

# **COMMUNITY BASED RESEARCH IN GAY MEN'S HEALTH PROGRAMS: A WORKSHOP ON USING PARTICIPATORY RESEARCH AS AN HIV INTERVENTION**

This is an outline of a workshop based on the manual: *Building Gay Men's Health: a peer-based approach to creating community change* by Andrew Barker, Man to Man Coordinator at AIDS Vancouver.

## **PURPOSE OF WORKSHOP**

The purpose of this workshop is to look at how community based peer-driven research can be applied to gay men's health programming in order to gain a deeper understanding of the health issues affecting gay men while empowering them to take charge of their own health. The workshop is participatory, and provides participants with an opportunity to develop research strategies to apply to their own communities and programs. Community based research is an effective form of engagement with the community and a way to build our knowledge and understanding of the people that we work with.

## **ESTABLISHING WORKSHOP GROUND RULES**

Workshop participants put forward:

- Confidentiality. What's said in the room stays in the room.
- Respect. There are no stupid comments or questions.
- One person speaks at a time.
- Rounds. Everyone gets to say something on a topic or pass.
- "I" statements. Speak for yourself.

## **INTRODUCTIONS**

Active listening and interviewing exercise. Break off into pairs for ten minutes and do an interview with each other. Name, agency, the population you're working with. What are you up against in your work with gay men and HIV? Introduce the person that you interviewed.

What are you up against in your work with gay men and HIV? Participants said:

- fatigue, impatience
- generational changes that have brought a re-ordering of sexualities
- new pockets of discrimination in the gay community
- difficulty reaching youth due to perceptions of non-inclusion in the general group of gay men
- difficulty finding open communication about sex and HIV
- frustration about complacency, ie. involvement in programs
- frustration about the slow moving nature of ASO bureaucracy
- divisions in the community
- HIV prevention programs don't have funds and support
- HIV prevention fatigue
- program not funded and the space they're in is not appropriate
- rebuilding the self esteem of positive young gay men through education and undoing the stereotypes about positive people.

- frustrated with the level of apathy in the gay community
- like to be able to bridge the gap between older gay men and young gay men
- how do we reposition HIV as in a continuum of health, including gay health and HIV
- reducing vulnerability in gay men who are involved in high risk behaviour
- severe lacking in funding, programming and recognition of the unique needs of gay men
- main obstacles are with the school boards, since they have to approve all programs and presentations that group does there
- lack of participation on the part of youth, trying to get them involved in the programs
- trying to find youth community within the gay community; lack of cohesion, no real structure to the youth gay community.
- traditional prevention methods are not effective
- how to reach gay men in who don't want to be reached
- why people are having bareback sex and how do we address it

### **HISTORICAL CONTEXT OF MAN TO MAN PROGRAM**

Outline of why they undertook community based research in the Man to Man Program:

- program had fallen apart and there were few volunteers
- realized that there were a number of changes in the gay community
- needed to rebuild this program
- considered doing a traditional needs assessment but realized (a) no funds and (b) it might not be the best approach
- wanted to involve the community in program development
- decided to do community based research
- see manual for history of Man to Man Program

What was changing in the gay community?

- combination therapies created an optimism
- AIDS less visible in community
- younger generation hadn't seen the effects of HIV and AIDS
- prevention fatigue
- changing epidemiology. HIV/AIDS was affected other populations especially injection drug users
- shifting public perceptions that the gay community had HIV under control
- barebacking trend

About Man to Man's community based research project:

- wanted to know what was happening in the lives of gay men in Vancouver; what were the values, norms, attitudes and beliefs of the gay community?
- used focus groups to gather information
- published paper entitled: *'Between what is said and what is done': cultural constructs and young gay men's HIV vulnerability* by Terry Trussler, Paul Perchal and Andrew Barker
- used population health framework
- addressed underlying issues affecting gay men, beyond condoms

Discussion points from workshop participants on why HIV infections may be rising in gay men:

- impact of HIV on gay community
- grief and multiple loss

- anger in community
- community renewal
- internalized homophobia
- self-esteem and younger gay men
- bareback sex

Why use community based research?

- "It's more productive if one shifts the focus to the kind of practices that people have and just see what they do. When one goes for the cause and the second guessing, one misses the target."
- "We need to learn more about what people are doing and the circumstances and meanings and associations with what's going on."
- "Rather than second guessing. We used a mechanism for going into the community and asking people and then incorporating what people say into programming."

## AN OVERVIEW OF PEER BASED PARTICIPATORY RESEARCH

Considerations:

- Study Plan Do model: health promotion in AIDS work (see *Field Guide*)
- Transformational learning and community health
- Origins of many health issues lie in social problems and not in the organism.

Rationale for community AIDS groups using CBR:

- **Local Focus:** General solutions to social problems are rarely effective. Knowledge of local cultures is necessary to sort out the receptivity and capacity for social change - "development".
- **Collective Enterprise:** Participation in knowledge production blurs the distinction between researcher and researched. If knowledge is power, learning the tools of knowledge production is the route to empowerment. Equity in: questions to be asked, data to be analyzed and actions to be taken.
- **Experienced Based:** All participants have data, can acquire data from other community "members" and have the requisite knowledge to arrive at a fitting interpretation.
- **Action Oriented:** The "process" of inquiry may turn out to be more liberating than the data it generates or the outcomes of the study.
- **Practice Improvement:** Interpretation of experience can be put to work immediately without having to publish the study according to standard research conventions, ie. published article.

Discussion points:

- doing CBR increases confidence
- variety of models of community based research
- incorporate CBR into what people are doing in their practice in the community organization

## ASSESSING YOUR COMMUNITY

- refer to issues from the beginning of workshop to identify the community you want to assess
- identify what factors are in place to help you do your research. What's already there and what isn't there?

- answer some basic questions: "what population are you going to be working with", "what types of people are there", "who are the stakeholders", "is the community united or fragmented", "what kind of issues are you up against"
- refer to manual; Section "Assessing your Community" pages 38-40

Discussion points from assessment exercise:

- gay men's health and HIV prevention not on policy map and receives no funding; research on organizational leadership and policy makers in the system needed; also research on who's doing what and what their assumptions are about funding policy with respect to gay men
- housing a community program: need to find independent funders
- anybody doing this kind of work at any level becomes some sort of maverick or a lone ranger
- diverse gay community needing services; this is both important and daunting; completed focus groups with youth and found program not accessible to youth
- some groups are accessing programs; hard to provide services for all different types of people; trying to approach HIV and AIDS information for youth in a different way - talking about employing healthy relationships and lifestyles
- informal research by asking questions about needs
- who doesn't use community services? Who don't we see?
- impact of vaccine trial on gay community
- doing the research has been the process of the interactions between people, hearing peoples' stories and quantifying that; experiencing the gap between epidemiology where they're talking about statistics and the stories gay men tell
- community based research has many similarities to community development
- CBR helps gather peoples' individual stories

Using the Vulnerability Grid to assess gay men:

- see Manual; pages 62-65
- Man to Man used the vulnerability grid to help them understand what they were dealing with and to interpret the data they generated from focus groups
- vulnerability grid first used in development work to detail vulnerabilities in a community and figure out capacities of a community
- helps create a broader interpretation beyond simply sexual behaviour
- grid gives a range of ways to look at a problem
- individual: deals with vulnerabilities as they relate to the person. Someone's knowledge or position in society, their psychological makeup, their age etc
- interpersonal: the one to one interpersonal vulnerability of differences in power, differences in age, differences in communication, negotiating sexuality, negotiating sexual safety etc
- social: patterns in the local culture, influence of the local culture on an individual and how what's perceived to be the way things are done affects how an individual gets along in that culture, etc.
- structural: big ordered society, discrimination, homophobia, has an impact on the individual. But other things as well, like the environment.

Case study example: gay youth and HIV vulnerabilities (and capacities)

Individual

- isolation, feeling of aloneness, no local supports, no kindred spirit
- internalized homophobia

- personal powerlessness
- resilience (capacity)
- self-determination (capacity)
- courage: coming out in high school, setting up gay-straight alliance clubs (capacity)
- feeling of invulnerability
- fear, denial

#### Interpersonal

- difficulty talking to peers about HIV/AIDS, sexual safety, sex
- difficulty being able to have open frank discussions about sex and sexual behaviour and choices and relationships and the interplay of HIV and AIDS with others in a group setting
- difficulty in bringing up the topic of HIV and AIDS with their partner
- negotiating a safe encounter: language, experience, comfort
- need for contact: to be loved, fucked, wanted
- lack of experience with personal boundaries; don't know what want sexually (eg. to be top or bottom)
- lack of experience with gay sex (why anal sex hurt; why this felt good etc)
- lack of education
- age and power differentials
- young gay men just coming out being taken advantage by experienced gay men over 30 for example

#### Cultural and social

- attitude of "let them look after themselves"
- exploitation of youth
- male misuse of power
- men are becoming more responsible about sexual behaviour, but still a segment of men who are abusive
- assumptions and meanings of sexual behaviour (eg. meaning of being approached by somebody with or without a condom can have cultural associations that can lead to different conclusions)

#### Structural

- position of gays in society is "changing"
- more pressure on youth to out and queer
- shame from traditional society
- parental expectations
- institutional denial (eg. from schools)
- danger of violence at schools
- trying to be out in small city or rural environment

How can we take what we know and what we see we don't know and use that as the basis to go forward and learn more from the community?

- focus groups
- one on one interviews
- participant observation
- surveys

A major reason for doing community based research is to involve the community directly in the program development work by developing community ownership and mobilizing community members.

Community based research can also be used as an intervention. Gay men said to Man to Man volunteers, "wow, I've never sat and had a conversation with gay men about being in a serodiscordant relationship or about what it means that I go out to the bar every weekend and do cocaine and how it impacts on my life".

#### **BRIEF OVERVIEW OF CONDUCTING A FOCUS GROUP**

- see manual page 48 and Appendix I and J
- introductions and icebreaker: create safety first
- outline the purpose
- housekeeping
- ground rules
- tape recorder, confidentiality, consent forms
- information form with demographics, anonymous
- focus group questions
- closure, check in with participants, offer resources
- staying involved
- participant evaluation form

#### **Discussion Points**

- support for focus group participants on emotional issues
- confidentiality and confidentiality forms
- training of volunteers
- follow up and resources for focus group participants
- no honoraria budget
- using social networks
- identifying community gatekeepers to help with recruitment
- some research topics not conducive to focus groups
- location of focus group will affect discussion; comfort and food
- go out into community; don't bring to work location
- facilitators debriefing and evaluation form

#### **DEVELOPING QUESTIONS FOR FOCUS GROUPS**

- see Manual pages 49-50
- Man to Man wanted to know about sex lives of gay men coming to focus groups but believed that asking them indirectly would provide a more in depth understanding
- asked: "OK, you're making a movie about gay life in Vancouver. What's it going to be? A comedy or a drama?" To unpack more about what was going on in relationships - "monogamy's bullshit, right?" Or "well, say your best friend just told you that his partner is HIV positive. How would you react?" Embedded in that question are a lot of ethical issues. And then real fantasy questions - "suppose you just won the lottery - what would you do? How would that change your life". These evoked responses that were far richer than if we asked questions directly.

## Case Study: Developing questions for gay youth

What information on gay youth is wanted:

- What gay youth feel are their lifestyle priorities?
- What gay youth are dealing with on a day to day basis? How that ties in with the programs and services that we can offer to help them address whatever it is they're dealing with.
- Their sexual health and the programs to match those needs.
- How do you rebuild the self-esteem of positive young gay men?
- How do you deal with apathy within the gay community?
- How do you bridge the generational gap?
- What have your interactions with older gay men been like - positive or negative?
- What are the values, norms, attitudes and belief of gay youth?
- How do gay youth think others see them?
- What is the characteristics of a program that would be attractive to youth?
- How do you identify? What do you mean by this?
- What are the most difficult things you have to deal with or cope with on a daily basis?
- What are the most joyous moments in your day?
- What do you see in the future?
- How do you want the future to be?
- Miracle based questions (envisioning possibilities)

Different styles of questions: (See Manual page 50)

- Scenario: placing participants in a specific place or situation
- Projection: allows participants to talk about an issue without relating it to themselves
- Future: asking participants to envision their future
- Deconstructive: making participants rethink what they take for granted
- Reactive: designed to produce strong reactions
- Fantasy (like miracle question): allows participants to dream

Questions to ask focus group of gay youth to get information:

Scenario:

- You're the coordinator of a new gay youth drop-in centre (youth festival, alternative to night life). What programs would you offer?
- Your favourite teacher (best friend) just came out. How would you/peers/the school react?
- You've been approached by friends to start a gay/straight alliance in your school. What do you think the barriers might be? How would you react?
- You've just found out that you're HIV positive. What's going through your mind? Who do you tell?

Future:

- 10 year high school reunion: Who would you see? Who would be gay? Who would you bring with you?

Reactive:

- All older guys are dirty old men looking for sex. What do you think?
- Gay love is a contradiction in terms. True or false.
- Your parent (Mom) just came out to you. How do you react?

- Gay youth only go to raves and care about themselves. What do you think?
- Fantasy:
- You get the privilege of nuking the West End. What are you going to build in its place?

### **ANALYZING THE DATA**

- word for word transcription of the tapes
- volunteers read and discuss one transcript
- use a highlighter to mark significant statements
- write down main comments
- break down comments into individual, interpersonal, cultural, structural aspects
- relate comments to issues
- use experienced qualitative researcher to do an indepth interpretation of data
- useful for volunteers to come up with an interpretation of text
- useful to be able to transcribe the text, read it and learn from it enough that you can apply it to the next level of activity that you go on to with your community

### **EMPLOYING THE RESULTS**

- See Manual page 61-65 for how Man to Man used the results
- find ways to take results back to the community
- take them back to the people who've been in the focus groups
- for example, publish results in the newspaper
- do a brochure or newsletter and send it out to participants, to community groups
- involve the community in every step of the process

Case Study: Man to Man research results:

- Individual: developed pocket guides providing basic information on gay health issues, HIV, STDs, gay bashing
- Interpersonal: started up a book discussion group for gay men
- Cultural: applied findings to health services for gay men and advocacy initiatives
- Structural: trained gay male sex workers group to run their own focus groups and gather information; sex workers made suggestions for programs based on findings

### **FEEDBACK**

How will you proceed?

- do focus groups with gay men on health issues
- research health issues for HIV negative gay men
- incorporate questions that are less personal or threatening into one on one interviews
- attend a focus group, then organize a focus group
- do focus groups with gay youth on programs and incorporate gay health issues
- tape record a discussion group, transcribe tape