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Issue 3

Persons Aging with Hearing & Vision Loss (PAHVL)

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Project Update

Since our last newsletter, we have received several more responses to our first survey. A total of 368 participants have now completed Survey 1. In January of 2005 we mailed out the second survey to our study group. We have received a response from 292 people so far, and surveys are still coming in (see page 2 for results from Survey 2). Thanks to all of you who have participated! If you have not returned your survey yet, it's not too late. Contact us if you need another copy of the survey or you would like a telephone interview.

Unfortunately, since our last newsletter, the number of people in our study group has decreased. Some people have decided that they don't have time to participate, completing the surveys was too difficult for others, for some their health has declined, and some have passed away.

As of today, we have 336 people signed up for the study. This means we still need quite a few more people to reach our goal of 406 participants. If you know someone who qualifies for the study, please ask them to contact us.

Results from Survey 2

Our second survey covered three topic areas: Communication, Assistive Technology, and Employment. Here are some of the highlights of the information we obtained from our study group:

Communication

Expressive communication. (form of communication most often used to express themselves, indicating the most common, second most common, etc.):

A large majority of the respondents (86%) use speech as the primary means of expressing themselves. An additional 3% use speech as a secondary method of expressing themselves. The second most common form of expressive communication was writing, which 35% use, mostly as a secondary form of communication. Next was sign language, with 14% using it and 9% of those using it as a primary form of

expressive communication. Other forms of expressive communication used, most often as secondary means, were the manual alphabet (9%) and print on palm (4%).

Receptive communication.

(the best ways for respondents to receive information from others, indicating the best, second best, etc.):

A majority of the respondents (74%) use listening as the primary means of receiving information, with another 4% using it as a secondary means. Reading was the next most frequently mentioned form of receptive communication, with almost 40% of the sample reading print or Braille. Most of these used it as a secondary means of communication, although 7% used reading as their primary means of receptive communication. Fourteen percent of the group use lip reading, and another 14% use sign language to receive

information from others. Some use visual sign language (7.2%), some use tactual sign language (4.3%), and some use both (2.5%). Other less frequently used methods of receptive communication were the manual alphabet (9%) and print on palm (4%).

Information missed due to communication problems.

The majority of our study group feel like they are missing at least a moderate amount of information because of their communication problems – 57% report missing a moderate amount, a lot, or almost everything in communicating with people they know well, and over 70% report missing a moderate amount, a lot, or almost everything in communicating with people they don't know.

Avoid communicating due to communication problems.

We asked first whether study group members thought others avoided communicating with them due

to communication problems – a large majority (77%) thought this happened at least occasionally. Next we asked whether they avoided communicating with others for this reason – again a large majority (70%) said that this happened at least occasionally.

Share information about communication strategies.

When asked to share information about communication strategies or systems that were helpful to them, many of our study group members responded. There were several responses that occurred repeatedly; first use hearing aids! Several people talked about the importance of having a doctor (or audiologist) prescribe the correct hearing aid and getting the hearing aid fitted properly. Other hearing devices that several considered helpful were FM systems. Another common response was to learn Braille – several people considered it indispensable. Finally, several people mentioned that

assertiveness is important. Some specific comments are:

“Get over embarrassment and tell what your problem is. Take whatever devices you need, use all your skills.”
 “Have patience, don’t be afraid to ask someone to repeat something, and get as much back-up information as possible in Braille.”

Assistive Technology

In this section we first asked whether respondents used certain types of assistive technology, then asked them to identify the specific technology they used under each category. Following are the responses, from the most commonly used to the least commonly used:

Use any assistive communication devices to help you function more easily & perform daily activities independently?

88% do, with the most popular devices being talking books (59%), reading aids (37%), large print or Braille calendars

(34%), and signature guides (29%).

Use talking assistive devices? 70% do, with the most popular devices being talking books (59%), talking watch or clock (47%), talking alarm clocks (33%), and talking scales (16%).

Use assistive devices to help you understand what people are saying to you? 67% do, with the most popular devices being hearing aids (51% use some type of hearing aid), telephone amplifiers (34%), and FM systems (9%).

Use assistive devices to help you function in your home?

67% do, with the most popular devices being special markings on appliances (55%), kitchen and cooking aids (25%), clothing labels (21%), and adapted measuring aids (22%).

Use assistive devices to help you see better?

64% do, with the most popular devices being a hand-held magnifier (48%), lighted magnifier (30%), CCTV magnification system (28%), and computer screen magnifiers (17%).

Use signaling and telecommunications assistive devices?

38% do, with the most popular devices being a flashing light for doorbell, phone, or other sounds (15%), a TDD or TTY (14%), telephone relay system (13%), and large print closed captioning system for TDD or TV (12%).

Familiarity with assistive devices. We also asked study group members how familiar they are with devices created for blindness or low vision, deafness or hearing loss, and dual sensory loss. Our group was the most familiar with devices for those with blindness or low vision – 79% felt they were somewhat familiar or familiar with these devices. A majority were also somewhat familiar or familiar with devices for those who are deaf or hard of hearing (67%).

Fewer people felt familiar with devices designed for those with both hearing and vision loss (42%). See the “Useful Information” section on page 7 for a description of some of these devices. We will provide some information in an upcoming pamphlet on devices for people with hearing loss.

Using devices needed. We know that many people with hearing and vision loss do not use assistive devices, or may not use all of the devices that would be helpful to them. We asked our group why they were not using assistive devices. The most common answer was that this question did not apply – that they were using the assistive devices they need (47%), which is good news! For people to whom the question did apply, the most common reason was that assistive devices cost too much (37%). The second most common reason, identified by 30% of the group, was that they do not know what devices would be helpful. The third and fourth

most common reasons were also related to lack of information – didn't know who to talk to or where to find information (20%) or didn't know how to use them (12%).

Share information about assistive devices.

We had a lot of responses to this question also. Some of the most common responses were use hearing aids (again) and use CCTVs. Many people felt their CCTVs were indispensable. Other common responses were to get training and to really learn about the devices you have, so that you can get the most out of them as possible. Other people simply suggested trying and using any devices that could help you. Some specific comments were:

“All of the assistive devices that I use are very helpful. I would encourage anyone to at least try them.”

“By using the proper device and learning to use it well, you improve your living skills greatly.”

“The more familiar you can become the better off you will be.”

“The more you use them, the better you become.”

“They helped me to live independently.”

Employment

Although this is a study focusing on persons who are older, 36 people who have responded to this survey are still working. That represents 13% of the sample. In addition, there are 56 more people who have indicated that they would like to work now! We were interested in learning about the types of jobs people have had or currently have and some of their experiences at work, especially related to their sensory losses.

Many people in our study group (44%) reported that the reason they stopped working was related to their sensory loss(es). Most people felt that their sensory loss(es) affected

their ability to work. Of the group who are no longer working, 62% said their sensory loss(es) did affect their ability significantly. Of the group who are currently working, 69% said their sensory loss(es) did affect their ability to work, but only 14% felt their sensory loss(es) significantly affected their ability. Of the seven respondents who reported that they have never worked, all but one of them said that their sensory loss(es) were the reason for not working.

Unfortunately, several people indicated that they had

their ability to work to some degree, and 35% felt it

experienced discrimination at work related to their sensory loss(es). For the group who are no longer working, 29% reported that they had experienced discrimination from employers or coworkers, while 45% of the group who are currently working had. In addition, 26% of the people who are no longer working report being denied a job due to sensory loss(es) and 30% of those who are still working reported this experience.

Useful Information

Information about assistive devices for dual sensory loss:

Several of the assistive devices available for persons with dual sensory loss require that the person read Braille to use the device; other devices rely on tactile cues. We will start with a description of a few devices that require the use of Braille.

The Tellatouch is a mechanical device used for communication between a person with a dual sensory loss who knows Braille and a sighted or blind person. The machine includes a typewriter keyboard and a standard

Braille keyboard on one side and a refreshable single cell Braille display on the other side. The person with a dual sensory loss can read, in Braille, what the other person types. The person with a dual sensory loss then talks to the hearing person. The advantage of this device is that it allows people without specialized training to communicate with a person with dual sensory loss. It is available from Howe Press: (617) 924-3434 or <http://www.perkins.org>.

The Screen Braille Communicator is an electronic device that allows for two-way communication between a person with dual sensory loss and sighted persons. The SBC has a refreshable Braille display with a Perkins style keyboard for the person with dual sensory loss to read and Braille. On the other side there is a keyboard along with an LED print display for the sighted person to read and type. This device allows persons with dual sensory loss who do not have

understandable speech to communicate with others. For more information contact: Chris Lagarde, Schotenhof 4, Prinsensbeek 4841, The Netherlands, Phone: +31 76 5420 463, Email: clagarde@xs4all.nl

Alerting devices are also important for persons with dual sensory loss. These devices rely on tactile cues. One of them is the Alertmaster 6000 (with remote and tactile receiver), which is a wireless doorbell and telephone alerting system. A personal tactile pager uses different vibrating motions and a touch switch to notify you to activities monitored by transmitters. Optional accessories may include: alarm clock, baby cry, and smoke alarm. For more information contact: Ameriphone at 1-888-449-0444 or info@onlinephonestore.com

The Silent Call Good Vibrations System uses advanced electronics to monitor a wide variety of important household devices.

It is a personal alert system for people who are deaf-blind, which can monitor any or all of the following devices: a doorbell, telephone, smoke detector, sound monitor, personal pager, fire alarm, knock sensor, and door/window access. When the receiver vibrates, the person wearing the unit presses each of the four buttons in a learned order. Only the button activated will cause the receiver to vibrate, thus notifying the user which transmitter sent the coded signal. A benefit to the system is that you can purchase the complete system or only the parts that you want. For more information contact: Silent

Call© Communications Corporation, (800) 572 5227 (Voice or TTY)

Another type of assistive device that uses tactile cues is the Miniguide. This small device uses ultrasound to help people detect obstacles in their paths when walking. It can detect obstacles up to 13 feet away and uses vibration to indicate the distance of objects – the faster the vibration rate the closer the object is. This device is meant only to augment primary mobility aids, such as a white cane or a dog guide. It is available from the Sendero Group: (530) 757-6800, www.senderogroup.com

Did you know...

About Bookshare.org?
Bookshare.org is an online community that allows people with visual impairments to legally share scanned books and newspapers. They currently have over 19,000 books available. Members

can listen to books with screen readers (one is included in the price of membership), enlarge the book with screen magnification software, or read the book in Braille using refreshable Braille readers or

in hard-copy Braille. There is a membership fee of \$50 per year, along with an initial \$25 fee upon joining.

Bookshare.org has recently teamed up with the National Federation of the Blind's (NFB's) Newsline service (see below) to provide access to newspapers and magazines in addition to books.

About NFB's Newsline service? This is a free service for people who cannot read

regular newsprint. Newsline has over 140 newspapers and some magazines available for you to listen to over the telephone, by calling toll-free: 1-888-882-1629. To be eligible to use this service, you simply have to complete NFB's application form, either online or by calling 1-866-504-7300. NFB will then send you an identification number which allows you to access the service.

Next Steps

Recruiting: We would still like to recruit more people to participate in the study. If you know of anyone who is at least 55 years old and who has both a hearing and a vision loss, please let them know about this study and ask them to contact us if they are interested in participating.

Interviews with participants who are deaf: Several of our participants who were born deaf or lost their hearing at a

young age use American Sign Language as their primary means of communicating. For some of these people, completing a long written survey has been difficult. For that reason, we will be doing in-person interviews with some participants who were not able to complete the written surveys. Roy Freeman will be doing these interviews in several states, including Louisiana, California, and Massachusetts. If you are

interested in participating, contact Roy at videophone (866) 327-8877 (IP Address: 130.18.108.49) or TDD 662-325-8693.

Upcoming surveys: We have begun working on the third survey for the study group, which will cover housing, transportation, services, and community integration. We hope to have it completed and out to our participants soon. A fourth survey is also being planned, and it will cover psycho-social issues, which is an area that was not originally going to be part of the study. However, the Participatory Action Research team for the study and participants in focus groups both considered it a very important topic for this group of people. Depression

is known to be more common in older people with vision loss and/or hearing loss, and we think it is important to get information about emotional experiences related to your sensory losses.

Conference: During February 8-10, 2006, we will be sponsoring a conference entitled *Persons Aging with Hearing and Vision Loss: Creating Roads to Independence* in Atlanta, Georgia. This conference is meant for both older individuals who have combined hearing and vision loss and the professionals who work with them. Additional information about the conference will be available soon.

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