

COMMUNITY BASED AIDS ORGANISATIONS & COMMUNITY BASED RESEARCH: THE LOVE THAT DARE NOT SPEAK ITS NAME

The following is an outline of a variety of issues that I see CBAOs may encounter or may need to deal with as they are getting involved with community based research, hence these may be relevant for a web site on CBR to consider for CBAOs:

1- Strategic/Work/Program/Policy Development/Budget Plan(s):

- How does CBR fit into plans? Is there an objective/program area/strategic direction that specifically addresses CBR initiatives or the role of CBR in the organization?
- What are the priorities for CBR in an organization? There are many wonderful research projects to consider or become involved with but usually limited resources, what are the priorities? How are these priorities made?
- How does the organization reflect its vision, values, and plans in any CBR they get involved with or assist in any way?
- What policies does the organization have that address CBR within the organization? Do the policies allow staff to make decisions about what CBR to be associated with? What CBR to assist in any way?
- How do CBAOs make practical decisions about what research to get involved with at what levels?
- With ever tightening contracts with funders, how do CBAOs allow for the opportunity to become involved with new and emerging CBR work?
- What resources(staff, volunteers, \$) are available to get involved in CBR projects?
- What is the priority of CBR work in relation to program delivery?

2- What kind of knowledge?

- How would you describe the ways in which your organization likes to learn about stuff?

-corporeal- gut feeling, personal experiences, visceral, lived experiences, one of us, one of our own

- intellectual- lit reviews, doing studies on "client groups", analyzing data, critical reflection, studying a target population

- visual- watching, observing, participant observation

- spiritual and/or emotional- feelings, therapy, counseling, support groups, transformation, making meaning

- These are just a few examples of the ways a CBAOs may talk about issues they deal with on a daily basis.

- It is important to be aware of this because these may be the ways you will want to connect with a potential CBR partner.

- How are researcher(s) talking about the issue? What language do they use to describe what they want to learn? What has their previous work explored and how did they go about doing it? What kind of work did they do before becoming researchers? Do you want them to talk about their own experiences in relation to the issue(s) you are curious about?

- This is not about choosing the right one but about choosing the right one for you, all kinds of knowledge is valuable, what and how do you want to learn?

- CBAOs and universities are different, people who work within these organizations are attending to different needs in doing research. It is important to acknowledge and clarify these upfront, as well as any difference in the way work is done.

3- Whose data and whose thinkin'?

- Much of the funding now available for CBR work requires an ethics certificate.
- For insurance purposes, and possibly other reasons, many institutions that grant ethics certificates require that they own the data and the research findings once completed.
- Who can use the findings? Is it important for you to present the information to other CBAOs, funders, and/or your members?
- For a CBAO, do you consider it important to have access to the data during and after the project is completed? Do you consider it important to have equal say in how the data gets interpreted? For your contributions, do you expect to be acknowledged in any papers that are written or presented? Who will become PI if the PI quits or dies?
- A partnership agreement may be able to address some or all of these elements.
- Make sure to discuss some of these elements before submitting a proposal.

4- What the heck is community based research anyway?

- Our own experience with CBR is that a few of us who have, or are completing, a Master's degree end up bridging two worlds, that of our membership(heart and soul) and the academics(big giant head).
- We are very fortunate to have people who are very strong from a community perspective, i.e. 10-15 years experience with a variety of CBAO work, strong commitment to our membership(PHA driven work), recognition from other CBAOs as resources in the work, and a sense of humour. Some of these people are or have been involved with a variety of other research projects over the years and some have completed their own research for school.
- The capacity this brings to a CBAO is the combination of experience, curiosity, and the confidence with research and ability to have conversations with academics.
- While the various capacity building projects that swept the nation a couple of years ago were helpful in putting CBR on the agenda for our CBAO, the reality is that, as a member driven organization, there's a mediation quality to the role that people who have the academic credentials play in CBR projects.
- This mediation role may consist of plain languaging researcher speak and academising community speak; providing context, history, and understanding of CBAO issues and people; contextualising academic concepts.
- While CBR provides many opportunities for CBAOs, what would be helpful from a site is a comprehensive plain language(max grade 8 level) outline of the elements of community based research, the different approaches to or philosophies of community based research and the role of each, and a step by step outline of what a CBAO should consider when entering into a CBR project and/or a CBR partnership with an academic(kind of like a dating guide- what might be asked when first meeting, what are your bottom lines or things that you need someone to know and respect, etc)