

Persons Aging with Hearing and Vision Loss
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Study Group Nears 400

Hello, and welcome to the second edition of our PAHVL newsletter! We have been working on the PAHVL research project for 1 year and 8 months now, and in that time we have formed and met with our participatory action research team two times, identified almost 400 people to be in the study group, conducted several focus groups with consumers, and sent out our first survey. We now have some preliminary results from both the focus groups and the first survey to share, along with some other news and information.

In January 2004 we sent out our first survey to our study group, the volunteers who agreed to participate in the study. As of the end of May, 316 people completed the survey, which represents over 79% of the study group. **We'd really like to hear from ALL of you who signed up!** If you haven't had a chance to complete the survey yet, please do so. If you need another copy of the survey, or would like to complete it over the phone, please call us toll-free at 1-800-675-7782 or TTY: (662) 325-8693.

Preliminary Results of First Survey

As you may remember, our first survey focused primarily on getting some basic information about you (referred to as demographic information), and information about your hearing and vision loss. We've selected the information we thought you would find the most interesting to share with you. If you have any questions or want more detailed or specific information from the first survey, please contact Michele Capella at our toll-free number or email address with your requests.

AGE AND MARITAL STATUS: The average age of our study group is 72 years (standard deviation = 11 years), with 54% of the group in the "young-old" age category

(55 to 70) and the remaining 46% in the “old-old” age category (over 70). A small majority (52%) of the study group members are married.

LIVING SITUATION: A surprisingly large percentage of the group live alone (43%), while a slightly larger percent live with one other person (45.5%). The remaining 11.5% live with two or more persons. A large majority live in a private residence (85%), another 10.5% live in supportive housing, such as a retirement community, 3% live in a nursing home or assisted living facility, and 4% live with their adult children. Most participants report being very satisfied or satisfied with their current living situation (90%), while the remaining 10% report being unsatisfied or very unsatisfied with their living situation.

EMPLOYMENT: Almost 13% of the study group members are currently employed, while another 7% state that they would like to work. The remaining 80% are not employed and are not looking for work. Of those not currently working, only 4% have never been employed, 64% are retired, 24% are no longer able to work because of their disability, and 9% chose to stop working on their own.

LEVEL OF VISION & HEARING LOSS: 26% of the study group members are totally blind, 57% are legally blind, 12% have a less severe visual loss, and 5% are unsure of their level of vision loss. With best correction, 29% report a mild hearing loss, 39% report a moderate hearing loss, 14% report a severe hearing loss, and 18% report a profound hearing loss or deafness.

CAUSES OF VISION & HEARING LOSS: The top four most common reasons reported for vision loss are: macular degeneration (23%), retinitis pigmentosa (20%), other reasons not listed (18%) and glaucoma (14%). The remaining causes of vision loss were reported by less than 10% of the group. The top four most common reasons reported for hearing loss are: other reasons not listed (25%), unknown causes (25%), presbycusis (related to aging – 19%), and Usher syndrome (16%). The remaining causes of hearing loss were reported by less than 5% of the study group. Several of the participants who listed “other” or “unknown” causes they reported being born with a hearing loss or being born deaf.

USE OF HEARING AIDS AND OTHER ASSISTIVE LISTENING DEVICES (ALD): A large percentage of the study group report using hearing aids all the time (43%), while another large percentage never use hearing aids (33%). The remaining participants report using hearing aids frequently (8%), sometimes (9%), or rarely (6%).

Twelve members (approximately 4%) of the study group have a cochlear implant. The most commonly reported ALDs used were a telephone amplifier (38%), other device not listed (16%), and an FM system (9%).

HEALTH ITEMS: The majority of our study group members report at least one health problem. The most commonly reported health problems were: arthritis (52%), high blood pressure (41%), heart disease (22%), Usher syndrome (19%), and diabetes (15%). Most participants reported one or two health problems. A large percentage (43%) describe their general health as “excellent” or “very good,” while 37% report “good” health, and the remaining 20% report “fair” or “poor” health. To the question about which health problem or disability decreases independence the most, the majority of the respondents stated that their vision loss does (59%), while 13% thought musculoskeletal problems did, and another 12% thought their hearing loss decreased independence the most. Several participants indicated the combined effect of their hearing and vision loss affected their independence.

Results from Focus Groups

We send our most sincere thanks to each of you who participated in one of our focus groups or interviews at the National Conferences of the National Federation of the Blind, the American Council of the Blind, Deaf Seniors of America, the American Association of the Deaf-Blind and the focus groups in the San Diego area at the Braille Institute. Focus groups are made up of 3-6 consumers who share ideas on particular subjects to help direct our research questions. Initial results from the focus groups indicate the following areas of interest or concern:

- There is major concern about the lack of trained professionals to provide services and guidance to seniors losing vision and hearing. It was felt by some that since they were not eligible for Vocational Rehabilitation Services, there were no other options for finding persons with experience or training to assist them. Others felt that there were unique issues related to aging and sensory

loss that professionals were not equipped to address.

- Persons who lost their vision first would like more access to information about assistive listening devices, especially hearing aids.
- Telecommunications, especially the use of cell phones and email, are difficult for many people.
- Transportation continues to be a critical issue for most people.
- Several people were very concerned about their financial resources, and felt that they needed to return to work, but options were very limited.
- Those who are Deaf expressed concern about the lack of helpful information about preventing loss of vision and about various eye diseases. They also expressed concern about the lack of access to interpreters and Support Service Providers (SSPs).
- Generally people felt that there was technology that could help them, but that they had neither the financial resources nor training available to allow them to access it.
- There was concern about the lack of resources to assist with the psychological and social adjustment to the combined sensory loss.
- There was a related concern about loss of independence and accessible housing. For some persons, moving in with working adult children was the only option; but as a result they felt very isolated and dependent.
- Some persons who participated in peer support groups felt the group provided a valuable source of information and social interaction, but that often the environment was too noisy to make it enjoyable.
- Depression was an issue for many participants. Depression was aggravated by the lack of understanding of both family and professionals

On The Road Again

Our research team will again be “hitting the road” this summer to attend many consumer conferences, as well as some professional ones. We will be presenting on the PAHVL research study at all of the conferences and will also have a booth where we will be available to talk with conventioners. We will be attending the following conferences this summer:

American Council of the Blind in Birmingham, Alabama in July

National Federation of the Blind in Atlanta, Georgia in June & July

National Association of the Deaf in Kansas City, Kansas in July

Association for Education and Rehabilitation of the Blind and Visually Impaired in Orlando, Florida in July

Inter-tribal Deaf Conference in Toppenish, Washington in July

Blinded Veterans Association Conference in Reno, NV in August

Southeast Regional Institute on Deafness in Nashville, TN in October

We will again be conducting focus groups at the consumer conferences. A focus group consists of 3 to 6 people (in this case, people 55 or older who have both a hearing and vision loss) who get together to have a discussion which is guided by a moderator. (The moderator will be one of us from the research team.)

If you are going to be in attendance at one of these conferences, please consider participating in the focus group. If you're unable to attend the focus group, come to our presentation or stop by to see us at our booth. We'd love to meet you in person!

Next Steps

Although we have almost reached our goal of 406 study group members, our group is not yet nationally representative in terms of age group, gender, race, and region of the country. We particularly need to find more people who live in the northeast region of the country and more people from minority backgrounds. Also, not everyone who has signed up has completed the first survey. For these reasons, we are still actively trying to recruit people to participate in the study. If you know of anyone who is 55 or older with a hearing or vision loss, please tell them about the study!

We are currently working on our second survey. We will have it completed this summer and hope to have it out to you by September. The main focuses of the second survey are employment, community integration and involvement, and communication techniques. We are taking the brief information we learned in the first survey about your work experience to help us tailor the second survey to you, in terms of whether you are currently employed, not employed now but have been in the past, or have never been employed. As a result, we won't have to include all questions on everyone's survey, some of which would not apply to each person with respect to employment history. At this time, we are also beginning development of our third survey, and we hope to have that one out in early 2005.

Again, thank you very much for your interest and participation in this project. It would be meaningless without your input!

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