Developing Capacity for Policy and Practice Relevant Research Within and Outside Academic Institutions

Elaine Wethington

Karl A. Pillemer

Rhoda Meador

Cornell Institute for Translational Research on Aging,
Cornell University, Ithaca NY

May 14, 2008

Acknowledgments

■ **Funders**
  – National Institutes on Aging
  – RAND Corp./Hartford Foundation Interdisciplinary Geriatric Research Centers Initiative
  – Bronfenbrenner Life Course Center, Cornell-Ithaca
  – College of Human Ecology, Cornell-Ithaca
  – Weill Cornell Medical College

■ **Collaborators and contributors**
  – Mark S. Lachs, MD
  – Martha Bruce
  – M. Carrington Reid, MD, PhD
  – Myra Sabir, PhD
  – Risa Breckman, MSW
  – CITRA's National Advisory Board members Marcia Ory and Leonard I. Pearlin

Background

- Developing a community-based research approach to issues affecting older people is a priority recognized by the National Institutes of Health in the US (Office of Behavioral and Social Sciences Research, 2007)

- No published research syntheses document in a rigorous way the value added to research projects by using community based-research methods

- Similarly, no research currently documents benefits to research organizations by adopting community-based research methods

Aims of the Presentation

- Briefly describe The Cornell Institute for Translational Research on Aging (CITRA), an Edward R. Roybal Center engaged in research translation

- Synthesize lessons learned from the opportunities and barriers encountered when implementing *community-based research methods* (CBM) as a means of research translation

- Present data from the ongoing process evaluation of our efforts

The Cornell Institute for Translational Research on Aging (CITRA)

- A community-researcher collaboration in the service of older New Yorkers

- Co-directors: Karl A. Pillemer, Elaine Wethington, and Mark S. Lachs

- Multi-disciplinary and inter-disciplinary – connects researchers in at Cornell Ithaca with researchers in the Weill Medical College Division of Geriatrics in New York City and the Westchester Psychiatric Division in White Plains, NY

CITRA Includes a "Research Ready" Network of 265 Agencies That Deliver Direct Service to **300,000** Older Residents of New York City

- Senior Centers
- Case Management Agencies
- Home Care
- Home Delivered Meals
- Senior Housing
- Adult Day Care

CSCS
Council of Senior
Centers and Services
of New York City, Inc.

Three Foci of CITRA

- Scientifically-based, high quality research practical enough to engage and benefit community, through community-based research practices

- Education and mentoring of young and re-tooling investigators in translational research

- Rapid dissemination of research findings throughout the community

Major CITRA Activities by Core Staff

- Survey community needs on an ongoing basis
- Educate researchers and community agency directors and staff about the importance of scientific research translation in the field of aging
  - Community educational events: educational workshops and researcher-community practitioner *consensus conferences* (Sabir et al., *The Gerontologist,* 2006)
- Maintain a research-ready network of sites where research can be conducted in partnership with community partners

■ Mentor researchers in a pilot studies program (Wethington et al., 2007)

– CITRA efforts supplemented by a seminar series for investigators sponsored by a grant from RAND/Hartford (New York City Interdisciplinary Geriatric Research Center)

Translation through Community-Based Research*

- Involves community members, community organizations, and academic researchers equally in *all* aspects of the research process including problem definition, data collection, data interpretation, and application of the results to address community concerns

*Includes Community-Based Participatory Research (CBPR) and other variants (CPPR; PAR; etc.)

Potential Benefits of Community-Based Research Methods

- Improve the relevance and usefulness of research
- Improve the selection of desired outcomes
- Bring together research and community partners with diverse skills, expertise, and sensitivities
- Engage local knowledge and local theory to improve validity of research
- Increase a community's capacity to solve its own problems

Potential Detriments of Community-Based Research Methods

- Longer development period and extra costs may not lead to better study outcomes
- Perceived decreases in scholarly productivity
- Concern about scientific rigor of designs negotiated with community stakeholders
- Difficulties with Institutional Review Boards
- Lack of formal community outreach training among researchers
- Projects end with community dissemination and comment, not with the close of data collection

Evaluation Targets

- Four components of the CITRA community-based research model
  - Build community partnerships
  - Develop means to foster two-way interaction between researchers and practitioners
  - Enhance community capacity and improve dissemination
  - Assess impact on researchers and their institutions

Issues in Evaluating Community-Based (CBM) versus Conventional Research Studies

- What are the points that should be compared?
- Does CBM provide value that conventional research does not?
- Is CBM applicable to the same sorts of research problems?
- Is CBM worth the additional cost, and how do we decide how to decide?

Levels of Evaluation Presented Today

- University organizational level outcomes

- Development of community capacity

One Framework for Evaluation: RE-AIM (R. Glasgow)*

- **Reach** – reaching the targeted population
- **Effectiveness** – assessing intervention outcomes
- **Adoption** – organizational support to adopt the intervention
- **Implementation** -- assuring proper delivery of the intervention
- **Maintenance** – assuring delivery of intervention over the long-term*

*RE-AIM for Program Planning: *Overview and Applications*, by B. Belza, D. J. Toobert, & R. E. Glasgow.

Available at www.re-aim.org

	Developing Community Capacity	**Research Organization Level**
Reach	Does the program reach its intended audience?	Does the program attract new investigators?
Effectiveness	Are there improvements in the intended intervention outcomes, i.e. capacity?	Does the program offer new investigators useful research help?
Adoption	Is the program adopted by more organizations, including low-resource?	Do the new investigators adopt the techniques for their research?
Implementation	Can the program be delivered with fidelity, even in low-resource settings?	Do the new investigators effectively apply the techniques?
Maintenance	Can the outcomes be maintained? Can the program be institutionalized?	Do investigators apply CBM principles in future studies?

Reach
(research organization level)

- Does the program attract new investigators? Out of 14 pilot investigators:

    - 2 were "new" to aging research
    - 8 were "new" to our research institute
    - 12 were "new" to translational research

Effectiveness
(research organization level)

- Does the program offer new investigators useful research help?

  - CITRA Work-in-progress seminar

  - Formal class on CBM offered via videoconference to multiple sites, for course credit
    - Very well-evaluated by students over a 2 year period

Adoption
(research organization level)

- Do the new investigators adopt the techniques for their research?

  - Not yet completely assessed

  - 6/14 have adopted some CBM-style techniques in their research (6/7 if only those funded in years 2-5 of CITRA are included)

Implementation
(research organization level)

- Do the new investigators effectively apply the techniques?

  – Current evaluation is ongoing

  – Preliminary findings suggest that new investigators require monitoring by more experienced investigators (Wethington et al., *The Gerontologist,* 2007)

Maintenance
(research organization level)

- Do investigators apply CBM principles in future studies?
  - – Evaluation still ongoing
  - – So far, 4/14 have adopted CBM principles in subsequent studies or in proposals designed to supplement their pilot studies

  - – The *training* is in the process of being institutionalized in the new Weill Cornell Clinical and Translational Science Center

Conventional Indicator of Pilot Project Productivity: New Funding Secured

- Projects funded through CITRA pilots: 14
- Number of related "pilot" projects funded through other sources: 4
- Number of projects with funding to continue research: 11 (79%)
- Number of projects seeking continuing funding: 2 (11%)

Broken Down by Inclusion of CBM Elements

- Of the 7 projects funded in years 2-5 with CBM elements:

    - 4 have secured funding to continue the project

    - 1 had its pilot funding withdrawn

    - 2 are seeking additional funding

Reach
(community capacity)

- Does the program reach its intended audience? Evidence:
  - Nearly 300 organizations are linked to CITRA through its community network
  - The linked organizations include several levels of government, including the state of New York
  - New organizations (e.g. state wide practitioner coalitions) contact CITRA to collaborate on projects

Effectiveness (community capacity)

- Are there improvements in the intended intervention outcomes, i.e. capacity?
  - Evidence is still limited:
    - About 10 senior agencies are currently involved in funded research projects or in developing new projects
      - Effectiveness will be formally evaluated
    - Word has spread that CITRA is a good partner
      - Two state-wide researcher-practitioner initiatives are underway to apply CITRA resources for research (elder mistreatment) and/or policy change (managing care transitions)

Adoption
(community capacity)

- Is the program adopted by more organizations, including low-resource?
    - Projects funded through CITRA pilots: 14
    - (Approximate) number of senior centers and agencies involved: 25
    - A state-wide practitioner organization has adopted the CITRA researcher-practitioner consensus conference model to promote policy changes
    - Yet -- several problems have arisen in adoption efforts

- Low resource organizations lack the resources to collaborate

- Practitioners often perceive a lack of time to participate fully in research activities – even in higher capacity organizations

- Difficulties collaborating with IRBs that review projects for agencies

Implementation (community capacity)

- Can the program be delivered with fidelity, even in low-resource settings?
  - Consensus conference model
    - The main difficulty is producing a scientifically up-to-date research review – it takes a lot of researcher time
    - Community groups lack the capacity to do this without university supervision
      - One practitioner organization has done so successfully with favorable outcomes

– Research programs:

- Low resource programs have difficulty implementing research protocols in compliance with university human participant review board standards

  - Low resource programs often do not have staff who can implement fully informed consent (even with required educational training)

  - Low resource programs lack capacity to implement recruitment in compliance with project guidelines

Maintenance
(community capacity)

- Can the outcomes be maintained? Can the program be institutionalized? CITRA efforts:
  - Three researcher-practitioner working groups have been developed from CITRA consensus conferences and community workshops
    - Success: A coalition on "managing care transitions" includes an official from a state regulatory agency who will provide input to policy changes and implementation

- Success: A "Persistent Pain Working Group" is advising an innovative research project in order to improve the eventual NIH proposal submission

- The third group (introducing Hospitality management principles into senior service delivery) is having trouble organizing
  - This was a high-risk, high-gain topic which may have been too far ahead of the curve

Lessons Learned

- At the research organization level
  - Researchers must feel that they are being offered "value" for their time
    - The work in progress seminar is a key resource
  - Educational programs are necessary; many researchers lack capacity to collaborate with community partners
  - Our mentoring program seems to have resulted in benefit for investigators

– Monitoring by more experienced investigators is necessary to maintain fidelity to CBM

– American IRBs can be formidable barriers to adopting and implementing CBM

Building community capacity

- Low resource agencies will require extra incentives and financial support to take part in CBM projects
- Not all communities are alike
  - Not all are interested in writing up the research
  - Many collaborators perceive that they lack time to take part
  - A "roles and responsibilities" approach – everyone serving a role in which they are expert – may work most efficiently in some settings

- Evaluation of the value of CBM for a particular research area/project needs to be built into the research project
  - Evaluation can be done without planning ahead for the evaluation
  - Data must be collected along the way