University/Community Engagement to Reduce Racial Ethnic Health Disparities

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Presentation Outline

• Defining Health Disparity
  o Vulnerable Populations
  o Unequal Treatment
  o Disparities in Health and Health Care

• Defining Community
  o Community Voices
  o What is Community

• Community Engaged Scholarship
  o What is CBPR
  o CBPR and Disparities Research

• Q&A – Discussion
What is a health disparity?

- Differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation. - US DHHS, 2000

- Differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States. - NIH, 2000

- Racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences and appropriateness of intervention. - IOM, 2003
Vulnerable Populations: What You Need to Remember…

• In health care, vulnerability indicates the likelihood of poor health, illness, or disability.
• Vulnerability is complex.
• Vulnerable status in health care is the result of multiple factors and characteristics.
• Some are modifiable, but most are not without intervention and support:
  – Predisposing (race, ethnicity, geography)
  – Enabling (socioeconomic status, individual assets)
  – Need (health status, quality of life)
Unequal Treatment
Racial/ethnic disparities exist in health care, resulting in worse outcomes among minority groups, and occur independently of insurance status, socioeconomic status, or patient preferences and treatment refusals.

Racial/ethnic disparities in health care are part of a larger pattern of racial and ethnic bias in society.
BIAS PRODUCING FACTORS

- RACE
- ETHNICITY
- CLASS
- CULTURE
- AGE
- DISABILITY
- SEXUAL PREFERENCE
- GEOGRAPHY

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<tr>
<th>Disparities in Health</th>
<th>Disparities in Health Care</th>
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<td>Cancer incidence rates are twice as high for African-American persons as they are for white persons.</td>
<td>Hispanic women get mammograms less often than non-Hispanic women.</td>
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<td>African-Americans are 1.4-2.2 more likely than whites to have diabetes.</td>
<td>Black seniors in Medicare are more than twice as likely than whites to go without prescription drugs.</td>
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<td>Infant mortality among African-Americans (14.1) is over twice higher than among whites (6.9) per 1,000 births.</td>
<td>Only 68% of Hispanics see a doctor each year compared to 80% of Whites and African-Americans.</td>
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UNC Draft Definition

• Inequities in the health status of populations, resulting from differences in socioeconomic status, the environment, economic policies, and social systems and processes, which systematically place certain population subgroups* and communities at social, institutional, and economic disadvantage.

• These inequities result in disproportionately higher rates of death, disease, and disability, and have adverse consequences on the physical, mental, spiritual, and social well-being of population groups who, historically and currently, do not experience equivalent social disadvantage.

*for example; African Americans, Native Americans, Hispanic/Latinos, Asian Americans, Hawaiians and Pacific Islanders, people with disabilities, LGBTQ, and people with lower incomes
Community Voices: Back to the Future

• “The need is not merely for the provision of more curative and preventive health services, but also for the development of new organizational patterns to make the distribution of such services uniquely effective for severely deprived populations.

• “Clearly, conventional approaches to health improvement, or approaches that deal only with narrow definitions of health and illness and do not have effects on other elements of the poverty cycle, are unlikely to make major changes in problems of this magnitude.

Meeting with Sergeant Shriver at the Office of Economic Opportunity, 1966
What Others Mean by Community

- Warren – The Community in America, 1978 “that combination of social units and systems that perform the major social functions” relative to meeting people’s needs on the local level.
  - Production-distribution-consumption
  - Socialization
  - Social control
  - Social participation
  - Mutual Support
- 1985 – 90 different definitions led to the following, “a system of values, norms, and moral codes which provoke a sense of identity within the bounded whole of its members … the arena in which people acquire their most fundamental and substantial experience of social life outside the confines of the home.”
- Fellin 1987 – a group of people who form a social unit based on common location, interest, identification, culture and/or activities.”
- Key concepts: space, people, interaction and shared identity.
What We Mean by Community

- Freeman CCHERS (1997) – social worker trained in community organizing, planning and community development, who describes his four P’s typology of communities as:
  - Places
  - People
  - Principles
  - Processes

- Barnes-Boyd UIC (2003) – provides tips for defining community
  - Community does not always imply “neighborhood” or place
  - Recognize that there is no “one” definition of community, do not limit the definition
  - The purpose drives the definition therefore each effort must “define” its community
  - An intentional process is needed to gain consensus on the “community of focus”

- Bayer UMSofPH (2003) – Prevention Research Center
  - The “community being researched” that includes those individuals who are affected in some way and have experience with the problems being studied
  - The Genesee County community that includes everyone who lives or works in Greater Flint and is concerned about the problems the PRC is trying to address
Factors that Influence Health: Individuals and Communities

- Spiritual Environment
- Built Environment
- Community Safety
- Health/Well-Being & Substance Issues
- Arts/Culture/Heritage & Recreation
- Economy/Employment
- Transportation/Mobility
- Natural Environment
- Government/Politics
- Education
- Housing

- Genetics 20%
- Medical Delivery system 10%
- Environment 20%
- Lifestyle 50%
Challenges of Community Engagement

- No one group can claim to speak for the community.
- Lack of community infrastructure and process to engage in research.
- Understanding the science of health services and clinical research.
- Community engagement is a dynamic and fluid process requiring flexibility in collaboration.
- Tenuous nature of university and community relationships.
- Issues of power differentials between institutions and communities.
- Financial and political realities that determine university research and collaboration.
- Research subject, design, methodology and perceived usefulness.
Community-Based Participatory Research
Improving Research Quality, Enhancing Community Capacity
and Improving Health Outcomes

• CBPR is 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 translation of this research into interventions and policies to improve health.

• The significance of an approach that builds the capacity of communities to function as co-investigators with health agencies and academic institutions before, during and after the research process has re-emerged...as the academic and public health communities struggle to address the persistent problem of disparities.

Principles of CBPR

• The project addresses an identified/expressed community need and originates from a community or academic entity with a development plan of a community-academic partnership.
• The project aims to help address an issue for the community of focus.
• The project ensures community involvement at all stages of the research including objectives, design, data analysis, interpretation, and dissemination of findings to the public.
• The project has established a formal role for a community academic liaison who is responsible for facilitating ongoing communication among project members.
• The partners adequately address issues of sharing power and resources.
Community Placed vs. Community-Based
Levels of Community Involvement

- Community **notification** - inform the community of the intentions of the research risks and benefits relating to the individuals and communities involved.

- Community **consent** - obtaining some expression of community approval.

- Community **endorsement** - community representatives are asked to formally support the research activities.

- Community **participation** - seeking and obtaining community advice in planning, development, execution, and dissemination of the research.

- Community **origination** - research purpose and goals set by expressed community needs.

Jenkins, B. “Health Disparities: Why we have not solved the problem, Why we need new approaches.” The Research Center on Health Disparities, Morehouse College, April 2004.
Challenges for Community in CBPR

- Building relationships based on trust.
- Coping with differentials in power and issues of control.
- Understanding the academic research enterprise.
- Building research capacity and infrastructure.
- Being seen as credible partners with “expertise”.
- Establishing a structure and process for inclusion, communication and decision making.
- Allocation of financial resources and fiscal control.

Looking for **Causes ...** in all the **WRONG PLACES**

There’s an old joke about a man who late one night dropped his keys in the middle of a dark parking lot. He moves some distance over to the side of the lot and begins a fruitless search for them under a bright light. When asked why he was not looking where he actually dropped them, he replied, “because this is where the light is.”

*Network*, New England Research Institutes, Summer, 2002
Lupus Awareness and Community Education (LACE) Project

- Brigham & Women’s Hospital/Harvard Medical School, Massachusetts Department of Public Health & Women of Courage.
- Promote awareness of lupus and risk exposures to organic/petroleum products; conduct case finding; and determine associations.
- Power dynamics; racial/ethnic politics; and roles of the partners in project.
- Team building retreats; formative research and focus groups; community education.
- State tracking of lupus; education of primary care practitioners; environmental health policy advocacy.
Boston Area Community Health (BACH) Survey

- New England Research Institutes, CCHERS and Boston communities.
- Five year longitudinal study of urological problems in men with focus on minority males.
- Randomized sample methodology; jobs for community people; role of community advisory board; benefit/return to community.
- Introduction to community groups/organizations; organization of community advisory board; work with social marketing firm.
- Vision of study comparable to the Framingham Heart Study; not sure of any implications for policy.
Boston Clinical Pharmacy Practice Network

- CCHERS, Northeastern University School of Pharmacy, & Whittier Street, Neponset and Uphams Corner health centers.
- Assess the impact of introduction of clinical pharmacy services on effective management of underserved patients with chronic illnesses.
- Clinical roles on primary care team; sustainability; and chronic care model.
- Project management; 340B contracting; and health policy research and analysis.
- Clinical practice; scope of practice for pharmacists; access to affordable prescription drugs; medication assistance program.
Asthma Center on Community Environment and Social Stress (ACCESS)

- Channing Laboratory of Brigham and Women’s Hospital, Harvard School of Public Health & CCHERS.
- National center for reducing disparities in asthma with longitudinal study of 1000 pre-natal; genetic testing and assessment of environmental and community stressors and triggers of asthma.
- Organizational cultures; power differentials; and building a partnership.
- Co-investigators; qualitative community researchers; organize and convene Community Advisory Board.
- AHRQ Evidence Report No. 99; Kellogg Commission; Boston Housing Authority Healthy Homes; policy advocacy; community organizing.
All I Really Need to Know … I Learned in Kindergarten

• Share everything.
• Play fair.
• Don’t hit people.
• Put things back where you found them.
• Clean up your own mess.
• Don’t take things that aren’t yours.
• Say you’re sorry when you hurt somebody.
• Wash your hands before you eat.
• Live a balanced life.
• Take a nap every afternoon.
• When you go out into the world, watch out for traffic, hold hands, and stick together.
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