Expected and Unexpected Results:

Establishment of a new Community-Participatory Research Center

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Objectives

- Review the organization of a health disparities based community based participatory research project;
- Discuss progress and issues encountered during the first two project years from different perspectives;
- Explore lessons learned and next steps.





The Prevention Research Center Program

"A network of academic researchers, public health agencies, and community members that conducts applied research in disease prevention and control."





PRC program history

- Enacted by congress in 1984.
- By 1996, 13 PRCs were established.
- Each PRC is expected to collaborate with one or more community committees.
- Today, there are 33 PRCs.





PRC program management

The PRCs provide input into the management of the program through 5 committees:

- PRC Steering Committee
- Evaluation Committee
- Policy Committee
- Communication & Dissemination Committee
- National Community Committee





NCDHR National Center for Deaf Health Research

- Only PRC that focuses on the American Sign Language (ASL) Community.
- Over time, NCDHR will work with other community committees for hard-of-hearing, late-deafened and other deaf and hard-of-hearing groups who are not members of the ASL community.



The Deaf and hard-of-hearing communities are not homogenous.

- People who are culturally Deaf
- People who are oral deaf
- People who are hard-of-hearing
- People who are late-deafened
- People with cochlear implants
- People who are D/deaf-blind
- People who are D/deaf with additional disabilities

Each of these groups has very different communication needs and distinct cultural characteristics.





Guiding principles for the NCDHR:

- NCDHR's goals are guided by a "cultural model," not a clinical model.
- Cultural Model: Deaf people are a minority or underserved group who share a common language American Sign Language and culture.
- Clinical Model: Deafness is a condition that should be prevented or treated.
- The uppercase "D" refers to a specific sociocultural group whereas the lowercase "d" is used when a more general reference to hearing loss is intended.



Deaf & hard-of-hearing population estimates

- Unable to hear or understand spoken language: 5 million Americans
- Average English language reading ability among deaf high school graduates is at approximately the 4th grade level, which makes much written health information inaccessible.
- Over 90% of deaf children are born to hearing parents.





American Sign Language (ASL)

- Most important common bond among culturally Deaf Americans.
- Distinct language which has no grammatical relationship with English.
- English is their second language.





Communication inaccessibility and insensitivity in healthcare settings

- More difficulty communicating with physicians than hearing patients.
- Low "fund of information."
- Unfamiliarity with family health histories.
- Health disparities suspected.





The Deaf community in Rochester, NY

- Highest per capita prevalence of deaf people in the U.S.
- 3X the density of deaf people than other cities in NYS.
- 10,000-15,000 Rochesterians use ASL.





Previous Deaf-focused work

- Deaf Wellness Center
- Deaf Health Task Force
- National Technical Institute for the Deaf at Rochester Institute of Technology



Evaluation: assessment of performance indicators #1-13

puts

RPRC Sponsor: U.of Roch.

and prevention research

Dept. of Psychiatry - Deaf

Communications and data/

Research administration

Evaluation and outcomes

Faculty and staff with D/HOH

PRC offices in Dept. of Comm.

D/HOH presumed to be an underserved cultural and linguistic minority, but little is known about health knowledge, attitudes, risk behaviors, risk factors or disease prevalence to allow definition of local and national health priorities or health disparities

expertise

Wellness Center

& Prev. Med.

informatics

RPRC Community Committee: Health Systems Agency Deaf Health Task Force

- organizations for and of D/HOH people
- providers of health services for D/HOHeducational
- institutions
- research institutions assessment

Relationships with Partners

External
Ext. Advisory Com.
MCDOH; NYSDOH
NTID

NTID
Roch. School for the Deaf
Finger Lakes HSA
Health Association
DOE/NIDRR
CDC
PRCs

Comm. & Prev. Med.
Family Medicine
Nursing
Pediatrics
Psychiatry/DWC
Preventive Medicine
Residency Program
Medical Education

Program/URSMD

Motivating Conditions

1. large D/HOH community; 2. large unmet needs; 3. inclusion, empowerment and self-determination; 4. first center for D/HOH health research in the U.S. and world

Activities

Engage the Community formative research; methods development; surveillance; media/education

Establish Research

Agenda define health priorities; plan research agenda; organize research teams

Conduct Core Research methods development; surveillance; determinant research; intervention research dissemination research

Training/Assistance/
Mentoring
research training
curricula;
continuing professional
education;
community education;
mentoring D/HOH
people in health

Output

Tools, Interventions and Programs
data collection methods;
adaptation of BRFS, NCHS
and YRBS for D/HOH people;
visually-based materials and
technologies for health
education; risk reduction
programs; tools for visual/
gestural interpreting research
and practice in healthcare;
products shared with other
PRCs for their D/HOH pop's.

Research Findings
research methods and
expertise; prevalence and risk
of disease; D/HOH health
report cards; outreach to D/
HOH community; health
disparities in D/HOH pop.;
determinants of risk; risk
reduction interventions;
adaptation of evidence-based
programs to D/HOH pop.;
presentations and publications

Recipients of Training
D/HOH health curriculum for
primary, secondary education
and college; D/HOH health
curriculum for RN, MD, DDS,
MSW, interpreters; research
theses in D/HOH health;
interventions for medical
practices; continuing
professional education

Out

Short Term

organization of D/HOH population around health issues; health data for planners & policymakers; data-driven health priorities; education of D/HOH on risks and diseases; increased awareness of D/HOH health needs; improved knowledge of D/HOH health in healthcare providers

Intermediate Term

improved understanding of determinants of health in D/HOH population; community-wide programs addressing health priorities; change in knowledge and attitudes about risk behaviors in D/HOH population; curricula for D/HOH health promotion; research training programs for D/HOH health research

Long Term

policies to enhance preventive services in D/HOH population; educational programs for D/HOH health promotion; environmental changes to reduce barriers; use of evidence-based tools to improve D/HOH healthcare; health professionals with training in D/HOH health; increase in providers and researchers who are D/HOH

Expanded Resources

External grants, gifts and Special Interest Projects to RPRC and partners; Programs and interventions from other PRCs applied to D/HOH; Programs and interventions from URMC and partners applied to D/HOH population

Contextual Conditions: 1. Heterogeneity and complexity of the deaf and hard of hearing population; 2. Multifaceted barriers to communication; 3. Limited "fund of information" greatly impacts healthcare access and quality and is typically unrecognized; 4. Key role of interpreters; 5. Frequently underserved; 6. Severely understudied — little prior information on health; 7. High prevalence of low socio-economic status.





Improved health and reduced disparities in D/HOH pop. as measured by adapted BRFS, NCHS and YRBS surveys administered serially

NCDHR's mission

Promote health and prevent disease in Deaf and hard-of-hearing (D/hoh) populations through community participatory research.





Research track

- New data collection methods; adapted into sign language form:
- Set of three health risk behavior surveys:
 - for high-school age children
 - young adults
 - adults.
- Previously undescribed research findings, including prevalence and risk of disease in the D/hoh population.





Training track

- Increased awareness of D/hoh health needs within the community.
- Improved knowledge of D/hoh health among healthcare providers.
- Changes in knowledge and attitudes regarding risk behaviors within the D/hoh community.
- Research training programs focusing on D/hoh health.
- Training health professionals in D/hoh health.
- Increase in the number of providers and researchers from the D/hoh community.





NCDHR organizational structure

Executive Committee - Program Director - Committee Chairs - Administrator - Community Committee convening agency **External Advisory Community Committee** Committee **Evaluation Committee** - Program Director - Committee Chairs - Administrator - Partner representatives - Selected local experts Communication/ Education/Training Research Subcommittee Dissemination Subcommittee Subcommittee





Implementation

- 5-year grant beginning late 2004
- \$3.5 million
- Chose to focus initially on ASL users:
 - Not a value judgment.
 - ◆ A practical decision to prioritize efforts.
 - ◆ ASL users suspected to experience greatest health disparities.





Goal 1: The NCDHR establishes itself as a leading organization in Deaf health research.

- Committees established
- Physical presence
- Web presence
- Deaf staff members and subcontractors
- DHCC governance guidelines
- Primary focus on research efforts
- Supplemental funds granted





Goal 2: The NCDHR, its partners and Deaf Community are united through a solid, enduring collaborative relationship.

- DHCC provides input; forum for discussion.
- Partner types defined.
- Subcontracts with key partners.





Goal 3: Establish a rich, generalizable evidence base regarding health risks and determinants of health in the Deaf community and assure its dissemination.

- "Modified" English health risk behavior survey administered to Deaf and hearing college students.
- Development of sign language-based survey instrument in progress.



Goal 4: Reduce health disparities in the Deaf community in the local area.

- A longer-term goal.
- Dependent on the collection of evidence.



Goal 5: The health research and provider communities are aware of and take interest in the needs of Deaf communities and individuals.

- Student interns
- Five presentations by nationally- recognized experts.
- Deaf Strong Hospital





Lesson 1: Create a consensus about CBPR at the outset.

- Create a consensus document.
- Recognize that CBPR is an evolving process.
- NCDHR next step: a consensus-building retreat and follow-up meetings.



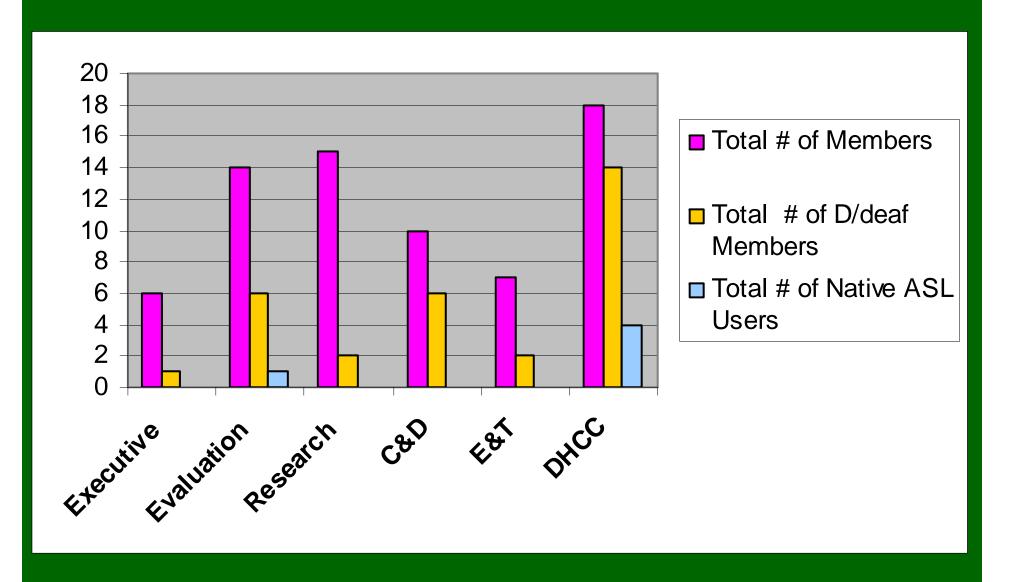


Lesson 2: Create structure that reflects CBPR consensus.

- Form follows function.
- Culturally and linguistically competency.
- Organizational structure may need to change to reflect consensus model of CBPR.
- NCDHR next steps: refine committee structure and guidelines.









Lesson 3: Balance committee membership and member commitments.

- Overlapping committee memberships.
- Multiple roles for certain individuals.
- Culture of research.
- NCDHR next steps: review committee make-up and diversity; clarify expectations and time commitments.



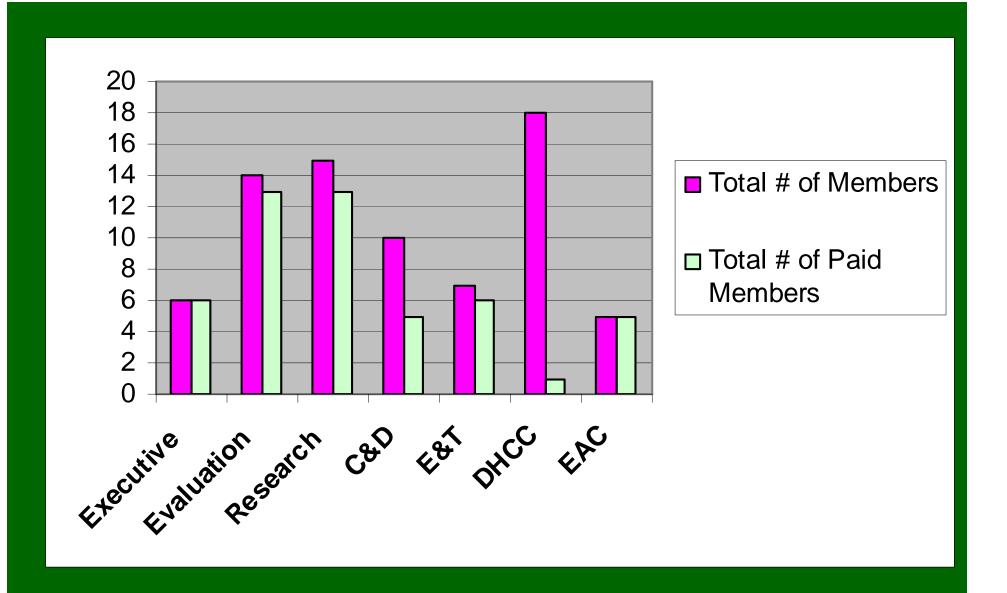


Lesson 4: Creating an effective community committee.

- Organizational representation or individual representation?
- Paid faculty and staff versus community volunteers.
- Mixed hearing/Deaf community committee or Deaf-focused committee?
- Trust
- NCDHR next steps: reaffirm role of DHCC; clarify time commitments and member expectations.









Summary

- Despite our history of service to and collaboration with the community, building a partnership required significant effort and encountered challenges.
- Achieving a rich communication is often frustrated by time constraints, differing cultures of decision-making and varying views of what constitutes appropriate community involvement.
- Complexities of the research process contributed to these challenges.
- While external funding was essential it complicated existing and new partner and community relationships and expectations.





What matters deafness of the ear, when the mind hears? The one true deafness, the incurable deafness, is that of the mind. Victor Hugo





Recommended Readings

- Dolnick, E (1993) *Deafness as Culture* The Atlantic Monthly
- Baker-Shenk, C & Kyle, J.G. Research with Deaf People: issues and conflicts, Disability, Handicap & Society, Vol. 5, No.1, 1990

