

**Community Empowered  
Research Training:  
*Some thoughts about  
research methodology***

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# A view from the ivory tower

- Historically, researchers have been academics
- Enormous gains in knowledge
- Basic vs applied research in the sciences
- Funding basic and applied research

# Impetus for change

- Gains from 'traditional' research and funding
  - Extensive knowledge base; breakthroughs in diagnostics; health indices; effective therapies etc.
  - Significant impact on increased life expectancies
- No appreciable effect on health practice
- Health disparities remain even when access issues are taken into account
- Spending disparity: Poorer countries that spend less on health care are in better health than US

*Banks J, Marmot M, Oldfield Z, Smith J. Disease and disadvantage in the United States and England. JAMA. 2006;295:2037-2045.3.*

*Siddiqui A, Herman C. Towards an epidemiological understanding of the effects of long-term institutional changes on population health: a case study of Canada vs. USA. Soc.Sci.Med.2007;64:589 -603.*

# Roots of change

## ■ Kurt Lewin: 1940's

- 'action research': research not just to understand phenomena, but also to be able to shape it
- Address and redress social inequalities
- Challenged traditional concept of 'scientific objectivity'
- Rejected idea that researchers had to remove themselves from the community in order to study it

# Paulo Friere

- ❑ Education is a dialogue ....conversation
  - ❑ co-operative activity that involves respect and exchange.
  - ❑ “Banking” metaphor
- ❑ Praxis: action and making a change in the world. Not one person acting on another, but with another
- ❑ Conscientization - developing consciousness, that has the power to transform reality.
- ❑ Situating action in the lived experience of the individual

# Stepping down from the ivory tower

- ❑ Many non-clinical factors contributory to disease process not traditionally seen as part of research
- ❑ Prevention and control of disease: social/cultural, political, environmental conditions are complex contributors
- ❑ Diagnosis: a process of 'acculturation'
- ❑ Maintenance: health as a sustainable process
- ❑ Doing research IN a community is different from doing WITH a community
- ❑ Took a long time for 'revolutionary' ideas to gain traction with medical and research community

# Hypertension: An example

- Prevalence of hypertension increasing despite slew of research studies about hypertension management
- Uncontrolled cases account for two-thirds of those diagnosed
- Some populations more intensely treated, yet more poorly controlled
- Access: medical and environmental

All politics is local.....

Thomas “Tip” O’Neill



# How is this related to methodology?

- ❑ Fundamental assumptions about the correlation and causal relationships that under gird the issue under investigation IS what guides methodology.
- ❑ Fundamental shift in assumptions: centrality of role of community and communal factors
- ❑ Research shift: from “knowing” to combining knowledge with action to achieve social change

# Research WITH vs IN

- Recognition of community as a distinct social entity with a sense of identity and shared life' rather than as a physical location or setting
- Recognition of the importance of social, political, cultural, and economic systems to health behavior and outcomes
- Engages community members in choosing and developing research topics, data collection and interpretation

Adapted from Viswanathan *et al* (2004) AHRQ Publication #04-E022-2

# Translating assumptions into principles that guide research

- ❑ Recognizes community as a unit of identity
- ❑ Builds on strengths and resources within the community
- ❑ Facilitates collaborative partnerships in all phases of the research
- ❑ Integrates knowledge and action for mutual benefit of all partners
- ❑ Promotes a co-learning and empowering process that attends to social inequalities
- ❑ Involves a cyclical and iterative process
- ❑ Addresses health from both positive and ecological perspectives
- ❑ Disseminates findings and knowledge gained to all partners

# Consequence on Methodology

- Emphasis on qualitative as well as quantitative methodologies
- High priority on translation of basic, intervention, and applied research into changes in policy and practice.
- Change assessments need to be built into design of study

# Community Engagement and Research Methodology

Community can be involved at every level: “it’s never too early, never too late”

- ❑ Select research question
- ❑ Develop proposal
- ❑ Financial responsibility
- ❑ Study design
- ❑ Recruiting and retaining subjects
- ❑ Participate in design of instruments and data collection
- ❑ Develop intervention
- ❑ Interpret and disseminate findings
- ❑ Apply findings: translate research → practice

QuickTime™ and a  
decompressor  
are needed to see this picture.



# Study Types

- Basically two types:

- Interventional:

- Health is Gold: Vietnamese American (2003)

- Health is Strength: Korean American (1997)

- Non-interventional:

- Health promotion for South Asian women (2002)

- Identifying older Chinese immigrants at high risk for osteoporosis (2003)

# Study Design

- Experimental (RCT)
  - Participants randomly assigned to groups
- Quasi experimental
  - Comparison of identified populations
- Nonexperimental
  - Qualitative data
  - Correlational data
  - Training, workshops, educational programs, etc.



# Strengths and Challenges: Strengths

“Lack of fit” between traditional methods of research and community-based versions: both a strength and challenge.

## ■ Strengths:

- Increased participation
- Increased external validity: generalizability
- Decreased attrition
- ‘action-based’ :
- Increased community capacity
- ANRQ study: no trend towards correlation of community involvement and rigorous research methodology

# Challenges

## ■ Challenges:

- Not all researchers receptive or trained in methodologies required for community-based approaches
- Not all review panels receptive to 'community based approaches'
- Time:
  - Building relationships take time
  - Length of funding: typical funding cycles 5 yrs.
- Role of publications:
- Does the community always come up with the 'strongest' designs?

# Some last thoughts

## “Spillover” effects

- ❑ Loss of internal validity: biased recruitment or selection
- ❑ Loss of randomization: communication between comparison and control groups
- ❑ Loss of external validity: highly motivated intervention groups
- ❑ Biased interpretations