

**HEALTHY LIVING WITH HEARING LOSS**  
**HL2**  
**EXPLORATORY TASK FORCE**

**September 23, 2013**

**SUMMARY REPORT**

A Community Based Participatory Research Committee  
In alliance with  
Rochester Prevention Research Center: National Center for Deaf Health Research  
University of Rochester Medical Center  
Rochester, NY

Prepared by HL2 members  
Mary Chizuk, RN, M.S. Ed. Co-Chairperson  
Donald W Bataille, AIA, CCS, Co-chairperson  
Elise de Papp, M.D.  
Basya Herbert, M.D.

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## ACKNOWLEDGMENT

HL2 committee members would like to acknowledge the support and guidance provided by NCDHR administration and staff, and expresses a sincere thank you for their assistance and valuable input at HL2 committee meetings. HL2 committee members also appreciate the hearing assistance provided via a meeting room with assistive listening systems, a hearing loop and live captioning, and the preparation and distribution of meeting minutes. HL2 is grateful for their continued interest in people with hearing loss including Thomas Pearson, MD, MPH, PhD, Steven Barnett, MD, Erika Sutter, MPH, Matt Starr, MPH, Jamie Marsden, MSSEd, and Kim Kelstone, CI/CT.

This work was supported by Cooperative Agreement Numbers U48DP001910 and U48DP000031 from the US Centers for Disease Control and Prevention (CDC). The contents of this report are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

## BACKGROUND

Hearing loss, the most common disability in the United States, is often referred to as an invisible disability. There are an estimated 48 million Americans with hearing loss (numbers vary according to source). Additional statistics indicate<sup>1</sup>:

- 60 percent of the people with hearing loss are either in the work force or in education settings.
- About 17 percent of adults in the United States report some degree of hearing loss as compared to 1.4 percent that have a physical impairment.
- At age 65, one out of three people has a hearing loss.
- About 80% of older adults, 80 years of age or older, have hearing loss.
- While people in the workplace with the mildest hearing loss show little or no drop in income compared to normal hearing peers, as the hearing loss increases so does the reduction in compensation.
- About 2-3 of every 1,000 children have hearing loss or are deaf.
- It is estimated that 30 school age children per 1,000 have a hearing loss.
- Health insurance addressing hearing loss is not consistent; for example, if John Smith age 12, John Smith age 30, and John Smith age 67 have the same degree of hearing loss, it is

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<sup>1</sup> Statistical sources: National Information Center on Deafness and Other Communication Disorders, National Institute of Health, National Council on Aging and the Marke Trak VII Study by Sergei Kochkin, Ph.D. and 2010 World Health Organization.)

possible that the child receives full or partial cost of his or her hearing aids provided by his health insurance, while the adults usually do not.

- Twenty Six (26) million adults age 50 and older have a clinically significant hearing loss. Reportedly only 15% of the people over age 50 with significant hearing loss wear hearing aids.<sup>2</sup>

It is evident that hearing loss represents a significant number of the population in the United States at all socioeconomic levels. Those with hearing loss represent a diverse group. Hearing loss not only affects those who actually have hearing loss but also those who live, work, or socialize with them.

“People with hearing loss,” “hard of hearing,” and “hearing impaired” are terms commonly used for people with hearing loss. These terminologies are synonymous and are commonly interchanged, although one or the other may be preferred by various organizations. HL2 prefers to use “people with hearing loss.”

Hearing loss can be classified by audiologic testing into different levels: mild, moderate, moderately severe, severe, profound and deaf. Each person’s hearing is different, similar to a fingerprint. Decibel and frequency loss and discrimination scoring (the ability to understand speech) is unique to each individual. Each person’s ability to cope with their level of hearing loss is different.

The ear hears but the brain understands; “listening is where hearing meets the brain”. The ear is the outer portion of the most delicate and intricate organ system in the human body, with finely balanced excitatory and inhibitory impulses. The ear recognizes sound waves, i.e., hears. The ear changes incoming sound waves into neural impulses that are sent to multiple centers in the brain, impulses that the brain can work with, i.e., understand. In view of this incredibly complex system, it’s not surprising that each person’s hearing loss is different from every other person’s hearing loss.

People with hearing loss are often grouped with deaf people, although the communication needs are generally different. Hearing loss has a broad spectrum, ranging from those with minimal or slight hearing loss to those with profound hearing loss who cannot hear or understand speech even in the presence of amplification. Hearing aids alone may help receptive communication for some people with hearing loss, while those with profound loss may use visual modalities, such as caption services, for receptive communication. Most people with hearing loss do not consider themselves “deaf,” and most people who have hearing loss or are deaf do not learn American Sign Language (ASL).

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<sup>2</sup> Lin FR. Hearing Loss in Older Adults-who’s listening? JAMA 2012; 307 (11): 1147-8.  
Chien W, Lin FR. Prevalence of hearing aid use among older adults in the United States. Arch Intern Med. 2012 Feb;172(3):292–3.

Numerous technological ALDs (assistive listening devices) or ALS (assistive listening systems) have been and continue to be developed. These include: HL (hearing loop), FM (radio signal) and IR (infrared) systems (all used with hearing aids and cochlear implants), and RTC (real time captioning) and CART (communication access real time translation) captioning.

Some headset systems are more useful to those who do not use hearing aids. Headsets cannot be used with hearing aids as they would cause feedback or whistling. Cochlear implants benefit some people with profound hearing loss. Mainstream technology such as email, texting with smart phones and captioned telephones provide benefit to those with hearing loss.

It is also not surprising that hearing aids do not always solve the problem. It is often said that hearing aids do not do for hearing what eye glasses do for vision. Vision problems corrected by glasses, in general, deal with correcting the curvature of the anterior portion of the eye, hopefully resulting in 20/20 vision. Hearing aids respond to the connectivity between the ear and multiple auditory centers in the brain and do not restore normal hearing.

People with hearing loss use voice as their primary form of communication and often use technology to understand others. Hearing aids are, or have been, the primary form of this technology. Hearing aids are a crucial part of the treatment for this population. Many people get along quite well with only hearing aids. Those with greater levels of hearing loss may require additional assistive listening devices (ALD's). These devices, usually used in conjunction with hearing aids, further enhance communication and include hearing loop, FM, or IR systems. Those who do not have hearing aids sometimes use other types of hearing assistance equipped with headsets or ear buds.

People with hearing loss may be challenging to identify since some may or may not wear hearing aids, may not consider themselves as having a hearing loss, or are in denial. As a group, they do have some identifiable characteristics. When conversing, they learn to face each other and not to cover their faces, especially their mouths (needed for lip reading), and not to talk "over" each other (but to take turns), and sometimes to speak more slowly.<sup>3</sup>

People function in society by interacting with other people, by verbally communicating with them. People with significant hearing loss have difficulty carrying on conversations in many situations that typically would not pose a problem to a hearing person, especially in noisy venues. People with hearing loss may not pick up the specific sounds needed to understand some words, in many cases they are unable to filter out background noise, something hearing people do routinely.

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<sup>3</sup> Christensen J. Hearing loss an 'invisible,' and widely uninsured, problem. Available at: <http://www.cnn.com/2012/07/10/health/hearing-aid-insurance>

Bluffing or “faking it” is often the mechanism resorted to by individuals with hearing loss as a defense mechanism. It is ineffective. If one has not “heard” the information correctly, one cannot participate, discuss or answer questions about the subject.

Pretending that one has heard what they have not heard, can put them in very uncomfortable, even embarrassing situations. They often are laughed at when they have misinterpreted instructions, directions or a story. People with hearing loss are often left feeling quite stupid, just “not with it”. It becomes easier for the person with hearing loss to withdraw and not even try to participate, easier to stay at home or if they do go out easier to be a “loner” and not interact with others.

### **Barriers to hearing aid use**

Intervention with hearing aids and assistive listening devices does not restore hearing to normal. Hearing and listening with understanding is a learned behavior. The longer one is deprived of hearing, the more difficult it becomes to understand the meaning of sounds, especially speech. Brain mapping has shown that other functions take over the parts of the brain that are not being used.

Of those who would benefit from hearing aids, only about 15% actually do use hearing aids. There are a number of reasons why this is a reality:

- (1) Denial of hearing loss,
- (2) The stigma associated with using hearing aids and aging,
- (3) Hearing aids may not meet expectations,
- (4) Initial high cost plus on-going repair and replacement expenses.

Being able to hear should not be a luxury; many people with hearing loss consider hearing aids to be unaffordable. The reality of “the cost to hear” for many individuals may be too much to bear financially. Hearing aids can cost \$2,000-6,000 every 3-5 years. Hearing Loss Association of America states that the average time lapse between when a person thinks he or she has a hearing loss and uses hearing aids is seven (7) years. It is interesting, however, that in countries, such as the UK, where hearing aids are covered under health insurance policies, the percentage of people with hearing loss who get hearing aids is not significantly higher than in the US.

Hearing aid companies unwittingly add to the stigma associated with hearing aids by advertising how small/hidden they are and how their color can be matched to your hair so they remain all but invisible. Quite unlike the fashion statement of eye glass frames! Many people put their new hearing aids in and expect immediate clear improvement in their ability to hear, i.e. understand. They may become discouraged when that doesn’t happen. They may not take the time and make the effort to use the hearing aids to their fullest benefit. Few people get quick satisfactory results with only a single hearing aid fitting/visit.

Many return visits to the audiologist's office are often required to properly fit and program their hearing aids. These fitting or programming sessions are analogous to being hooked up to a computer and having the computer take over your brain, or at least those parts of the brain involved with hearing (at least 13 different areas mapped out at present time). It is not uncommon for a working person to use most of their allotted sick time for hearing aid fittings and adjustments.

People with hearing loss, historically, have been underserved by the health care delivery system, through poor communication, and lack of recognition of the problem by both the health care insurance industry and medical educators. Historically hearing loss as a medical problem has been relegated to a minor role in medical and nursing educational programs. With the exception of the Veterans Administration health insurance companies, the federal government and/or Medicare in general do not recognize hearing loss as a medical necessity requiring intervention; hearing aids are considered elective. Veterans, however, do have hearing aid benefits and are able to obtain them even if their hearing loss is not connected to their military service. If their hearing loss affects their ability to communicate with their health care provider, Veterans will be diagnosed and treated with the hearing aids for which they will most benefit. Some states' (18) Medicaid Health Insurance Programs provide basic level hearing aids. Most health insurance programs have not provided coverage for hearing aids or assistive listening devices for adults and if covered it is usually a minimum amount.

### Hearing loss and healthcare

In terms of health and health care, the most obvious impact of not being able to hear clearly is misunderstanding or totally missing what the health care professional says to the patient during office visits or in the hospital. This may result in inappropriate follow-up, and lead to adverse health effects, and may also result in a greater expenditure of time, effort, and money in the health care system. Examples include:

- Incorrectly understanding the dosage of medications, dietary restrictions, levels of physical activity.
- The mother, who doesn't hear well and puts the baby's eye drops in the formula rather than in baby's eyes.
- The diabetic patient who doesn't understand or didn't really hear the regimen of figuring out how many carbs are going to be consumed in the next meal and regulating their insulin accordingly, and is afraid to ask again.
- The patient who doesn't realize that their medication has been changed and that's it's important to go to the pharmacy and get the new medication right away.

Even though most health care information is given to patients in writing when they leave, it's not uncommon for people to go by what they just heard. And there's no question that people with hearing loss often did not hear exactly what was just said. Missing one soft sound such as a consonant can totally change a word -- hit-hip, shoot-shoe -- and therefore the whole sentence. The joke about the 3 golfers, some of whom don't hear too well:

Sam: "It's windy isn't it?"

Joe: No, I think its Thursday."

Pete: "So am I, let's get a drink."

Individuals with various degrees of hearing loss are concerned with communication gaps while receiving healthcare. Anxiety occurs at many levels when receiving health care; whether waiting to be called, answering the health care staff's questions, receiving instructions or trying to understand important information.

### **Hearing loss and health**

There is a growing body of evidence suggesting that hearing loss, especially in the older population, leads to withdrawal, isolation and depression. Some studies suggest an association between acquired hearing loss and dementia.

Since much of hearing, the auditory processing part, is done in the brain, people with hearing loss have to work harder to understand speech, increasing their cognitive load. As we live longer and longer, the aging population is increasing in number, along with increasing numbers of people with hearing loss. The prevalence of hearing loss increases with age although hearing loss is not a natural part of aging. There are some known risk factors for acquired hearing loss: genetics, ototoxic drugs, and exposure to noise, smoking and some diseases. For example, the Framingham Heart Study shows a vascular component linking low frequency hearing loss and cardiovascular events, thought to be related to microvascular disease and auditory nerve atrophy.

CDC reported in Health Disparities Among Adults With Hearing Loss: United States, 2000-2006, that "Adults who were deaf or had a lot of trouble hearing and those who had a little trouble hearing were more likely than adults with good hearing to: (a) currently smoke cigarettes; (b) have had five or more drinks in 1 day in the past year (a proxy for at-risk drinking); (c) have engaged in no leisure-time physical activity (a measure of sedentary behavior); (d) be obese; and (e) usually sleep 6 hours or less."<sup>4</sup>

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<sup>4</sup> Schoenborn CA, Heyman K. Health Disparities Among Adults With Hearing Loss: United States, 2000-2006. Centers for Disease Control and Prevention, Division of Health Interview Statistics; 2010. Available at: <http://www.cdc.gov/nchs/data/hestat/hearing00-06/hearing00-06.htm>.



Anxiety creates a vicious cycle and may cause spikes in blood pressure. 40% of people with diabetes mellitus have hearing loss (perhaps also related to microvascular disease). Along with our aging population, dementia is also increasing in numbers of patients affected. Not a week goes by that the media doesn't have front page news on the startling statistics of dementia. Is dementia related to hearing loss? There are a few studies showing a loss of 25dB of hearing power to be equivalent to 7 years of aging. Another study of 2000 adults over 70 years of age shows a one third faster rate of cognitive decline in those with hearing loss as compared to those with normal hearing. Dr. Frank Lin points out that whereas other medical problems in the aging are treated with interventional therapy to help offset the onset of dementia – high BP and sedentary lifestyles are routinely treated with antihypertensive medications, exercise and dietary regimens to forestall strokes and possible resultant dementia – patients with hearing loss and likely cognitive decline and possible dementia, receive no intervention. AMD (advanced macular degeneration) is considered a public health problem affecting 1.75 million adults. Hearing loss is not seen or understood as a public health issue by many, but to the 48 million in the US who have hearing loss, and their family members, it clearly is.

### **Can better hearing provide better health?**

Very few studies have been done to actually document the benefit of treating hearing loss, either quantitatively or psychologically. Even fewer studies have investigated the length of time hearing aids should be worn, although many audiologists recommend they should be worn during all waking hours, except possibly in very noisy environments. Health insurance companies want specific data, large scientific studies to prove the usefulness of what they are willing to cover. The National Council on Aging report on untreated hearing loss compared survey responses from individuals with hearing loss and their family members. The study found better outcomes for those with treated hearing loss on a number of domains, including mental health, family relationships and independence.<sup>5</sup>

The final report of the American Academy of Audiology Task Force on the Health-Related Quality of Life (HRQoL) Benefits of Amplification in Adults describes a systemic review and meta-analysis to examine the association between the use of hearing aids and HRQoL. The report concludes that hearing aids are associated with better HRQoL, and that the mechanism is through the association between hearing aid use and the psychological, social and emotional effects of sensorineural hearing loss. The report recommends a randomized control trial to evaluate the health benefits of hearing aids.<sup>6</sup>

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<sup>5</sup> The Consequences of Untreated Hearing Loss in Older Persons. Washington, D.C.: National Council on Aging; 1999.

<sup>6</sup> Chisolm TH, Johnson CE, Danhauer JL, et al. A systematic review of health-related quality of life and hearing aids: final report of the American Academy of Audiology Task Force on the Health-Related Quality of Life Benefits of Amplification in Adults. J Am Acad Audiology 2007;18, 151-8.

Mental health and quality of life issues are recurrent themes in many articles and books by and about people with hearing loss. The association of hearing loss treatment with health and quality of life outcomes represents important but as yet unanswered research questions that can be answered by well-designed research studies.

## **PURPOSE and PROCESS**

To address the knowledge gaps, disparities and priorities related to people with hearing loss and health, NCDHR worked with HLAA-Rochester members to form a stakeholder group to identify health research priorities.

In 2005-2006 there was a discussion among NCDHR staff to create a community committee of people with hearing loss. From 2005 to present, individuals with hearing loss were involved in workshops, town hall meetings and retreats to help formulate a plan to increase group participation.

In 2010-2011, a group of people with hearing loss continued to meet to discuss:

- 1) their health concerns secondary to suboptimal communication with their health care providers,
- 2) affordability of hearing health care including hearing aids,
- 3) the health needs of people with hearing loss, as representatives of a minority (part of a population differing from others in some characteristics and often subjected to differential treatment) underserved group and
- 4) the relationship of hearing-related intervention, including hearing aids, with the health of people with hearing loss and their families.

The group agreed to establish regular meetings to further define group composition and their health concerns. In September 2011, the group identified themselves as an Exploratory Task Force (ETF). Additional meetings focused on communication barriers and health related issues. Health priorities became more encompassing and the concept of Community Based Participatory Research (CBPR) in collaboration with NCDHR was formalized through a series of scheduled group meetings. This process provided ETF members with the confidence to express their health concerns in an open discussion format.

Outreach efforts for group participation were extended to Hearing Loss Association of America (HLAA-R) Rochester Chapter, public program meetings, HLAA Board and Professional Advisory Council meetings, public speaker programs on hearing loss, and word of mouth. HLAA-R is part of a national non-profit organization. HLAA is the premier source of information for people with hearing loss. HLAA-R's monthly newsletter reaches approximately 500 people, including 200 dues-paying members.

ETF membership represented diverse stakeholders, including people with and without hearing loss, their family members and people who work with people with hearing loss. Community-based organizations; healthcare systems, including those that focus on work with Veterans and older adults; healthcare professionals, including physicians, nurses and audiologists were represented. Both large and small employers; as well as educators teaching on several levels; elementary, high school, special education and university were included.

NCDHR Director Dr. Thomas Pearson and Associate Director, Dr. Steven Barnett presented programs at HLAA Meetings from 2009 through 2013 to inform and invite participation in the process of identifying health disparities, health information and their health priorities.

Committee membership by age ranged from 30-80 with the majority 60-70. Most used hearing aids and benefited from ALDs. One used ASL. Monthly meetings were held with prepared agendas. Minutes were taken by a hearing NCDHR Administrative Assistant with edits by the Chairperson. Additional communication and minutes were sent in an electronic format via a listserv.

NCDHR's facilities provided consistent accessibility and communication services. A phased array hearing loop was permanently installed in a conference room, and captioning (CART) was provided as well as sign language interpreter services for inclusive and accessible communication that included deaf sign language users from NCDHR. Every effort was made to accommodate all members' communication needs. All members followed established communication rules that included using a microphone when speaking, identifying themselves, speaking one person at a time. Average attendance ranged from 5 to 10 participants.

April 2011, Don Bataille, Pres. HLAA-R, presented request from NCDHR to HLAA-R Board of Directors (BOD) for assistance and involvement in a community engaged process to identify important health issues for individuals with hearing loss and their families. The desired outcome of the process was a list of priority health research topics. The HLAA-R BOD unanimously approved participation in the process. The NCDHR National External Advisory Committee, at their May 2010, meeting discussed health issues of those with hearing loss as a public health issue and established short and long term goals to prioritize health research topics that would benefit those with hearing loss.

In early 2012, a facilitator was provided by the NCDHR and University of Rochester to channel group thinking towards a Mission Statement and Vision Statement process. The process continued as members offered their ideas and suggestions in person and electronically until a consensus was obtained.

### **Mission Statement**

To study the relationship between hearing loss and health by partnering with the community of people with hearing loss, clinicians and researchers.

### **Vision Statement**

To affect public policy supported by evidence-based research, to identify health risks associated with hearing loss and promote solutions.

### **Name**

After agreeing upon the Mission and Vision Statements numerous group names were considered. The group agreed it should be a way to provide clear identification and present a consistent and concise message in line with the group's Mission and Vision. The name Healthy Living with Hearing Loss, or HL2, was agreed upon.

### **Focus**

HL2's focus is to better understand the potential cause and effect relationship of hearing and health, to improve the health of people with hearing loss, and to bring awareness/recognition of hearing loss to the medical community.

When the discussion began seeking input from those with hearing loss, HL2 participants came to the realization that they themselves were "The Experts". After reviewing some of the relevant literature, the members discovered they were indeed on solid ground. The group gained confidence and realized their thinking aligned with other writers, researchers and people with hearing loss, and their individual thoughts were representative of the group at large. HL2 now represents the community based participatory research committee.

## **METHODS**

In August of 2011, the HL2 initiated distribution of a survey questionnaire, predominantly at HLAA-Rochester monthly daytime and evening meetings. A copy of the questionnaire used in collection of data is provided in the appendix. The questionnaire was also distributed at other public programs for those with hearing loss, at the HLAA-R Board of Directors and Professional Advisory Committee, at a few audiology and ENT offices, and by word of mouth. Over 90 responses were received. Many of the responses were similar in nature. In the fall of 2012, HL2 members utilized a small group breakout format to discuss research areas.

During the January 2013 HL2 meeting, HL2 members reviewed the list of responses and discussed further steps with Dr. Steve Barnett, a consultant and a leader in health research with deaf sign language users and individuals with hearing loss. HL2 discussed the data and created a list of 18 candidate health priority topics. That list of 18 topics was shared with all HL2 members by email, and based on subsequent feedback by email, HL2 had a final list of 20 candidate health priority topics.

### **HL2 20 candidate health priority topics (in no particular order):**

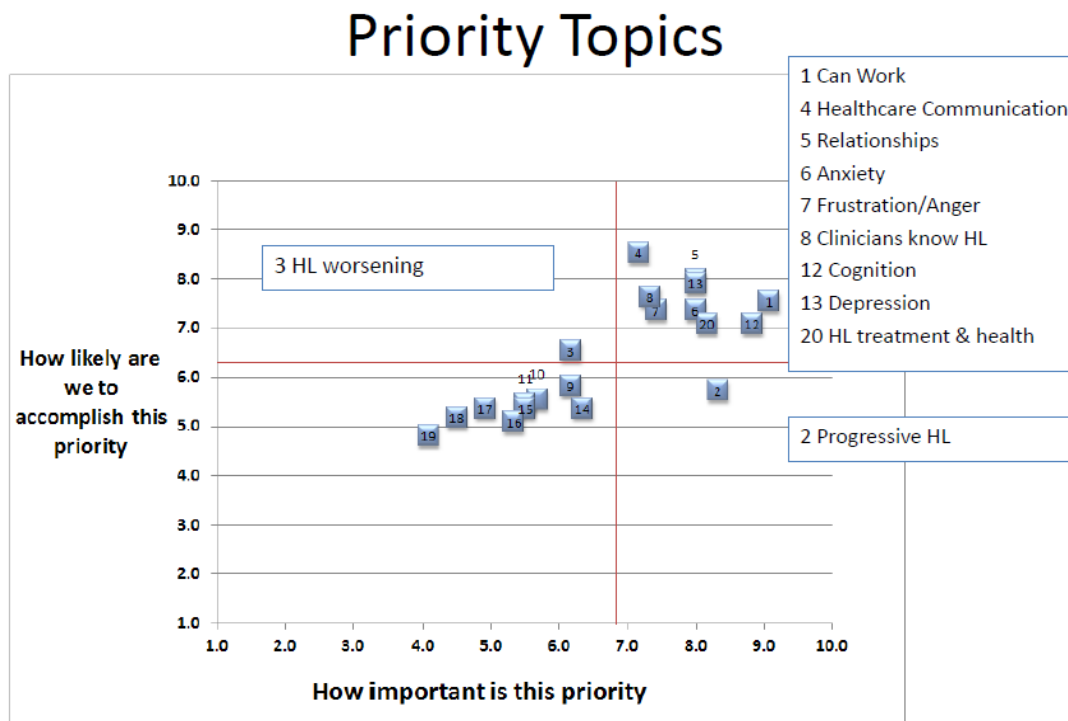
#### Priority Topics

1. Hearing loss (HL) & Ability to Work
2. Progressive HL (Hearing loss that gets worse)
3. HL worsening due to exposures
4. HL & Healthcare Communication
5. HL & Interpersonal Relationships (including raising a family)
6. HL & Anxiety
7. HL & Frustration/Anger
8. Culturally Appropriate Clinicians (mental health and other clinicians with the knowledge and understanding to work with people with hearing loss)
9. People with HL & Vertigo/Dizziness/Balance Issues
10. People with HL & Tinnitus (ringing in ears)
11. People with HL & sleep disturbance (including Insomnia)
12. People with HL & Cognition (including memory, thinking, cognitive decline and dementia)
13. People with HL & Depression
14. Vision & people with HL (including 'Dual Sensory Loss')
15. People with HL & Cardiovascular Disease (including Stroke, Heart Attack, Blood Pressure, Cholesterol, etc.)
16. People with HL & Cancer
17. People with HL & Diabetes
18. HL & Overweight/Obesity
19. People with HL & other medical conditions (Osteoporosis, etc.)
20. The association of HL treatment with overall health and well-being of people with HL.

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HL2 members then rated each topic on a scale of 1-10 on two different scales. On scale related to the topic's importance. A second scale related to the likelihood the topic could be address/accomplished in a research study. NCDHR created an online survey using REDCap, and 12 HL2 members completed the survey. Each of the 20 topics had an average score on each of the scales. The 20 topics were graphed based on their average score on both scale, and the graph and findings were discussed at the February 2013 HL2 meeting. HL2 members reviewed the graph and agreed with the 9 topics with high importance and high likelihood for success.

**Graph of HL2 20 candidate health priority topics**



**HL2 9 final health priority topics (in no particular order):**

1. HL & Ability to Work
2. HL & Healthcare Communication
3. HL & Interpersonal Relationships (includes family)
4. HL & Anxiety
5. HL & Frustration/Anger.
6. Clinicians with knowledge to work with people with HL
7. HL & Cognition
8. HL & Depression
9. HL treatment & overall health/well-being

**RESULTS**

The nine HL2 health research priorities listed above can be grouped into five general categories (below).

**Categorized HL2 9 final health priority topics (in no particular order):**

**Social**

- Hearing Loss & Ability to Work
- Hearing Loss & Interpersonal Relationships (includes family)

**Healthcare**

- Hearing Loss & Healthcare Communication
- Clinicians who are aware of the needs of people with hearing loss.

**Mental Health**

- Hearing Loss & Anxiety
- Hearing Loss & Frustration/Anger
- Hearing Loss & Depression

**Audiology**

- Hearing Loss treatment & overall health/well-being

**Cognition**

- Hearing Loss & Cognition

## **Conclusions**

HL2 members were impressed with consistency of responses especially those relating to Communication and Mental (Behavioral) Health.

Hearing loss causes communication anxiety in so many realms: your loved ones - especially young children, friends, co-workers, managers, health care providers, at religious services, etc which must have some impact on one's health.

At the time of their hearing loss diagnosis, no HL2 member was offered any mental health counseling. Hearing loss is indeed a loss that causes one to experience grief. It is purely speculation that if people who were diagnosed with hearing loss, had the opportunity to grieve that they may have been more accepting of their loss and taken stronger initiatives to adapt to the interventions available such as hearing aids and ALDs.

All HL2 members who had a hearing loss were fortunate to have hearing aids and were familiar with ALDs, so they know they can understand and participate when these devices are provided.

Of concern are the people who have a hearing loss and do NOT have hearing aids. Are their anxieties magnified? Does cognition suffer a major blow? Does depression deepen? If people with hearing loss are unaided (not using hearing aids) do they seek healthcare only out of desperation? Are they diagnosed with illness at a later more complicated and costly stage? What is the effect of "no hearing loss intervention/treatment" on their quality of life?

## **Recommendations**

HL2 members and NCDHR will work with other stakeholders to broadly disseminate this report and the list of health research priority topics.

HL2 members and NCDHR will work with other stakeholders to identify potential funders and develop research proposals to begin to address the health research priorities reported here.

HL2 and NCDHR will continue community participatory based research programs.

HL2 will continue to develop more fully recruit additional members of interest.

HL2 will identify their research plans to affect public policy by evidence based research.

One area of special interest and noted previously is the American Academy of Audiologist recommendation to conduct a randomized control trial to evaluate the health benefits of hearing aids.

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J. M Acad. Audiology 2007;



## Appendix

1. HL2 Members
  - a. Mary Chizuk, Co-Chair
  - b. Donald Bataille, Co-Chair
  - c. Paul Allen
  - d. Marilyn Argenta
  - e. Paul Caccamise
  - f. Elise DePapp
  - g. Allen Ford
  - h. Peter Fackler
  - i. Bess Herbert
  - j. Andy Howard
  - k. Joe Kozelsky
  - l. David Koon
  - m. Barb Law
  - n. Matthew McDonald
  - o. Tim Witcher
  - p. Marlene Sutiff
2. Questionnaire
3. Steve Barnett, MD power point presentation.
4. Reference meetings:

2003 through 2010 NCDHR Supporter 1<sup>st</sup> Application for Rochester Prevention Research Center, Evaluation Committee Member and Communication Sub-Committee Member, 1<sup>st</sup> and 2<sup>nd</sup> External Advisory Annual Meeting, attended by Mary Chizuk.

NCDHR Health Study Workshops attended by HLAA members Don Bataille, Mary Chizuk, and Joe Kozelsky.

December 4<sup>th</sup> 2010 NCDHR holds all day retreat to promote partnership, transparency, communication, trust and respect among deaf and those with hearing loss. Don Bataille attends.

March 15, 2011 NCDHR meeting to discuss Phases I, II and III Hearing Loss Task Force and CBPR protocol, Donald Bataille, representing HLAA attended.

April 12, 2011 HLAA, Board meeting Don Bataille, BOD president, presented new business item, a request from Mr. Matt Starr of NCDHR, for HLAA's assistance and involvement in Phase II – NCDHR grant research program titled Health Issues of Individuals with Hearing Loss. Purpose: to establish and quantify health issues of individuals with hearing

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loss as a group and to define particular research grant application programs affecting individuals with hearing loss. BOD unanimously approved participation in the Study.

May 4 & 5, 2011      NCDHR External Advisory Committee EAC 2011 Annual Meeting, Don Bataille and Peter Fackler attending, Don Bataille PPT program, HLAA Rochester Chapter agreement to participate as an CBPR opportunity, communication issues facing people with hearing loss program, health issues as a public health and health care concerns, and formation of HOH hearing loss task force and short and long term goals to prioritize health research topics that will benefit people with hearing loss

May 10, 2011      HLAA BOD, Don Bataille reviews survey representing 36 member questionnaire indicating 58% interest in participation in a research program. Mary Chizuk provided NCDHR meeting report.    What is this questionnaire?

July 20, 2011      ETF Meeting and welcome from NCDHR Program Director, Dr. Tom Pearson

2011 and 2012      HL2 Co-chairs Mary Chizuk and Don Bataille attend CDC PRC - National Community Committee Annual Meetings, University of Rochester and University Maryland.

August 2013      HL2 Co-host with NCDHR 2 Town Hall Meetings.

2013      HL2 monthly meeting schedule maintained.