Centers for Disease Control and Prevention
Prevention Research Center’s National Community Committee

Impacting Research Policy & Practice at Local & National Levels

CCPH Educational Conference Call Series: Building Community Capacity for Research
November 18, 2009
Centers for Disease Control and Prevention

Prevention Research

Center’s National Community Committee

History of Development

E. Yvonne Lewis

Co-Founder, Past Chair
Brief History

• Prevention Research Centers

• Community Engagement

• Enhanced Community Involvement

• National Community Committee
Engaging Community Members

“...effective community-based research needs to be conducted with and in communities—not on communities.”

“ENGAGING COMMUNITY MEMBERS IN THE PREVENTION RESEARCH CENTERS PROGRAM,” WHITE PAPER, JANUARY 2001
Definition

- The National Community Committee of the Centers for Disease Control and Prevention, Prevention Research Centers is equitably comprised of individuals who represent the specific population or community as well as individuals who are living the experience directly impacted by the prevention research activities.
NCC Member Involvement

- Committees Established
- Policies Procedures Operations (PPO)
- Content
- Fund Development
- Communications
Mission

- The PRC’s National Community Committee is dedicated to helping build capacity in communities within local PRCs that were not traditionally involved in the planning, development, implementation, and evaluation of prevention research initiatives.
Vision

• A national network of community representatives engaged in equitable partnerships with researchers to define local health priorities, drive prevention research agendas, and develop solutions to improve the overall health and quality of life of all communities.
NCC Structure

• Formalized process
  – Chair
  – Chair-elect
  – Vice-Chair
  – Immediate Past Chair
  – Secretary
  – Regional Directors
  – Subcommittee Chairs
Capacity Building

- **Regular Meetings**
  - Telephone Conferences
  - List Serve
  - Retreat/Annual Planning Meeting

- **Training/Skill Building**
  - Advocacy for Prevention
  - Applying Evidence Based Practices
  - Developing Grant Program
Trust

“The relationships among state, community, and academic representatives are unique and hold such promise for public health. The alignment of partners’ perceptions and the creation of a positive, trusting working environment is necessary not only for appropriate functioning of the PRCs, but also for the future of these types of partnerships in any public health arena.”

SHARRICE WHITE-COOPER, PRC PROGRAM NCC LIAISON
Commitment to National Unity

- PRC Program Office involvement
- NCC member representation on Committees
- NCC included in overall PRC Program logic model
- Ongoing support of NCC
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Community Partnership Board Development
Ella Greene-Moton
Co-Founder, Past Chair
The bottom line: Without a strong board or leadership structure, nonprofit organizations show limited success in meeting both organizational and community needs.
Board/Leadership Building

• Building an effective board/leadership structure is similar to creating a winning sports team. Recruiting talented players that fit the team and training them to play their best are key ingredients.

• Board/leadership team members join an organization for a limited amount of time and pledge their personal, professional, and financial resources to advance the mission of the organization.
General Leadership Questions to Consider

• What gaps in expertise exist on the current board or in the current leadership?

• Who is likely to be interested in the mission of the organization?

• What does the position offer to the prospective board/leadership team member? Why join?
The NCC Strategy?

- Partnership
- Membership
- Leadership Structure
- Process
What are Partnerships?

- Intentional relationships between two or more individuals, groups or organizations
  - Committed to pursuing an agenda or goal of mutual benefit
  - May be for information exchange, input, or joint planning and implementation
The NCC Partnership

- The National Community Committee of the Centers for Disease Control and Prevention, Prevention Research Centers is equitably comprised of individuals who represent the specific population or community as well as individuals who are living the experience directly impacted by the prevention research activities.
Influenced by Principles of Partnerships

– Mutual respect among partners - recognizing the value of different types of contributions, approaches, and perspectives

– Trust - in how we interact with each other, in how funding is allocated, in how we disseminate and give credit for work

– Shared decision making

– Opportunity to engage in any part of the process
Principles (cont)

– Recognition of cultural differences among all partners - faculty, staff, students, practitioners, community members: acknowledge that cultural differences exist between institutions, geographic areas, racial/ethnic groups, life experiences. These differences influence our interaction with each other and need to be incorporated in how we engage

– Capacity building- enhance capacity of the community, practice and academic partners

– Sustainability- the more “community” involvement the more likely it is that projects will be sustained

– Equity and elimination of health disparities
A Partnership guided by Community-Based Participatory Research

- *Develop trust*: show respect, follow through, attend to each other’s interests and needs
- *Provide leadership*: shared leadership, delegation, task/maintenance functions
- *Develop processes for shared power and influence*: equity, mutual influence, co-learning, balance of power
- *Address conflict*: necessary part of group process, identify reasons for conflict, establish norms for conflict management
- *Establish shared decision-making processes*: determine how decisions will be made and enable all members of the group to be engaged as appropriate
NCC Membership

• The general membership of the Organization is comprised of NCC Representatives and NCC Alternates.
  – NCC Representatives
    • Each PRC is responsible for selecting at least one community representative from its local community committee(s) to represent their center/communities on the NCC
  – NCC Alternates
    • Each PRC is responsible for selecting at least one alternate community representative from their local community committee(s) to represent their center/communities on the NCC
NCC Leadership

The leadership structure of the Organization is comprised of the following elected or appointed Officers: Chair, Chair-Elect, Vice-Chair, Past-Chairs, Six (6) Regional Directors, and Chairs/Co-chairs of the four (4) standing subcommittees. The leadership structure shall also include a leadership team.
NCC Leadership Team

- Comprised of up to fourteen voting members
- Responsible for providing oversight and guidance to the Organization based on the collective voice of the membership
- Responsible for deliberating on identified issues, developing recommendations, providing said recommendations to the membership, and makes decisions on behalf of the membership unless otherwise stated in this document
Engaging NCC Partners

- What are the rights and responsibilities of each partner?
- Who has decision making power?
- Is there respect for all voices/concerns?
- What is the expectation of engagement in various activities needed to accomplish goals?
NCC Goals

- Lift up the community “dimension” of the PRC Program
- Assist in bridging gaps between the local PRC communities and the PRC academic researchers
- Highlight similarities and celebrate differences
- Offer training and development opportunities for community committee members
NCC Goals

- Promote collaboration and cooperation among local community committees without limiting or restricting research activities or creating conflict detrimental to the growth and development of the PRC Program
- Promote some consistency across local community committees without encouraging “Cookie Cutter” committees
The NCC Process

The NCC Operating Procedures – a living document developed by NCC, for NCC, and used to guide the operations of the organization.
Definition of Community Based-Participatory Research

- The W.K. Kellogg Foundation Community Health Scholars Program defines CBPR as follows:
  - 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 to improve health outcomes and eliminate health disparities.

Characteristics of CBPR

- Relationship between the researchers and the research participants is different
- Shared decision making
- Mutual ownership of the research process and products
- Goal of translating research findings into practice

Skills Needed for Researchers

- Sensitivity to community needs and connection to the community
- Interpersonal and facilitation skills
- Good communication skills
- Capacity to work within different power structures
- Translate the process and findings into policy
- Commitment to the partnership process
Local CBPR Advocacy

- University of North Carolina Center for Health Promotion and Disease Prevention Community Action Council for Seeds of HOPE and its affiliated projects
- Themed open ended question responses
- Created Advocacy Committee to address issues raised, produced one-pagers
- Presented one-pagers to our representative to the NC House Of Representatives
National CBPR Advocacy

• NCC participated in advocacy training with Research!America [http://www.researchamerica.org/]
  – Learned the importance of a consistent message, and how to partner with media to deliver the message
  – “Less then 1 cent of every health care dollar is spent on prevention”

• Partnership with organizations that support the work of CBPR
  – CCPH and National Community-Based Organization Network (NCBON)
Advocacy in Action

- NCC Annual Planning Meeting at the University of West Virginia, October 2008
- Key research: underlying behaviors and social conditions related to tobacco use
- NCC members visited a local restaurant where smoking was allowed
- NCC wrote a letter to the city council to urge for a policy change
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What’s in Our Future?
Freda Motton
Immediate Past Chair
NCC Vision

A national network of community representative engaged in equitable partnerships with researchers to define local health priorities, drive prevention research agendas, and develop solutions to improve the overall health and quality of life of all communities.
NCC Niche

- The NCC is comprised of community representatives from diverse racial and ethnic groups across the U.S.
- The NCC is geographically divided into 6 regions
NCC Past Projects

- Special Interest Project 13
- 2007 Midwest Genomics Project
Special Interest Project 13
Improving & Translating the Evidence

Increasing physical activity among adults in racially/ethnically diverse communities in the United States
2007 Midwest Genomics Forums

- Partnership between NCC and the Center of Public Health and Community Genomics at the School of Public Health at the University of Michigan-Ann Arbor
- Midwest Region (Illinois, Iowa, Michigan, Missouri, and Minnesota) who planned and coordinated forums on October 12, 2007 to increase awareness and literacy levels of genetics/genomics across the region
NCC Future

- Serve as a community advocate for CBPR
- Increase community capacity for spreading/translating/adapting prevention strategies
- Promote health policy changes