

*Interactive Notebook for Families with a Young
Child Who Is Deaf or Hard of Hearing:
A Survey Assessing It's Usefulness to
Parents*



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March 2010

Learning Objectives



- ❧ Understand the importance of a comprehensive written resource on hearing loss targeted to families and parents
- ❧ Understand the process of distribution for a state-wide resource on hearing loss
- ❧ Understand what parents' written information needs may be following the diagnosis of hearing loss
- ❧ Understand how parents may use a written resource
- ❧ Understand recommendations for your own future implementation and assessment of a comprehensive written resource for families following the diagnosis of hearing loss

Problem



- ❧ Following the diagnosis of hearing loss, parents are required to make a variety of decisions usually based on new and often overwhelming information
- ❧ George, O'Neal and Daly (1987) showed approximately 90% of parents wanted written information at hearing loss confirmation, while less than 50% actually received this information.
- ❧ Minchom, Shepherd, White, Hill and Lund (2003), showed more than half of parents reported they did not receive any information or enough information for topics such as cochlear implants, sign language, cause/diagnosis of hearing loss and Deaf culture

Written Information Provided by EHDI programs



- ❧ 17 state EHDI programs were contacted to see if they provided a “comprehensive, written resource” for families after their child had been diagnosed with hearing loss
- ❧ Less than half (7 of 17) of the programs reached reported having a *comprehensive*, written resource they provided to parents
- ❧ Many programs reported using brochures or pamphlets discussing state resources or some topics on hearing loss. While others reported that they deferred to other organizations to provide certain information.

Distribution of the Parent Notebook



- ❧ 77 notebooks mailed initially to families of all children in UT diagnosed between January 2008 - August 2009
- ❧ Following the initial mailing, notebooks were mailed out within weeks of each child's diagnosis.
 - ❧ 16 additional notebooks mailed out to families of children diagnosed till December 2009
- ❧ Total notebooks mailed to families: 93

Obtaining Parent Feedback



- ❧ To evaluate this resource, feedback needed to be obtained from parents on the usefulness of this information to them
- ❧ Phone survey was chosen as method of receiving information from parents and families

Barriers to Contacting Families



- ❧ Barriers to completing phone interviews:
 - ❧ 6 undeliverable due to incorrect/missing address
 - ❧ 18 families had incorrect/missing phone numbers
 - ❧ 16 were Spanish speakers
- ❧ Resulting in: 53 possible families to interview
- ❧ All families were called two weeks after being sent the notebook

Participants



- ❧ 16 surveys were obtained from the 53 families
 - ❧ 30% response rate
- ❧ 37 non-participants
 - ❧ 4 parents chose not to participate
 - ❧ 10 requested call-backs at a later date
 - ❧ 3 families reported not receiving the notebook and requested it be sent
 - ❧ 2 families reported their child's hearing loss was resolved or is still undiagnosed
 - ❧ 18 families were never ever able to be contacted

Participants



- ❧ Problems for obtaining a large number of participants:
 - ❧ At the initial two week call, parents didn't have enough time to look through the notebook
 - ❧ Difficulties getting families on the phone/requesting multiple call-backs
 - ❧ 4 parents chose not to participate
 - ❧ 2 parents reported their child being diagnosed so long ago/feeling that they'd "already covered the information they needed"
 - ❧ 1 parent reported the Parent Infant Program answered their questions in the home

Results



- 2 of the 16 parents chose not to answer questions about the parent notebook but contributed qualitative feedback on their information needs after their child's diagnosis. The following results were from 14 parent reports.

Results



- ❧ 10 of 14 families wanted written information sooner; there was a delay in receiving the parent notebook
- ❧ 11 of 14 families reported the parent notebook improved their understanding of their child's hearing loss
- ❧ 9 of 14 families reported that the parent notebook gave them information they did not receive from another source

What Parents Found the Most Helpful or Useful About the Notebook



Parent stories

Anatomy/physiology of hearing

Communication options

Information on cochlear implants

Speech banana & explanations of the
audiogram

Ability to store all the information on
hearing loss in one place



What Additional Information Parents Wanted



- ❧ 4 of the 14 parents reported specific topics of information they needed that they felt were not included in the parent notebook or required further information

What Additional Information Parents Wanted



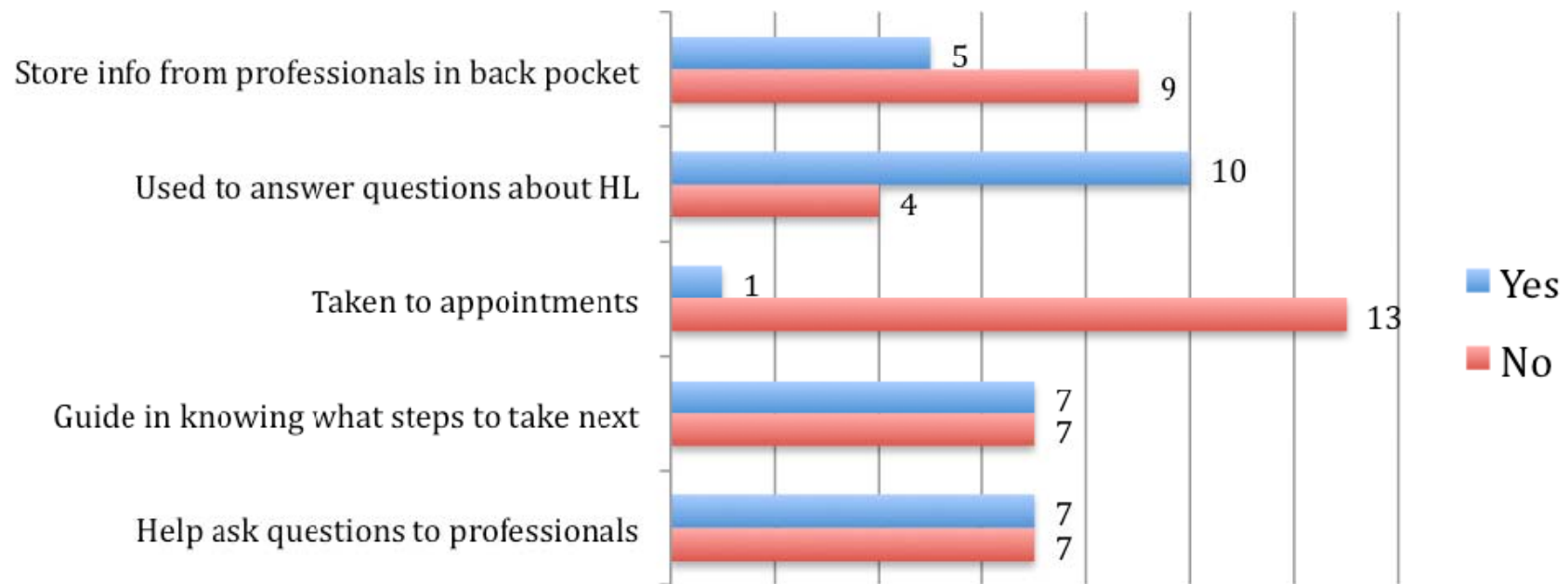
- ❧ Further explanation on the diagnostic process
 - ❧ “How many ABR’s does my child need?”
 - ❧ “What is an eABR? How is it different?”
- ❧ Local sources for therapy
- ❧ More information on what happens before and after cochlear implantation



How are Parents Using the Notebook?



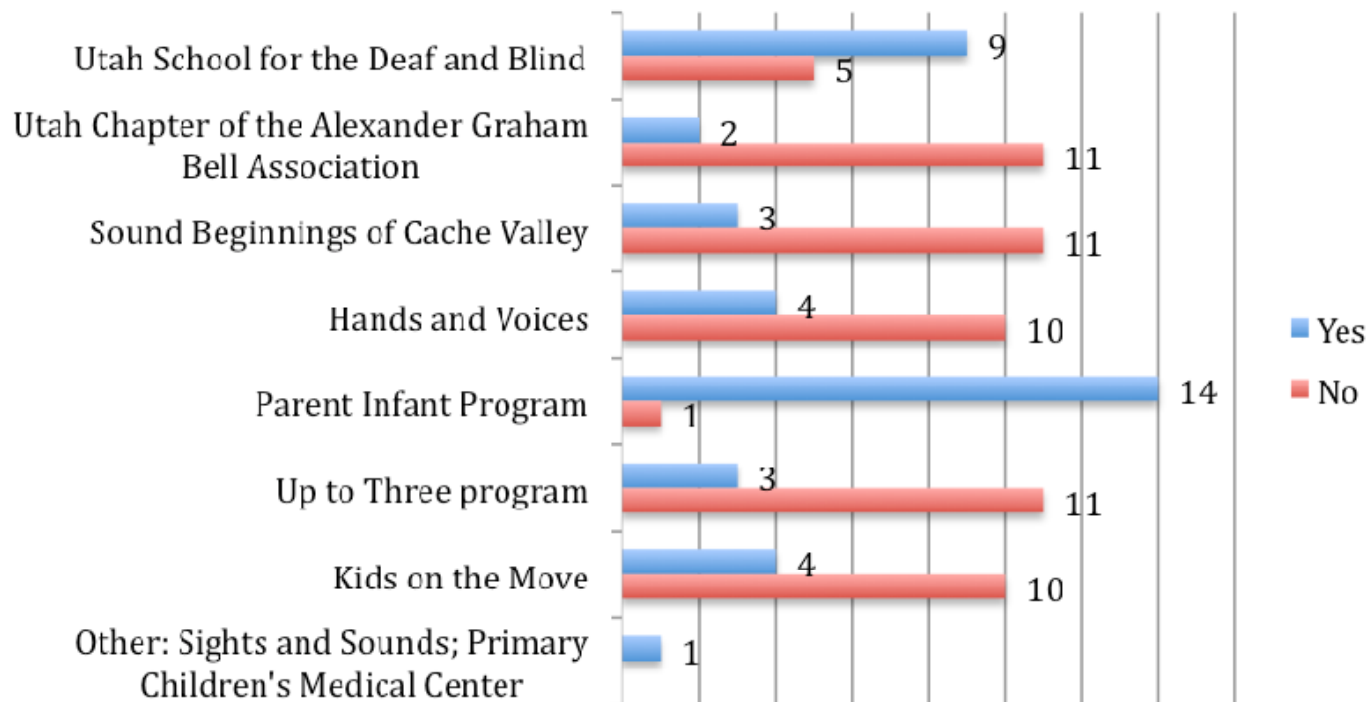
Fig 7. Have you used the Parent Notebook to do any of the following



Where are Parents Getting Written Information?

- ☞ The Parent Infant Program and the Utah School for the Deaf and Blind were reported as the most common source for written information

Fig 8. Have you received any written information from the:



Important Consideration: Timing



- ❧ 10 of the 16 families surveyed received the information when their child was over a year old
- ❧ As this was a new resource and to increase the number of possible participants, the parent notebook was sent to families of children diagnosed between Jan. 2008-Aug. 2009



Timing of Written Information



- ❧ Multiple parents reported the information in the notebook needed to come sooner
- ❧ Quotes from parents:
 - ❧ “My child was diagnosed at one week. This was *much* too late. The notebook was pointless.”
 - ❧ “This information would have helped a year ago. I had to research this all online. I needed it earlier.”

Timing of Written Information



- ❧ Quotes continued...
 - ❧ “It seemed really helpful but I needed it sooner.”
 - ❧ “I wish I’d known some of this information when I was making decisions for my child.”
- ❧ Parents need and want this information!
 - ❧ Feedback showed the longer it took to receive information from the time of diagnosis, the less valuable the information was to families

The Future of the Parent Notebook



- ❧ Parent reports support the creation and distribution of the parent notebook
- ❧ Starting in October 2009, the parent notebook was mailed to families in Utah within weeks of their child's diagnosis
- ❧ Parents' feedback will continue to be received through survey measures to help in improvement of this resource for the future

Future Considerations



- ❧ Audiologist giving a comprehensive resource at the time of diagnosis
 - ❧ Provides immediate written information to answer parents' questions
 - ❧ May help with distribution issues due to inaccurate and/or missing address information

- ❧ Creating a version in Spanish
 - ❧ 17% of families mailed the notebook were Spanish speakers— this is a significant number of families where language may be a barrier to receiving this information

Future Considerations



- ❧ Providing the resource available online
 - ❧ Parents still are provided a comprehensive resource on hearing loss all in one place
 - ❧ More cost-effective
 - ❧ Allowing for parents/providers in other states to have access to the information

Questions?

