

# **NCDHR Retreat #1**

## **April 3, 2013**

### **Accomplishments (see slides)**

- Infrastructure
- Research
- Community partnerships
- Communication and dissemination
- Education and training

### **Discussion (Facilitators: Jim DeCaro and Scot Atkins)**

#### **1. How are we doing?**

- DHCC
  - NCDHR more sensitive to Deaf culture
  - Improved partnership between NCDHR and DHCC
  - Learning curve – sometimes communication needs to improve (transparency)
  - Need more participation from NCDHR staff/faculty at events
  - Community engagement – still some parts of the community we have not been able to reach
    - Better use of social media
  - Need more clarification of roles/involvement of DHCC members
  - More collaboration (“cross fertilization”) between HL2 and DHCC
- HL2
  - Time constraints (getting items on agenda, understanding issues, etc)
  - Improved communication with loop system
  - Terminology – National Center for Deaf Health Research – excludes hard of hearing people
  - Need more outreach to people with hearing loss
  - Good dialogue about needs of people with hearing loss (health, emotional well-being, etc)
  - More recognition of the hearing loss community
- LPAB
  - More engagement of community partners on LPAB
    - Invite more individuals to participate on committee?
    - LPAB could be more involved in the future
    - More clear mission for LPAB
  - Collaboration with organizations (i.e. DHCC and GVR/RID)
- NCDHR
  - A lot of time spent educating the public about Deaf Community – advocacy rather than research
  - Growth of research team
  - Task Force Report

- Need a project with people with hearing loss
- Deaf health issues – now we have data to use for publications, advocacy
- Need an understanding of grant writing process; matching personnel to research ideas (in terms of passion, enthusiasm etc)

## **2. What should the next step be?**

- Collaboration between people who are deaf and people with hearing loss
  - Dementia (Dr. Franklin at Johns Hopkins – association between hearing loss and dementia)
  - Depression
- Marketing – increase publicity
- Clarification of NCDHR's mission – promote health and prevent disease using CBPR, not a service provider
- Communicate findings in a way that can be understood by lay people
  - Translate research into a useable format
- Increase awareness about hearing loss
- Connecting HL2 with researchers for the grant writing process
- Identify priorities for both Deaf and hearing loss communities
  - Doesn't have to be same priority
  - Distinct communities/cultures
- Identify recruitment strategies with help from the community
- Employment-related issues for deaf/people with hearing loss
- Continue to grow DHCC/partnership with NCDHR
- Persistence with awareness-raising by DHCC and HL2
- Increase visibility – keep up with vlogs, tweets, Facebook posts, etc.

## **3. Who else should be involved?**

- Audiologists/ENTs
- Deaf community leaders – community has evolved over time, find out WHO leaders are
- NTID professionals/students
- People who are new to Rochester

## **Funding Opportunity Announcement (FOA) Process (see slides)**

- Timeline
  - Retreat 2013 #1 - April
  - Town hall meetings (May-July)
  - August – funding award announcement released (??)
  - Retreat 2013 #2 - September

## **Comments from 3x5 cards**

- Another group to be involved – insurance agencies
- Perhaps we need to separate Deaf and Hard of Hearing?
- Can we use the “Rochester Clinical research” newsletter to publish a small article on us in the next newsletter?