Elements and Outcomes of Successful Community-Based Health Disparities Research

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2012 CBC Spring Health Braintrust and National Minority Quality Forum
9th Annual Health Disparities Leadership Summit

Day 2 April 24, 2012
Hispanic Health Council

- Community-based Organization in Hartford, CT
- Mission: To improve the health and social well-being of Latinos and other diverse communities

Core Strategies

- Community based participatory research
- Evidence based direct services
- Policy advocacy
- Training
HHC Case Study Context, Founding Story

Context:
- 1970s, growing numbers of Latinos (mostly Puerto Ricans) in Hartford
- Service system, including health service system not developing according to cultural and other needs of Latinos

Founding story
- Death of eight-month old Rosa Maria Rivera (1973)
- Puerto Rican Health Committee established by community activists, university faculty and students
- Grant received from NIMH to study PR health beliefs and how the community accessed health care
- Grant received from local foundation (HFPG) to fund infrastructure for new organization focusing on Hispanic health, HHC incorporated in 1978
- Original vision: use research to identify needed system and policy changes, advocate for changes
HHC Early Work - Research

- National Institute of Mental Health (NIMH) grant received to study PR health beliefs and how the community accessed health care – late 1970s
  - Findings – high rates of sterilization among women surveyed
  - Results: state law instituted requiring informed consent in language of preference

- HIV/AIDS Work – started in 1980’s
  - Pioneered community education on taboo subject
  - Conducted community assessment on attitudes toward syringe exchange (SE), used results to advocate for SE funding
  - Evaluated SE, used results to advocate for continued funding

- Hunger and Food Security Work – starting in late 1980’s
  - Conducted Hartford Community Childhood Hunger Identification Project, part of national study, first to document “hunger”
  - Results released at press conference and policy report used for advocacy, education
  - Results:
    - Establishment of one of the first Food Policy Advisory Commissions to Mayor’s Office and City Council – still exists
    - Continued hunger/food security work at HHC
HHC Early Work – Direct Services

Direct service provision - starting in 1980s

- HHC adds direct service provision to its other two core strategies
  - HHC notes gaps in services and existing services that are ineffective with Latinos and other targeted populations.
  - HHC recognizes its ability to and its responsibility to fill existing gaps

- HHC develops and tests culturally appropriate interventions

- Federal demonstration grant secured in partnership with CT Dept. of Public Health in response to high infant mortality rates in Hartford neighborhoods
  - HHC’s first Community Health Worker (CHW) service program developed
  - Comadrona Program continues today as part of citywide MCH service system

- Cross cultural training of health and service providers and students
  - Conducted since HHC’s founding
  - 2002 – received grant to train 150 staff of WIC Program
  - 2004-5 – received 2 foundation grants to train medical faculty
  - Continued in various forms
Elements and Outcomes of Successful Community-Based Health Disparities Research

HHC in Partnership: HHC-UConn (Dr. Perez-Escamilla), Starting 1995 SNAP-Ed Program

- Formative Evaluation
- Hispanic FNP
- Marketing Campaigns
- Breastfeeding Promotion
- Research & Evaluation
- Culturally Competent Nutrition Education Materials
- PANA Nutrition Education Program

UCONN Family Nutrition Program, Hispanic Health Council, and the Cooperative Extension
Evidence-Based Community Health Worker (CHW) Service Models

- Developed based on assessment and formative research
- Empowered, hands-on roles
- Rigorous training and supervision
- Culturally relevant
- Integrated into Clinical Health Care Teams
- Clear delineation of function/tasks - CHW: Clinician
- Evaluated
  - two randomized trials,
    - one on health promotion
    - one on chronic disease management
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Continued Partnership – HHC, Uconn (Perez-Escamilla), Hartford Hospital

CHW Model for Breastfeeding Promotion (a key obesity-prevention strategy):
Breastfeeding Heritage and Pride Program

Developed From Formative/Assessment Research
- Qualitative interviews, focus groups, community surveys

Main research findings
- Misinformation and lack of information
- Lack of role models and support figures
- Shame and embarrassment regarding breastfeeding

Program Goal
- To increase the rates of breastfeeding initiation and duration of breastfeeding among low-income women who give birth at Hartford Hospital

Client services
- Prenatal and post partum, home, clinic and hospital visits, post partum hospital rounds
- Telephone outreach and support
- Pump lending

Evaluation
- Randomized Controlled Trial (HHC-UConn-Hartford Hospital)
- Funded by Centers for Disease Control and Prevention through the Association of Teachers of Preventive Medicine, CT Family Nutrition Program, and Hartford Hospital
- Objective: to assess the effectiveness of an existing breastfeeding peer counseling program serving a predominantly low-income Latina population in Hartford, CT
CHW Health Promotion Model: Breastfeeding: Heritage and Pride Program

Evaluation Results
- BHP Effective – significant differences in initiation and duration
- BHP Cost-effective - healthier children, savings to society

Recommendation
- Expansion of peer counseling efforts

Impact
- Included in CDC Guide to Breastfeeding Interventions
- Continued breastfeeding peer counseling and related research
- Research influences decision of federal government to fund peer counseling in every state through the WIC Program, HHC one recipient of those funds in CT
- Program expanded and replicated

Continued Research by HHC/UConn-Yale, Hartford Hospital Research Team
- Use of peer counselors to support Exclusive Breastfeeding (funded by CDC)
- Use of peer counselors to support breastfeeding among obese women (funded by Donaghue Fndtn.)
- Eddy – Understanding effect of BESTOW peer counselor intervention through analysis of video-taped feeding sessions (funded by CDC)

- case-control needs assessment (N=201)
- self-reported diabetes without complications
- Latino women between 35 – 60 years old

Results:
- high level of health problems/inadequate health care access - subspecialty care
- high level of food insecurity
- low level of basic nutrition knowledge and food label utilization
- low understanding and low self-efficacy levels regarding overall diabetes care
- low levels of social support – suggested high levels of depression
- clinical symptoms of inadequate diabetes management
Connecticut EXPORT Center for Eliminating Health Disparities among Latinos (CEHDL)

Three Institutional Partners:
- UConn (PI, Rafael Pérez-Escamilla)
- The Hispanic Health Council (co-PI, Grace Damio)
- Hartford Hospital (co-PI, Laurine Bow)

Funder: NIH-NCMHD
Funding Level: $8.2 million
Period: 2005-2011
HHC budget – 45%
Community Infrastructure/HHC Case Study – Partnerships Highlight CEHDL Partnership

Adaptation of CHW Health Promotion Model to Chronic Disease Management: Diabetes among Latinos Best Practices Trial (DIALBEST)

- Randomized longitudinal trial examining the impact of home-based peer counseling on behavioral, metabolic, and health outcomes among inner-city Latino(a)s with type 2 diabetes
- 17 home visits in 12 months; intervention includes education and care coordination/advocacy
- Peer counselors met with clinical team weekly for case conferencing
- Extensive data collection, including blood draws, at baseline, 3, 6, 9, 12 mo. & 6 mo. post intervention

HHC Roles:
- Co-Investigator, Coordinator, Peer Counselors, Interviewer/Phlebotomist
- Data collection, cleaning, management
- Peer counseling services
- Peer counseling manual development
- Participation in evaluation, authorship, presentations
Community Infrastructure/HHC Case Study – Partnerships
Highlight CEHDL Partnership

CHW Models: Diabetes Peer Counseling Intervention Study (DIALBEST)

Results/Impact:

- HbA1C level reduction at 12 months:
  - 1 point in the intervention (PC) group
  - 0.4 point in the control (no PC) group
  - Impact sustained through the six-month post-intervention period (18 months)

- Gaps in health care identified by peer counselors, resulting in:

- Training of medical residents:
  - Case presentations by peer counselors
  - Cross cultural training by HHC program

- Follow-up study underway: impact on glycemic control among Latinos with diabetes of stress reduction training conducted by community health educator

- Implications for inclusion of CHWs in health care reform
CEHDL (Research) Partnership

Other HHC CEHDL Projects

- Community focus groups on health disparity topics
- Facilitated community dialogues on health on health disparity topics, involving responses from community leaders
- Formative research on a community informed strategy to increase fruit and vegetable access
- Cross cultural training using broad health disparity-related framework in academic, clinical, public health, community settings
- Community newsletter on health disparity topics targeting Community Health Workers
- Evaluation of HHC’s annual health fair, new model developed based on evaluation results
Elements of Successful Community-Academic Partnerships (CEHDL)

- Planning included HHC from beginning
- HHC played key leadership roles
- Budget shared equitably based on work performed
- Indirect cost allocation provided to HHC based on its full negotiated rate
- HHC involved in data analysis, evaluation of results
- HHC involved in dissemination of results (conferences, authorships)
- HHC brings to partnership its own research capacity

Challenges Often Encountered in Community-Academic Partnerships (non-CEHDL)

- Don’t engage HHC from the beginning
- Don’t acknowledge HHC’s capacity
- Don’t take into account the real cost involved in doing community based research – expect free work or don’t plan a feasible project
- Don’t include HHC in planning and leadership structures of project
- Expect HHC to provide them with intellectual property owned by HHC and/or an external PI

THESE WOULD IMPACT PROJECT SUCCESS/RESULTS
HHC’s Successes and Challenges Securing Infrastructure for Community-B Health Disparities Research

- **Strengths/Successes Securing Funding:**
  - History of securing NIH grants directly, mostly HIV/Substance Abuse research
  - History of securing funding through authentic, equitable partnerships
  - Strong grant writers

- **Challenges in securing research funding directly:**
  - Difficult to diversify research topics without expert/PI already on staff;
  - Scientific capacity leaves when researcher leaves, sometimes loss of grants/funds;
  - Existing staff have limited time for producing publications and grant writing

- **Strengths/Successes :**
  - Social justice orientation/ties to the community are attractive to researchers
  - Relationship with the community facilitates hiring of research assistants, associates
  - Use of %s of program evaluator time for research development/roles in other research
  - Research staff and leadership that has been at HHC for 10-25 years

- **Challenges:**
  - Competition with hard salaries and some other compensation at universities
  - Competition with university infrastructure and idea that university is the “real research environment”
HHC’s Successes and Challenges Securing Infrastructure for Community-B Health Disparities Research

Establishing and maintaining an IRB, Managing data during and post research

**Successes/Strengths:**
- HHC IRB established in 1990’s, has operated continuously since
- HHC has successfully managed data during and after studies
- IRB led by former HHC staff and (later) Board President, passionately committed to HHC
- IRB is multi-disciplinary
- HHC has adequate technology capacity for data management, storage

**Challenges:**
- Maintaining consistent staff to support IRB application process, ongoing IRB-related obligations during and post-study
- Resources for maintaining and updating/upgrading technology as needed
Conclusions:

- In order for research conducted to understand and solve health disparities to be successful, communities affected by health disparities must be actively involved.

- HHC was founded as a community based research organization and has a regular practice of conducting research.

- HHC has the capacity to partner with academic and clinical institutions on rigorous community based research projects.
  - HHC’s role in CEHDL is a clear example of a partnership that brought significant research infrastructure to the agency.

- Organizations without HHC’s research foundation would need significant training/capacity building to partner in research.

- It is appropriate that some research funding be channeled directly to community based research organizations. The capacity of these organizations to secure research grants and conduct research independently depends on some level of consistent research infrastructure.
Federal Policy Recommendations

1. Funding for authentic community-based participatory research (CBPR)

2. Funding to community organizations for research capacity-building & infrastructure

3. Requirement for authentic community engagement in Clinical & Translational Science Awards (CTSAs)

4. Ombudsman for community-academic disputes

5. Audits of federal research funding
   - Applicants, grantees & reviewers: # and % of community organizations
   - Breakdown of NIH funding by applicant organization, type of research
   - Indirect rates and where the money goes