

A Healthy Balance

community alliance for health research on women's unpaid caregiving

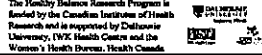
Finding Neverland

The Elusive Alliances of Communities and Universities
Susan Nasser, Healthy Balance Research Program
ARTC, December 17, 2004

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Town and Gown: Engaging communities and organizations as research partners

- community
- organizations
- partners
- engaging
- research

Five Research Teams

- Focus groups - Dr. Jacqueline Gahagan, Dalhousie
- Secondary data analysis - Dr. Shelley Phipps, Dalhousie
- Caregiver portraits - Dr. Brenda Beagan, Dalhousie
- Survey - Dr. Janice Keefe, MSVU
- No life like it - Dr. Cyndi Brannen, post-doc researcher with HBRP

Community-Based Research

"...a collaboration between community groups and researchers for the purpose of creating new knowledge or understanding about a practical community issue in order to bring about change. The issue is generated by the community and community members participate in all aspects of the research process. Community-based research therefore is collaborative, participatory, empowering, systematic and transformative"

• Hills & Mullett, 2000, Uvic Community Health Promotion Coalition

Community-Based Participatory Research

- "... a collaborative approach to research that combines methods of inquiry with community capacity-building strategies to bridge the gap between knowledge produced through research and what is practiced in communities to improve health."
- Builds the capacity of communities to function as co-investigators

Community-based Participatory Research: Assessing the Evidence, 2004
 Agency for Health Care Research and Quality (AHRQ)

SO ...

"Community-based research formalizes the community issue into a researchable question, and systematically plans for "data" collection and analysis, and presentation of the results. ... It is the focus on knowledge development that distinguishes community-based research from community development."

Hills & Mullett, Uvic Community Health Promotion Coalition

Barriers to Community-Based Participatory Research

- poor community incentives and capacity to be partners
- poor academic incentives and capacity to be partners
- inadequate funding and insensitive funding mechanisms

AHRQ

Modes of Participation

- contractual - researchers contract with local people for taking part in research
- consultative - local people asked for opinions and advice
- collaborative - researchers and local people work together; researchers manage the research
- collegiate - researchers and local people work together as partners; mutual learning; independent research done by local people

AHRQ

A suggestion for removing one barrier to community participation:

- appoint researchers as guardians of the data during the study and assure guardianship to the community at the end of the study (AHRQ)
- ethics review??

A Challenge

"...lack of fit' between the dynamics of true community collaborations and the peer-review funding approach to setting research priorities, maintaining timelines, and exercising budgetary control. Partnership development between communities and researchers takes time: if such work is to be truly community guided, then it requires a different way of thinking about choosing research topics and allocating funding"

AHRQ

"researchers must combine excellent science with compassionate and respectful community partnerships"

AHRQ

"... the balance required to produce results that are both good and useful" - meets accepted standards of excellence and scientific productivity and responds to community needs and concerns

CURA evaluation

Principles of Community-Based Research

- involve community partners as early as possible
- community partners have real influence, leverage
- research benefits the community
- community members are part of analysis, interpretation and distribution of findings
- partnership lasts beyond the end of the research
- community members are empowered to initiate their own research projects

U Washington School of Public Health

CURA Objectives

- foster innovative research
- promote sharing of knowledge, resources and expertise between universities and organizations in the community
- enrich university teaching
- reinforce community decision-making and problem-solving capacity
- enhance students' education and employability

Community Organizations

- permanently funded government departments and paragonovernmental agencies
- NGO's, not-for-profits, community-based agencies without permanent funding support

CURA Evaluation - Some Findings

- outputs
 - 127 peer-reviewed articles; 328 non-peer reviewed documents, reports
 - 160 peer-reviewed conference presentations; 245 non-adjudicated presentations
- projects arrayed on a continuum re: primary orientation
 - producing research results ↔ working with partners
- more evidence that community capacity has been developed than that university capacity has been developed
- uptake of CURA leadership much lower among community organizations

CURA Information Gaps

- how CURAs have enriched research, teaching methods and curricula in universities
- outcomes of participating students
- knowledge mobilization audiences and outcomes

CAHR - Community Alliances for Health Research

- to enable CIHR to develop links and partnerships at the local level

"The public health networks and facilities of all levels of government in Canada are envisioned as partners in research initiatives, to ensure that regional research priorities are addressed."

CAHR Partnerships

- equal and active partnerships between a community organization(s) and a research team(s)
- the partner is a joint participant with the research team in all aspects of the research project
- guiding principle: "groups from the community be active and ongoing participants in research, training and dissemination activities, and that their roles have been agreed upon in a spirit of equity and mutual benefit"

Possible Partners

- health oriented service clubs
- community foundations and organizations
- local, provincial and national health charities
- hospital and research institute foundations
- municipal and regional health authorities
- district health councils
- provincial government agencies

Partners contribute to....

- formulating research agendas
- providing input into the development of research and training projects
- disseminating findings
- applying the outcomes of research

A Community organization can lead a CAHR if ...

- incorporated not-for-profit
- has a research mandate
- subscribes to ethical and methodological standards
- has a record of research output in appropriate channels
- one or more staff with advanced research degrees assigned to research
- produce annual audited financial statements

Healthy Balance (HBRP) Who are the partners?

- Atlantic Centre of Excellence for Women's Health
- Nova Scotia Advisory Council on the Status of Women
- Women's Health Research Unit, University of Ottawa***

HBRP has 3 co-directors BUT one nominated PI

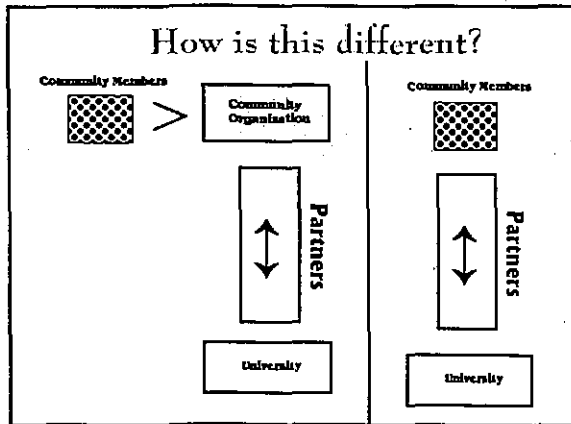
Other Partners

- Child Care Connection
- Family Caregivers Association of Nova Scotia
- Nova Scotia Centre on Aging (MSVU)
- Atlantic Provinces Economic Council
- various NS provincial government departments
- other Atlantic provinces Status of Women
- other Centres of Excellence

A new way of dealing directly with communities Equity Reference Groups

- constituted to include the perspectives of historically disadvantaged and under-represented groups; members speak directly from their experience

- Aboriginal/First Nations
- African Nova Scotian
- immigrant women
- women with disabilities



- ### How does this play out in more traditional paradigms?
- CURA - sharing between universities and organizations in the community
 - CAHR - partnerships between a community organization and a research team
 - community-based research - collaboration between community groups and researchers
 - CBPR - builds capacity of communities to function as co-investigators

- ### What have the Equity Reference Groups done?
- Focus groups - doubled the number of groups from the reference communities; drew facilitators from the communities
 - Caregiver portraits - RAs come from the communities
 - Secondary analysis - suggested that focus be on Atlantic region
 - Survey - lobbied for a way to have sufficient numbers from their communities to be able to have valid findings

- ### Final Thoughts
- shared understanding of definitions, parameters, and relationships is key
 - increasingly savvy communities and organizations have increasingly clear expectations of their role in partnerships with universities
 - if communities are partners, then measures of success have to reflect achievements that are important to them
 - respectful and productive community and university alliances are worth it