

Applying CBPR to Health Services Research, Policy & Practice

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Objectives for Workshop

- Provide overview of Community-Based Participatory Research (CBPR)
- Describe the concepts of “partners” and “partnership”
- Discuss ethical implications of a CBPR approach
- Provide application of a CBPR approach to Health Services Research
- Explore 2 case studies
- Discuss challenges and benefits of using a CBPR approach

Please feel free to ask questions or share your insights throughout the workshop!

What is Community?

How do YOU define “Community”?

Community is ...

A group of any size whose members reside or work in a specific locality, share government, and/or have a common cultural and historical heritage

Overview of Community-Based Participatory Research (CBPR)

Definition of CBPR

Community-Based Participatory Research (CBPR)

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change...”

– W.K. Kellogg Foundation Community Health Scholars Program

WK Kellogg Foundation: CHSP definition Adapted from Hartwig K, Calleson D, & Williams M, 2006

Community-Based Participatory Research (CBPR)

- Approach that combines research methods and community capacity-building strategies to bridge gap between knowledge produced through research and translation of this research into interventions/policies
- CBPR recognizes community as a social entity with a sense of identity
- Working with rather than in communities, CBPR attempts to strengthen a community's problem-solving capacity through collective engagement in the research process

Viswanathan M, et al. *Community-Based Participatory Research: Assessing the Evidence*. AHRQ, 2004

Roots of CBPR

History of CBPR: Northern Roots

Northern Tradition (originating in 1940s)

- Kurt Lewin ~ “Action Research” – to overcome social inequalities
- **Research goal:** Create cycle of problem-solving and develop collaborative methods to investigate results of action
- Used with organizational settings (e.g., schools, work) to engage small groups to solve problems

Wallerstein N & Duran B. In: *Community-Based Participatory Research for Health*, 2003.

History of CBPR: Southern Roots

Southern Tradition (~ 1970s) – “Participatory Research”

- Latin American, Asian, & African social scientists' critiques of underdevelopment, distance from experiences of people living in the community
 - Paulo Freire (1970's) ~ Popular Education, Communities identify own problems & solutions
- **Research goal:** critical consciousness, emancipation, social justice, challenging inequitable structures.
- Used with communities to understand and begin to create structural change

Why CBPR?

- “Traditional” research approaches have not eliminated complex health disparities
- “Traditional” research findings are rarely applied directly to develop community specific interventions
- “Traditional” research does little to build trust & respect between researchers and communities
- Community members
 - weary of being “guinea pigs”
 - demand that research address their locally identified needs
- Community involvement can lead to scientifically sound research

WK Kellogg Foundation: CHSP definition Adapted from Hartwig, Calleson, & Williams, 2006

Principles of CBPR

Principles of CBPR

- 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

WK Kellogg Foundation: CHSP definition
Adapted from Hartwig, Calleson, & Williams, 2006

Principles of CBPR continued...

- 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

WK Kellogg Foundation: CHSP definition
Adapted from Hartwig, Calleson, & Williams, 2006

CBPR: Partners & Partnerships

CBPR and Partnerships

- CBPR involves:
 - Co-learning and reciprocal transfer of expertise, by all research partners, with particular emphasis on the issues that can be studied with a CBPR approach
 - Shared decision-making power
 - Mutual ownership of the processes and products of the research enterprise

Viswanathan M, et al. *Community-Based Participatory Research: Assessing the Evidence*. AHRQ, 2004

Partner Roles and Responsibilities

- Roles & responsibilities in CBPR projects based on:
 - Interest levels of respective partners
 - Partner knowledge and skills
 - Capacity-building needs of partners
 - Partnership research objectives and activities
- Partners can play multiple roles
- Partners may vary in their level of participation
- Consider partner performance expectations (e.g., faculty need to publish to advance to tenure, community members may need paid positions, etc.)

Adapted from Palermo A and McGranaghan R, 2006

Characteristics of Effective Partners Organizational Partners

- Willing & committed – to get involved, create and maintain a partnership
- Organizational mission encourages, supports and/or understands and recognizes the value of CBPR
- Have trust and a history of engagement in the community
- Have staff and/or volunteer capacity to participate
- Have engaged, competent researchers and research staff
- Have support and involvement from leaders at all levels
- Representative partners ideally hold positions of authority and/or leadership within their organizations

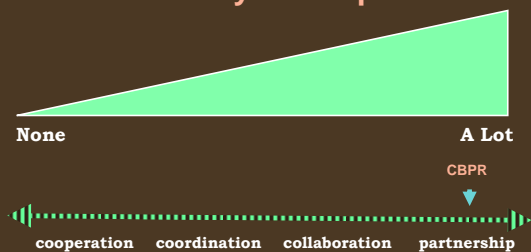
Characteristics of Effective Partners Individual Partners

- Knowledgeable about the community
- Strive for cultural competency
- Skills in collaboration
- Have interpersonal and facilitation skills
- Have technical skills (e.g., planning and organizing, evaluation, speaking/writing in multiple languages, conducting outreach and managing programs)
- Committed to the partnership process and the substantive issues being addressed

Partnership “Models”

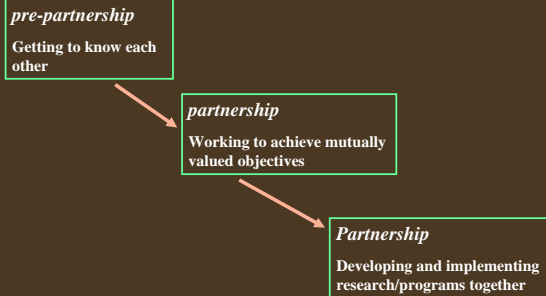
- **Advisory Board**
 - Usually key informants from community and other agencies
 - Advise researchers
 - Limited decision-making power
- **Steering Committee**
 - Key informants from community and other agencies
 - Guide the research process
 - Have decision-making power
 - Often “gatekeepers” of community
- **Organizational Control**
 - Community organization require application for partnership requests/projects
- **Individual Freedom**
 - Individual researchers directly approach community to initiate projects

Continuum of Community Participation



Adapted from Winer and Ray, 2000

Evolution of a Participatory Partnership



Ethical Considerations in CBPR

Some Ethical Considerations

Regarding Participation:

- Do academic researchers have a responsibility to seek participation from all groups/communities, or just those who are the most outspoken, or easiest, to work with?

Regarding Partner Roles:

- How does “equity” in the CBPR process get translated into practice so that divisions of labor & input are not exploitative to any one partner?

Regarding Results Dissemination:

- How do research results get re-presented and whose voice(s) is/are heard or represented?

WK Kellogg Foundation: CHSP definition Adapted from Hartwig, Calleson, & Williams, 2006

Health Services Research Using a CBPR Approach

Topical Areas in which a CBPR Approach has been Used

- Discrimination
- Health Care Quality
- Access to Health Care
- Injury Prevention
- Environmental Health
- Child Health
- Women’s Health
- Substance Abuse
- Community Health
- Birth Outcomes
- HIV/AIDS
- Health Disparities
- Insurance Coverage
- Medicaid Reform
- Disease Management
- Occupational Health
- Adolescent Health
- Domestic Violence
- Cancer Prevention
- Cardiovascular Diseases
- Osteoporosis
- Diabetes

Green et al., AHRQ; Israel et al., 2003

Study Designs using a CBPR Approach

Intervention

- Randomized Controlled Trials
- Quasi-experimental designs (e.g. non-random control group)
- Non-experimental (e.g. no control group, one group pre- and post-test)

Non-Intervention

- Observational
- Non-experimental (e.g. needs assessment, exploratory, descriptive)

AHRQ, 2004

Why CBPR in Health Services Research?

- Funding agencies, public officials, & communities calling for more comprehensive and participatory approaches to research and practice
- IOM report (2003) identified CBPR as 1 of 8 areas of competency in which all public health professionals need to be trained
- Interest rapidly growing for academic institutions, health agencies, and communities to form research partnerships

CBPR Case Studies: *Using a CBPR Approach in Health Services Research*

REACH

REACH Detroit Partnership



Racial and
Ethnic
Approaches to
Community
Health 2010

Centers for Disease Control and
Prevention Grant
No.U50/CCU522189

Goal

To reduce risks associated with type 2 diabetes and its complications among African Americans and Latinos in eastside and southwest Detroit by

- Increasing diabetes awareness
- Reducing barriers to and increasing resources for healthy lifestyles
- Promoting health and appropriate health care

REACH Detroit Partnership Steering Committee

- Community based organizations
Alkebu-lan Village , Community Health & Social Services (CHASS)
Center, Inc., Deiray United Action Council, Friends of Parkside,
Southwest Solutions-Community Partnership of Southwest Detroit
- Local and state health departments and organizations
Detroit Department of Health and Wellness Promotion
Michigan Department of Community Health
Southeast Michigan Diabetes Outreach Network (SEMDON)
- Major health system
Henry Ford System
- University
University of Michigan Schools of Social Work, Public Health,
and Medicine

CHASS Center, Inc.



REACH Detroit Partnership's Central Coordinating Organization is CHASS- Community Health & Social Services Center, Inc., a federally qualified community health center serving the Southwest Detroit community



REACH Detroit Organization

- Steering Committee (SC) meets monthly

SC

- 70% decision-making rule for SC

Work Groups

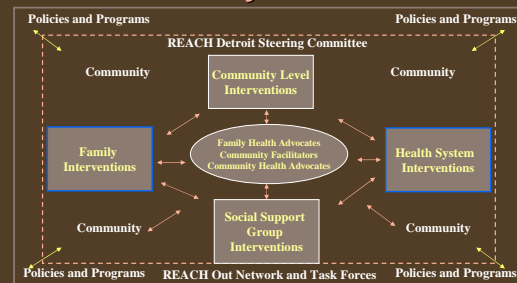
REACH-Out network

Origins

- Community concern about diabetes
- CDC's REACH 2010 Initiative
- Affiliation with Detroit Community-Academic Urban Research Center
- Work groups, community planning, focus groups & community organization meetings
- Steering Committee analyzed results and developed Community Action Plan

CBPR Principle: Facilitates collaborative, equitable partnership in all phases of the research, involving an empowering and power sharing process.

REACH Detroit Partnership Community Action Plan



CBPR Principle: Emphasis on local relevance of public health problems and ecological approaches that address the multiple determinants of health and disease

Family Intervention – Objectives

- Improve diabetes self-management care
- Increase physical activity and healthy eating
- Enhance family-provider relationships
- Increase access to community resources
- Increase healthcare consumer skills

Family Intervention – Design

- Patients with type 2 diabetes recruited from 2 hospitals, 1 community-based health center, (n=151)
- Legacy of distrust in the community → non-randomized, 1 group, pre-, post-test design

CBPR Principle: Integrates and creates a balance between knowledge generation and action for mutual benefit of all partners.

Family Health Advocates (FHAs)

- Provided the foundation for the intervention
- Community health workers
- Led 5-session Journey to Health/*El Camino a la Salud* curriculum
- Conducted home visits with clients
- Attended clinic visits

CBPR Principles: Promotes **co-learning** and **capacity building** among all partners involved. Begins with and builds on **strengths and resources within the community**.

Family Intervention – Outcomes

- Statistically significant improvements at 6-month follow-up:
 - Reduced hemoglobin A1c levels
 - Increased vegetable intake
 - Decreased consumption of fruit or soda drinks
 - Increased consumption of whole grain bread
 - Increased number of days following a healthy eating plan
 - Greater testing of blood sugar as often as doctor recommended
- No significant differences
 - Consumption of sweet foods or fried foods
 - Physical activity
 - Fruit intake

Two Feathers et al., 2005

Family Intervention Ongoing and Future Plans

- 2nd cohort – randomized, 6-month delayed intervention trial
- Cost-effectiveness analysis
- Long-term aim: to promote the use of community health workers as a reimbursable part of diabetes care

Health System Intervention

- Provider surveys – findings
 - Not enough support to meet needs of patients
 - Only 10% strongly agreed knowing about the world views, beliefs, and practices of cultural groups
 - None strongly agreed that there was a relationship between culture and health
- **Objective** – To increase the knowledge and ability of healthcare providers and health systems to provide high quality diabetes care to their patients

Health System Intervention

- Bi-annual CMEs addressing cultural competency, drug information, management of type 2 diabetes, case management
- Medical resident program at Henry Ford Health System incorporated community experience into training

Dissemination

- Project's progress, data, and evaluation findings are shared with the eastside and southwest Detroit communities
 - Community, state, and national meetings
 - Community activities
 - Newsletters and news media
 - REACH Detroit website
 - Publications

CBPR Principle: **Disseminates findings to all partners** and involves all partners in the dissemination process.

Sustainability of Intervention Components, Future of REACH

- Working with the state on a strategic plan to advocate for policy change to incorporate FHAs into reimbursable health care
- Ongoing CMEs at CHASS
- Similar FHA model being used at CHASS
 - Diabetes prevention project for pregnant women
- Grant application to be Great Lakes REACH-Out Network – Center of Excellence for Eliminating Disparities

CBPR Principle: Involves a [long-term process and commitment](#).

Acknowledgments

- Ricardo Guzman, REACH Project Director, Executive Director, CHASS
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- Friends of Parkside
- Southwest Solutions-Community Partnership of Southwest Detroit
- Detroit Dept of Health and Wellness Promotion
- Michigan Department of Community Health
- Southeast Michigan Diabetes Outreach Network
- University of Michigan Schools of Social Work, Public Health, and Medicine
- Henry Ford Health System

Thank You

For more information about REACH Detroit contact:

Gloria Palmisano

313- 961-1030

Or visit the website:

www.reachdetroit.org



Greensboro Health Disparities Collaborative

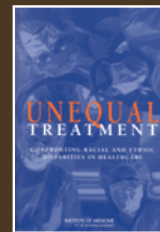
Greensboro, North Carolina

History of the Greensboro, NC Health Disparities Collaborative

- 4 ½ year collaboration between *The Partnership Project*, local health professionals, community members, and University of North Carolina at Chapel Hill
- Initially supported by an 18 month planning grant from the Moses Cone Community Health Foundation
- **Objective:** Identify and engage members of a new Collaborative focused on eliminating health disparities with a common grounding in undoing institutional racism

Institute of Medicine Definition of Healthcare Disparities

“...racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention”



(Institute of Medicine, 2002)

IOM Explanation of Findings:

Racial and ethnic healthcare disparities:

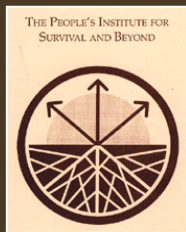
- Are impacted by bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers
- Are not explained by the few studies that suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment

Goal of the Greensboro Health Disparities Collaborative

Build community capacity through activities that include research, to understand and address disparities in health and health care.

Trainers, educators, organizers...

The People's Institute for Survival and Beyond
(New Orleans, LA)



- Grassroots leadership
- Undoing racism
- Learning from history
- Culture sharing
- Accountability
- Internalized racial oppression
- Internalized racial superiority
- Gatekeeping
- Power



- ALL members take part in a formal Undoing Racism training
- Designed and signed a *Full Value Contract*

The Collaborative's Research Grant Development Process

- 35-40 members total
- Community, academic, institutional and organizational partners
- Diverse expertise, experience and training
- A commitment - to broadening the membership of the Health disparities Collaborative, to include additional members from the Moses Cone Health System and local Greensboro medical community

Storytelling Sessions

- Small group discussions
- Reflecting and describing experiences of receiving treatment in the local healthcare setting during:
 - Childhood
 - Adolescence
 - Adulthood

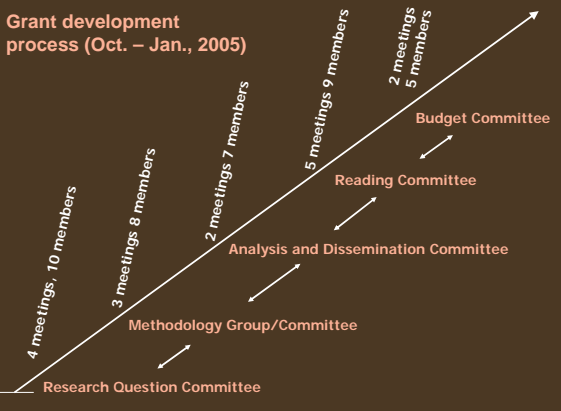
Storytelling Sessions: 3 Themes

- **Theme I:** Stemming from a legacy of legalized racism prior to 1964, the lack of common history and understanding between blacks and whites contributes to a culture of complacency and inferiority between health professionals and patients of color.
- **Theme II:** The absence of a public structure of accountability to prevent or stop racist behaviors and practices contributes to a culture which perpetuates such practices within sectors of the health care system.
- **Theme III:** "DIS-syndrome"- when people of color enter the health care system and experience disrespectful behaviors (verbal and non-verbal), are dismissed and disbelieved, experience distance when receiving care that is frequently filtered by stereotypes.

Health Care System Areas Identified During Story Telling Sessions:

- Doctor's offices / private practice
- Hospital (system, staff, patient experiences)
- Health clinics
- OB/Gynecologists
- Dentists
- Medical school / medical training
- Emergency Department (ED)
- Health care services provided within detention center
- Health care organizations

Grant development process (Oct. – Jan., 2005)



Cancer Care and Racial Equity Study: A CBPR Approach (CCARES)

- Seeks to enhance the understanding of racial disparities in breast cancer present within the local medical care community.

This study will:

- Collaboratively explore the issues listed above
- Serve as the impetus for advocating healthcare policy change & developing interventions to ensure that all breast cancer patients continue their recommended care & treatment

CCARES Study Objective

- Investigate within a NC local medical community, complexities in the system of care which may help to explain deviations from reasonable breast cancer care obtained by African American patients, as compared to White patients, and their potential association with racial disparities in breast cancer mortality

CCARES Aims & Methods

Aim 1

- Identify reasonable breast cancer care & characterize deviations from reasonable care received among patients (40+ yrs, race, zip code & stage of cancer)

Method

Extract & review information from breast cancer registry 2001-2002

CCARES Aims & Methods cont.

Aim 2

Identify factors that may:

- contribute to patients receiving reasonable breast cancer care
- contribute to patients receiving a deviation from reasonable care

Method

Interview 40 African American & 40 White women 3 times each to understand her experience with diagnosis, treatment, & follow-up

CCARES Intermediate Goal

Within a local medical community, develop an intervention that will:

- Monitor & prevent deviations of care
- Monitor & prevent discontinuation of care
- Ensure accountability for adopting new standards/protocols for breast cancer care & treatment

CCARES Long Term Goal

Eliminate disparities in breast cancer mortality

Key Elements of the Collaborative...

- Developed a common language & understanding
- Developed and cultivated trust
- Open communication
- Anticipated & embraced conflict
- Maintained respect, patience & flexibility
- Willingness to hear & listen
- Understanding the IRB process (community researcher certification process)



(J of Urban Health 2006)

Challenges & Benefits of CBPR

Challenges of CBPR

- Very time consuming - for all partners
- Addressing long-standing power dynamics
- Trust among partners can be fragile
- Who to include in partnership – to ensure representation?
 - Partners may change over time
- Sharing control re: important decisions (e.g., design)
- Including partners in all 'day-to-day' decision making
- Dissemination of findings in timely, useful way
- Risk of 'taking a stand' for social change

Israel, et al., 1998; Lopez, 2005

Benefits of CBPR

The CBPR approach has the potential to:

- Gain commitment & involvement from beginning
- Join partners with diverse expertise
- Increase trust & bridge cultural gaps among partners
- Enhance relevance & use of data
- Increase quality & validity of research/findings
- Allow findings to be translated toward development of further interventions & policy changes
- Enhance intervention design & implementation
- Result in interventions & increased knowledge that can directly benefit the community
- Provide resources for communities involved

Israel, et al., 1998

Is CBPR right for you?