

**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference
July 1, 2003**

Topic: Family Resources

TO: Ad Hoc Group for EHDI
FROM: Krista Biernath
SUBJECT: Conference call-in number and agenda.
DATE: July 1, 2003

The next EHDI teleconference will be on Tuesday, **July 1, 2003** from 2:00 to 3:00 pm **Eastern** time. To join in, call toll free: **866-842-6975 (new number)**. You will be greeted by an automated voice and asked to enter a CONFERENCE CODE. Dial **Code 218840**. Please call in 5 minutes before the conference starts so we can begin promptly at 2:00pm. If you have any questions, please contact Marcus Gaffney (*MGaffney@cdc.gov / 404-498-3031*)

An internet based captioning service will be available at no charge during this teleconference. If you would like further information or to schedule use of this caption service, please inform Marcus Gaffney (*MGaffney@cdc.gov / 404-498-3031*)

Agenda

- I. Welcome

- II. baby.org (Boystown Research Hospital)
 - Leisha Eiten

- III. SKY – HI Institute
 - Sue Watkins

- IV. Hearing Exchange
 - Paula Rosenthal

- V. Family Voices
 - Jennifer Cernoch

**CENTERS FOR DISEASE CONTROL AND PREVENTION
EARLY HEARING DETECTION AND INTERVENTION
AD HOC GROUP TELECONFERENCE
July 1, 2003 2:00pm (eastern)**

Captioning Provided By:
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MARCUS GAFFNEY: Good afternoon. This is Marcus Gaffney from CDC EHDI. We are going to go ahead and get started. First I'd just like to say that today's teleconference is about family resources and to thank our speakers and other participants for joining this call. I would also like to thank Dr. Krista Biernath of the CDC EHDI team for organizing this teleconference. If everybody can please keep their phone on mute, that will be very helpful to minimize background noise. A transcript of this call will be available on the EHDI website (www.cdc.gov/ncbddd/ehdi) after this teleconference. Our speakers will be speaking for about 10 minutes each, with 5 minutes for questions after that. Today's first speaker will be Leisha Eiten, who is going to tell us about the babyhearing.org website (www.babyhearing.org)

LEISHA EITEN: Okay. Thank you, Marcus. The www.babyhearing.org was really developed as one piece of a three-part information dissemination grant which was funded by the NIDCD, and we're coming up to the end of the first cycle on that grant.

So overall, the website was one part of that project. The grant had three main goals. The first goal was to increase knowledge about universal newborn hearing screening and early intervention among primary care physicians, and focused on pediatricians specifically. The second goal was to increase the skills of early interventionists that are working with infants with hearing loss and using a family-centered approach. The babyhearing website was actually the third goal of that project, and it was intended to increase parental understanding about hearing loss and also parental self-advocacy. We felt the more parents knew about what to expect with hearing loss, the better prepared that they would be.

In the very first part of the grant, we spent a lot of time reviewing what was already available to parents out on the web, in order to help us look at areas of need. Now this was 2000/2001, and what we found at that time was that the information that was available was fragmented. There were good, informative sites for parents such as the "gohear" and "listenup" websites with a lot of resource lists but when you're in those sites, you have to link to other sites to find information. It means a lot of linking to other places.

What we also found was sites that are more specific to syndromes and condition or sites that represent only one particular viewpoint about communication and education for hearing impaired children. Of course, there are parent chat lists that were widespread even at that time, but they tend to be pretty uneven in terms of how accurate their information is.

As many of you know, over the last couple of years the resources on the web are definitely improving. Now you can go to CDC's EHDI website for parents and professionals, but at that time, that wasn't out there.

So our decision was to provide a site that gave integrated information about audiological diagnosis and audiological habilitation, language and learning topics, and then parental perspectives. It was designed to provide information in those three distinct content areas but when you're in the website you notice that it definitely builds on itself. One example is that what the parents talk about in the parent section tends to be reinforced in the language and learning sections, also parents discuss things that are topically related in the hearing loss section.

Personally -- and this is my opinion -- the strength of the website particularly lies in the "Language and Learning" and the "Parent To Parent" sections because they are very unique compared to what else is out there on the web. The parent section was written by parents, and it really speaks to the heart of what

other parents are concerned about. I think parents are reassured but they're also empowered by the information provided in the Language and Learning section. There are a lot of topics in that Language and Learning section.

We wanted to start at the beginning for those parents who are experiencing a referral out of universal newborn hearing screening programs and move them through amplification and other audiological options, and start with the beginning of the early intervention process and carry people through school age, so that there was a real continuity there.

And I'm sure many of you have surfed the web, so you know there's a huge variety in the quality of websites, so our goal was a site that provided an interesting variety of multimedia elements, not just all text. It needed to be easy to navigate and also give information at different levels of information, from basic to in-depth topics. And just as a visitor might need, they could scroll through, skip and come back as they needed to. Just to give you some examples of those varying levels of information: when you're in the "Causes of Hearing Loss" section there are several embedded tutorials and PowerPoint illustrations that give you more in-depth information about genetics. If a person wants that information, they can go into the embedded section or they can skip it. Several of the sections in Language and Learning have short video segments that illustrate some of the points that are reviewed. People can view the video and then answer some multiple-choice questions to look for certain things that are discussed there. Those are really nice multimedia uses.

As far as what the website is being used for, I think we hoped that the babyhearing.org website would be used by primary care physicians to give information to parents when their child had referred from a universal newborn hearing screening program and might need reassurance about what was being done or what the diagnostic test processes were. Honestly, I don't know how often that happens. I think a lot of it depends on pediatricians' awareness of the website.

We're really excited because we have early interventionists and educational audiology professionals that refer parents to the site, particularly when they have a child that's initially diagnosed with hearing loss, and we've tried very hard to get that information about the babyhearing website into the hands of as many early interventionists and pediatric audiology people as possible since we launched in January of 2002.

Of course we've always hoped parents would find it, if they were searching for information about hearing loss. As I go through the web, I do find that more and more links to babyhearing are showing up. From my personal clinical perspective, I've found that it's really useful to give parents the babyhearing bookmark. If anyone has seen the bookmark, it's a handy way of getting that information out. I give it out at the point at which an initial diagnosis of hearing loss is made. It doesn't matter to me what age the child is, I always give the bookmark out, because parents need information repeated many times and they need to see it in different ways so that they can accept and process all this new information.

Also, if parents have specific questions about a topic and I know that that's covered on the website, I may just print up a particular page for them and give that to them in hard copy. We've also been hearing that medical professionals, audiologists and early interventionists have found it to be a good source of primary information for themselves, so it's helping to develop their resources and knowledge. So that's really been encouraging.

As I said, we launched in January of 2002, and we have been tracking how many visitors have been going to the website since that time. When we launched mid-January of 2002, we had 536 visitors in that month, and we've grown to over 10,000 visitors in April of 2003. Our last available data is from April 2003 at this point, and that's a mix of one-time and repeat visitors within each month. We've also been tracking the length of time people spend in the site, and the average length is about a half an hour at this point. We're feeling like people aren't just getting in and going out. They're really spending some time looking around in there and hopefully getting good information out of it.

Krista had asked me to talk a little bit about what the future plans are for the website, and at this point, the plan is to set up an evaluation section for visitors so that they can evaluate the information provided, the site overall and give us feedback. Also, we want to improve our multimedia elements and provide more

as we can over time. Currently, we've begun a collaboration with the University of Arkansas and Arkansas Children's Hospital in order to provide the web information in Spanish. We haven't seen too much going on with that at this point, but that collaboration is coming. The intention, too, is also to create some specific physician portals so pediatricians would have their own way into the website and maybe have more physician-focused information. We have applied for a grant renewal, so that we can continue updates and then provide the Spanish portion.

With that, I think I'm at about my 10 minutes, so I'm certainly open to questions at this point.

UNKNOWN SPEAKER: How can we get that bookmark?

LEISHA EITEN: The bookmark, I think the best way would be to e-mail either Mary Pat Moeller or myself and let us know how many you need and we can get you information about ordering.

UNKNOWN SPEAKER: And what – how do we get hold of you.

LEISHA EITEN: I'm at eiten@boystown.org.

UNKNOWN SPEAKER: Is there a cost for that?

LEISHA EITEN: Yes, I think there's going to be a minimal cost for the production of the bookmarks because we've continued to have a growing demand for them and it's gotten expensive to do that. I don't know exactly the cost of it at this point.

MARCUS GAFFNEY: Are there any other questions? Okay. I'd like to thank Leisha for that informative presentation. Our second speaker is Sue Watkins of the SKI-HI Institute.

SUE WATKINS: Hello, everyone. I'm really pleased to be with you on this teleconference today, and share just a few things that are going on at SKI-HI. Especially related to new resources.

I thought it might be a good idea just to take a wee bit of time and tell you just a little bit of SKI-HI for those who don't know much about us. We've existed here at Utah State University in Logan, Utah for, oh, golly, over 30 years now. And over the years, we have developed programs, materials, conducted research, provided training and technical assistance to early intervention programs throughout the country.

The focus of the institute is on family-centered early intervention for infants and young children with sensory loss, and the name SKI-HI refers to that. The first letter is sensory impaired intervention with a K thrown in for an acronym. We do have projects here at the institute for children who are deaf and hard-of-hearing like (inaudible) deaf mentor outreach, interact for visual impaired like visa outreach, an area of deaf-blind, the sparkle project, intervenor project, project write, and for multi-handicapped sensory impaired, infants and young children, insight.

We also have several projects that are not in a specific special needs area, but are for children with any special needs like project ahead at haul minute daycare or that are related to related (inaudible) like project child to child or project heritage that's for grandparents of children with special needs. New. Now, for the programming area for deaf/hard-of-hearing, that is also called SKI-HI, but in this case, that refers to services for infants and young children with hearing impairment and again the "K" thrown in for an acronym. SKI-HI for deaf and hard-of-hearing children and their families is currently in 44 states and Canada, and at any one time, we're serving more than about 5,000 families through SKI-HI programming.

If you want a current list of programs and the states they're in, you can contact Fran Payne at the SKI-HI Institute and I'll give you contact information at the end.

Okay. Over the years, here at SKI-HI we've developed an array of materials for service providers that we call parent advisers, and for the families that they serve, including curriculum manuals, assessments, videos, CDs, DVDs, monographs. Perhaps I could take just a second and highlight some of the materials that are currently available, specifically for infants and young children with hearing loss, and then I would

like to focus on our very newest materials in just a moment.

What is currently available, first of all, is the SKI-HI curriculum, which is a two-volume resource. The headline here is that a new and updated curriculum will be available late 2003/early 2004, and I'll tell you more about that in just a second with our new resources.

Also available currently is a deaf mentor curriculum. This is an over 700-page resource for deaf mentors who are working with families. The first one of its kind with ASL lessons, early visual communication lessons, and deaf culture topics.

Paula Pittman is here with us and if you have any questions related to that curriculum or to deaf mentor programming, you can contact her at the SKI-HI Institute, and she would be very willing to give you more information about that.

Okay. So let's see. Other currently-available materials, videos and CDs, cochlear implants, introduction to ASL, understanding and appreciating deafness, aural/oral sign options, just a few examples here, the total communication video series, the hearing aid management video, and so forth.

Now, we do have many videos that are not specifically for young deaf/hard-of-hearing infants and children, but that are for any parent adviser and family in early intervention such as making effective home visits, family-focused interviews, the transition process, so those are available too.

As it relates to print material, some examples specifically for infants and young children with hearing loss include a handbook of sign language for the family, a cognition monograph, we have SKI-HI topics summary and challenge sheets, and assessments like the SKI-HI language development scale that incidentally will have a second edition, a 2003 edition, available on that SKI-HI LDS very soon. As with the videos, there are many print materials that are not specifically for young deaf/hard-of-hearing, but apply to all parent advisers and families, and just a few examples of those would be the family resource book, monographs on building character and confidence in young people with special needs, grandparents' monograph, serving diverse families, working on teams and so forth.

And we do have many of -- well, some of the materials in print are available in Spanish, and you can contact us about that.

Okay. Now, for the new resources. The biggie is the new updated SKI-HI curriculum, and the focus of that curriculum is on children 0 to 3, but it can be used for children to age 5. There are 23 sections and we'll try to get it all in two huge volumes. There's just a lot of information.

The handouts, the activity sheets and visuals, will not be in a separate volume as they are now, but, rather, they'll be placed after each topic.

We started this project about three years ago, and it's involved persons and teams from throughout the country. For example, the section coordinator, principal writer for the new cochlear implant program is Jane Seton from Georgia, and contributors working with her include Mary Koch from Maryland, Patricia Spencer from Galluadet, Washington, D.C., Ann Marie that were from Vanderbilt, Tennessee, so the sections are spearheaded by fine leaders throughout the country in this area, working with teams to develop these sections.

Perhaps it would be helpful for me also to give you just a highlight of the new programs to give you a feel for the content of the new curriculum.

And I'll read these quickly. Assessment, first visits and family support, infant 0 to 12 months, hearing aids including high-tech amplification and cochlear implants, being deaf, basic communication issues and approaches, play and concept development, natural environments and routines, early visual communication, early auditory vocal verbal communication, methodologies and language programming including sim-com, bye-bye, aural/oral, cued speech, a literacy program, children who are deaf with other special needs, syndromes and medical conditions, auditory neuropathy, sensory integration, children who

have mild, moderate conductive unilateral loss, and so forth.

Okay. I think what I'll do is switch to other resources that will be available along with the SKI-HI curriculum late 2003/early 2004.

We have some fun family-friendly materials to teach families ASL and enhanced deaf mentor programming that will be available soon, including some deaf mentor lesson summary sheets that go with the curriculum, a deaf mentor sign language reference dictionary that goes with the curriculum, a new series of videotapes on sign language for the family, and some very fun games and activities to help families learn ASL.

We'll also have available an excellent interactive DVD that addresses sensory loss, including deafness. This has information on sensory loss, simulations and interactive quizzes. There are new monographs, videos, challenging situations, in-home visits, transition process for parents, CDs on syndromes, on bye-bye. Just an array, again, of new materials that will be available the end of this year, and early 2004.

Let me give you some contact information. Our phone number here at SKI-HI is area code 435-797-5600. And if you want to call on that list of programs or any questions that you might have, feel free. We'd love to talk to you. Our e-mail is Skihi-- one word --@CC.USU.EDU, and the website is SKI-HI -- again, one word --.org. Feel free to answer any questions.

IRENE FORSEMEN: Is there now or is there any plan to translate the materials into Spanish?

SUE WATKINS: Yes. We are in communication now with some agencies and we're planning to do that. For sure, we will translate the topic summary and challenge sheets into Spanish, as soon as we're finished with the curriculum. So at least that will be in Spanish. And then we're moving towards the whole curriculum in Spanish.

IRENE FORSEMEN: And do you have an idea on the price of the new curriculum?

SUE WATKINS: Not for sure, but if you need a ballpark for planning, we're wondering about coming in at about 250. The -- there's two very large volumes with the 23 complete programs and all the (inaudible) for families so we're told that's really a good deal so hopefully we can keep at that for the set, about 250.

MARCUS GAFFNEY: Are there any other questions for Sue at this point? Okay. Well, I'd like to thank Sue for telling us a little more about SKI-HI. That was very interesting. Our next speaker is Paula Rosenthal of the Hearing Exchange.

PAULA ROSENTHAL: Okay. The website is located at www.HearingExchange.com, and membership is free. You just log on and everything on the website is free. It began almost three years ago as a result of some personal experiences that I've had. I hearing paired person. I've worn hearing aids since I was 3 years old and I'm also the (inaudible) rapidly progressive hearing loss and we have a lot of difficulty finding a quality program for her and as well as information when she was first diagnosed at the age of two.

In the past year, she and I both have had cochlear implant surgery, and we're doing very well with it. And the website is an offshoot of many of our experiences, and we -- I now get about 5,000 people a week to the website, including, you know, many from doctor and audiology referrals. The website is for people with hearing loss, families, and professionals who work with them, and there's a large emphasis on providing information and support for parents and families of deaf and hard-of-hearing children as well as people with hearing loss.

I'm going to give you a list of many of the things that are available on the website, and I'll be happy to take your questions at the end.

One of the things that I do is I've been writing articles that have now been syndicated in magazines as well as other websites, and are often used as parent handouts by different types of organizations. The titles of some of these are five things to teach your deaf and hard-of-hearing child, eight tips for

encouraging self-esteem in deaf and hard-of-hearing children, evaluating school programs for deaf and hard-of-hearing children, and then I also have other things that are more general in nature, including considering cochlear implant surgery, read this first. Purchasing hearing aids. (inaudible) for people who have never done so before. And as well as an article on resources for people who cannot afford hearing aids and cochlear implants.

So I try very hard to pinpoint items that, you know, people have difficulty getting information from their local professionals, and I put that on-line for them.

These articles are all available for printing out and reproducing, so if anybody is interesting, please contact me and I'll give you my contact information at the end.

Another area that is very well read is the news section, where I gather information for all the latest things on technology and news related to deaf and hard-of-hearing people. Hearingexchange also offers message boards, which you know, are also forums. We have over 3300 registered members on these message boards, and there are more than 40 forums.

The different forums are segregated by topic. You know, there are main topics, including cochlear implants, deaf and hard-of-hearing, parenting, education, communication, an area specifically for professionals, research, and technology.

Another area that's very popular on our website are the live chats that are held on-line each week, and are hosted by Hearing Exchange members who have experience in their particular areas.

The two most popular are there's one held on Wednesday evenings at 9 p.m. Eastern for -- it's a cochlear implant chat. It's for people with cochlear implants as well as people and parents who are considering them.

Another chat is my Thursday night chat at 9 p.m. Eastern, and it often focuses on needs for parents, where I help them by providing support, networking and resources.

Hearing Exchange also has a resource directory, with over 300 hand-picked links to other terrific websites on-line. One of the ones that I frequently point people to, especially the parents, is the one on the audiology website that's called "how to read an audiogram," because I find that many people are not getting the information from their local audiologists about how to read their child's audiogram and it's so important. Give me one moment, please.

Okay. I publish a newsletter that's printed monthly, with information about all the latest items on the website. As well as sending out chat reminders for people who are interested in the different types of chats that we offer. Hearing Exchange also includes notices of workshops and conventions that are given around the country.

Another area that has been -- I get a lot of e-mail and people tell me that it's been very helpful are the on-line hearing loss journals that people will write. There's journaling software on the website and it's free for anyone to do. Several people have written about their cochlear implant experiences, including myself, and it's been very helpful for people. I also have a panel of experts who work with me to answer questions, because I receive hundreds of e-mails each week asking very specific questions that I, as a parent, you know, and a person with a hearing loss, are not qualified for. So I have a wonderful panel of experts who do that for me.

I also do phone calls and consultations with people, especially parents who often find that they just don't know where to start and are overwhelmed with all of the information or how to find the information. And I'm available by telephone at 516-938-5475, and I also am very happy to take e-mails from people. My e-mail is info@hearingexchange.com. In the future, what I'm interested in doing is gathering more people who are interested in volunteering with Hearing Exchange to make it continue to grow by writing articles that will be helpful for others based on their own experiences and research, people who are interested in hosting more chats because people really love the -- you know, the contact of speaking with someone live

as well as people interested in researching the news. And one of my other future goals is to open a nonprofit resource center in New York because just -- as an offshoot of Hearing Exchange, to include the website but also to provide, you know, things on a more national scale in other avenues. And if anybody has any questions, I'm happy to answer them for you.

UNKOWN SPEAKER: Can you repeat your telephone number slowly?

PAULA ROSENTHAL: Yes. My phone number is 516-938-5475. Another thing that I -- I forgot to mention is that I do offer a postcard brochure that is -- has been placed at some cochlear implant centers that parents pick up and then they will -- you know, can find the website easily, as well as doctors' offices and I'm happy to send those out free to anyone who would like them.

MARCUS GAFFNEY: Okay. Are there any other questions? Okay. We're going to move on to our last speaker, Jennifer Cernoch from Family Voices.

JENNIFER CERNOCH: Thank you very much. And it's a pleasure for me to be on this call. Family Voices is a national grass-roots organization of over 40,000 families and friends speaking on behalf of children with special healthcare needs. We do not focus on any specific disability or any particular healthcare need. We look at overall the healthcare status of children.

The definition that we use for children and youth with special healthcare needs is a broad-based definition that could include specific chronic conditions, to children with severe developmental disabilities. So our network is very broad.

Family Voices started 10 years ago as a group of family members who were primarily concerned about healthcare reform with -- within our country, and we wanted to assure that our children with special healthcare needs had a place at the table for any kind of healthcare reform package that was being proposed on a national level.

And over the past 10 years, we have continued to work within the healthcare system, looking to make sure that children and youth with special healthcare needs have access to quality healthcare services. Be it through the private sector, through the public sector, through managed care.

Our network is divided into 10 regions within the United States. These regions are based on the maternal and child health regions, and within each state within the United States, plus Washington, D.C., Puerto Rico, and the virgin islands we have either state coordinators or chapters in all of the states and the territories, to be able to provide family-to-family information out there for families within -- within the state. We work predominantly with the maternal and child health bureau looking at healthcare systems that are important to children and youth. Our website is www.familyvoices.org/, and our phone number is area code 505-872-4774.

Our state coordinators and/or our chapter representatives are all family members of children and youth with special healthcare needs. They either perform their duties within the state on a volunteer basis or are -- have developed their own agency within their state, their own Family Voices organization within their state, to provide those information services to families.

Many of our families that the children have hearing losses or some type of hearing impairment, so as I said, we are not any disability or disease-specific, but we cover -- we cover all areas of children with special healthcare needs.

We provide a variety of information and resources to families. We have developed a family leadership guide that has been very popular. We also have a number of materials. Back in 1999, we conducted a national survey of families of children with special healthcare needs and have produced those survey results in a report called "your voice counts." That finish is also on our website. We also produce one-pagers for families regarding specific issues or topic areas that families are finding that there is more of a need for information in those particular areas.

We have a strong advocacy component at Family Voices. We work with many partner agencies in looking at healthcare services for children with special healthcare needs and children with disabilities, and predominantly what we're working on now is the development of family-to-family health information centers in every single state. And this will be a place where families can go to or contact to get more information about healthcare services.

So in a nutshell, that is basically what we do, and I'll be more than happy to entertain any questions.

UNKNOWN SPEAKER: Jennifer, can you talk a little bit about how that family-to-family healthcare center would work?

JENNIFER CERNOCH: Oh, sure. Be more than happy to. Currently, we have seven funded family-to-family health information centers funded through the maternal and child health bureau. These family centers in some states are part of a larger organization, and in some states are -- they're separate nonprofit organizations. Every single state develops their family-to-family health information center based on the needs of their state.

For example, in -- let's just take Minnesota. The family to say family health information center is located at the pacer center in Minneapolis, and families can access a variety of information. They have a lending library at the pacer center. They provide one-on-one counseling for families. They provide access to information via their website, via printed information. They also have a database of information that is available to families for various topics, they have information printed in various languages for families if families need that type of information.

Many times they do a one on one almost case management type of support to families in helping them access information.

The family-to-family health information center in the state of California is divided across 14 regions within California. Each one of those regions provides different services to families. Some do an actual parent support group. Some do direct intervention for families. Some do training. Some do conferences. And -- but they all provide information to families in the state of California. Their information is printed right now in 12 different languages.

So it varies depending on the needs of the state. Most of the family-to-family health information centers have like a help line that families can call in to get specific information. Some work through the parent training information centers within their states to get information out to families through the schools. So it just varies from state to state.

UNKNOWN SPEAKER: Jennifer, where can you find out which state has the family information centers?

JENNIFER CERNOCH: Yes, it is. It's all on our website. And we're in the process of up-- redoing our website which should be available next week, but all of that information is currently on our website.

MARCUS GAFFNEY: Thank you Jennifer. Are there any questions for any of our speakers? Well, with that, I'd like just to take the opportunity once again to thank all our speakers for agreeing to present on this call, and everybody for calling in. I hope you found the teleconference informative. There will be a transcript available from this call on the CDC EHDI website probably by the end of the month, and I'd like to remind you that the next ad hoc teleconference will be on Tuesday, September 2nd. An announcement with some information about the topic will be sent closer to the date.

(Call ended at 2:50 p.m. eastern)