplement 1*; Jan/Feb 1993.

Very early in the epidemic those infected and those most intimately affected by AIDS assumed a leadership role by not remaining silent at a time when the disease and those living with it were receiving little attention. Through advocacy, organizational development and setting up community care, treatment and education, gay people led the way; p5.

# Assumptions

*It's as if you don't hear a rumour by noon, start one!*

Anyone working with AIDS will tell you how much of a shock to the system the experience can be. Few workplaces confront employees let alone volunteers with so much all at once. Life in the community based organization swirls in a vortex of virtually everything that is in conflict in the cultural forces of these times: health, sexuality, morality, money and power, to name only a few. No wonder assumptions are shattered.<sup>1</sup>

People coming into AIDS work do so with their eyes open, knowing the backdrop to this workplace falls off sharply into the abyss. Even so, they bring with them assumptions they have no way of knowing about until they arrive and take up their challenge. Soon, the awesome complexity of this struggle becomes their own personal crisis. Assumptions must alter to meet realities; sink or swim.

We asked people doing AIDS work about their mistaken assumptions and we learned more about what is really going on in AIDS work than from anything else they might describe. Here are their insights...

*The first thing that comes to mind is my assumption that people would be interested in AIDS — that we could trigger interest in general populations — I don't think the community organizations have been able to do that effectively.*

Arguably, whatever public consciousness there is about AIDS was built on the foundations of the leadership provided by community based organizations. Certainly, there are many more players now, but chipping away at the wall of denial continues to be a frustrating labour. Even in medicine...

*I guess I was aware that the medical profession had a lot they could learn from HIV positive people but I am continually blown away by how little they listen and the kind of assumptions they make.*

Even among the various people and organizations who have come into the work with apparently common aspirations, crisis and conflict are endemic...

*I assumed it would be easier and done a lot more quickly. I assumed there would be a lot more cooperation, not only within the organization but among the associated organizations in the city. That there would be a*

*lot more of a working professional relationship between all those groups. But there isn't. There wasn't.*

Because AIDS work is often at odds with conventional sources of power and authority, even everyday speech is open to question.

*What's blown my assumptions is that we have yet to find a universal language that allows for different people coming from different places to talk to each other. I wasn't aware of how much the work of AIDS was linguistically based. But it's very much that: a language of diversity, a language of health promotion, a language of self-help, self-care, of empowerment; a language of community.*

And the knowledge brought forward from grappling with the real life experience of HIV and AIDS is not necessarily heard in the most important places.

*It's the question of support that you get for the ideas that you have. We've met with a lot of success but the establishment has not validated our existence, our right to identity. It cannot seem to grapple with the issue of AIDS and homosexuality — let alone death — in ways that would be meaningful or supportive to our grass-roots initiatives. I made gross assumptions that I would see this change happen faster.*

Even in the gay community, where devastation has been commonplace, the enormity of the challenge was a surprise.

*I had an assumption the lesbian and gay community would be more responsive, that they would say "yes this is a way of achieving health and care in our communities, of making them stronger." But these are diverse communities. They are fractured into peer reference groups just as in any community. And the health promotion that we develop will have to come from there.*

No-one ever said this work would be easy.

As major cultural institutions continue policies of denial, AIDS work will increasingly need to penetrate the roots of basic assumptions. Otherwise, we would find ourselves at risk from the very things we take for granted. To get beyond that, health promotion tells us, we must do nothing less than shift consciousness.

**HEALTH PROMOTION AGENDA**

TAKING CARE OF EACH OTHER... 6

- *public interest*
- *professional conduct*
- *professional cooperation*
- *communication*
- *knowledge development*
- *community development*

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<sup>1</sup> Poland B. Learning to 'Walk our Talk': the Implications of Sociological Theory for Research Methodologies in Health Promotion. *CJPH Supplement 1* March/April '92;

...such a perspective would require a willingness to question common sense or taken-for-granted assumptions guiding daily action. These issues are central to the health promotion project insofar as it has been recast in more global terms...this will require explicit recognition of the (inter) subjectivity and contextuality of health-related behaviour, and therefore of the role and relationship of individual and environment in the re-creation of each; p34.

# Community

*Isn't it good to have someone with good intentions around you!*

The community focus of health promotion comes from a history of problem solving experience in public health. With AIDS, it was simply the best available response to a mounting crisis. Ten years ago, the community organizing efforts of a few concerned gay men brought AIDS out of the shadows and into the public agenda.

Health promotion is an up-from-the-community practice based on needs represented in and expressed by the community.<sup>1</sup> To get anything accomplished, to bring about real change, community development only makes practical sense. Experience with AIDS work has reinforced this deceptively simple wisdom.

"Community," however, is no conceptual holiday. One problem is cohesion — the factors that bind people to a common sense of place and being. Is sexual identity, we may continue to wonder, an adequate bond for successful community development?<sup>2</sup> Another problem is diversity. Do we imagine that a spectrum of differences makes up a diverse community or separate communities? As we encounter the second decade of AIDS, the thrust of these questions will make health promotion an increasingly complex community practice.

*I think we are pursuing an approach but I don't think everyone knows we are. I think we realize we have a leadership role to play, sharing resources, facilitating a response to AIDS. We do it every day but we never put our work into terms that describe what we are doing. We provide an example.*

In the emergencies of the first decade, safer sex education seemed to be the only sensible community development issue. The urgent cause was, essentially, to save lives and learn more about how to save lives in the "community." Still, in spite of the energy and creativity of those times, far too many people became infected with HIV before everyone that needed it got the message. And the legacy is still with us.

*There is a cohesion now to access care and treatment support for PWAs under the health promotion umbrella. People — the innovative thinkers — are starting to see that there is a bigger prize. All agencies realize that they can no longer go on educating the way they have been educating: throwing condoms at people. Tremendous dollars are being expended for very narrow programs that aren't directed at target audiences or communities. Change is there and it's happening. The speed is my concern.*

Prevention education is now in a state of flux as we learn more about the impact of earlier work from sero-prevalence studies.

*There is a shift going on around this work. People are realizing that information and behaviour change strategies may not be working broadly enough. Earlier work did make a difference, but we missed things. We are now realizing that and trying to change.*

Women have been making important contributions throughout the development of AIDS work, although gay men have dominated community organizations according to the urgent needs of an overwhelming male majority infected and at risk. Currently, however, AIDS may be increasing faster among women than men, at least in the US. In this alarming evolution of the epidemic, the role of women in AIDS work has never been more vital. And while the gay male image appears to prevail in many community organizations, women are increasingly challenging the gender assumptions of AIDS work and forging new perspectives.

*If there is a common approach to doing AIDS work with women, it is simply giving women a space to talk. We address AIDS issues, but first and foremost, women need a space to talk. The work is being done hand in hand with women who are positive. In this way we don't separate education from support.*

On one level, health promotion has been taking shape in AIDS work as a way to assist those who are living with HIV. On another level, people are beginning to sense that health promotion may mean something more; that health promotion embraces not only AIDS prevention, care and treatment, but also the community's health beyond AIDS.

*We need to be able to shift out of a reactive mode where AIDS work seems to be by definition, and honour the proactive vision, the hopefulness, the principles we want to be active in our work. It's hard when people are dying and issues need to be addressed yesterday to nurture ourselves and think this way. The community is experiencing difficulty in feeling right about doing this piece of work and yet I think this is what we must do to see the bigger picture and attain our goals.*

Still, urgent community needs may be blurring our vision of “the bigger prize” as competing interests and the realities behind them force us to deal with necessities.

*I think people who are negative have things going on — survivor guilt — these people feel they have to be involved somehow. I think there is a big difference in attitude. The sense of urgency, wanting to have*

*services in place because you (eventually) may need them, clinical trials to try out new things that come on the market. For me it's not completely an altruistic effort.*

Increasingly, health promotion must also address what is going on inside community based organizations in order to achieve hoped for results in the communities they serve.

*I see that there is an emotional component in our work that is getting in the way of us being able to dream together, the multiple loss, the stress, the sense of overwhelmingness. For many people it is a huge barrier of fear. Naming these issues is the beginning of the way out.*

And what may be learned from that experience could be what lies in the future of health promotion in community based AIDS work.

*We need to address the larger social institutions and organizations, to challenge them to be supportive of people.*

#### **HEALTH PROMOTION AGENDA**

- *define CBO approach*
- *focus and target HP effort*
- *shift prevention to HP strategy*
- *encourage women's initiatives*
- *develop proactive HP vision*
- *recognize HIV guilt/urgency*
- *identify emotional issues*
- *address larger social institutions*

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<sup>1</sup> Eakin, J. Maclean, H. Critical Perspective on Research and Knowledge Development in Health Promotion. *CJPH, Supplement 1* March/April '92

Within health promotion it is widely believed that the identification of problems and solutions should come "up" from the community rather than "down" from professional experts; p73.

Community participation in research is thought to ensure that what is studied is relevant to health promotion practice and to the self-defined needs and priorities of those on whom the research is focused; p74.

<sup>2</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs, *AJPH* V6N3 Jan/Feb 92

A competent community is one whose members can collaborate effectively in identifying problems, can reach consensus on goals and strategies and can cooperate in the necessary actions to acquire resources to solve those problems; p201.



# Effectiveness

*Why are people still seroconverting?*

Research is a built-in function in the practice of health promotion. Since the need to know what works and why is so fundamental to getting anything accomplished, health promotion has gone so far as to question the conduct of evaluative research. One thrust of this discussion among health promotion theorists is a new attention to the subjective experience of people in communities. Health promoters are recognizing that the medical research paradigm — based on objective sampling and double blind control groups — is inappropriate for the study.<sup>1</sup> For one thing, scientific reduction to numbers is no way to explain the subtle dynamics of living a community life. On the other hand, the methods and conduct of the research reported in this study — community participation, intensive interviewing, focus groups, verbal text analysis — could stand as one example of the kinds of “interpretive” techniques now moving health promotion theory.

To question how well the community based approach is working is central to practising health promotion in AIDS work. Because knowing how well things are going requires reliable information from research — the kind of information that, when put into practice, would have the power to transform a community. In this sense, health promotion is a process of action, reflection, and action.<sup>2</sup> Leave the reflective component out, and you only frustrate the effort to accomplish anything. No sense of reaction. No focus. Low impact. The deluge of poorly targeted AIDS prevention ads in the first decade is only one example of what can and did happen.

When we asked those currently working in Vancouver's CBOs to reflect on the effectiveness of the effort, we received some remarkable insights and some new agenda for future health promotion.

*When I grew up in the seventies, all there was (to the gay community) were beaches, bath houses and bars. The social world was impenetrable. It was based on a whole experience which you could only access very slowly through your sexual wiles. We were an emerging community. We had culture. We had values. But we had no institutions. We did not have health care associations or benevolent societies. There was no health promotion in those days.*

*If there had been no AIDS service organizations, we would not be where we are today. The gay community had previously never been involved in any social service effort around health. I'd like to think our education efforts have been successful. We've reached tens of thousands of people. I'd like to think our support services have helped a*

*lot of people. We've formed networks. We've mobilized people. We have forced change.*

Still, there are serious underlying problems affecting those who work in CBOs: the nagging perception of an uncaring world outside and incipient divisions on the inside.

*There are days when I think there is a movement. Then there are days when I feel it's scattered and dissipated.*

*I think the gay community is split into two, perhaps even more because I don't think a cohesive community really exists. There's HIV positive and HIV negative. I think AIDS Vancouver's profile is incredibly low in both camps, even though a lot of people are using our service, even at 1600 client transactions a month.*

Knowing that an effort is paying off is a matter of seeing it work. Quite often, however, the distance between action, reflection and then back to action creates a tension of uncertainty for those at work in the community.

*A lot of the effort is immeasurable. There are ways that we affect people but we have no idea that we have or in which way. We may never have contact with them again. We don't see them in their lives. It might not affect them for a year. What we say or do with people might plant a seed but we don't see the change.*

The role and impact of AIDS work for women is in such a state of doubt that some people working in CBOs are beginning to talk about two kinds of people living with HIV, women and men.

*For certain populations we've been very effective: gay men. But women still don't know where they can go to get confidential AIDS testing. Their doctors discourage it. And if they're tested automatically when pregnant, they are not told the result.*

*If a woman comes to a workshop and hears us speak about sexuality and she discovers that how she has an orgasm is normal, or she learns words for her anatomy, does that mean our "Women and HIV/AIDS" health promotion work is effective? I'd say it is. But it may not be in the way our funders are imagining what the work is.*

In spite of successes which should not be forgotten, the community needs leadership. The up-from-the-community philosophy of health promotion suggests that local CBOs should continue to be the proving ground.

*We haven't had many people surface who are macro thinkers or contextual thinkers who are able to see the myriad of issues and suggest a potential through line. Then we could evaluate how effective that was or was not.*

Newly focused thinking and planning influenced by health promotion theory could bring about significant change to AIDS work, and at the same time, serve to emphasize the leadership role that community organizations have already played in defining their own practice of health promotion.

*I think we've been ineffective in going out into the world from a place of pride in what we're doing. In the AIDS community we have been almost apologetic in our stance.*

*I see that where we're not being effective is modeling interdependence, really sharing the skills and expertise that we've been developing over the past few years and putting it forward unashamedly in the world.*

## HEALTH PROMOTION AGENDA

- *implement co-investigative research*
- *consider HP internal effects in community organizations*
- *recover HP external impact on communities*
- *evaluate HIV community divisions*
- *uncover women's needs*
- *encourage HP thinking and thinkers*
- *disseminate CBO models of HP*

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<sup>1</sup> Poland, B. Learning to 'Walk our Talk': the Implications of Sociological Theory for Research Methodologies in Health Promotion. *CJPH Supplement 1*, March/April '92

...the requirements for a new paradigm for health promotion research include a fundamental concern with the critical appraisal of subjective meanings as construed by human social agents, one that appreciates and struggles with the intersection of structure (as norms, codes of conduct, institutions) and human agency (individual volition, cognition, personality and biography) in a manner that remains sensitive to the biographical and historical context and to the role of feelings as well as rationality, and finally also one that grounds theory in empirical reality; p37.

<sup>2</sup> Labonte, R. Health Promotion Knowledge Development, Report of a meeting held in Toronto, January 27, 1993 presented at The 2nd National Health Promotion Conference, Vancouver March 29, 1993.

Most disease prevention activities take questions of social power and transform them into factors or variables to be considered in reducing disease. Health promotion uses disease as one of many entry points into the issues of social power, which is its primary concern... Health promotion as a social action practice is not easy to explain or plan. It is a process of action, reflection, action ... Health promotion may best be considered a facet of human development; p8.

# Empowerment

*My own personal feelings are my major influence. I rely on me a lot.*

Health promotion is also about shifting power dynamics. Its strategy of empowerment comes from abundant experience and research which show that a subtle shift in health consciousness produces profound results in health outcomes.<sup>1</sup> A deceptively simple mental manoeuvre — eschewing dependency on external sources of control over health to rely on one's own internal resources — makes all the difference.<sup>2</sup> The implications for professional conduct in health services and community based organizations are vast and multifaceted. Because empowering others also means letting go of the impulse to control.

The empowering philosophy of health promotion is central not only to individuals such as those living with HIV, but also to the functioning of whole organizations and communities.<sup>3</sup> Is it any wonder, then, that so much of life and the subject of discussion in AIDS work involves struggles over power and control?<sup>4</sup> On the personal scale, the residual effects of traditional power such as gender and social status make control a constant face to face issue. On a social scale, the power of global capitalism makes economic control the dominant theme of AIDS, in every possible way, from prevention to treatment. Community workers have to deal with all of this and their personal power and control issues as well.<sup>5</sup>

When we asked people working in Vancouver's CBOs what they felt were the issues of power and control affecting them, they were often critical about the power relations they saw operating in their own organizations.

*We are looking at a paradigm shift in AIDS work: a new language, a new way of being. How do we let go of the need to control and give it over to where it should be?*

There were worries over the destructiveness of some kinds of conduct...

*We have major control issues in the community of activism. It's very hard to bring everyone into a common voice. It's such a hard question to deal with. Rage, anger and resentment, if they are not properly challenged, can be so destructive in any organization.*

And explanations for the sometimes disturbing conflicts that take place as a matter of course in the everyday life of the community based organization.

*I think a lot of people who are living with HIV are disempowered and feel a loss of control. Doing this work is an attempt by many to regain that control.*

*The flip side of why people are trying to gain control, have control, be in control is because of fear. They are terrified. The way that we have learned to be in the world, and the way that people have been valued to be in the world is through their power over instead of power with.*

People living with HIV and AIDS experience control — the loss of it, the lack of it and the attempt to regain it — quite directly as an urgent, life absorbing reality.

*I feel I don't have control in my life right now. It's like a time bomb.*

*It's a lose-lose situation. Everybody who's gotten AIDS has died of it. Nobody's survived it yet. There are people living with it but nobody's survived it.*

Those working professionally in AIDS Vancouver often cite the overwhelming sense of the shortness of time as a central issue in the political life of CBOs because, as they say, people without the virus cannot appreciate the urgency of need. Consequently there is a growing recognition of the need to place positive people in key positions that would directly impact on those being served by CBOs. Even so, this trend has not completely stilled the often fractious, conflicted, and disturbing behaviour routinely witnessed in the life of these organizations.

*A lot of the destructive behaviour comes from gay men who are coming from abusive backgrounds. Abuse is epidemic in our community.*

*Anger in this work has to be expected. I don't think there's anything you can really do about it. You can attend as many workshops as you want, but you can't really do anything about it. It's how you cope.*

Some suggestions about “right conduct” in the life of CBOs came forward.

*The journey in our work is discovering what it is we're trying to be in control of. AIDS issues are all about control: getting in control of the body, control over emotions, and so on. So this is reflected in our organizations. Control issues in the work of AIDS stem from not enough “letting go” or “opening up” or even recognition of the tools and skills necessary for empowerment.*

*If we were in total control of the situation we wouldn't be truly living the intent of health promotion. I don't think we as an AIDS organization should be controlling the situation. We should be working with other groups, sharing the knowledge.*

## HEALTH PROMOTION AGENDA

- *examine power relationships*
- *encourage self-empowerment*
- *challenge abusive behaviour*
- *enhance workforce coping opportunities*

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<sup>1</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs. *AJPH*; V6N3 Jan/Feb 92

The health outcomes of powerlessness and empowerment are often unrecognized, despite the considerable research which documents the role of powerlessness in disease causation, and conversely, of empowerment in health promotion; p197.

<sup>2</sup> Lincoln, Y. Fourth Generation Evaluation: The Paradigm Revolution and Health Promotion *CJPH, Supplement 1, March/April '92*

Medical practitioners of all stripes are redefining health to be not the absence of disease, but rather wellness. Good medical and health practice is not just the healing of disease, but also the promotion of health -- a task which occurs on social, cultural, environmental and biological fronts... The professional posture of the medical model has, in the past, focussed on diagnosis and needed treatment, largely with the physician assuming responsibility for both, and the patient freed of accountability so long as he or she did as the doctor ordered... The emerging model in the health sciences demands a responsibility for the whole person, while the person shares accountability with the professional for the healing process and indeed for the maintenance and promotion of wellness... The promotion of health is no longer just a laboratory problem, it is a problem of social, cultural, environmental and educational difference; p8.

<sup>3</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs. *AJPH*; V6N3 Jan/Feb 92

In its broadest definition empowerment is a multi level construct that involves people assuming control and mastery over their lives in the contexts of their social and political environment; they gain a sense of control and purposefulness to exert political power as they participate in the democratic life of their community for social change; p198.

A study of empowerment implies not just studying individual change, but change in the social setting itself.

The most common use of the term empowerment in public health has unfortunately focused on one level, that of individual change. Individual empowerment is often viewed as separate from the social system, similar to self esteem, individual competence or self-efficacy; p198.

In an empowering organization, individuals assume genuine decision making roles and hence become empowered through their work. Empowered organizations are those which develop and exert influence in the larger community to promote system level change; p198.

Taken as a whole, empowerment reflects an understanding of the perceived and actual components of powerlessness and encompasses the linkages and interactions between the change processes on an individual, organizational and community system-wide level; p198.

*continued...*

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<sup>4</sup> Nutbeam, B. The concept of health promotion and AIDS prevention. A comprehensive and integrated basis for action in the 90s. *Health Promotion International*; V5N3, '90.

Strengthening community action has a fine sound to it -- something which we can all agree is a good thing until it threatens the basis of our professionalism and power. Genuine support for the process of strengthening community action requires letting go of power in the form of information resources, providing training to develop effective leadership and skills in self management, and above all, resisting the temptation to interfere when apparent professional skills tell us things could be done better; p239.

<sup>5</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs. *AJPH*; V6N3 Jan/Feb 92

Interventions which attempt to increase the internal locus of control, without changing the environmental condition, may increase frustration and lead to greater perceived powerlessness and ill health; p201.

Indirectly, community organizing affects health through enhancing the other community empowerment variables: social supports and networks, psychological empowerment, community participation, sense of community, community competence, and ultimately control over destiny; p201.

A working hypothesis is that lack of control over destiny promotes susceptibility to ill health for people who live in high demand or chronically marginalized situations and who lack adequate resources, supports or abilities to exert control in their lives; p202.

# Powerlessness

*You should have the right to your own treatment but you really don't.*

Perhaps it is inevitable that people working in CBOs experience at least an occasional sense of helplessness and sometimes burnout. Because there is not yet a cure for HIV, there is little to be hopeful about. The social stigma attached to AIDS affects even those who work with it. And the demands of working in an environment where crisis is routine means constant stress.<sup>1</sup>

Health promotion is an issue with AIDS caregivers because their health is vital to the healthy functioning of their organizations and therefore the health of those being served.<sup>2</sup> Understanding the feelings of powerlessness that people experience in this work may provide some clues to what needs to be done to achieve truly empowered community based organizations. People need to feel empowered through their day to day work if the organizations they represent are to assume the momentous task of exerting influence in the larger community to promote system level change.<sup>3</sup>

When asked how working in a CBO can bring on feelings of powerlessness, the pain of those at work is clear.

*I feel powerless because I personally can't do anything to stop people from dying. Loss after loss, both from my personal life and here at work, often makes me feel hopeless.*

Dealing with the feelings of loss is only part of the problem. The human loss is irreplaceable.

*We just lose too many people who have knowledge and information about the disease. That is a very frustrating reality. If I could go back and resurrect twenty people, I could change treatment activism in this country overnight. There are only so many people who have the skills and ability or the leadership qualities or the desire to attempt to make changes.*

Meetings, conferences and everyday contact between those living with HIV and community workers are often fractious and complicated.

*I feel out of control when I am in a room where a lot of what is going on is just raging. When I go to meeting after meeting where I feel we are*



*spinning our wheels and I speak to this and we still don't move anywhere, I feel totally inadequate.*

Some of the powerlessness has to do with the virus posing new problems.

*Substance abuse. We have so many PWAs involved in substance abuse and with pre-existing psychiatric conditions. What role should AV be playing? We're left alone to deal with these problems. Are we the hub or the spoke in their health promotion?*

*I feel the denial is enormous on the subject of women and HIV. We have no idea of how big an issue this is because women have not been tested, and find it difficult to get tested.*

Given these realities, AIDS work is full of angst, and this affects professional relations, feelings of adequacy and the workplace climate.

*It's all around feeling any support for doing this work. If there was a healthy community to work in, to unpack all the stuff, to regroup, to rejuvenate, then I feel I wouldn't burn out. It makes me angry not knowing whether my work will be challenged within the organization, that putting myself on the line with positions that I'm going to take will be supported. Not having an assumption of good will makes me furious.*

There are leadership and management issues involved.

*I feel powerless in terms of how other people at AV, staff and volunteers, take responsibility for their actions. I can't force people to be something they are not going to be. Situations come up where people handle situations in ways I can't control. When people are complaining, I can't be responsible for the way they are feeling. All I can do is to encourage them to be proactive, to find the solutions to their problems.*

*I'm powerless to make things right for everyone or resolve all the situations that people want resolved. Yet I feel that sometimes it's expected of me to make things right. I can't do this and besides it's not empowering. Everyone needs to be part of the solution.*

Although these expressions of AIDS work would seem to suggest that something urgently needs to be done, there is also a danger in doing so too directly, because ultimately, health

promotion is about those being served by the organizations. And in spite of everything affecting the state of community organizations, the good work is recognized.

*With the limited resources of ASOs, the people involved are performing miracles.*

## HEALTH PROMOTION AGENDA

- *recognize experiences of powerlessness*
- *examine roots of powerlessness*
- *develop strategies to cope with sources of powerlessness*
- *encourage and support healthy climate and workplace civility*
- *encourage self-empowering work strategies*

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<sup>1</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs. *AJPH*; V6N3 Jan/Feb 92

As people perceive their failure to achieve societal promises, they become psychologically damaged and internalize their powerlessness as their own fault, rather than as a response to system wide discrimination; p198. If people come from life situations that put them at risk for powerlessness and lack of control over their destiny, they carry that perspective with them into their interactions with professionals; p202.

<sup>2</sup> Strengthening community health services: an exercise in knowledge development. *Health Promotion*; summer '92

Caring for a chronically ill relative can create stress, anxiety, depression and feelings of great isolation — risk that the natural caregiver will experience deterioration in physical, mental, emotional, health — a function of the length of time providing care, and the availability of resources to get a break, socialize and acquire time management skills; p8.

<sup>3</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs. *AJPH*; V6N3 Jan/Feb 92

Empowerment education would always engage people through a group dialogue process in identifying their problems; in critically assessing the social, historical, and cultural roots of their problems; and in developing action strategies to change their personal and social lives; p203.

# Anger

*I figure if I can't get up and be angry, I have nothing to live for.*

People working in CBOs, particularly counsellors, have noticed how much anger surrounds the AIDS experience. Their roles involve witnessing angry exchanges, being targets for anger and feeling anger in themselves. The experience is often unsettling, disturbing, and at the very least stressful. But there is also some recognition that anger goes with the territory.

From a health promotion point of view, anger can be taken to be a signal.<sup>1</sup> Something powerful is occurring and it may be what will ultimately result in the shift that moves someone toward empowerment. Anger in its healthiest expression is motivation. The most obviously empowered people living with HIV participating in this study were often "feisty" individualists who had "found" their self-empowerment in the anger they felt from meeting obstacles and challenges in the health system.

If AIDS organizations are to be competent facilitators of community empowerment, the people working in them need to be able to deal with anger: to listen to anger, to learn from anger and ultimately to use anger to channel constructive action.<sup>2</sup> Seeing this, we wanted to find out what, in particular, were the situations in Vancouver's CBOs that made people angry.

*It makes me angry that people feel threatened by AIDS work.*

Some of the anger is simply frustration with the reality of infection.

*Anger is caused by HIV. The fact that you are sick and may be dying. Your anger at your own disease, that you are not feeling well, that things are not going your way. Because of your own mortality. Why is all this fighting going on? Because you are scrambling for something you can't ever have.*

And some anger is about the social conditions and situations that created the HIV epidemic.

*In terms of health promotion, I'm angry that it wasn't there for me. I had no experience or knowledge of self-care or self-help, no knowledge of the biological realities. I had no idea what an STD was when I came*

*out. In that way I'm sort of bitter now. Where was the Canadian Public Health Association at that time?*

And there is the urgency of AIDS work, and the mix of people and circumstance...

*I have an agenda. I want to see it go through as quickly as possible. So when there are obstacles to the accomplishments of this department [Support], I get very angry about it. It just means there will be a longer time before we can get something on the road and then a longer time before our service becomes more efficient.*

The obstacles and barriers against getting anything accomplished in the world beyond the CBO...

*I have a great sense of rage about what is not happening in my own profession of social work. The last people I feel I can discuss my ideas about the way to change things around AIDS are other social workers, because generally they're not doing anything.*

But one serious problem that nearly everyone mentions has come from uneasy social realities created by the virus.

*There are segments of the PWA community that feel they are the only ones entitled to do this work. But this would only serve to further stigmatize and marginalize the disease. The ownership question creates divisiveness, jealousy and competition.*

*The sense from people working in the community, that there is no place for people who are not HIV positive in this work, makes me angry. People who aren't HIV positive are often not treated well, even shamed. We don't want to hear that we're "PLOA," persons living off AIDS. We're hurt by expressions like that.*

Perhaps the tension between those with and without HIV needs to be recognized as one of the realities of working life in a CBO, as a bell weather of progress and a channel for empowerment.

*We often lose sight of what we are really here for. I get angry when AIDS is turned into an academic exercise. The real reason we are here is to empower people to take responsibility over their lives, to improve the quality of life of people who have HIV. That's the bottom line.*

## HEALTH PROMOTION AGENDA

- *recognize anger as endemic*
- *treat expressions of anger as a signal*
- *channel anger into empowerment opportunities*
- *encourage open dialogue on power relations*
- *develop participatory policy and decision making procedures*

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<sup>1</sup> Lord, J. McKillop Farlow, D. A study of personal empowerment: implications for health promotion, *Health Promotion*; Health & Welfare Canada, Fall '90.

Data suggest that anger (crisis, frustration, outrage) can act as powerful motivators and incite people to change conditions they find intolerable; p4.

<sup>2</sup> *ibid.*

By viewing ourselves as facilitators of empowerment rather than as teachers of health we will come to see health promotion as assisting people, not to change their illness-producing behaviours but to gain more control over certain aspects of their lives; p7.

# Participation

*It's important to have people outside of your friends to associate with.*

Participation is the essential activity of health promotion. The path toward empowerment is cut out of the thickets of isolation through the experience of contact and support in the community. Sharing experience, framing critical awareness and taking collective action form the core activities. Some health promotion theorists believe that community participation by itself creates the conditions necessary for health improvement.<sup>1</sup>

There is also a growing awareness that participation in research activities by the communities involved in health promotion works as a mechanism for empowerment. Participatory research engages communities in activities that create knowledge and extend theory. This is not necessarily an easy process, because there is always a potential power imbalance between research professionals and community members. Nevertheless, participatory research is a developing form of health promotion.<sup>2</sup>

We asked people working in Vancouver CBOs for their observations about participation in community action on AIDS.

*The people that participate around this place tend to live longer. They have better access to treatment and support than people who are isolated and marginalized. People in HIV closets die faster.*

*In this form of community development, where there is a huge cohort of HIV people to relate to each other, over 1,100 people form a community that exchanges information on what is affecting their lives: income issues, advocacy issues, treatment information issues, emotional support or just a place to participate and contribute. This model has been successful.*

Participation in community development has created new professional roles. In spite of the often conflicted realities of the AIDS workplace, this experience has also created its own form of empowerment.

*Pride. Making a difference. A sense of self-worth. People have been mobilizing for ten years in this way. We go to meetings as gay people with other straight people and find it doesn't matter. Our community has developed as a result of AIDS.*

*I have trouble saying that I enjoy doing AIDS work. And yet I do. There is something very exciting and stimulating about it. But there is also a sense of guilt about saying so because it may mean that I am enjoying living off the suffering of others. Yet, in some way it is the profession that I have chosen.*

Even with such high regard for the value of participation, however, there is a respectful recognition that not everyone who needs the support of the community can engage so directly in this form of health promotion.

*It does have positive results. But I think there are people who don't want to participate. Does this mean that their health promotion isn't complete because they are not participating? Does participation really mean you will live longer? Some people do not want peer group references or community participation. So how do you create a supportive environment for these people?*

Given this reality, people working in AIDS service organizations have come to recognize that the people they serve have different needs and capacities in the course of their experience with HIV. Demanding participation of someone ill, for example, would not be particularly empowering.<sup>3</sup> And yet those people are the focus of health promotion.

*Health promotion is a concept of empowerment, but it is also a service. If we recognize the need for a certain kind of facility and we see that it isn't there and that people could use it for their health promotion, I want to be active in trying to create those resources.*

Still, if the knowledge of the benefit of participation is to be taken seriously, problems of inclusion need to be recognized.

*The first thing I think about is all the resistance we've faced about women's issues. Community is a misnomer for women. Women who are HIV positive don't have a community.*

And in a complete view of the role of participation in health promotion, the potential hazards need to be better understood.

*There are more people being sacrificed to AIDS than have the virus. I have to ask whether I have sacrificed myself. Have I set myself up to have to go away? I have to wonder how much my ego is invested in this so that I can't let go and I don't want to leave.*

## HEALTH PROMOTION AGENDA

- *recognize participation as the vehicle, inclusion as the fuel*
- *allow variation in levels of participation without prejudice*
- *promote services as a form of participation*
- *critically examine the extent of exclusion*
- *honour change and encourage healthy departures*

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<sup>1</sup> Wallerstein, N. Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs. *AJPH*; V6N3 Jan/Feb 92.

... participation in community change promotes changed perceptions of self-worth and a belief in the mutability of harmful situations... the experience of mobilizing people in community groups strengthens social networks... empowerment education promotes actual improvement in environmental or health conditions; p203.

<sup>2</sup> Lord, J. McKillop Farlow, D. A study of personal empowerment: implications for health promotion, *Health Promotion*; Fall '90.

Participatory research has been said to be an excellent mechanism for enhancing participation and empowerment... research that engages people in generating knowledge—identifying problems, gathering information and working solutions — maximizes community participation; p6.

<sup>3</sup> *ibid.*

Ironically, always proposing and implementing service solutions may be perpetuating the very conditions of victimization we hope to change... any services developed on the basis of an empowerment philosophy will be dramatically different from those that keep people as dependent clients; p5.



# Environment

*I find the CBOs have a real problem with personality before principles.*

Perhaps the least understood context of health promotion is the contribution of supportive environments. Because we naturally think of health as an individual concern, it appears only logical that health promotion means that individual behaviour change is the way to enhance health outcomes and prevent illness. However, research has shown that prevention campaigns have less of an impact on lower status groups virtually anywhere in the world the pattern has been studied. Similarly, higher status groups appear to enjoy better health outcomes and longer life regardless of the relative economic status of the country they come from. Could this mean real change will never happen?<sup>1</sup>

Inevitably, health is an individual issue, although we still have much to learn about the social, cultural and political conditions that enhance health. There is a growing awareness in health promotion, however, that too much focus on individual behaviour change may be “blaming the victim.”<sup>2</sup> The developing supposition appears to be that individual behaviour change is more responsive to social trends that move like fads. As people find resonance with and mimic the trend setters, their behaviour changes much more easily than it would through hard persuasion.

All this begs a question about what conditions or social actions would create the kind of supportive environment needed to prevent HIV infection and prolong the lives of those already infected. The gay community only needs to reflect on the experience of fashion to envision how such key social changes might come about. We asked our group of people working in Vancouver's CBOs about their impressions of issues and trends toward a more supportive environment.

At best, there is recognition that the tide is changing.

*Financial support of the organization is much more diverse than before. More people are seeing that AIDS affects them, particularly those who are liberal, well educated, and urban. We've managed to swing that group around. The people in the Capital Campaign [a fund raising initiative to benefit PARC] are by no means the type of AIDS worker we have seen before. Still, I see a huge problem of stigma and homophobia out there and this continues to be a struggle. The government is more supportive, but I would like to see greater change.*

At worst, there is a perception that the majority of mainstream culture continues to be on the other side of the wall of denial.

*Sometimes I think AIDS has become boring and people don't care.*

Yet, the evolution of the gay community's concept of health is undeniable.

*The way we all migrated to the cities in the sixties allowed us to liberate ourselves, but there were no commonly held institutional structures or community value systems. So we were very vulnerable to epidemics of hepatitis and other STDs. Now that we're developing community standards and values — and they are developing, but very slowly — things will gradually change for us. I don't know if I will be around for it, but they will change. Because of the experience of gay reality during the last twenty five or thirty years, we have learned, through some very hard experiences and losses, that we are going to have to do it for ourselves: health care from the bottom up.*

And the agenda has moved to political and policy levels.

*Human rights for gays and lesbians is essential for health promotion.*

There are many contexts with which people perceive the “environment,” all equally valid.

*We need a more supportive environment around the death and dying issue. This is an organization in which people are dying all the time, our colleagues and friends. How do we deal with that? We don't even have a system for informing people that someone has died. We need a place in the office for this to happen. But there is fear about having such a place.*

These times are already showing the potential for major political change in mainstream society, change that could create a healthier environment.

*When I look around the table I feel I am becoming one of the elders of the tribe in the work of AIDS. I can see a groundswell coming. Yet, I fear there may be a reaction: religious and political polarization. How do we position ourselves in a such a way to use that?*

Perhaps this is not yet the time for self congratulation, but an awareness is developing about the spectacular nature of the community response to AIDS.

*If people had more information on what the gay and lesbian community has done about AIDS.... As Stephen Levine has said, never in history has there been such a response to disease such as that of the gay and*

*lesbian community. Our internalized homophobia keeps us from promoting ourselves, but we have accomplished something much bigger than we allow ourselves to know about.*

## HEALTH PROMOTION AGENDA

- *encourage positive image growth to dispel homophobia*
- *promote supportive practices and climate at work in CBOs*
- *practice human rights*
- *acknowledge and honour death and dying*
- *critically examine the roots of environmental conditions*

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<sup>1</sup> Poland, B. Learning to 'Walk our Talk': the Implications of Sociological Theory for Research Methodologies in Health Promotion. *CJPH Supplement 1*, March/April '92.

But there is a larger socio-economic and cultural context that merits attention: individualism and profit oriented world capitalist economy provide very real ideological and practical limits to the ability of state sponsored agencies to tackle the very broad social issues (e.g. consumerism, advertising reinforcement of health adverse products and behaviour, distribution of wealth, housing etc.) that are the major influences on health and health-related behaviour in our society; p34.

<sup>2</sup> Lord, J. McKillop Farlow, D. A study of personal empowerment: implications for health promotion, *Health Promotion*; Fall '90.

There is a clear distinction here between holding people accountable for their own health and enabling them to take control of it; p3.

## Support

*What really helped me was getting a buddy system.*

Support is the practical side of health promotion in community based organizations. The need for support services over and above self-care is the legacy of continuing inequities and inadequacies in the established social services system. People living with HIV need services to deal with the many small problems of living that people never think about when they are well: everything from the care of their pets while in hospital, to having help with cleaning the apartment when at home.

Providing direct services runs into a danger of creating dependency and so may be potentially disempowering.<sup>1</sup> Experience in AIDS service organizations has shown however, that answering day to day needs with specific support helps to reduce stress, and this creates the humanizing conditions for empowerment. In this way, support services are focused on keeping clients co-participants in the process of their care.

We asked people at work and those who use Vancouver CBOs' support services about their impressions.

*I can tell you what health promotion is for a PWA. It's not having to worry. Being able take care of yourself and think about your own life worth, for staying alive. And not having to worry about where your next meal is going to come from, or where your rent is going to come from, or that you can get your prescriptions paid. And then comes the macro support issues: the emotional framework, the community.*

The stigma attached to AIDS continues to be a decisive factor in access to the basic necessities of life.

*The most embarrassing thing I found coming from an upper middle class family was going from the penthouse to the outhouse in about a month and a half. I haven't found anything out there that can help me with how I can now live on \$755.00 a month.*

Experience at AIDS Vancouver has shown that providing support means more than comforting words.

*Counselling has been separated from "intake." Listening skills are needed, but counselling itself is now a referral. In this way, we find out more what is happening with the person. The person is asked if housing*

*is an issue, whether there is support, who is in their support network, whether they have a doctor, whether they are eating and how much.*

The list of support services is as simple as basic human needs.

*How do I see health promotion in terms of support? Not really a big question. It is what I'm doing: food, shelter, clothing, money, treatment information, access to treatment, supportive communities.*

Social assistance policies, developed on a province wide basis, have built-in inequities for those who have to cope with the additional costs of living in urban areas. Shelter costs alone leave little room for even basic needs, let alone therapies.

*I've budgeted a huge amount of money for supplements to the food bank. We're going to buy about a thousand dollars a month or more of items such as toilet paper, laundry detergent, razors, batteries — everything basically that PWAs need, most of whom are collecting GAIN — so they won't have to spend money on them. And in that sense, it may give people a bit more pocket money. That's a tangible service. It's something we're doing because the effects are there. I'm not sure how they can be measured because you're measuring somebody's quality of life. Maybe quality of life does go up because thirty bucks in your pocket makes you feel better.*

People living with HIV need support over and above food, shelter and clothing, however, because other social supports fail them as well.

*I find the medical system here in BC to be completely inadequate as far as the emotional needs of anybody who is sick and is in a hospital. It's done on a Henry Ford theory of medicine: get 'em in and get 'em out. There is very little personality, or anything for emotional or spiritual needs. Anything beyond giving you a pain killer is negligible.*

Finding the people who can fill such support roles requires more than a passive approach.

*Practical support needs daytime hours. And daytime hours are hard to get. And if you notice, most volunteers who go into support or education have night-time hours because a lot of them work.*

*It's a very difficult job to deal with PWAs in crisis. That eliminates a lot of people who would not be attracted to that kind of work. Now we're seeking volunteers in different places rather than just waiting for them to wander in here. We're looking at colleges and different social work institutions.*

The health promotion needs of people living with HIV encapsulate the changes needed in support services.

*I want personal support networks — so everyone can have one. I want as many practical programs as possible in order to make PWAs lives as easy as possible at any stage of the disease. I'd like to have more housing subsidies so people can have a better quality of life. I'd like to have more money for people. I want more resources, such as Adult Day Care. I'd like to see more community development ....*

#### HEALTH PROMOTION AGENDA

- *recognize service use as a form of participation*
- *advocate improvements to social assistance systems*
- *encourage proactive attention to basic needs*
- *develop supportive approaches to basic assistance services*
- *promote volunteerism for basic support services*
- *create supportive networks*

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<sup>1</sup> Lord, J. McKillop Farlow, D. A study of personal empowerment: implications for health promotion, *Health Promotion*; Fall '90.

Ironically, always proposing and implementing service solutions may be perpetuating the very conditions of victimization we hope to change... any services developed on the basis of an empowerment philosophy will be dramatically different from those that keep people as dependent clients; p5.

# Education

*I have a hard time with all this medical data.*

The role of education is changing for community based organizations with the influence of health promotion. While the need for full-scale prevention education has not diminished, many more agencies have taken over the task. And education needs have expanded far beyond safer sex campaigns. Now, treatment information, self-care training, and professional re-education are the focus of new demands.<sup>1</sup>

The "community up" approach to health promotion cannot help but bring real human needs into attention. Recognizing them and doing something about them poses a formidable education challenge for AIDS service organizations; education on this level begins to take on the shape and thrust of advocacy, as previously entrenched forms and systems of health care encounter health promotion.

We asked people at work and those who participate in Vancouver's CBOs about their sense of the education challenges ahead.

*Health promotion is bringing about a major change in the thrust of education which was previously only oriented to prevention. Now even the funders recognize that there are interconnections between prevention and treatment. Health promotion embraces both prevention and treatment, and this philosophy has helped to refocus the training of staff and others. Education and support work together more closely. More crossovers are possible.*

The education needs of people living with HIV have grown alongside treatment options that are prolonging life.

*If there was a friendly, open environment where I could come in and say, "you know, the thirty minutes with my doctor was not enough. Here are the facts he gave me that I don't understand. And I don't want to go through eight thousand pages of medical literature to figure out what my doctor told me."*

*In my mind, I can see an agency strictly devoted to helping people with counselling, explaining different treatments to them, helping people make an educated choice as to what they want to do with their life.*

Even those working in CBOs will need education to bring the full implications of health promotion into their practices.

*At AIDS Vancouver, we are just beginning to recognize the health needs of staff and volunteers. There has been a lot of burnout and staff turnover. Everybody has been in a crisis mode. It is a sensitive issue of balance between the needs of people with AIDS and our own workplace health needs.*

Beyond the frontlines, people working with AIDS are beginning to recognize there are major education needs in the health care system that must be addressed if health promotion is to become a reality.

*Experience from PWAs suggests that few are satisfied with the treatment they are getting. The medical model seems the antithesis of health promotion.*

*We don't have the facilities to be able to deal with substance abuse problems; we don't have people who are able to deal with mental health problems. The agencies who deal with those things aren't really dealing with HIV. So just now, people are coming to the table to discuss what they can do.*

*The systems that were set up to assist sick people were not designed to help people with AIDS. GAIN for the handicapped, for example, was not designed for people who need thousands of dollars of medication to stay alive. There have to be policy changes across the board, not just having to fight to have individual people treated properly.*

## HEALTH PROMOTION AGENDA

- *extend education to embrace HP goals*
- *design treatment information services*
- *promote self-care education*
- *develop internal HP education for staff and volunteers*
- *form partnerships to advocate professional re-education*

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<sup>1</sup> Nutbeam, B. The concept of health promotion and AIDS prevention. A comprehensive and integrated basis for action in the 90s. *Health Promotion International*; V5N3, '90.

AIDS has exposed a huge training need among health professionals both to help them improve basic knowledge and to change attitudes and prejudice — more fundamentally, it may challenge the base of the traditional client/professional relationship; p240.



## Visions

*One thing I've learned is you can hate the virus, but don't hate yourself.*

Health promotion is a vision harnessing knowledge. It is a system of knowing and doing which opposes health against illness by encouraging supportive conditions in lieu of simply attacking apparent symptoms. The implications of this paradigm reach as deep into the mental discipline of those who practice health promotion, as they do wide, into the programs and policies whole societies might undertake to reach the fullest possible potential of human life.<sup>1</sup>

What projects will we create? What dreams will we discover? How will we know we're actually doing it?

We have to think of the personal level,

*This is my journey. I want to walk through my rage and not be overpowered by the things I can't live with, to be a part of a solution. Working with AIDS is giving me a baseline to start looking at that. It is a way of looking at my own efficacy, of not being in a place of learned helplessness.*

... what we know about the future agenda,

*The future of AIDS work should be the end of AIDS work. With no cure in sight, we are unlikely to see this end very soon. So we must do our best to slow down the process of illness. To do this, we need to continue to build the skills and experience of ASOs to keep vigilant over change and to continue our empowerment.*

... and what needs to be accomplished right now.

*Community development is right at the top of the list. When we start thinking about a strategy of AIDS prevention and education, we have to start thinking about the global health issues of people. We have to become health planners. We have to start thinking about the co-factors of AIDS. There is a broader health planning reality involved in AIDS work that has to be brought down to the affected communities and*

*targeted specifically. We do not need another AIDS poster, we need people doing actual community development work in health planning.*

We will need to enact strategies to accomplish change on many different levels.

*I have a vision of facilitating social change activists — not just AIDS activists — to encourage processes where AIDS service can come together with women's equality, human rights issues and so on, where we can share our similar goals toward shifting into a new way of being.*

*We would impact change around legislation on sexual assault, on policy in the medical community about their duty to inform.*

*A group in the country needs to be empowered with a Red Cross type of mandate to disseminate accurate information and to make training on HIV a requirement in medical education.*

We may encounter new kinds of work to accomplish what we set out for.

*I think we have to get over our internalized homophobia. We have to move on. I don't have the patience to deal with destructive forces and lack of vision. We have to move faster on issues. We need vision and we need leadership and we need people who will commit to the work.*

*Keep expanding the network. We need to know how much of our lives are affected by AIDS, even if not directly. Expand the network for information, for financial assistance, for participation.*

*Communication is key. The one thing I would like to see, though difficult to achieve, is improved communication. We need a communication strategy. We need to do work with one another in terms of how we communicate, and work on skills, within a communication strategy.*

The potential results may well be already within our powers.

*The work of AIDS is about pioneering and it is not alone in this. What we are dealing with are new world order kinds of questions. AIDS can teach us about so many other global realities if we allow it. In a practical way it is about new levels of service, it is about new roles for consumers of service, it is about new ideas like empowerment.*

*The future of AIDS work is interdependence. The work of AIDS has to get to a place where it is not ghettoized as it is right now. I think we have to struggle with what that may look like. AIDS work is about new ways of being in the world.*

## HEALTH PROMOTION AGENDA

- *recognize AIDS as a vehicle for global change*
- *initiate community development efforts for health promotion beyond AIDS*
- *promote partnerships with related social change activists*
- *advocate revisioning of medical education*
- *promote successful AIDS advocates to global leadership roles*
- *advance communication strategies on all levels*
- *empower visionaries to actualize their dreams*

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<sup>1</sup> Labonte, R. Health Promotion Knowledge Development, Report of a meeting held in Toronto, January 27, 1993 presented at the second National Health Promotion Conference Vancouver March 29, 1993.

There are very powerful transnational economic and political interests at work in our current global economic restructuring. The question health promotion has to face at this level is: how should we reorganize our social economies and our communities in a sensitive way? What strategies might we use to advance this reorganization? The power to create solutions for most of what concerns people's lives today resides at national and transnational levels... Community control over economy and polity is declining. But we are being urged and we are urging others, to somehow rebuild this experience of community. In doing this are we swimming upstream, are we bucking the trend? Are we making a mistake by hooking health promotion to "community"? Should we be looking elsewhere, at different social structural levels?; p15.

# Synthesis

*No-one ever promised us a life of eighty years, so we might as well make use of the time we have while we're here.*

Seeing how health promotion might be applied to a variety of relevant situations may well be a worthwhile step toward realizing the fuller potential of AIDS work, but virtually nothing can change without refining its practice. We shift here from what health promotion might mean to how to really do it. After all, we have assumed from the beginning that AIDS work is health promotion. The way of refinement must surely be found in everyday transactions within the life of community based organizations and in relationships with all the surrounding institutions. So what are the rules of thumb?

Before we proceed, a caution. Within health promotion there is an understandable resistance to simple models because they often end up being too limiting or even disempowering. Health promotion is about breaking free of such constraints. It takes expansive, multifaceted views of life to see how social, cultural and political habits affect the health of communities, and ultimately, of individuals.

Narrow vision poses dangers. We are already witnessing the political adoption of health promotion — conceived as positive health based on self-care — ostensibly to enable medical cost reductions. What happens, then, to health promotion's ability to critique the economic system responsible for expensive medical care?

Still, health promotion offers practical guidance that could be implemented into the everyday life of community based organizations through the thoughts and actions of people working in them. In this sense, health promotion is not the answer to all the ills in AIDS work, but a way of seeing through them. As such, you might see health promotion as a form of software, a mental technology allowing far-reaching possibilities, at least until a more refined idea comes along.

To begin with, health promotion is a way of framing life processes. The path from illness to health is all about supportive action. The way of health promotion is to encourage supportive conditions rather than to attack apparent symptoms. You can take this axiom from the sickroom to the boardroom and find within it a way of seeing what's happening, and what to do about it. But this is just the beginning.

The path of health promotion cuts less like a laser and more like a sightseeing trail. Health promotion is action with pauses for reflection. Think of reflection as a naturally flowing mental process which has the effect of putting experience into context. When we allow it, reflection brings perspective, and it is this information that offers us the sense of assurance we need to take more action. It is not simply a matter of accomplishing what was promised but a way of finding more than what was envisioned in the first place. You can take this

principle and apply it to any situation undergoing development and find within it a way of seeing what to do next.

Health promotion also provides a sense of direction for moving through levels of social action. The sense of security gained by moving from the community up, for example, is its own justification. Other similar notions provide a way of seeing what to do when what is going on appears too confusing to make any move. The conscious manoeuvre to shift the locus of control from external sources to internal resources is the basic principle and the healthiest direction for much of what goes on in community life, from interpersonal dealings to social change projects. Anyone with a little community experience knows how much safer it is to start from within before advocating what others should do, allowing the circle to extend as confidence increases. As such, partnerships and strategic alliances are powerful principles in health promotion. Once a network is established, the job is carried forward by all the converted, not just a few lonely souls.

Beyond knowing what to do, health promotion also offers some promise about ways to develop and share what you learn from doing it. In fact, practising health promotion, in its fullest sense, produces knowledge. Participatory research, for instance, is a developing phenomenon in health promotion, but few trained researchers are very comfortable with the participatory power dynamics. Research professionals, however, have no particular claim on knowledge. The key to producing knowledge is recovering experience. Once you see this, you can apply it to anything going on in the life of organizations and systematically shape it to move forward and help others move forward.

As a collective activity, the fundamental principle of knowledge production is co-investigation. Any organization can set this up among its members. The idea is to establish a routine and share the work of collecting material. What material will depend on the subject of investigation, but often enough, what is of interest is something going on in the everyday life of AIDS work. So the subject of co-investigation is the experience of people in the community. Recovering that experience takes a form very much like the processes used in *Taking Care of Each Other*: identifying a problem in experience, interviewing people to find out how they see it, analyzing the interview material, comparing it to published views and theorizing what it all seems to be saying. You could take a subject like grief or even humour, for example, investigate it according to this model and add it as a chapter to this study.

In terms of strategic planning, health promotion also offers a way of shaping policies, programs and projects with consistent intent. Organizations are defined by their programs, but without projects within those programs, nothing much gets done. To make anything happen, implementing the fuller implications of health promotion into AIDS work will be a project in itself, to be brought into everyday decisions as well as policy and program planning. Evaluation, undertaken as a co-investigation, could help to establish how well this process is working. The key to evaluation is to establish the base experience before a project begins, to account for actions taken while the project is underway, and to sample experiences from the results. In this way, an organization could assemble a history of its

work through evaluations of its projects and use this knowledge to refine its practices ad infinitum.

We now arrive at a leap in thinking that takes us to the “third space,” or the meta level of understanding health promotion in AIDS work. In this space, we are thinking not only about how to realize health promotion, but how to learn from and refine the processes as we move along through the experience; in other words, how to do health promotion by refining our own practices in AIDS work. The figure on the following page is a proposal for such a model that includes whole communities practising health promotion, a way of seeing the impact of particular actions culminate as a powerful expression of self-care.

### *TAKING CARE OF EACH OTHER*

#### *Health Promotion Strategy in AIDS work: a meta model*

This model, derived from the foregoing research, describes a way of refining practices in AIDS work through education, support, communication and administration activities which are informed by health promotion. Because these activities interlace, the descriptions do not necessarily represent departments or programs. The model could represent the complete scope of action, embracing health promotion within a department or a program as much as within an entire organization or community. The focus of internal strategy is conduct within a community organization; the focus of external strategy, the desired effects of this work on others in the community and its surrounding environment. A third dimension suggests a scale of intended effects — micro to macro — for each initiative.

Taken as a whole, the model proposes *taking care of each other* as the basic theme guiding the evolving practice of community based AIDS work.

note:

#### *internal strategy*

- refers to everyone working in a community based organization, including staff, members and volunteers

#### *external strategy*

- refers to effects on others: clients, strategic alliances, partnerships, communities and society

**TAKING CARE OF EACH OTHER**  
a model of practice

**INTERNAL  
STRATEGY**

**EXTERNAL  
STRATEGY**

---

**EDUCATION**

micro  
|  
macro

personal reflection  
co-investigation  
collective learning

self-care  
professional care  
caring communities

**SUPPORT**

micro  
|  
macro

direct action  
pro-active service  
workforce training

sustaining services  
support networks  
social advocacy

**COMMUNICATION**

micro  
|  
macro

power analysis  
interpersonal tactics  
campaign strategy

focus  
target  
influence

**ADMINISTRATION**

micro  
|  
macro

empowered workforce  
professional conduct  
vision oriented

community driven  
advocacy partners  
empowered leadership

## TAKING CARE OF EACH OTHER

Let's explore this expression of community health by studying each strategy separately...

### EDUCATION

*internal strategy*

#### **personal reflection**

Learning to shift control over health from sources outside the self to one's own internal experience develops from personal reflection. By paying attention to patterns of action, thoughts and feelings, people begin to take charge of their own experience. Reflecting on what may be empowering or disempowering is a personal act, something that everyone practising health promotion must do for themselves. So the function of education is to facilitate reflection as a crucial first step in enabling people to take care of each other.

#### **co-investigation**

Co-investigation creates the knowledge needed for community empowerment. As an education strategy, co-investigation emphasizes the equal control of information and knowledge development by participants in learning, a system in which there are no teachers. This places authority in the hands of those who need information instead of encouraging dependency on authorities to provide it. The education function is to guide such efforts, arranging collective experiences of discovery and sharing the results as a way to move forward on any given initiative.

#### **collective learning**

The overall effect of participating in personal reflection and co-investigation could be expressed as a collective learning model of education. This is an ideal state for a community organization to be in, free of dependency, open to change and operating dynamically with the surrounding environment. The effect would have the whole community engaged in reshaping itself according to the highly informed experience of its participants — learning *how* to take care of each other.

*external strategy (affecting individuals, caregivers and communities)*

#### **self-care**

Promoting self-care on an individual level embraces both HIV prevention and the health of those already living with the virus. On a community level, this sort of self-care actually means taking care of each other. Knowledge from health promotion has shown that too much emphasis on individual behaviour is less productive in terms of health outcomes than we might assume. By shifting attention to the social, we end up affecting the personal with less resistance than we would encounter more directly. So a message like “take pride in yourself - take care of each other” makes as much sense for the community as it does for individual health.



### **professional care**

Health promotion for anyone affected by HIV or AIDS must involve professional caregivers in some kind of shared understanding about how to establish and support conditions where health can flourish. Evidently, how much this understanding is shared among professionals or between patients and professionals dealing with HIV is virtually unknown. The experience of those living with HIV involves a lot of frustration, even acknowledging the anxiety of so many unknowns. Thus, health professionals working with AIDS are a logical target audience for a community organization's research, information sharing, knowledge development and partnership building.

### **caring communities**

Education on the community scale is the same as community development. Community organizing is a process of continuous learning — a consciously willed agreement among participants to work together for information, knowledge and ultimately, power. Through participation, empowerment and the experience of collective action, whole communities engage the real life process of learning to take care of each other.

## **SUPPORT**

### *internal strategy*

#### **direct action**

Support is the direct action of taking care of each other. But in the health promotion sense, it is not just jumping in and helping people. That would be disempowering. There is a personal discipline involved, acting from principles: empowering others, enabling their action, encouraging supportive conditions. In this way, helping facilitates self-care. This is a discipline that will evolve in AIDS work as experience in taking care of each other grows.

#### **pro-active service**

Experience in AIDS work has shown that service demands can suddenly and unexpectedly overrun the capacities of providing organizations. So the idea of pro-active service has evolved from the trenches. Essentially a strategic device, pro-active service anticipates future demands based on current information coming in from the client environment — one reason why people living with HIV are so appropriate for this work. Reliable information with which to make pro-active decisions about taking care of others could be one product of co-investigative activities, collecting data and experience directly from both service users and providers.

#### **workforce training**

Instilling the discipline of health promotion in support makes staff and volunteer training a necessity. Support training is different from AIDS education in the same way that training to fly a plane is different from learning the principles of aviation. Introductory core training is the critical first step with which to guide the workforce into the ways of AIDS work. But by itself this would be insufficient. Training should not only provide the tools for taking care of each other, but set the tone for continuous learning through participation, reflection, and co-investigation, as well as further training for specialized services.

*external strategy (supporting people living with HIV)*

### **sustaining services**

Health promotion for people living with HIV requires a range of program options for changeable circumstances brought on by chronic illness and financial uncertainty.

Sustaining services have arisen to help those most in need of basic supports as diverse as food, food preparation, housecleaning, pet sitting and rides to the doctor's office. This is obviously the most direct approach to taking care of those living with HIV.

### **support networks**

Because the immediate social supports of persons living with HIV are so important to both their ongoing quality of life and their care during illness, support service tries to ensure the availability of friends, family, volunteers and professionals. Such direct intervention may not be required by all; however, this focus highlights the recognized value of personal relationships in the overall scheme of health. At the very least, it serves as a maintenance check on social ties that are already taking care of each other.

### **social advocacy**

Systems of care established to answer needs arising from a broad range of difficulties which affect people's lives have not been adequate for the specifics of HIV and AIDS. Issues arising from the housing, nutrition and therapy needs of those living with HIV must be articulated at levels that affect not only policy, but the attitudes and practices of health-care providers, social workers, welfare agents, human rights officers and so on: all those who work directly with people living with HIV and those whose decisions affect them.

## COMMUNICATION

### *internal strategy*

#### **power analysis**

Because words and language are the roots of power and because communication expresses power, a frame of analysis needs to be made explicit both to construct messages going out and to deconstruct those coming in. Shaping appropriate language to describe the experience of HIV, without the baggage of oppression, has been ongoing throughout the history of the epidemic. The ongoing challenge to clarify the underlying power analysis of everyday language will continue to be a vital empowerment tool.

#### **interpersonal tactics**

Basic face to face communication between people is the critical power transaction in everyday life and is also the crux of self-empowerment. Understanding *how* requires learning from direct experience. People living with HIV or AIDS may find instruction and practice in how to talk to physicians in the consulting room a valuable experience. And those who serve may need safe experiences in which they can see and alter their unintentional, though disempowering, ways. As such, interpersonal communication is a necessary focus of practical learning in AIDS work, especially in support and education functions.

### **campaign strategy**

Large scale communication in all media requires strategy and disciplined execution to achieve a responsive audience. Health promotion messages which actually accomplish anything are tough to create. For this reason, audience research is a vital component in communication campaign planning — to find out what would trigger audience attention and action. Even so, creative slogans only condition an audience for the real effects which take place face to face: where people actually do take care of each other.

*external strategy (effects on audiences)*

#### **focus**

To be effective, messages need to be highly intentional and focused on desired action — what you want the audience to do. Many if not most public health communication campaigns suffer from poor focus because their creators have not thought enough about precisely how they want the audience to respond to their message. In AIDS prevention campaigns, this can have and has had disastrous consequences. In health promotion, what the audience will do with the message is the only reason that communication would be of any use in the first place.

#### **target**

Different audiences require separate messages in AIDS work, even when the intent is the same. Ethnocultural experience has shown how much this is true. For communication to achieve its desired effect, good information is needed about the character of the target audience. Research is the key to this process. Often, this research extends to trying out various messages on a sample of the target audience to see how they react.

#### **influence**

Ultimately, what is expected of both communication and health promotion is influence. However, the media alone are not enough. Ample research and experience has shown that successfully influencing target audiences is a face to face, person to person, peer to peer affair. So what communication planning for AIDS work must do is arrange for such occasions to take place — real experiences of taking care of each other.

## **ADMINISTRATION**

*internal strategy*

#### **empowered workforce**

If empowerment is the fundamental level of health promotion's effect on the individual, then those working in the service, both staff and volunteers, must themselves be empowered. However, people experience different levels of empowerment, and not everyone performs equally. Dealing with this requires an unusually enlightened management, capable of working with the community-up movement of health promotion, while consciously resisting the impulse to assert top-down order.

#### **professional conduct**

Because health promotion is so sensitive to power relations in the social environment, the conduct of business among those in the service must be carefully considered. AIDS exposes a complete range of human nature from compassionate to mean-spirited. Yet what health promotion demands of professionals is a code of conduct similar to “unconditional positive regard” to achieve its ends. Though desirable, such a code would be political and thus remains a long way from consensus.

### **vision oriented**

Communities of people working together often, if not always, have a common vision in mind. This is no less true of health promotion. So a vision of the possible future needs to be articulated far in advance of the practical means of getting there. In this sense, health promotion in communities affected by AIDS should go beyond specific concerns about HIV to envision the full health potential of a community of people taking care of each other.

*external strategy (effects on communities)*

### **community driven**

"Up" from the community is the way of health promotion. The boundaries of community may well be at issue, but the work of organizing people into face to face situations, forming coalitions and forging partnerships is the heart and soul of health promotion work. In this sense HIV and AIDS may be the trigger for community development, but other health issues ranging from addiction to aging may be involved. So organizing the community to take care of each other is a grass roots movement with far reaching effects.

### **advocacy partnerships**

There are many situations where people who are not necessarily involved in a community's health promotion activities nevertheless affect the health of its members. In AIDS work this includes a pantheon of characters from politicians, to bureaucrats, to business leaders. Setting up partnerships with these interests to exchange information and advocate for the community is thus an essential activity in the whole scheme of taking care of each other.

### **empowered leadership**

Above all, a fully empowered community based organization never waits for acknowledgement of its initiatives from elsewhere. Such leadership gets its strength from the community's power. And when people are truly taking care of each other, the effects will show, in the global reality, for all the world to see.

## ***USING THE META MODEL***

The way to approach *Taking Care of Each Other* as a model is to think of it as a reflective device for evaluating ongoing and future projects. Ask to what extent a particular initiative embraces the fullest potential of practicing AIDS work. Is the initiative community driven? Does the initiative support and involve those living with HIV? Does it stimulate self-care? Is the workforce trained and empowered? Does the initiative invite opportunities for partnership. Is the message focused and targeted? And so on...

# Conclusions

*Practice is political!*

When we shared the foregoing work with a staff group at AIDS Vancouver prior to drawing our conclusions we found ourselves unprepared for, though not surprised at, the lively discussion that ensued. We found that, in spite of our clarifications, the meanings people associate with health promotion seem to raise more issues about its political intent than about its practice. Virtually everything about the field appears to be in contention, from the meaning of health to the exercise of gender power in defining it. On reflection, however, health promotion seems no more or less contentious than AIDS work.

Resistance to health promotion appears to come from the kind of fundamental suspicion people reserve for any publicly trumpeted "solution" to overwhelming circumstance. Obviously, health promotion is no solution to AIDS. Only eliminating the cause and finding a cure could be considered any kind of solution to AIDS. In the meantime, we are forced to continue AIDS work and hopefully, if we are going to get better at it, to refine AIDS work. In this way, practising health promotion could not only bring a new level of efficacy to AIDS work, but also redefine health promotion in the process — even though we may never agree to name it as such.

In concluding this particular venture, which began in pursuit of the meaning of health promotion in community AIDS work, we find ourselves at the threshold of action. For we are nowhere near a conclusion to community AIDS work. We are only just a decade out from the beginning. What follows is a statement of a collective action initiated by the AV staff as a result of their encounter with *Taking Care of Each Other*.

1. *Prepare a statement of principles of practice in community AIDS work that could be used as a measure of performance.*
2. *Revisit statements of mission to incorporate the principles.*
3. *Initiate a co-investigation of medical practice in relation to HIV and AIDS based on consumer experience.*
4. *Undertake advocacy on medical education and standards of care using research knowledge as a policy instrument.*
5. *Create a forum for discussion about community AIDS work, principles and practice.*
6. *Liberate and empower the community AIDS workforce to more accurately reflect the principle of bubble up rather than trickle down.*

# Appendix

## *Health promotion agenda at a glance*

### ASSUMPTIONS

- *public interest*
- *professional conduct*
- *professional cooperation*
- *communication*
- *knowledge development*
- *community development*

### COMMUNITY

- *define CBO approach*
- *focus and target HP effort*
- *shift prevention to HP strategy*
- *encourage women's initiatives*
- *develop proactive HP vision*
- *recognize HIV guilt/urgency*
- *identify emotional issues*
- *address larger social institutions*

### EFFECTIVENESS

- *implement co-investigative research*
- *consider HP internal effects*
- *recover HP external impact*
- *evaluate HIV community divisions*
- *uncover women's needs*
- *encourage HP thinking and thinkers*
- *disseminate CBO models of HP*

### EMPOWERMENT

- *examine power relationships*
- *encourage self-empowerment*
- *challenge abusive behaviour*
- *enhance workforce coping opportunities*

### POWERLESSNESS

- *recognize experiences of powerlessness*
- *examine roots of powerlessness*
- *develop coping with sources of powerlessness*
- *encourage workplace civility*
- *encourage self-empowering work strategies*

### ANGER

- *recognize anger as endemic*
- *treat expressions of anger as a signal*
- *channel anger into empowerment opportunities*
- *encourage open dialogue on power relations*
- *develop participatory policy and decision making procedures*

### PARTICIPATION

- *recognize participation as the vehicle, inclusion as the fuel*
- *allow variation in levels of participation without prejudice*
- *promote services as a form of participation*
- *critically examine the extent of exclusion*
- *honour change and encourage healthy departures*

### ENVIRONMENT

- *encourage positive image growth to dispel homophobia*
- *promote supportive practices and climate at work*
- *practice human rights*
- *acknowledge and honour death and dying*
- *critically examine roots of environmental conditions*

### SUPPORT

- *recognize service use as a form of participation*
- *advocate improvements to social assistance systems*
- *encourage proactive attention to basic needs*
- *develop supportive approaches to basic assistance services*
- *promote volunteerism for basic support services*
- *create supportive networks*

### EDUCATION

- *extend education to embrace HP goals*
- *design treatment information services*
- *promote self-care education*
- *develop internal HP education for staff and volunteers*
- *form partnerships to advocate professional re-education*

### VISIONS

- *recognize AIDS as a vehicle for global change*
- *initiate community development efforts for health promotion beyond AIDS*
- *promote partnerships with related social change activists*
- *advocate revisioning of medical education*
- *promote successful AIDS advocates to global leadership roles*
- *advance communication strategies on all levels*
- *empower visionaries to actualize their dreams*