

Paying to Hear: An Online Poll

By Ellen A. Rhoades and Kay R. Powell

Findings of an online poll show that insurance companies don't pass muster when it comes to enabling us to hear. About half of all survey participants report having no financial help whatsoever when it came to their hearing aids. However, more than a quarter of survey respondents indicate that public assistance programs are helping them when all else fails, but these benefit primarily very young children. What will happen when our children grow up? What about those people who now suffer in silence?

— Ellen A. Rhoades

I happened to log onto an online discussion group and read a posted message from my dear friend, Kay Powell. She was using a questionnaire to poll parents and adults who had experience with hearing aids. Her questionnaire focused on cost reimbursement issues. As a lifelong hearing aid user who became a cochlear implant user just a few years ago, and with a brother who is critically dependent on hearing aids, this is a topic that personally affects me. I immediately contacted Kay and requested participation in her survey.

While Kay's survey was not intended to be subjected to sophisticated statistical analyses, it was an effective poll that made use of a simple and straightforward questionnaire. The questions asked were:

- How many children/adults (please specify) live in your home who wear hearing aids?
- Do they have health insurance?
- Was the cost of these hearing aids covered at least in part, by:
a) health insurance plan; b) public assistance healthcare program; c) private organization; or, d) no assistance was available.
- If you answered a) health insurance plan, was this plan through the military?
- If you answered a) health insurance plan, were these hearing aids for an adult or child?
- Did the availability of assistance (and your out-of-pocket cost)

affect the decision as to which hearing aids were purchased?

- Is there currently an adult/child (please specify) living in your home who does not have hearing aids because of the cost?

Following these questions was a section entitled "Additional Comments."

After about a month passed, I learned of Kay's survey findings from her website (www.listen-up.org) and felt this was interesting enough to share with those who might not have access to her hundreds of web pages. Toward that end, I had a cyberspace conversation with Kay, and the following is a recap of that exchange:

Ellen: What prompted you to initiate this survey?

Kay: I have a friend on a discussion list who testified at a state senate hearing for proposed legislation to mandate insurance coverage of hearing aids. She told us of some results from an audiologist's study. I felt this was interesting and thought about putting it on my website, but then decided to do my own survey so that if there were questions from visitors to my website, I would be in a better position to answer them. It's one thing to report numbers, but it's another thing to know where the numbers came from.

I also felt that if those testifying and working toward insurance coverage for hearing aids could give specific numbers during their testimony, our senators and congressmen would have a better idea of how current hearing aid coverage by insurance companies affects those they serve.

Ellen: How did you locate your respondents?

Kay: Our questionnaire was submitted to eight online discussion groups, not only those frequented by members using prosthetic devices (hearing aids and/or cochlear implants). In the discussion group that I oversee, we have several members whose children do not necessarily wear hearing prostheses; whether it's out of choice or for financial reasons.

We also know that our questionnaire was forwarded to several other groups that support many of the hearing loss-related syndromes. As you can see, we wanted to reach the widest possible audience, not just those groups whose members use prosthetic devices. At one point, I considered asking if the non-use of a hearing aid was due to personal choice or for financial reasons, but decided the answer to that wasn't really helpful to the purposes of our poll.

Ellen: So the respondents to your questionnaire were of all ages?

Kay: Yes. The completed questionnaires that I received represent a total of 126 people: 92 from parents of children with hearing loss; and 34 from adult hearing aid users. This translates to about two-third parental replies and one-third self-reporting respondents.

Nearly all survey participants were covered by health insurance plans: 99 percent parents with their children; and 97 percent adults.

Just one adult and one child reported not having any health insurance coverage whatsoever.

Ellen: As I understand it, virtually all of the respondents to your questionnaire had insurance coverage, yet costs of their respective hearing aids were covered by a variety of sources. Please explain this.

Kay: I assigned the many different cost reimbursement sources into five categories. The first is that of private health insurance that actually reimbursed 15 percent of the respondents for at least some of the costs; these insurance reimbursements came from either individual or group health plans. Unfortunately, I expected this low rate of reimbursement from private insurance carriers. It is noteworthy that the amount of coverage by these private insurance companies ranged from 100 percent to an amount as little as \$267.

Comments from Participants

48 percent of all poll participants were unable to secure any financial assistance whatsoever in their hearing aid purchases. Many respondents had to dig deep into their own pockets so that they could hear.

"I changed not only jobs but careers, giving up three years of graduate school education to go back to an industry where I could get health insurance that covered hearing aids."

"Our son went a very long time—about three years—with hearing aids that provided little or no benefit to him. We didn't have the means to purchase appropriate aids without the help of insurance. Finally, we got on a payment plan with the audiologist when my son's hearing aids completely broke down."

"Hearing aids are definitely a necessity and a safety item for people like me (I have Usher Syndrome). I would love to purchase new ones and if it was not for my mother, I wouldn't be wearing anything now."



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The second group consists of military health plans which, while paid for by the federal government, are administered by a health insurance company, available only to service persons and, therefore, is an employee benefit. A total of eight survey participants or six percent fall into this military category. A special program in military health plans covers 100 percent of hearing aid costs for active duty dependents, minus \$15-\$40 per month (depending on rank). Hearing aids for service members are available at no cost through military hospitals.

Interestingly, the third source of hearing aid reimbursements is that of public assistance programs which benefited the largest number of people in this survey; that is, a whopping 28 percent.

Public assistance programs include, but are not limited to Medicaid, Medicare, early intervention programs, school programs, and state agencies or special state programs. For example, in my state we have PACT, Program for Amplification for Children of Texas. Those receiving public assistance for the purchase of hearing aids typically had higher out-of-pocket expenses than those covered by private health insurance.

A fourth category is that of "other" from which four percent of the survey participants had their hearing aid costs at least partially covered by such private organizations as civic clubs and charities. This low percentage surprised me. It is clear that we cannot assume private organizations will take up the slack when insurance companies or public assistance programs fail to help pay for hearing aids.

Finally, there is a fifth category of "none" which best describes nearly half of the respondents. In other words, 48 percent of all poll participants were unable to secure any financial assistance whatsoever in their hearing aid purchases. Many respondents had to dig deep into their own pockets so that they could hear.

Ellen: Given that nearly half of the survey participants are entirely responsible for the financial burden of purchasing hearing prostheses despite their respective health insurance plans, did this affect their purchase of hearing aids?

Kay: Unfortunately, yes. In many instances, even out-of-pocket costs were significant enough to have had an impact on which hearing aids were purchased, and this concerns me. Among the 126 participants, 31 percent reported that out-of-pocket costs affected their hearing aid purchases as compared to 69 percent who stated that costs did not affect their purchase. This means that the amplification of nearly one-third of the poll respondents was likely com-

centage might be considerably higher with the general population that's not participating in any of the online groups for hearing loss. Seven percent of survey participants reported that amplification was delayed because of hearing aid costs. In one case, there was a delay of three years before a hearing aid was purchased! In another, only one hearing aid was purchased and the parent is just now getting around to being able to afford to amplify the second ear for her seven-year-old daughter!

Almost one-third of the people covered by our survey reported using amplification that isn't their audiologist's first choice for meeting their needs. This concerns me because, as a parent of a child with a

progressive hearing loss, I know the impact of appropriate amplification on an individual. When my son's amplification no longer meets his needs, I see that it affects him physically, emotionally, and educationally.

Ellen: Your questionnaire had space for comments. Were there any that you can share with us?

Hearing Aids: Coverage and Reality (126 people were polled.)

Insurance Type	Coverage	Financial Assistance
Private	92%	15%
Military	2%	6%
Public Assistance	0%	28%
Other	0%	4%
None	2%	48%

promised due to cost.

Some of the strategies used for obtaining these hearing prostheses included buying by credit card, "renting" hearing aids from the hospital where their children receive services, purchasing hearing aids on layaway plans, receiving contributions from extended family members, and/or pleading for their child's school district to cover the cost.

Ellen: Since your questionnaire was submitted to those online discussion groups whose members likely use prosthetic devices, would you have any data on the non-hearing part of our population?

Kay: Actually, I do have some. Results indicate that, among 126 respondents, four or five percent of them reportedly forego or are currently foregoing a hearing aid in one or both ears because of the cost. I would imagine that this per-

Kay: Yes, I received many of interest, but too many to list here. You can read some of the comments on my web page (www.listen-up.org/poll.htm). It saddened me to learn that a gentleman is wearing the same hearing aid for 17 years that no longer works well because he cannot afford to buy a new one.

One parent wrote: "The hearing aids that the agency would pay for weren't very helpful and for two years my daughter chose to go unaided. Last summer we took her to an independent audiologist and paid for new programmable aids out of pocket. What a difference! My daughter chooses to wear these aids all the time although she's 14 now...I can only wonder what could have happened if she'd had better service at an earlier age."

Ellen: That breaks my heart. We live in a country that supposedly

takes care of its people with disabilities. We've enacted landmark legislation for people with disabilities. We're considered a worldwide leader in early intervention services. We are trailblazers for Universal Newborn Hearing Screening. We have wonderful international support from non-profit organizations such as SHHH, NAD, ALDA, AG Bell, HEAR NOW. And, yet, we have people with significant hearing loss who are either not amplified at all or inappropriately amplified! I find this incredible...and, I wonder how this can be?! Now that you have completed your informal poll, what are your thoughts on this issue of hearing aid reimbursement?

Kay: I believe that whether or not someone with a hearing loss uses a hearing aid should be a personal choice of the adult or parent. Our society has already shown a commitment to children and adults with disabilities by enacting the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act

(ADA). Forty-two states have either passed newborn hearing testing legislation or have bills pending.

Once our children have been amplified, there are laws in place to see that they receive training and therapy through early intervention, the school system, or in vocational rehabilitation programs. My survey results show that in about one third of the cases, the appropriateness of amplification is the weak link in the equation.

Selection of hearing aids should be made according to the appropriateness of a specific hearing aid to a specific hearing loss. I find it disturbing that such a high percentage of people with hearing loss are being forced to do with less than the optimal hearing aid for their needs, and yet almost all of them have health insurance coverage.

I'm not advocating for socialized medicine, but simply for insurance companies to stop excluding hearing aids. I find some consolation in the fact that the percentage of cost affecting purchase is lower for children during their critical language-learning years. It should be noted

that some who wrote that out-of-pocket expenses did not influence which hearing aids were purchased did delay purchasing the hearing aid for a number of years due to involved costs. Unfortunately, this also happened when children were concerned.

Ellen: Absolutely! Kay, I concur with you 100 percent. This is a deplorable state of affairs! Hearing aids profoundly affect the (re)habilitation of each patient. It seems to me that if the insurance companies were to spend their money wisely, they would cover all hearing devices needed for optimal effective therapeutic intervention and maximum participation in the mainstream of living. Without a doubt, the purchase of the most effective hearing prosthetic device for each patient is the single most important purchase needed for cost-effective treatment that will, in turn, have the greatest impact on the person's life.

It is of interest to note that we now have just three states that provide hearing aid coverage for their

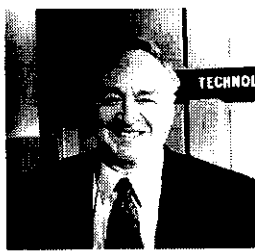
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state employees: California, Minnesota, and New York. Hearing aid coverage bills have been submitted in a dozen states but are not currently passed. Hearing aid coverage now seems to be used as a bargaining unit for unions in the process of negotiating future contracts. And, some federal employee plans are including hearing aid coverage.

Currently, Medicare is specifically prohibited from paying for hearing aids by federal law. The Medicare Aural Rehabilitation and Hearing Aid Coverage Act (HR 2934), introduced last year, would provide Medicare coverage for aural rehabilitation services by audiologists and hearing aids, as needed, every three years for seniors with hearing loss. This Act would repeal the current prohibition and add hearing aids to the list of covered durable medical equipment.

Maybe there are some readers of SHHH who are willing to help take on the health insurance industry. Perhaps, together, we can effect legislative change! □

Kay R. Powell is the parent of a teenager who has a hearing loss. She is the creator of the Listen-Up Web, which has won 10 awards for excellence. Through her website she provides information to those with questions about hearing loss, and consults with families. She is accredited in Occupational Hearing Conservation. Her website address is www.listen-up.org. The site provides extensive information on hearing loss and many of its ramifications.

Ellen A. Rhoades, Ed.S., Cert. AVT, CED, after 30 years of establishing and directing auditory-verbal programs, now trains professionals to provide auditory-verbal therapy and consults with families. She is recipient of the Auditory Verbal International (AVI) Helen H. Beebe Award for Outstanding Auditory-Verbal Clinician and of the League for the Hard of Hearing's Nitchie Award in Human Communication. She is a founding/charter member of AVI, served as director on the board of the A.G. Bell Association for six years, and currently resides in Florida. Her website address is www.AuditoryVerbalTraining.com. The site provides information on rehabilitation.

SHHH Comments on "Paying to Hear"

By Timothy Creagan

Kay Powell recently completed an online poll on the availability of hearing aid insurance coverage. She found that a majority of the respondents were unable to obtain coverage and that they paid for their hearing aids themselves.

This is not surprising, as insurance coverage for hearing aids has been a very low priority on the list of most insurers. Studies have shown that hearing aids in general are an underutilized piece of medical technology. In countries where the cost of hearing aids is completely subsidized by the state, only 20 percent of the people who could benefit from hearing aids use them. This suggests that cost, while a significant figure in hearing aid use, is not the sole criteria. Other criteria include denial of the need for hearing aids, and vanity.

This online survey focuses on the importance of cost in the availability of hearing health services. Recent trends, including a renewed focus at the state level in attempting to get hearing aid insurance legislation passed, as well as a current bill in the United States Congress to amend Medicare to allow coverage for hearing aids, [HR 2934] are promising in addressing this issue.

SHHH, through its outreach efforts, seeks to educate people with hearing loss, their families and friends, members of the public and decision makers at the state and federal levels as to the importance of hearing technology in the lives of people with hearing loss. One study, done by the National Council on Aging, studied the effects of untreated hearing loss in older Americans, and concluded that those older Americans who used hearing aids to address their hearing loss were more likely to report significant benefits resulting from the use of hearing aids, including improved family relationships, mental health and greater independence and security. See, "The Consequences of Untreated Hearing Loss in Older Persons," May 1999, www.ncoa.org.)

SHHH welcomes the dissemination of information on hearing loss, and we encourage our readers to keep abreast of current trends by reading *Hearing Loss: The Journal of Self Help for Hard of Hearing People*, by visiting the SHHH Website, (especially the Public Policy page for legislative updates), and by attending and participating in local chapter meetings.

Timothy Creagan is the telecommunications legal advisor for SHHH.

Are You Interested in Starting a Chapter in Your Town?

Contact the state chapter coordinator in your state. To find the contact information, go to www.shhh.org, click on Chapters. If there is no state chapter coordinator for your state, contact chapters@shhh.org or chapters at 7910 Woodmont Avenue, Suite 1200, Bethesda, Maryland 20814. 301/657-2248. We will send you materials to get you started.