

November 2003 Project Newsletter for Persons Aging with Hearing and Vision Loss

5-Year Project to Study Persons Aging with Hearing and Vision Loss

Welcome to the first PAHVL newsletter! Mississippi State University's Rehabilitation Research and Training Center (RRTC) on Blindness and Low Vision, in collaboration with the Helen Keller National Center for Deaf-Blind Youths and Adults and San Diego State University, are working on a 5-year research project concerning persons aging with hearing and vision loss.

The project will focus on exploring strategies to improve outcomes and services for persons over the age of 55 who have both a hearing and vision loss. Further emphasis will be placed on persons who have one sensory loss, and after the age of 55, acquire the second sensory loss.

The project involves several different priorities, including determining the prevalence of these populations, investigating the employment and community integration options available to them, and identifying and evaluating technology and service delivery options and consumers' access to them.

A key early priority is to identify 406 persons who fit into the population of interest to participate in a study group. Disseminating our findings to consumers and service providers is also an important priority of the project. Researchers from the three centers will be working closely with the PAR (Participatory Action Research) team and will routinely ask for their advice and feedback.

First PAR Team Meeting

To maximize the involvement of consumers and other stakeholders in this research project, our PAR team is made up of consumers from different consumer organizations. The PAR team's job is to provide input into all aspects of the project. They will be meeting with the researchers on an annual basis to provide formal feedback on project activities. PAR team members are: **Patty Sarchi** representing the American Council of the Blind, **McArthur Garrett** representing the National Federation of the Blind, **Rocky Stone** and **Marcia Fenisdore** representing Self Help for the Hard of Hearing, **Harry Anderson** representing the American Association of the Deaf-Blind, **Tom Miller** representing the Blinded Veterans Association and an open slot that has been designated for the National Association of the Deaf.

The PAR team met last February in Starkville, MS at Mississippi State University, and has been in contact through email correspondence since then. They were very resourceful in providing the names of various agencies to contact to identify participants for the study group. They were also very adamant about the

importance of including psycho-social adjustment as an issue to be investigated which was not part of our initial research focus. Since the first meeting, the PAR team continues to be very active in promoting the project, recruiting research participants and helping identify consumer issues. We appreciate the time and talent that they have donated to the project, and look forward to several years of exciting interactions with them.

A Busy Summer

This summer we attended several consumer conferences, and had the opportunity to meet and discuss the project with many enthusiastic conventioners. The project was very well received by consumers at Deaf Seniors of America in Boston, the National Federation of the Blind in Louisville, the American Counsel of the Blind in Pittsburgh, the American Association of Deaf-Blind in San Diego, and, most recently, the Deaf-Blind International conference in Ontario, Canada. Our primary goal for each conference was to spread the word about the project. After all, research has no value if people don't know about it. We also recruited several participants for the sample group. So, if you're eligible and we missed you at one of the conferences, be sure to get signed up!

We conducted several focus groups at the conferences this summer. With the goal of finding out what issues are most important to persons who are experiencing hearing and vision loss due to aging, we met with small groups of vested consumers to discuss issues related to communication, community integration, assistive technology, employment, and service delivery options.

Through the focus group discussions, we identified some issues that were not initially included as research priorities. In addition to psycho-social concerns, consumers expressed a need for more information about treatment and prognosis of eye conditions and low vision aids (among those who experience vision loss later in life), and the need for more information about assistive listening devices and hearing aids (among those who experience hearing loss later in life). Another concern expressed was the shortage of qualified personnel to work with older persons who experience both hearing and vision loss.

Study Group Status

The formation of a study group is integral to the success of this project. Participants in the study group will provide information through mail surveys and possibly phone interviews. We will use this information to accurately determine the needs that exist for this population and how to address those needs, which is an overarching goal of the project. To date, we have 130 people signed up for the study group. One of the research goals is to have a study group that is nationally representative in terms of age group, gender, race, and region. That

means we need a minimum of 276 more participants. As you can see, we still need lots of help in this area! We think the best way for us to find participants is going to be word of mouth. So **please help us spread the word!** If you know anyone who is 55 years or older and who is experiencing both a hearing and vision loss, please tell them about the project, share the newsletter, and ask them to contact us. **Our toll-free phone number is 1-800-675-7782.**

Next Steps

We are developing our first study group survey. We hope to have it ready by November, so be on the look-out study group members! We plan to conduct about two surveys each year, for the next 3 years. As we collect and analyze data from these surveys, we will share the information with everyone through the newsletter. We are planning to publish a newsletter periodically to update all interested parties on the progress of the project. This will provide us the opportunity to let you know what we're doing, what our next steps are, and how you can help us out. We hope you will find the newsletter informative and we encourage feedback, comments, and suggestions. Thanks for your interest in the project!

Calendar of Events

8th Biennial Deaf Seniors of America Conference

August 31 - September 5, 2005

San Francisco Hilton and Towers

San Francisco, California

2004 American Council of the Blind National Convention

"Birmingham by the Numbers"

July 3 - 10, 2004

Sheraton Birmingham

Birmingham, Alabama

2004 International Self Help for the Hard of Hearing (SHHH) Convention

June 10 - 13, 2004

Omaha, Nebraska

2004 National Federation of the Blind National Convention

June 29 - July 5, 2004

Atlanta Marriott Marquis

Atlanta, Georgia

RRTC on Blindness and Low Vision

P.O. Box 6189
Mississippi State, MS
39762

PHONE:
(800) 675-7782
(662) 325-2001

TTY:
(662) 325-8693

FAX:
(662) 325-8989

E-MAIL:
drp@colled.msstate.edu

WEB:
www.blind.msstate.edu/pahvl/pahvl.html

Mississippi State University does not discriminate on the basis of sex, age, race, color, religion, national origin, veteran status, or disability.