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

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National Center for Deaf Health Research
Rochester Prevention Research Center

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.

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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.

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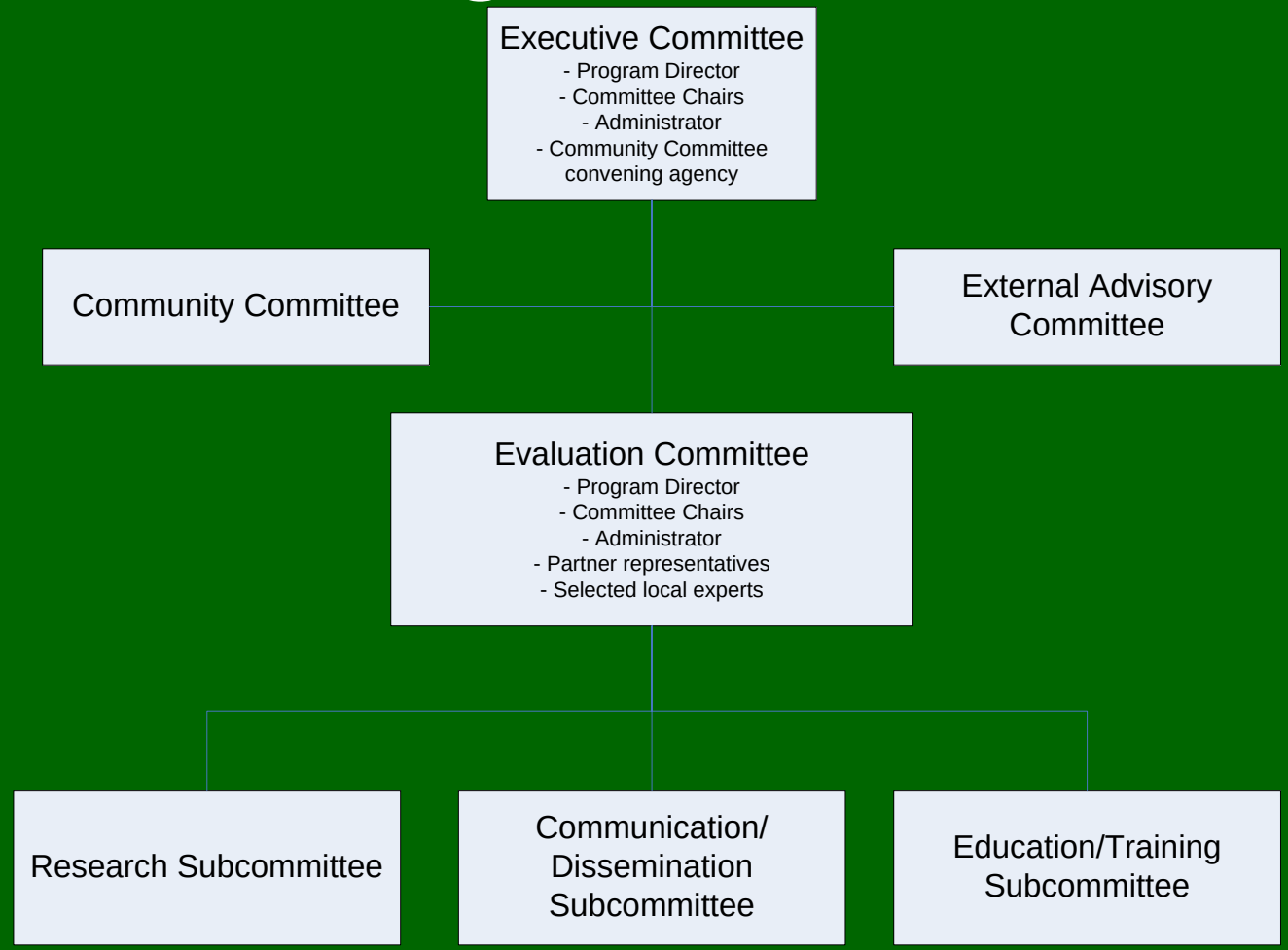
Research track

- 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.

National Center for

NCDHR organizational structure



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.

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.

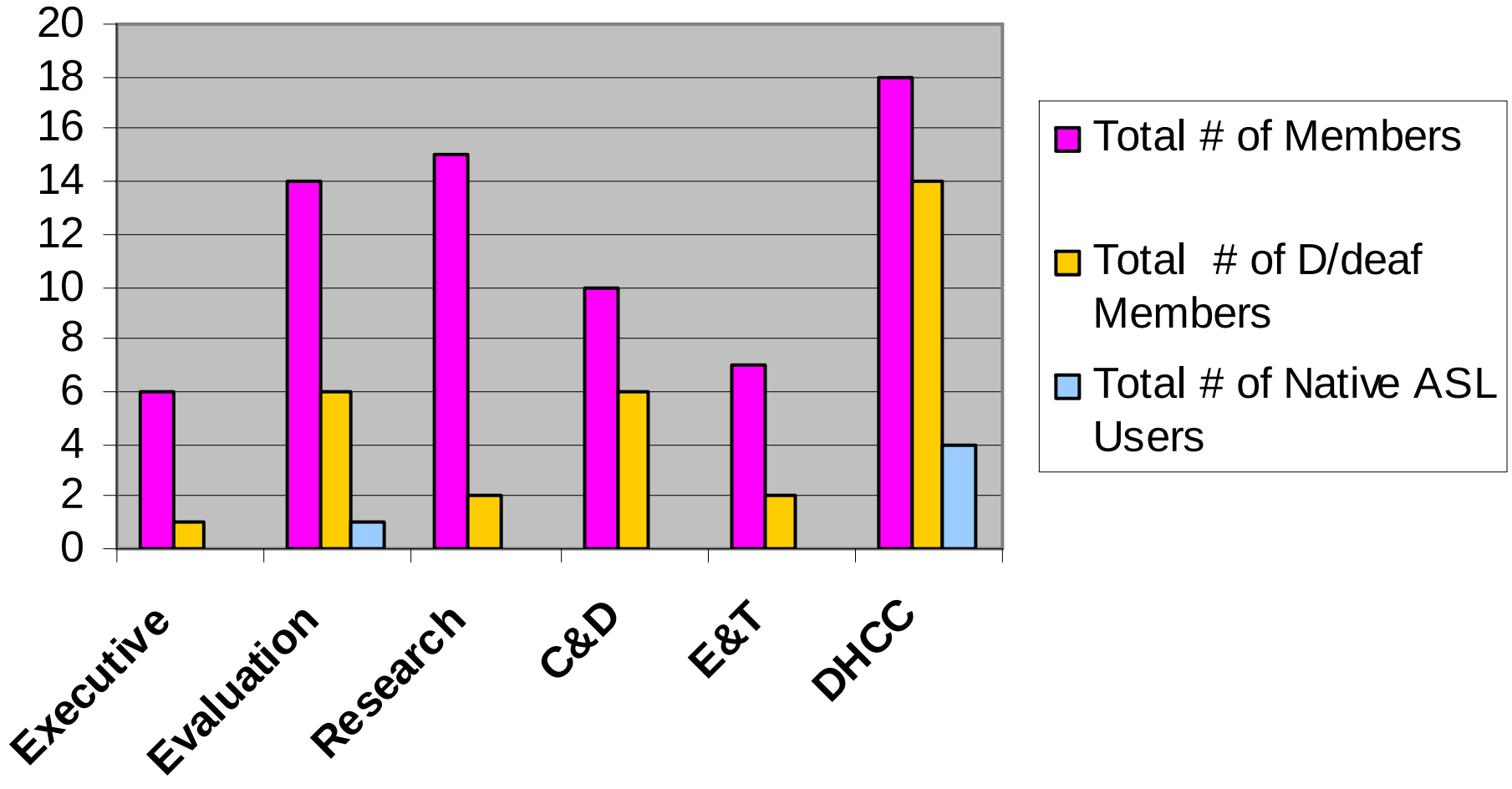
- Student interns
- Five presentations by nationally- recognized experts.
- Deaf Strong Hospital

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.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8
6
4
2
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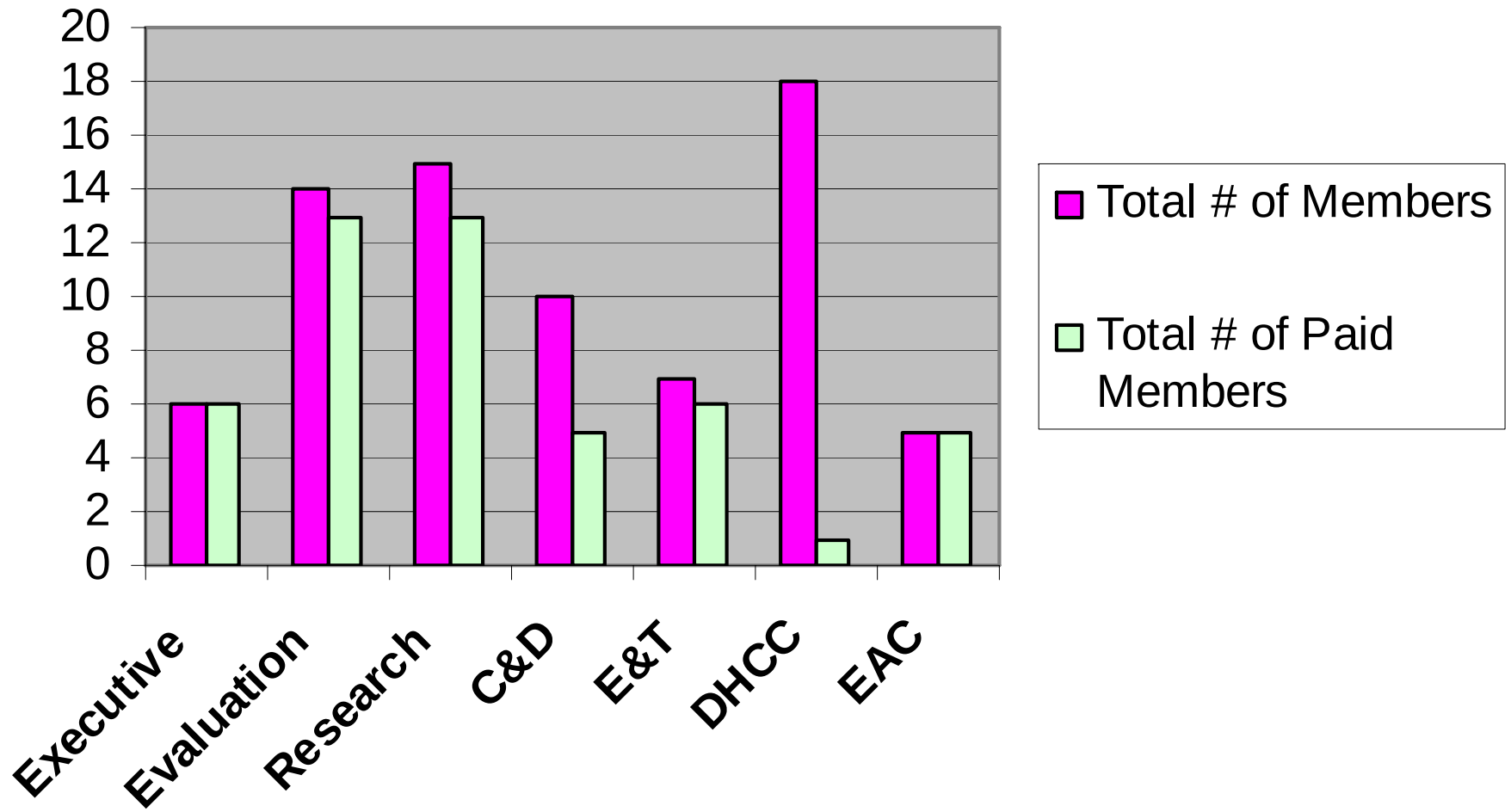
Executive
Evaluation
Research
C&D
E&T
DHCC
Total # of Members
Total # of D/deaf Members
Total # of Native ASL Users

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.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Executive
Evaluation
Research
C&D
E&T
DHCC
EAC
Total # of Members
Total # of Paid Members

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