Newsletter Issue 4 Persons Aging with Hearing and Vision Loss

Project Update

Hello, and welcome to the fourth issue of our research project's newsletter! We've had a lot of activity on the project since our last newsletter 10 months ago. We sent out Survey 3 in January 2006, and to date we have received 279 completed copies. Some copies are still coming in, but see page 2 for our results so far from. Thank you to all who have participated!

We had our national conference in February 2006 in Atlanta, Georgia. Please see page 8 for a story about the conference. We also recently completed Survey 4, which covers psycho-social issues related to hearing and vision loss. We believe this is an important topic area, but it has not received much attention. Learning about your experiences and feelings will increase knowledge in this area, and we hope that you will be willing to answer the questions in Survey 4. We have already sent out the survey, so if you have not received a copy yet, please let us know.

We've had more people sign up to participate in the study during the last year, but unfortunately have also "lost" some participants. We have lost contact with some people and have been informed by family members that others have passed away. We are still hoping to find more people aged 55 and older who have both a hearing and a vision loss to complete our surveys. If you know of anyone, please ask them to contact us.

Thank you...

As a way to thank our study group for their continued participation in this research study, we are offering \$30 to participants who complete all four surveys. After we receive the four surveys from you, we will mail you a money order for \$30. This money order can be cashed at Wal-mart or at any local bank. It will have your name on it (to protect it from being stolen in the mail), so you will need identification to cash it. This is just a small way to show our appreciation for our study group participants, without whose help this study would not have been possible.

Results from Survey 3

Our third survey covered four topic areas: housing, transportation, services, and community integration. Listed below are a few of the highlights of what we learned from our study group in each of these areas.

Housing

In this section, we asked participants about where they live, emergency systems and plans, and assistance needed and received. Most of our study group lives in their own private home or apartment (84.4%), while 8.5% live in a retirement facility, 4% live in an assisted living facility or nursing home, and 3% live with a child or other family member in his/her home. In terms of emergency systems, most participants have a fire alarm system (87.1%), a way to call for emergency help (82.6%), and a way to find out about severe storms (76.6%). Smaller percentages of people have a carbon monoxide alert (26.7%) or an emergency evaluation plan (46.3%).

Most participants reported that they needed help in several areas due to their hearing and vision losses. The most common areas that people required help were:

- 1. Getting to medical appointments 78.2%
- 2. Grocery shopping 74.3%
- 3. Reading mail 59.8%
- 4. Paying bills 52.4%
- 5. Cleaning house/apartment 50%
- 6. Mowing grass and/or shoveling snow 44.1%.

In terms of who provided help in these areas, the most common helpers for most areas were family members, but for some (cleaning and mowing grass/shoveling snow), paid help was more common. We also asked who provides assistance to help participants maintain their independence. The most common response was friends (54.4%) or family, including spouse (44.5%), children (40.4%), and other family members (31%). A sizeable number of participants also rely on paid or volunteer help (31%). More than 10% of respondents indicated that they are completely independent and do not need help from anyone.

The majority of our participants reported that they could use help in some areas but do not receive it. In terms of areas that they needed help, the most common answer was "other," which included responses concerning a variety of different areas. Some common response were clothes (shopping or dressing), transportation, and exercise. Other areas that participants needed help but didn't receive it were cleaning house/apartment (10.3%), grocery shopping (7.4%), and getting to medical appointments (6.3%). In terms of needing help, one participant commented that "essentials are covered but some of the fun things are missed because of lack of help."

Transportation

Respondents reported on types of public or special transportation available in their areas, use of these systems, typical forms of transportation used, and provided information about their experiences with orientation and mobility (O&M). In terms of types of public or special transportation, almost all respondents were aware of at least one available in their area. The most commonly available forms of transportation were: para-transit system for seniors or persons with disabilities (69.5%), taxi service (62.6%), and buses or subways (55.3%). These three were also the systems most often used by respondents. Only 31.1% reported not using any of the public or special transportation systems in their areas. About half of the respondents who have a public transportation system available in their area reported having difficulty using it.

The most common form of transportation used by respondents was being a passenger in a personal car (74%). The second most common transportation mode reported was walking (39%), and the third was public transportation (27.5%). Half of the group reported that lack of transportation never or occasionally prevented participation in activities, while this could be considered a larger problem for the other half of the group:

Never – 25% Occasionally – 25% Sometimes – 24% Frequently – 15% Almost always – 11%.

Most of our respondents reported that they have received O&M services (67%), and most of them received training after, or both before and after, they experienced hearing loss or deafness. A small percentage (18%) of respondents indicated that someone

suggested a change in their hearing aids based on O&M experiences.

Many respondents reported that concern about their O&M skills affected their use of public transportation (31% said "a lot," 36% said "somewhat," and 33% said "not at all"). Only 38% of respondents who were experienced white cane or dog guide users prior to hearing loss reported that they continue to travel comfortably as usual after hearing loss. The remainder report no longer being comfortable traveling alone (31%) or being more unsure of themselves when traveling alone (31%).

Services

Most participants were aware of services in their area for people with vision loss or blindness (72%), but fewer were aware of services for people with hearing loss or deafness (51%) or for people with dual sensory loss (39%). Unfortunately, 24% of respondents were not aware of any of these services in their area.

The most common organization that respondents had received services from was a state vocational rehabilitation agency (64%). Approximately 30% of respondents had received services from a senior center, an older blind program or independent living service, and a private agency for the blind or visually impaired. Other organizations that many respondents received services from were residential training centers for the blind or visually impaired (27%) and self-help groups (25%). The majority of respondents felt that all or most people who provided services to them understood their hearing and vision loss pretty well (55%). Others felt that only some people who provided services understood their sensory losses (33.5%), and a few did not think their service providers understood their sensory losses (11.5%).

When asked about needs that are not being met by service providers in their area, 100 participants provided an answer. While responses varied, some of the most common responses were transportation, SSPs, computer training, recreation or exercise, and social needs.

Community Integration

Most of our respondents are active in terms of communicating with or getting together with friends or family. A small percentage of the group (12%) had limited participation in these social activities, while many were very active socially (42%). Talking to friends or family with a telecommunication device was much more common than getting together with them, and communicating with or getting together with friends was more common than with family.

The majority of respondents (68%) are involved in clubs or organizations, and many report belonging to more than one. Most respondents (66%) also indicated that the amount they participate in social or community activities has decreased, with 59% who report participation decreases related to vision loss or blindness and 39% who report decreases related to hearing loss or deafness. When asked how this affected them, the most common response was depression, followed by loneliness or isolation. Some respondents indicated that they have accepted this change and look for things to do at home, read more, and participate in more solitary activities. Other expressed the desire to be more active, as they once were.

While a large percentage of respondents were happy with the amount of social activities they engaged in (46% reported being happy or very happy), many were neutral on this (28%), and many were not happy (26% unhappy or very unhappy).

While most respondents have a good support network of family and community, there was a sizeable number who reported having family help when needed sometimes or less frequently (47%) and fair or poor support systems in the community (44%). Most respondents report providing assistance to others, some quite frequently (27% several times per week) and many others once a month or more (40%).

Many respondents reported having some trouble getting information about local news and community events (46%). The most common way to get information was word of mouth from friends or family (71%), followed by television (64%) and the newspaper (41%). While most participants are aware of tax breaks connected with legal blindness (61.5%), many are not.

Did you know...

There are certain tax benefits available to persons who are legally blind. The federal benefit includes an exemption on your federal income tax, but in some states there are additional benefits that might include additional relief for legally blind or disabled homeowners who have homestead exemptions, and additional deductions on state income tax. In order to be eligible, most states require you to have a document stating that you are legally blind or otherwise disabled from either a doctor or a qualified rehabilitation agency, and you must register in advance. If you have a deduction for disability other than blindness you might check to see if there is an increase in the benefit for legal blindness.

For property taxes in most states the registration is at the beginning of the year, although some are as late as July 30th. Registration can be done through the county tax assessor's office in the county where you live. Benefits range from \$500 - \$5,000

additional reduction in the taxable value of your property or a percentage of the value of the property. In some states there is a financial eligibility for all or part of this benefit, so that would be an important thing to check out for your state. In some states, only one co-owner needs to be disabled, whereas in other states, all homeowners, but not necessarilyy all residents, need to be disabled. Also some counties and municipalities have additional deductions from county or city property taxes.

In addition, in many states there are reduced or free benefits for fishing licenses, and in at least one state you can obtain a free hunting license if you are legally blind. (Not something we necessarily recommend, by the way.)

National Conference Report

Creating Roads to Independence for Persons Aging with Hearing and Vision Loss, Atlanta, Georgia, February 8-10, 2006.

Over 100 people gathered in Atlanta to learn and exchange ideas about the numerous issues encountered by persons aging with vision and hearing loss. Attendees of the conference primarily consisted of persons who provide services to this population. There were excellent speakers on a variety of topics including Dr. John Crews from the Center for Disease Control, Dr. Michael Brennan, private psychologist, and Mia Bach from HKNC on Psychological Aspects of Adjustment, Judith Goode from the New England Home for the Deaf on Housing Options, Jamie Pope and Elizabeth Spiers from the American Association of the Deaf-Blind on The Basics of Using an SSP, Harry and Elaine Anderson on Keeping the Love and Laughs in Marriage, Gene Bouguoin on Orientation & Mobility Strategies, Dr. Holly Kaplan on the Basics of Audiology, and Bob Green on Accessible Cell Phones and Pagers.

There were also a number of presenters from the research project staff including William Sansing (MSU) on Prevalence of Seniors with Vision and Hearing Loss, Paige Berry (HKNC) on Assessment and Technology in the Home, Dr. Carren Stika (SDSU) on Hearing Loss 101, Stacy Butler (MSU) on the Low Down on Low Vision Aids, BJ LeJeune (MSU) on Vision Loss 101, and Bernadette Wynn (HKNC) on the Seven Keys to Success.

The overwhelming sentiment on the conference evaluation was that it was an excellent gathering, and there was tremendous interest in having another conference soon. We are currently exploring the possibility of having one in the Dallas or Kansas City area in 2007.

HOW TO CONTACT US:

MAIL:

RRTC on Blindness & Low Vision Mississippi State University P.O. Box 6189 Mississippi State, MS 39762

E-MAIL:

drrp@colled.msstate.edu

PHONE:

800-675-7782

TTY or VIDEOPHONE:

662-325-8693

FAX:

662-325-8989

WEB:

www.blind.msstate.edu/pahvl/index.html

This newsletter is funded by a grant from the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. Opinions expressed herein are not necessarily those of NIDRR and no endorsement by NIDRR should be inferred. The grant is a collaborative effort of the RRTC on Blindness and Low Vision at Mississippi State University, the Helen Keller National Center for Deafblind Youths and Adults, and San Diego State University.

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