

Working with communities as partners in research – from inception to publication

Community-Defined Evidence: Creativity, Health and the Power of People

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Introduction

WHO?

- scientific chair of the Ethics committee of the CIUSS centre-Ouest
- researcher
- visible minority, female

WHAT?

- confront some of the necessary areas which we, the academics, need to consider
- finds ways to forge **better and more respectful** alliances with community organizations

HOW?

- not a plethora of academic references, but with experiences based on the **WHO** and **WHAT**

We and they becoming us

- Expertise of academic findings (references, citations, evidence-based) are important but limiting and limited – are researching what the community needs or what we want?;
- ‘Real’ expertise found in the community is often ignored;
- Community workers know the terrain but we don’t recognize or acknowledge it – therefore, what we ‘know’ is often not based in reality
- We are not privy to the lived reality of persons in the community
- We have no handle on personal environmental, political, social, & structural problems
- Most problems in the community are ‘wicked problem’

What is a wicked problem?

Characteristics of a "Wicked Problem"

- Difficult to clearly define
- Many interdependencies and often multicausal
- Attempts to address the problem often lead to unforeseen consequences
- Frequently not stable
- Usually no clear solution
- Socially complex
- Rarely is the responsibility of only one stakeholder
- Solutions involve changing behaviors
- Can be characterized by chronic policy failure

The current paradigm

- We ask them to do the most difficult part of the research – recruitment and “selling” the research question
- We behave as though they should be ‘happy’ to be asked to work for us
- Imposition of what we consider to be the ‘interesting problem’
- Benefits accrue to us, our students, our careers and our institutions on the backs of community organizations and participants.
- Still stuck in the ancient paradigm of middle and upper class ladies performing charitable functions and helping the downtrodden and ‘those less fortunate;
- There are now university classes in community development and degrees to be gained in the discipline
- We do not interact with community organizations as if they are equals.

Partnering

- Community Based Participatory Research (Doornbos et al. 2015)
- We must treat them as equals rather than assuming that we are always the givers and they the receivers
- Must offer meaningful support and accompaniment in explaining project to subjects
- Include community representative as equal partners in the development of projects, funding of projects, interpretation of results, transfers of knowledge, writing of reports, full credits on articles
- Working on the recruitment documents to be presented to subjects
- Share research results in a digestible form – reduce the jargon
- Most community organizers are professionals and should be treated as such
- Advocate for community organizers to be paid decent salaries

What do we need to do?

- Emphasis on *community* and *participatory*
- Where, who and how – calls for a change in paradigm
- Recognize that more ‘asks’ are being made of these organizations
- More and more is being devolved unto them with no commensurate rise in salary
- Underpaid at (\$19.0 – \$21.0 hr.) 40hr. Per week. Always on call but no money for it.
- – we can advocate for better and fair pay – it is in our interest to speak out
- Need to write fair grant applications – sharing of ALL resources (not merely *thanks a lot*)

What does inclusion do?

- Representation (*We see ourselves, and what we say is important*)
- Belonging (*We belong here, our input is sought, we are respected*)
- Sense of community (*This place is ours, we take responsibility for it*)
- Better mental health (*reduced isolation, anger, helplessness, more hopefulness*)
- Richer 'educational' experiences (*cultural exchanges, cultural knowledge, cultural humility*)
- Promotes cultural humility and safety

From the inside out!

- “If one really wishes to know how justice is administered in a country, one does not question the policemen, the lawyers, the judges, or the protected members of the middle class. One goes to the unprotected – those, precisely, who need the law’s protection most! – and listens to their testimony.” (Baldwin, 1972, *No Name in the Street*)