

# Expected and Unexpected Results: Establishment of a new Community-Participatory Research Center

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# Health Data



*White Americans*



*African Americans*



*Deaf Americans*

Cancer	193.9 per 100,000	243.1 per 100,000	No data
Diabetes	23.0 per 100,000	49.2 per 100,000	No data
Infant Mortality	5.7 per 1,000 live births	13.3 per 1,000 live births	No data
Adult Immunization	70.2 %	52%	No data

Source: [www.cdc.gov](http://www.cdc.gov)



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# Health Survey

- Very little or no data about Deaf Health
- Health surveys are typically done by telephone or in print
- Deaf people (linguistic minority) are not usually targeted in health surveys
- Developing ASL Health Survey (translated from National Health Surveys)



# Presentation Objectives

- Introduce Preventive Research Centers (PRCs) and National Center for Deaf Health Research (NCDHR)
- Introduce the Community Based Participatory Research concept (relatively new in health research)
- Discuss progress/issues encountered during the establishment and growth of the Center



# The Prevention Research Centers Program

- “A network of academic researchers, public health agencies, and community members that conducts applied research in disease prevention and health promotion.”

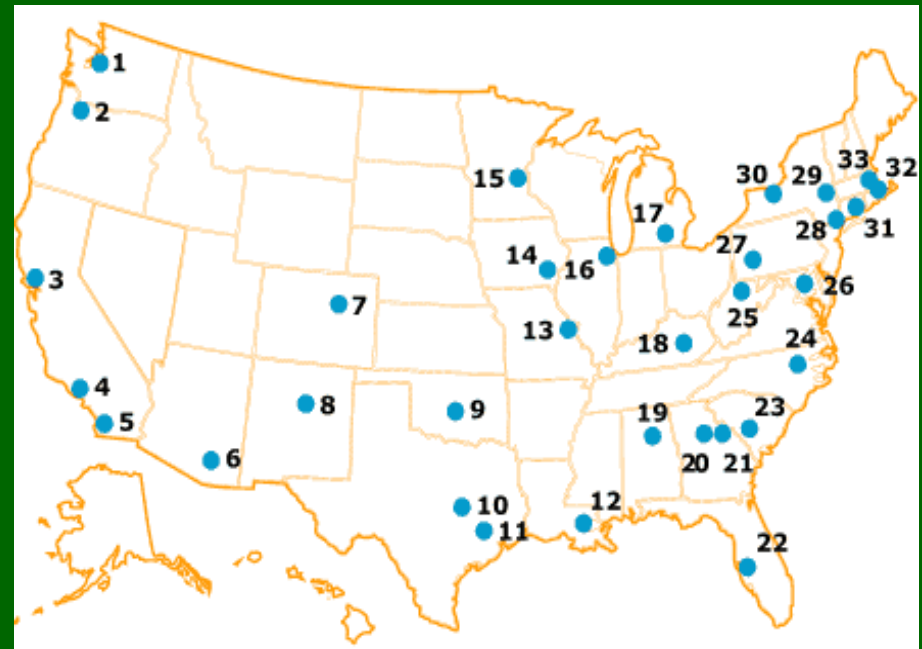


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# PRCs: Community-Institutional Partnerships

- Enacted by congress in 1984
- Primarily focuses on underrepresented/underserved communities
- Each PRC is expected to collaborate with one or more community committees
- Today, there are 33 PRCs



[www.cdc.gov/prc](http://www.cdc.gov/prc)



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# Why involve the community in Health research endeavors?

- Historically, research has rarely directly benefited and sometimes actually harmed the communities involved.
- Interventions have often not been as effective as they could be because communities were not involved.
- Research has tended to exclude these communities from influence over the research process.



# NCDHR

## National Center for Deaf Health Research

- One of 33 PRCs
- 5-year grant beginning late 2004, funded by CDC
- Only PRC that focuses on the ASL community
  - ◆ Deaf people suspected to experience greatest health disparities
- NCDHR's goals are guided by a "cultural model," not a clinical model
- Over time, NCDHR will work with community committees for other deaf and hard-of-hearing groups who are not members of the ASL community



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# NCDHR's Mission Statement

Promote health and prevent disease in Deaf populations through community-based participatory research (CBPR)



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# Working Together for Deaf Health Research



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# Community-Based Participatory Research (CBPR)

“ A collaborative process of research that involve researchers and community representatives in *all* phases of research.”



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# Key Elements of CBPR

- All partners are involved
- All partners share expertise and responsibilities
- Research topics are important to the Community
- Research is combined with intervention to improve health and eliminate disparities



# Key Advice from the Experts

- Do not impose someone else's CBPR principles on your partnership
  - ◆ Must be specific to the culture and community
  - ◆ Must “own” your own set of principles



# More Advice

- All partners need to decide on the meaning of a “collaborative, equitable partnership”
  - ◆ What is fair?
  - ◆ How is power shared?
  - ◆ How are decisions made?
  - ◆ How is money spent?
  - ◆ One group should not dictate to another



# What should we strive for?

- Nine key principles (Israel et al. 2000)
- Recognize that collaboration will evolve and change over time



# 9 Key Principles of CBPR

1. Community is central (unit of identity)
2. Builds on community strengths and resources
3. Collaborative, equitable partnership in all phases of research
4. Learning and capacity building among partners
5. Balance between research and intervention
6. Local relevance (problems identified by community)
7. Cyclical and iterative process
8. Disseminates findings to all partners; involves partners in dissemination (co-authors)
9. Long term process; long term commitment

*<http://www.ahrq.gov/About/cpcr/cbpr/>*



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# Partners of NCDHR



*Deaf Health Community Committee (DHCC)*

*NCDHR Staff & Researchers*



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# What does the DHCC do?

- Provide community perspectives
- Participate in design of proposed research projects
- Interpret & prioritize research results
- Advocate for the community
- Promote the “cultural model”
- Recruit Deaf subjects
- Meets monthly
- More information in Governance Guidelines (folder)



# Expected and Unexpected Results

Our experience ...



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### **Expected Result:**

The partnership builds upon identified strengths and assets of the community.

### **Unexpected Result:**

A translation team (English-to-ASL) was formed without participation from the DHCC.

### **Solution:**

A compromise was made, due to DHCC advocacy efforts. Three members each from the Research Subcommittee and DHCC were chosen to form the Translation Workgroup (TWG).

### **Lesson learned:**

The most important rule in a CBPR strategy is for researchers to consider the community participants as co-researchers and to consider themselves as co-learners (\*)

(\*) Airhinenbuwa, et. al: Transforming Scientific Intervention Research Strategies to Strengthen Community Capability, Race & Research: Perspectives on Minority Participation in Health Studies, APHA, 2004



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## **Expected Result:**

The partnership fosters equitable decision-making process.

## **Unexpected Result:**

DHCC was viewed as an “advisory” committee. There is involvement, but it’s passive.

## **Solution:**

The Executive Committee, a decision-making body of the NCDHR, is now represented by the DHCC.

## **Lesson Learned:**

It is time to debunk the notion that knowledge (read: professional values) is a more superior entity than belief (read: community values) when there should not be a hierarchy of importance. (\*)

(\*) Airhinenbuwa, et. al: Transforming Scientific Intervention Research Strategies to Strengthen Community Capability, Race & Research: Perspectives on Minority Participation in Health Studies, APHA, 2004



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### **Expected Result:**

The NCDHR, its partners and Deaf Community are united through a solid, enduring collaborative relationship.

### **Unexpected Result:**

Achieving a rich communication is often frustrated by time constraints, differing cultures of decision-making and varying views of what constitutes appropriate community involvement.

### **Proposed Solution:**

To better understand the intersection of cultures: Deaf/hearing, non-researcher/researcher, using Rapid Assessment Procedure (RAP), an anthropological qualitative study design.

### **Lesson learned: TBA**

Recommendations of how to improve communication and collaboration across cultures. Community-researcher relations are complicated when the community involved is diverse and complex



### **Expected Result:**

Creating an effective community committee.

### **Unexpected Result:**

“What’s in it for me?” Paid faculty and staff versus community volunteers.  
Compensation disparity noted.

### **Solution:**

Issue not yet resolved.

### **Lesson Learned:**

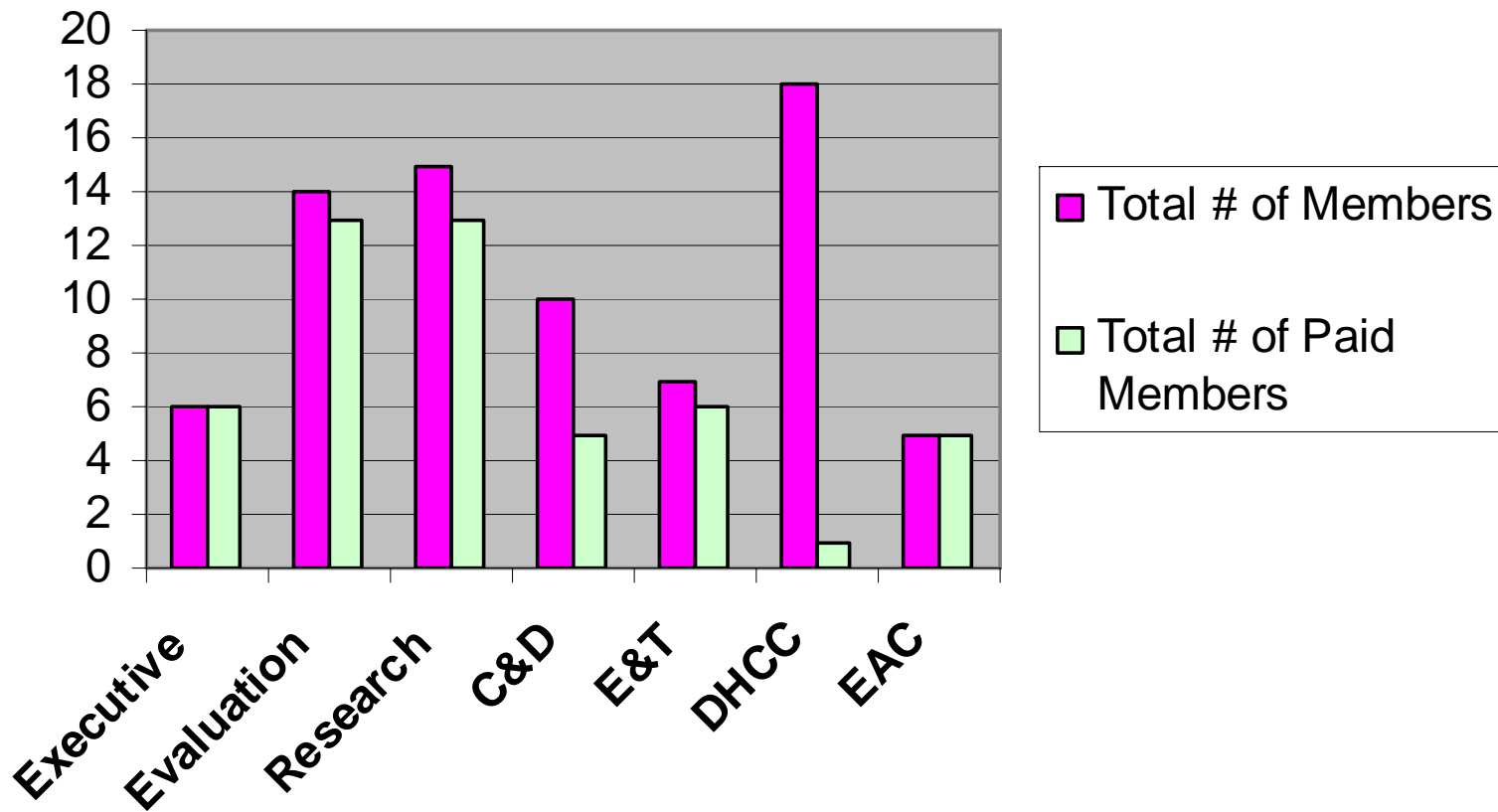
These are difficult and sensitive issues, but they must be discussed among CBPR partners from the beginning. Establish ground rules and formal contracts with clear descriptions of roles and expectations. (\*)

(\*) **Community Incentives and Capacity Building for CBPR: Successfully Promoting Community Interests through Research, AHRQ, November 2001**



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*Year 2 (2005 – 2006)*



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### **Expected Result:**

The Research Subcommittee is well-represented by researchers who are from the targeted community (i.e., Deaf researchers).

### **Unexpected Result:**

Scarcity of culturally and linguistically competent researchers (Read: Very few Deaf researchers).

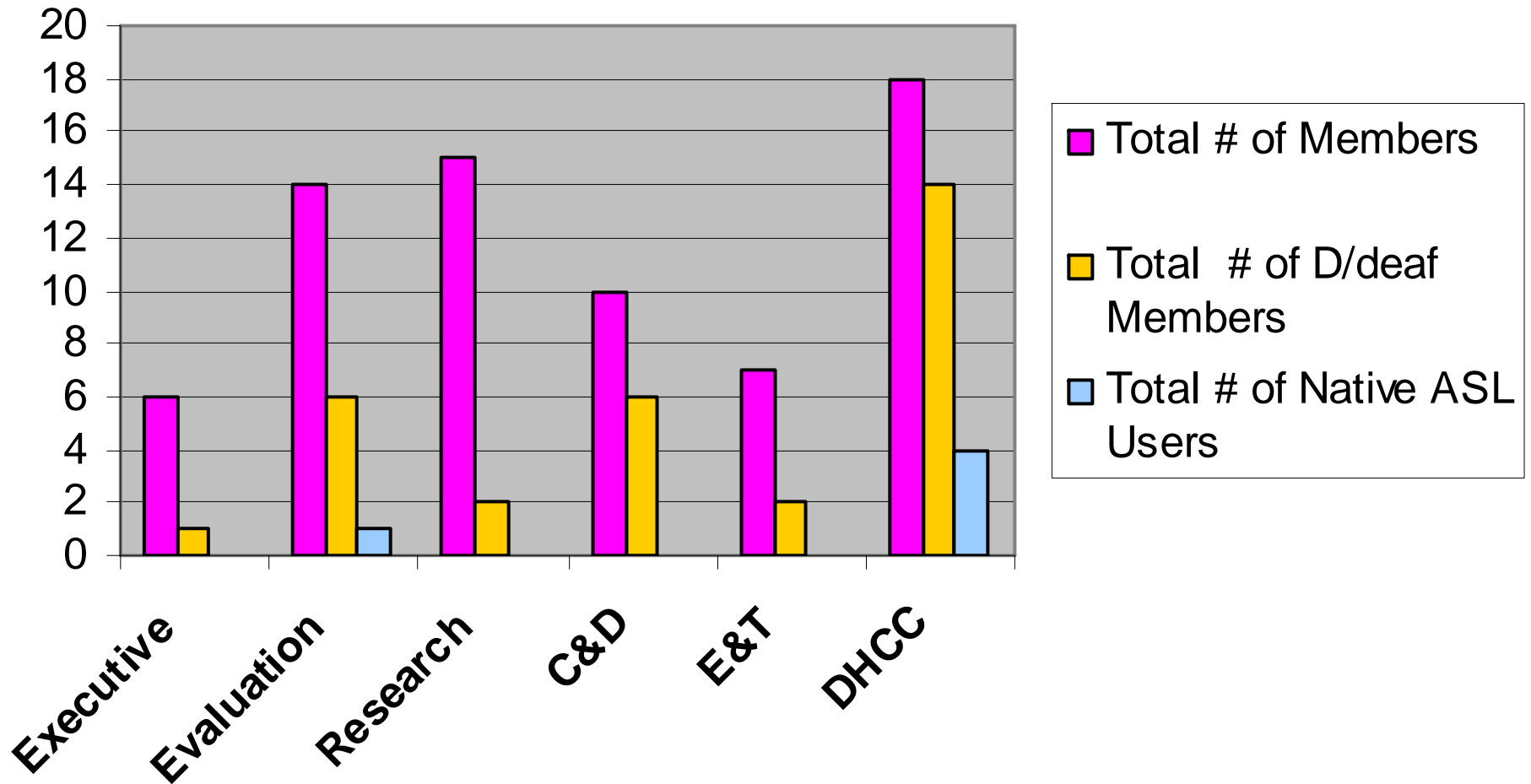
### **Solution:**

Hired Deaf Health Research coordinator. Career development grant-writing in progress to bring in two Deaf health care professionals. Increased national networking through Internet.



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*Year 2 (2005 – 2006)*



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Center-wide Retreat: November 2006



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# Achievements

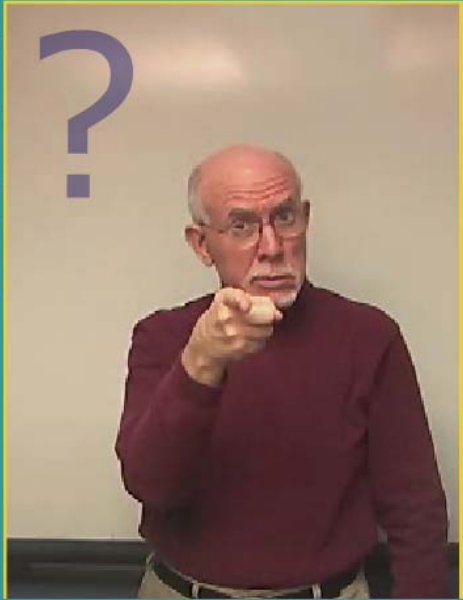
- DHCC governance guidelines
- NCDHR a highly visible member of PRC network
- Completed survey for college-aged students
- ASL adaptation of survey with involvement of community members (ASL Translation Workgroup)
- Deaf Strong Hospital
- ASL Health Risk behavior Survey Instrument nearly ready for data collection.



?

Vision

Patrick



Do you wear glasses/contacts?

?. Do you wear glasses/contacts?

A. Yes

B. No

Back Skip







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# Wrap Up

QUESTIONS?

COMMENTS?

...THANK YOU...



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If there is no struggle,  
there is no progress.

Frederick Douglass

*US abolitionist (1817 - 1895)*



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