

Community-Based Research (CBR) has evolved in the field of HIV/AIDS health promotion as a distinct expression of participatory action research in adult education. The authors of this chapter reflect on more than a decade of local knowledge construction to organize and improve the practice of HIV/AIDS health promotion in a variety of contexts.

**Reflections on Adult Education Practice in HIV/AIDS Community Based
Research**

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Picture this: a cloudless summer day at a beach park on Canada's west coast and the heat is on. Hundreds of sun worshipping men are milling about, grooving to the beat of club music. Curiously, dozens are intently filling out forms on clip-boards. Just as soon as one completes his, another guy is waiting for the clipboard. The whole scene is throbbing like a new dance craze. A notion washes over like a surfable wave: "this is a 'moment' in adult education".

The above describes what it was like to be leading the *Sex Now* survey at Vancouver's Gay Pride Festival, the authors' most recent launch in "creating knowledge" for HIV/AIDS health promotion. (Trussler, Marchand, and Barker, 2003) With HIV incidence on the rise in a new generation of gay men (Stall and others, 2000; Adam, 2001), the community's urgent need to know "why" and "how to address it" begged for a survey. From beginning to end a steep collective learning curve was encountered. To design the protocol and write the questionnaire meant facilitating the real-time, experiential learning of community stakeholders in pursuit of knowledge from research. Whether conceived as "local" knowledge, "applied" knowledge or "practical" knowledge, what was urgently needed was knowledge by the only standard that counts in addressing a health crisis: that it actually improves health.

HIV/AIDS work has always been a fertile ground for adult education,

though by its relative absence from the disciplinary discourse, under-recognized. Nevertheless, framed as "capacity building" and "community development", adult learning is a cornerstone of the community response to HIV/AIDS worldwide (UNAIDS, 1997). For more than a decade, those working in HIV/AIDS affected communities with advanced training in social research have recognized that research activities make optimal frameworks for building community and developing capacity for action on HIV/AIDS (Green and others, 1995; CBRC, 2000; Marchand, Trussler, and Coleman, 2000).

Yet, because such "community research" is often considered marginal within the bio-science dominated HIV/AIDS field (Egan, 2002; Foucault, 1980), the considerable value of knowledge created in communities fighting AIDS has also yet to be fully recognized. In this chapter we use our experience from the frontlines of community-based research (CBR) to address the discipline of adult education and, at the same time, the multidisciplinary field of HIV/AIDS work, for the "politics of knowledge construction" in both deeply affects progress in fighting the global epidemic.

The *Sex Now* survey evolved over years of direct encounter with a health disaster: local experience, experimentation and dialogue. As it happens, our arrival on the scene in the mid eighties as new doctoral graduates in adult education coincided with the arrival of AIDS as a global pandemic. What had been fresh and leading in graduate level adult education of the time was bridging between experiential learning and action research (Hall, 1992; Trussler, 1982). Applied to community and organizational life, the practice of adult education would have seemed synonymous with participatory action research to a new adult education graduate of the mid eighties.

The experiences of many adult education graduates from such diverse fields as international development, the environment and human rights seem to parallel our own with "assisting adults in constructing their own knowledge about their life-world" (Deshler and Grudens-Schuck, 2000,

p. 592). That participatory research, from such varied practice contexts, has given rise to foundation debates within the discipline is an indication of how power dynamics working between field practice and academic adult education continue to affect things.

Similarly, the evolution of community-based research in HIV/AIDS health promotion exposed an unforeseen hegemonic antagonism between academic social science and knowledge creation in community organizations charged with front-line responsibilities for community health promotion. (Quigley, 1997) A decade ago, we argued that the Ottawa Charter for Health Promotion (WHO, 1986) and subsequent policy of Health Canada placed enormous responsibilities on communities without describing the means by which they would go about accomplishing their health goals (Trussler and Marchand, 1997). Our argument that community organizations need to engage in their own knowledge construction to gain control of local circumstances set off a long simmering debate with conventional social science in the AIDS field over what knowledge is and who should be allowed to construct it.

But by now the *Sex Now* survey is just one example of what is gradually becoming a standard of practice for HIV/AIDS organizations in Canada: using research to build local knowledge for local action (CBRC, 2000). We contend that the fundamental question underlying the development of community-based research in the HIV/AIDS field is not about what knowledge "is" or "is not" but about what knowledge is "for".

For Organizational Development

In the AIDS outbreak years of the mid eighties, there was an urgent need to keep on top of what was happening. Once HIV had been identified, "Save lives. Prevent new infections." became the predominant operating condition. Community AIDS organizations were sites of intense convergence for a broad range of social and professional perspectives (Stall and others, 2000).

Whether it was preventing new infections or caring for the sick and

dying, there was little "accepted knowledge" to work with. It was a new disease with an uncertain trajectory, strong opinions on what it was and what to do, and many unexamined assumptions. Given the situation, research activities seemed a likely way to bring personnel together on their common mission by investigating what they needed to know to be effective.

It was only a small leap, or so it seemed, to overlay the conventions of social science on the situation. People who were already passionately engaged would be only too willing to participate in designing, executing and interpreting research with its predictable structure and from which they would learn crucial details about how to proceed. Inevitably, however, there was resistance.

In the intense environment of a community AIDS organization, research seemed last on any list of priorities. The situation appeared to demand "action not research": the possibility of "research in action" was not such an obvious strategy. That potential had to be demonstrated before CBR actually caught on.

Our efforts began with the intense convergence of experience within the organizational environment itself as a point of departure. (Argyris and Schon, 1974) And so, as our entry into participatory action research, we provoked a staff unit of the largest AIDS organization in Vancouver to engage in a qualitative study of their own working conditions.

Suggesting such a study was not just our doing, nor just a natural product of our professional training in research and adult education. The staff had a question about what they were going through every day: a question of practice, which was inevitably a question about knowing their own work and what it was for. "What does 'health promotion' mean for AIDS work?" (WHO, 1986)

As a manager and research consultant working together, we had little true knowledge of what staff and volunteer personnel faced daily in their efforts. But we recognized that in their question, there was

(beyond its deconstructive irony about "health" in a fatal illness) a genuine desire to be more effective at improving people's lives. So it seemed that the way to learn more about the experience of practice in AIDS work would be to listen deeply to those daily experiences.

That "listening" became the basis of our first collaborative research project. The staff group selected a panel to be interviewed including some from their own ranks, managers and members of the board of directors. There were regular progress reports as interviews were completed, transcribed and distilled. A summary report was compiled and reviewed by the staff group. A retreat day was set aside to consider the findings and how to implement its recommendations. Eventually, the project wound up with an in-house publication about AIDS work, *Taking Care of Each Other*, which was presented to the board of directors and shared with AIDS organizations across Canada (Trussler and Marchand, 1993).

The impact of this modest project reverberated well beyond its origins in Vancouver, providing the grist for widespread reflection about health promotion practice in community-based HIV/AIDS organizations (Trussler and Marchand, 1994). A major point had been made: there was critical value in documenting HIV/AIDS work systematically, whether it was outreach in the streets or care of the ill in their homes. Research activities made the work both visible and improvable. Virtually anyone working for an HIV/AIDS agency could participate by "listening": documenting and interpreting interviews and discussion groups to develop strategies for more effective programs.

For Community Benefit

Community-based organizations exist to improve human situations, by building on skills, knowledge and competence of those in the action, doing the work. Without reflective opportunities, day to day crisis management invariably overtakes strategic action. Community-based research not only encourages critical reflectivity on the current state

of things represented in data, but provides a structured format for organizational learning on the way to accomplishing humanly significant goals. Nothing could be more practical and necessary for strategic action, planning or innovation in practice. But is 'knowledge' necessarily the result? Not always, nor is formal knowledge always necessary.

Reliable information is often hard to come by, but is essential to the successful accomplishment of health goals and outcomes. To gain more control over what is known in a health crisis like HIV/AIDS is to gain control over the fundamentals of the illness itself, a primary condition of the practice of health promotion (Green and Kreuter, 1991). Because reliability is so critical to the effective management of health conditions, community-based research is compelled by the same precision as all knowledge construction. Our experience has shown that professional research and community inquiry are both knowledge construction in their own right, and both are necessary, especially in light of what all knowledge is ultimately for: improvement of the human condition.

Adult educators may have a profound effect on the fortunes of community organizations and the health outcomes they seek in the role of researcher or research coordinator. By guiding personnel through the information gathering and interpretive tasks of a research problem, the adult educator steers organizational learning not just for the construction of knowledge, but for ultimate outcomes of a community's well being.

For Best Practice Improvement

The foundations shaping many of our ideas about community-based research arise from our exposure, in academic adult education, to the topics of experiential learning (Kolb, 1984), theory & practice reflection in community and organizational development (Freire, 1970; Mezirow, 1991) and formal inquiry into the nature of experience as found

in existential phenomenology (Schutz, 1967; Darroch and Silvers, 1982). People value "learning from experience" but often overlook the potential of experience as a source of knowledge. The notion that all experience is potentially available to inquiry profoundly opens up the world to community-based research.

From those perspectives, qualitative studies seemed a natural first step in shaping organizational knowledge construction. The rapid growth of methodological resources for qualitative research during the nineties provided an important source of support for the development of community-based research in the HIV/AIDS field (Denzin, 1997; Gubrium and Holstein, 1997; Stringer, 1996; van Manen, 1990). As ethnographic approaches to health issues became more common in academic discourse (Morse, 1993), qualitative inquiry, already occurring in the health promotion field, was considerably strengthened.

Following the thrust of our first initiative, we organized a national inquiry into the health promotion practices of community-based organizations, centered in the ongoing life of AIDS Vancouver. We canvassed widely for examples of work from other organizations and communities where people had felt particularly accomplished about what had occurred in a local initiative. We engaged a national network of community AIDS groups in the project, publishing the work stage by stage in a newsletter. Each edition featured an in-depth interview with an individual whose practice had all the hallmarks of making a difference. The interviews were transcribed and edited for publication and each edition of the newsletter contained a "think piece" reflecting on the practice issues arising from the story.

Taking Care, in that way became a vehicle for the advancement of HIV/AIDS health promotion. Interview after interview revealed a common theme: what made most of the initiatives successful was their explicit engagement in research activities to learn more about the experience of the people that most needed to be reached. Whether it was in-depth interviews with injection drug users or targeted phone calls to

corporate vice presidents, what seemed to make the resulting initiative effective was its grounding in prior research.

As the case files grew, the meta-analysis became undeniable. There was something very productive and affirming about community initiatives where systematic inquiry was employed. We collected the interviews together in a book and outlined a meta-model we found to be operative in virtually every successful project (Trussler and Marchand, 1997). The *Field Guide* proposed "study-plan-do" as an implicit model of practice in successful HIV/AIDS health promotion. Community-based research was not only an aspect of community HIV/AIDS health promotion, but, in its "best practice", integrated within it.

To extend our own insights from these developments, we designed a "practice workshop" (entitled *Study-Plan-Do*) to feature the contribution of research in all kinds of community health promotion activities. In the workshop we presented study-plan-do as a practical model of HIV/AIDS health promotion and encouraged participants to consider how they might make use of listening activities to solve their most distressing problems in day-to-day work. Each participant created a poster outlining the practice problem they were up against, and an agenda to use research activities as a way to move forward. This reflective workshop made enormous impressions on participants wherever we offered it both in Canada and internationally. For the first time, some participants realized that they could often best solve their own practice problems by asking questions of the people they were trying to serve.

For Policy Development

The "knowledge development" capacities of community-based research (CBR) came to be highly valued within the network of HIV/AIDS organizations in Canada. Though getting research off the ground was often elusive, such a general consensus grew concerning the potential benefits that community-based research was featured as a cornerstone of HIV/AIDS policy renewal in 1998 (Health Canada, 2004). Canada's national

AIDS strategy set aside \$1 million for community-based research.

While consensus on the benefits of community-based research was an accomplishment in its own way, very little detail existed on how to get it going more universally in the field. The million dollar fund would be made available through competitive grants similar to all scientific research. But few community level organizations had control of the expertise involved in writing research grant proposals. Because a previous scientific review process was simply overlaid on community-based research, the development of capacities in the network of community organizations stalled on the way to the "knowledge development" capacities everyone wanted.

Frustration quickly replaced the elation of the policy's announcement. Instinctively we thought of the situation as another opportunity to undertake a community-based study (Trussler and Marchand, 1998). We set up interviews with major stakeholders in community organizations, universities and government. Most of the interviews were conducted over the telephone and audio taped. We focused on what each stakeholder was expecting from CBR, what problems they were experiencing and what they felt would be necessary to overcome some of the barriers.

This was one of the first opportunities to embrace the possibility of organizing the community of HIV/AIDS community-based researchers in Canada. However, we uncovered some basic disagreements and misconceptions. One of the most contested was the definition of community-based research itself and the inherent meaning of community. For university employed researchers, CBR was about a partnership between organized community and research professionals. For community organizers, CBR was about in-house studies conducted with or without the support of research professionals. One thing almost everyone agreed on was the need for a more structured approach to build capacities for community-based research throughout the national network and a virtual centre to lead the way.

We took up the problem of defining community-based research in a

new way by organizing an international workshop on CBR in connection with an existing biannual conference of social science on AIDS (Marchand, Trussler, and Coleman, 2000). In this project we invited participants who would be attending the conference to relate their experiences with community-based research in their own countries. The evidence showed that many different models of working with research in communities existed throughout the world, with none superior to others. Where participants were able to reach consensus was to define core principles of community-based research. The outcome was an international consensus statement on the ethics and practice of community-based research on HIV/AIDS (CBRC, 2000).

For Health Promotion

While these events were unfolding, developments of concern to the spread of HIV itself suggested a critical need to take up a new course of CBR in Vancouver. A scientific paper was released from a cohort study of young gay men that suggested unprotected sex was increasing at an alarming rate in the region (Strathdee and others, 1998). The implication was that HIV incidence increases would follow. This strongly suggested a need to set up a community-based study to investigate further. Given the nascent state of national CBR policy, the way forward appeared to be to launch a study using available resources rather than wait through a national grant competition.

Launching GMAP, the Gay Men's Action Plan, was an explicit attempt to fully integrate CBR with community prevention activities. AIDS Vancouver offered an opportunity for young men under 26 to receive special training in combining research with outreach activities. In a series of evening and weekend workshops the group undertook learning about ethnographic research skills: participant observation, interviewing and focus group facilitation. As confidence developed the "peer ethnographers" conceived a project that involved hosting taped pizza discussion groups of young men in their own milieu (most often in

their own homes).

While this project revealed many insights concerning the vulnerabilities of young men's sexual culture in Vancouver (Trussler, 2002; Trussler, Perchal, and Barker, 2000), there were clear signs of problems with supporting the project itself. Every source the agency turned to for assistance with the project declined. In spite of the apparent urgency, public health funders were skeptical of community-based research activities. Research grants required a long wait through an uncertain competitive process, where conventional social science clearly had the upper hand. GMAP had to proceed with very slim resources.

Nevertheless, GMAP was certainly in the lead with what had been hoped for in community-based research: participants learning directly from experience how to use research skills along side their outreach activities. Even more promising, the findings assisted concretely with improving outreach activities for the population at risk. Further, the whole project was of interest to other centers experiencing similar issues. Yet without the support of understanding funding administrators (who could see the value of integrating research skills with outreach activities), projects like GMAP would be unlikely to form again.

For Emancipation and Empowerment

Experience with GMAP, the prevention issues and the practice barriers it exposed, led to the formation of a new institution on the HIV/AIDS map of Canada and Vancouver: the Community-Based Research Centre (CBRC). A group of HIV/AIDS veterans in Vancouver saw a great need to advocate for and support studies that would have practical value in addressing emerging HIV issues. The action of creating such an organization was in itself another very large experiential learning curve taken on directly by a group of people pursuing unmet needs in their community. The CBRC was conceived over monthly dinners where discussion undertook the development of a non-profit society, funding

proposals and charitable tax status.

Founding the CBRC seemed to us what it must have been like for historic adult education experiences like the Antigonish Movement and the formation of fishers' credit unions. (Cookson, 1989) Our initiative was about the "support for" and "conduct of" research for urgent and locally relevant issues. While AIDS helped extend the comfort zone for gay men in Canadian society, there was still obviously little real social support to assist with improving the conditions that brought about the HIV epidemic (Mann, 1994). That required continued struggle and the CBRC would be at least a proving ground if not a front.

One of the CBRC's opening moves was to recognize an opportunity that existed in the Health Canada's fledgling CBR program. There was a need for a coordinating centre for the advancement of community-based research. One of the earliest proposals the CBRC conceived was to develop a web site where participating individuals and organizations could post their interests, needs and completed studies.

To get the project under way, the CBRC proposed a feasibility study. Here again the use of research tactics to address an unmet need and set a development process in motion proved very successful but not without critical steps in learning how to use the internet to accomplish these goals (Trussler and Marchand, 2000). The web site feasibility project used interviews and an e-mail survey to canvas stakeholders for a description of their wants and needs. We sought expert advice on setting up "online communities" and the use of web sites to stimulate learning. Most importantly, we set up a prototype for the web site which required engagement in all the steps to conceive, create and produce an internet presence for community-based research.

It took two years from the completion of the feasibility study to the actual creation of the web site, due in large measure to the slow pace of developments in the federal CBR program. Once on air, however, www.hiv-cbr.net was widely appreciated not only for its technological functionality but its important contribution to developing the community

of community-based researchers. The site features interactive software that allows members to post studies to an electronic library and others to comment on the presented work. In its own way hiv-cbr.net was an answer to the deadlock that conventional social science holds over the production of knowledge through academic journals.

For Rapid Assessment

While in the midst of developing the CBRC, a change in HIV incidence among gay men brought the work accomplished thus far into even sharper focus. As predicted, when unsafe sex began to increase, an increase in HIV incidence shortly followed. (Health Canada, 2001) The need for CBR became much more urgent. To address the situation, the CBRC called together a group of local stakeholders, including outreach workers, physicians, street nurses and public health professionals. The clash of opinion that ensued made it clear to everyone that not enough was known to move forward with an action plan to bring HIV incidence back down (Marchand, 2001).

From all the experience leading up to the time, the CBRC was in a good position to make a bold suggestion - a large sample survey focusing on the sexual safety of local gay men. Indeed the survey was another opportunity to take on more capacity building among local players because few had the capability to design questionnaires let alone interpret them. Using established international networks, the CBRC invited Sigma Research in London, United Kingdom to consult with our local network on survey design, distribution and interpretation based on their own decade of experience with large samples of 10,000 or more of British gay men (Hickson and others, 2001).

Here we found ourselves again in the midst of a steep learning curve about how to address an urgent local issue with newly forming research skills among stakeholders. Our work with Sigma helped us through conceptualizing the knowledge contribution which would be needed to advance practical aims of HIV prevention among gay men. We invited a

Sigma consultant to join us for a week of workshops and support in developing our questionnaire. In those meetings our local group conceived the *Sex Now* survey project - an initiative which would not only bring new data to light about prevention needs, but which would also reach a lot of gay men with the important message that HIV was once again on the rise.

Everyone recognized that the critical piece would be attracting men to participate in a survey about intimate details. That helped focus the need for tight organization and creativity in how the survey would be marketed. All of these issues were collective learning hurdles along the way. There was much anticipation and worry, but the payoff for all the effort could not have been realized in more concrete terms: that hot summer day on the beach at the Pride Festival brought 1500 participants into the survey.

The project, of course, could not end there. The data had to be coded and entered into SPSS for statistical analyses. There were more consultations with Sigma through the analysis. Once preliminary findings were available, we brought the local network back together to consider what our data said and how to move forward in prevention practice. That was just another step in a now familiar pattern. There was learning to do: not only how to read tables but how to interpret the data effectively and translate findings into action.

Sex Now brought several important insights to the fore which were immediately put to use in local prevention work even before the final report was written. One of them concerned erroneous assumptions men were making about the safety of the sex they were engaged in. A local prevention group used that evidence to win a competitive grant for a media campaign featuring the fallacies of such assumptions.

Reflections

Looking back on more than a decade of work making community-based research a reality in HIV/AIDS organizations, we would have to say that

our capacities grew with those of the people we worked with. By now CBR is so desired by community HIV/AIDS groups in Canada, that available resources are severely stretched. Community-based research is in such demand because it concerns shared learning from direct experience to become more effective with urgent matters of the day, the ongoing reality of HIV/AIDS.

Whether CBR studies should be considered contributions to formal knowledge or not, hardly matters when such collaborations clearly contribute to improvements in practice. We all become better knowledge managers. The process is as important as the outcome. And yet, situations arise where little direction exists and the contribution from community-based research is exemplary knowledge construction translating into advances in the health of the community. Is such an occasion not a triumph for adult education, demonstrating the capacity of its practice to produce compelling contributions to social science?

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